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Cross-cultural adaptation of the EAST and CASE screening tools for elder abuse in South Africa

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Abstract

Elder abuse is globally considered a hidden problem with great variations in its conceptualization across cultures, non-uniformity in understanding, and manifestations of abuse and neglect. Currently there are no validated or culturally adapted screening measures for elder abuse in South Africa. The aim of this study was to test the cultural appropriateness of the Elder Abuse Screening Tool (EAST) and the Caregiver Abuse Screen (CASE) in two regions and four languages in South Africa. Using a cognitive interviewing methodology, 23 carers and 19 older adults were interviewed. Findings show that questions in the EAST and CASE are generally well understood, but that adaptations of both tools are necessary for use within South Africa. Fear, knowledge, and experience of crime also showed that strangers, like family, deliberately use deception to build trust and abuse. Further validation is needed to determine suitable scoring and use by health and social care practitioners.

INTRODUCTION

Elder abuse is defined as *"a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person"* (WHO, 2019a). Elder abuse can be physical, psychological, financial or sexual in nature, and include both intentional acts or neglect (WHO, 2019a). This definition provides an overarching framework of elder abuse including criminal and non-criminal acts (Joosten et al., 2017). Earlier definitions excluded perpetrators that are not related to the abused older adult, but later evolved to include strangers who purposefully gain trust in order to abuse (Goergen & Beaulieu, 2013; Jackson, 2016). Elder abuse is globally considered a hidden problem with one in every six persons 60 years and over, and two out of three people living with dementia, having experienced some form of abuse (WHO, 2016, 2017). Rigorous data on the extent of the problem are limited (WHO, 2018), with estimations of only 4% of cases being reported worldwide (WHO, 2016).

Hidden nature of elder abuse

Given its occurrence within the context of a trusting relationship (Downes et al., 2013; Jackson & Hafemeister, 2016; Momtaz et al., 2013), older adults may hide abuse for various reasons. This may include fear of retaliation, feelings of shame and helplessness, or worry about getting the abuser in trouble (WHO, 2016). Older persons also may not recognize their situation as an abusive one, or may be reluctant to disclose because they feel responsible for the abuser's actions especially when the abuser is their child (Joosten et al., 2017). Lack of disclosure may be amplified in people with dementia (Downes et al., 2013), where cognitive impairment can limit insight, recall or communication skills. These realities keep elder abuse hidden.

Complexities in detecting elder abuse

Screening for elder abuse across cultures is complex, especially considering the great variation in how abuse is understood and manifested differently across contexts (Moon & Benton, 2000). Screening for elder abuse among persons living with dementia is even more complicated as existing tools exclude persons with cognitive impairment (Wiglesworth et al., 2010; Yaffe et al., 2008). Where cognitive impairment is suspected (and where there is no visible signs of abuse), indirect methods such as screening family members, potential perpetrators, or available healthcare and support providers, becomes critical in detecting abuse (Beach et al., 2016). However, such strategies are often unsuccessful as perpetrators do not want to incriminate themselves, while healthcare and support providers often face significant challenges to incorporate screening into their work, received no training on identifying elder abuse, and are generally unsupported by clear, responsive referral pathways and services (Brijnath et al., 2020). However, despite these challenges, studies have found that carers for people living with dementia or physical impairments are more open to reporting their frustrations, abusive behaviors and neglect (Beach et al., 2016). All perpetrators are not equal and range in culpability from pre-mediated, deliberate acts to genuine incapability to meet care demands (Jackson, 2016).

These realities remain a challenge for elder abuse detection and highlight the value of contextually relevant and culturally appropriate tools that elicit responses in non-confrontational ways, especially when potential perpetrators are screened.

Elder abuse screening tools

Elder abuse screening tools seek to (1) identify factors for the development of abuse; (2) support the detection of risk and experience of violence, maltreatment and neglect; and (3) provide a basis to facilitate early intervention (Gallione et al., 2017). A positive screening outcome would suggest the need for further investigation. Unsurprisingly, there have been a plethora of elder abuse screening tools developed globally, including; the Hwalek-Sengstock Elder abuse screening test (H-S/EAST) (Neale et al., 1991), the Vulnerability to abuse screening scale (VASS) (Schofield & Mishra, 2003), Indicators of Abuse (IOA) (Reis & Nahmiash, 1998b) and the related Elderly Indicators of Abuse (E-IOA) (Cohen et al., 2006), the Elder Abuse Suspicion Index (EASI) (Yaffe et al., 2008), and the Brief Abuse Screen for the Elderly (BASE) (Reis & Nahmiash, 1998a) and its related Caregiver Abuse Screen (CASE) (Reis & Nahmiash, 1995). Although these tools capture similar constructs and have been psychometrically validated across various contexts, the majority do not include the older adults self-report (Gallione et al., 2017). Such screening tools are often limited by lengthy administration times, requiring specialist training, or have limited scope (e.g. financial abuse not detected in the E-IOA) (Gallione et al., 2017). Importantly, all current tools exclude the self-report by persons with cognitive impairment, such as people living with dementia.

Screening for elder abuse in South Africa

Despite global developments in screening for elder abuse, there are no validated and culturally appropriate screening tools in South Africa. There are no government reporting or data available on elder abuse and little published evidence, with a handful of studies suggesting that rates are high (Bigala & Ayiga, 2014; Kotzé, 2018; Makiwane & Kwizera, 2006; Marais et al., 2006). Poverty, inequality, high levels of crime and

substance abuse are considered important factors promoting violence within the home environment, and resulting in older persons becoming targets for abuse and exploitation (WHO, 2002). Older persons, especially older women, often feel insecure at home and are particularly vulnerable to abuse within their communities (Lloyd-Sherlock et al., 2018).

South Africa is a multi-cultural nation with eleven official languages and a variety of cultural beliefs and traditions that influence how tools are interpreted and understood within context. Using screening tools from other research settings without cross-cultural adaption is therefore problematic as local understandings and interpretations have implications for accurate measurement beyond the one-way translation of tools to local languages. Direct translations therefore do not necessarily retain the original language validity (Beaton et al., 2000).

Due to the hidden nature of elder abuse and the exclusion of older adults with cognitive impairment, South Africa needs culturally appropriate screening tools that aim to detect abuse to promote the detection of elder abuse at community level. This study therefore set out to cross-culturally adapt two elder abuse screening tools, one each from the perspective of the *older adults* and *carers*[1]. Our investigation focused on the content *respondents* considered when answering questions. This allowed us to gain insight to their interpretations of questions, understanding of concepts, and appropriateness of

[1] Lived experience feedback has highlighted the different interpretations of the word *carer*. This can include individuals with personal or professional relationships with the older adult, however for this study it includes someone who provides care for an older adult and knows the adult best.

response options. Assessing how well elder abuse screening tools can be used by healthcare workers and allied professionals would be a further step in the adaptation process and beyond the scope of this study.

METHODS

Study objective

To cross-culturally adapt and cognitively test the appropriateness of the Elder Abuse Screening Tool (EAST)[2] and the Caregiver Abuse Screen (CASE) for use in South Africa across four languages, English, isiXhosa, Afrikaans, and Sepedi.

Selected tools

Two tools were selected for cross-cultural adaptation in South Africa: The CASE, originally developed in Canada (Reis & Nahmiash, 1995) and the EAST, developed as a collaboration between the World Health Organization (WHO) and the South African National Department of Health (SADoH) in 2008:

(1) The CASE is an 8-item tool that assesses risk of potential elder abuse perpetrated by a carer, with binary response options (Y/N) and a score that ranges between 0 and 8 (a score of 1 can be indicative of risk, and values higher than 4 indicates high risk of abuse). The CASE is directed at carers and specifically words questions in a non-blaming, non-confrontational manner to

[2] The Elder abuse screening Tool (EAST) was developed in South Africa and is distinct from the Hwalek-Sengstock Elder Abuse Screening Test (H-S/EAST).

facilitate earnest responses about caregiving experiences and feelings. Doing so potentially manages inherent biases in self-reporting of abusive caregiving practices by not confronting respondents with inferred allegations of abuse (Cohen, 2011; Reis & Nahmiash, 1995). The CASE has been shown to have strong internal consistency (α = .86) and strong correlations with known risk factors of abuse such as carer burden and dealing with dementia-related behavioral disturbances of persons living with Alzheimer's disease in Italy (Melchiorre et al., 2017). The CASE was also adapted and validated in other contexts such as Spain (α = .84) (Pérez-Rojo et al., 2015), Iran (α = .86) (Sakar et al., 2019), and Pakistan (α = .88) (Khan et al., 2020).

(2) The EAST was originally designed by the SADoH and WHO for healthcare workers to screen for risk of elder abuse. The tool consists of three sections: (1) a questionnaire for health care workers to identify potential abuse; (2) a recording form; and (3) a referral form (NDOH, 2011). The questionnaire for the healthcare worker comprises of two parts: observational questions directed at the healthcare worker to screen for signs of abuse (e.g., cuts, scratches, bruises, burns, etc.), while the second half asks questions to the older person as respondent (12-items with binary response options (Y/N)). We only used the older adult reported component for this study. To the best of our knowledge, the EAST is the only screening tool for elder abuse developed for use in South Africa. The tool adapted the questions from the 6-item Elder Abuse Suspicion Index (EASI), developed in Canada (Yaffe et al., 2008), to comprise 12 items that separate types of abuse in more individually focused questions. The EAST has never been tested or validated in South Africa, and no information on its development and utility has ever been published.

Setting

Nested within a prevalence study of dementia in South Africa under the STRiDE project (i.e., *Strengthening responses to dementia in developing countries*), this study was based in two target areas: The Western Cape (predominantly urban) and Limpopo provinces (predominantly rural) with data collected between November 2019 and March 2020. Local languages spoken in these provinces were selected for translation and cross-cultural adaptation, including cognitive interviewing. Sepedi was selected in Limpopo, whilst English, Afrikaans, and isiXhosa were selected in the Western Cape. Participants were recruited from the Mankweng and Dikgale area in Limpopo, while areas purposively sampled to provide a diverse range of socio-economic status and languages in the Western Cape province included Stellenbosch, Khayelitsha, Gugulethu, Wynberg, Athlone, Grassy Park, Kuilsriver and Lotus River.

Participants

Participants were purposively selected from two target groups: (1) *Older adults* had to be 60 years and older, be fluent in the target language, of varied sex, and had to be able to respond to questions and participate in the interview; (2) *Carers* had to be 18 years or older, be fluent in the target language and provide unpaid care for someone preferably with dementia but could include caring for a person with any chronic illness or disability. Recruitment strategies were pragmatic and varied across the two sites and included (a) referrals by dementia-specific non-government organisations (NGOs), such as Alzheimer's South Africa (ASA) and Dementia-SA; (b) snowballing; and (c) self-referrals recruited via flyers circulated on existing community-safety neighborhood WhatsApp groups or circulated through existing contacts.

Procedure

The following process was conducted to prepare the tool in terms of its translation and cultural adaption for appropriate use in the South African setting.

Translation process

Translation was guided by the ISPOR Principles of Good Practice for translation and cultural adaptation of instruments (WHO, 2019b; Wild et al., 2005). The broader cross-cultural adaptation process is described elsewhere (Farina et al., 2022) however a summary of the translation process followed for this study comprised the following steps: (1) Two independent forward translations by two translators that are proficient in English and the target languages; (2) Synthesis of the two independent forward translations through item-by-item comparison, discussion and consensus into a single translation; (3) two independent back-translations performed by two additional translators proficient in English and the target languages; (4) synthesis through item-by-item comparison, discussion and consensus in a reconciliation group comprising of at least one translator (lead translator) and at least two members of the research team; (5) pre-testing via cognitive interviewing (see description below); and (6) final appraisal where the content participants considered when responding to questions inform the adaptation of the tool to maintain the intended meaning of the original version, but in a culturally appropriate manner.

Cognitive interviewing

Participants were interviewed to assess how each item of the EAST and CASE was understood and which experiences and content they considered when responding to a question. A cognitive interviewing protocol was followed where participant responses were documented with detailed notes, combining think aloud and verbal probing

techniques (Daouk-Öyry & McDowal, 2013), to determine how each of the questions in the EAST and the CASE performed in terms of their interpretative value (Miller et al., 2014). Cognitive interviews ranged between 5 and 31 minutes for the CASE and 7 to 40 minutes for the EAST. The variability in interview times were due to the differences in probing for participants' *in-* and *out-of-scope* interpretations. For older adults responding to the EAST, longer interviews were noted where concept checking revealed *out-of-scope* interpretations that required further exploration. For carers responding to the CASE, longer interviews were noted where *in-scope* interpretations presented cathartic opportunities to share their experiences in caring for a family member living with dementia. Shorter administration times reflect instances where minimal probing was needed.

Where participants felt comfortable with a digital recorder present, interviews were audio-recorded for quality purposes. Interviews were conducted at places of convenience for participants and included seniors' centers, luncheon clubs or participants' homes. Space limitations within homes and other venues are common realities in South Africa, however where interviews were conducted in shared spaces, care was exercised to ensure it is not within listening distance of others in the vicinity. A social worker from Alzheimer's SA or Dementia-SA was available in each of the research settings to provide support where needed. All interviews were conducted in the preferred language of the participant, with the lead author (RJ) conducting interviews in English and Afrikaans, the co-author (MS) conducting interviews in English, while Sepedi and isiXhosa interviews were led by two pairs of research assistants with RJ or MS attending each to help guide the interview. For the Sepedi and Xhosa-speaking participants, the assistant interviewers regularly translated what the participants had said for RJ or MS to follow the discussions. Interviewers were fluent

in both English and one of the target languages (isiXhosa, Afrikaans, or Sepedi) and were responsible for translating participant responses in detailed, paraphrased notes for each question and related probes during the interview through on-the-spot translations to English.

Analysis

Following the approach of Miller et al., (2014) in analyzing cognitive interviews, analysis comprised of these steps:

(1) Step 1: Collecting narratives via individual interviews,

(2) Step 2: Synthesizing narratives into detailed summaries to capture specific events and experiences considered when responding to each item;

(3) Step 3: Comparing summaries across respondents to produce thematic maps. These summaries were grouped under each tool item and loaded into NVivo 12 software for Windows (https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home), for further analysis (see step 4);

(4) Step 4: Comparing themes across items to produce advanced thematic maps. Comparisons were done using NVivo 12, grouping narratives and tabulating the evidence-base for the thematic maps.

(5) Step 5: Produce final study conclusions of the performance of each question and the individual instruments.

Participants' narratives were compared for each item across the four languages to inductively develop themes from the raw data, searching for patterns of *in* and *out-of-scope* interpretations. *In-scope* interpretations are those responses that reflect a synergy between the participant's understanding of the question and the intended scope of the

question; whereas *out-of-scope* interpretations are responses based on participants' experiences that are outside of the intended scope of the question (Miller et al., 2014). In this study, we present the *out-of-scope* interpretations for each of the tools and provide analysis on *in-scope* interpretations that give context to participants' experiences. We will also indicate where participant interpretations lead to false positives for elder abuse (i.e., where they responded 'yes' to abuse when in fact their interpretation was out-of-scope and should have been 'no').

Reflexivity and rigor

Sepedi and isiXhosa-speaking assistant interviewers were trained on the cognitive interviewing approach and protocol and further supported by RJ and MS during the interview where questions arose, or further probing was required. Assistant interviewers were debriefed after each interview to reflect on the content and process of the interviews, and to verify equivalence in concepts between the original English and target languages. Analysis was led by the lead author (RJ), a researcher from South Africa who is native to South Africa and has good insight into different South African cultures. She has however had no personal experience with elder abuse. As such, her own experiences of the culture may bias coding and interpretation. To address this, the developing themes were reviewed by co-authors, MS (South Africa) and NF (UK).

Ethical considerations

All participants were interviewed in settings they were comfortable in and without being accompanied or in hearing distance of their carers or care-recipients (where applicable). At the time of the interviews, carers of persons living with dementia were attending (or have already been supported by) local support groups run by a social worker from Alzheimer's South Africa (ASA) or Dementia-SA. Individual consent was

obtained in writing, while safeguarding the identities of participants by anonymizing data.

RESULTS

Demographic information

A total of 42 participants were interviewed across the 4 languages, with participants recruited until data saturation has been achieved (English (n=8), Afrikaans (n=11), isiXhosa (n=12), Sepedi (n=11)). The sample consisted of 23 carers and 19 older adults with participants in both groups being predominantly female. Older adults ranged between 63 and 79 years of age, where carers ranged between 35 and 78 years with almost half (11 of 23) being 60 years and over (see Table 1). At the time of the interviews, no participants completing the EAST were known or suspected to have cognitive impairment, such as dementia. Carers interviewed (using the CASE) were all providing support for an immediate family member (parent, sibling, or spouse) living with dementia, disability or other health condition that required full-time care.

Table 1: Demographic information for carer and older adult participants
<Insert Table 1 here>

Elder abuse screening tool (EAST)

Several components emerged from the analysis across all four languages including (a) out-of-scope interpretations; (b) participants' fear, knowledge, and experiences of general crime as a recurrent theme in the content considered when responding to the EAST; and (c) the need to adjust translations. Each of these are discussed separately.

Out-of-scope interpretations of the EAST

Participant responses reflected a general understanding of concepts across all target languages (e.g., 'abuse', 'forced', 'hurt', 'harmed', 'threatened'). However, when assessing how questions were understood and what content participants thought of when responding, interpretations included a broad range of general experiences that had previously made participants feel unhappy or unsafe. These responses were *out-of-scope* of the intended interpretation and generated false-positives in screening for elder abuse. Table 2 summarizes the out-of-scope interpretations for the EAST questions, with examples (narratives) from the participants. Common themes that were out-of-scope included events that led to changes in relationships, employment dynamics, household responsibilities, standalone incidents of rudeness, misunderstandings and expectations, and accidental occurrences such as losing a wallet. There were no out-of-scope interpretations noted for questions 7, 9, 11 and 12.

Table 2: Older adult quotes in response to probes related to the EAST items. Quotes present out-of-scope interpretations when older adults responded to the EAST (n=19)
<Insert Table 2 here >

Participants' fear, knowledge, and experiences of crime

Interestingly, references to general crime (i.e., robbery, theft, burglary, assault) were commonly reported when responding to ten of the twelve EAST questions (i.e., questions 1, 3-5, 7-12, see Table 3 for narratives). Participants' interpretations for these questions were in-scope of the EAST's intended meanings but also reflects how the *fear of crime*, *knowledge*, and *victimization* informs older adults' experiences in South Africa.

Table 3: Older adult quotes in response to probes related to the EAST items. Items and example quotes are conceptually grouped into the sub-themes: fear, knowledge, and experiences of general crime.*<Insert Table 3 here>*

Adjusting translations

Translations to isiXhosa and Sepedi were correctly interpreted for all EAST questions. The Afrikaans wording however was identified as problematic for only one question. When asked if *anyone in the last two months touched you in ways you did not want (question 4)*, participants interpreted the Afrikaans translation for 'touched you' (i.e., *'jou aangeraak'*) as meaning 'affected you' in broader terms than the question's probe for physical or sexual abuse: *"Yes. Someone was rude and behaved rudely" (RJAFR0005, 64 year old female, Afrikaans).* When changing the wording to mean 'touched you' more directly in Afrikaans (i.e., *'aan jou gevat'*), the same participant's response changed from a 'yes' to a 'no' response indicating this as a more appropriate translation.

EAST Response options

The binary (Y/N) response options for the EAST were easily understood and accepted by participants.

The Caregiver Abuse Screen (CASE)

Analysis across all 4 languages showed that the CASE questions were largely interpreted *in-scope* of the intended meanings. However, this section presents (a) examples of out-of-scope interpretations for one of the CASE questions (question 2);

and (b) emerging themes that reflect care-experiences and risk of elder abuse in South Africa.

Out-of-scope interpretations of the CASE

When asked if carers "often feel if they are being forced to 'act out of character' or do things they feel bad about", their out-of-scope responses included the following examples: (1) shifting roles and responsibilities from being a daughter to a carer; (2) managing their care-recipient's hygiene needs; and (3) to uncharacteristically step-in to confront a family member who is ill-treating the care-recipient (see Table 4). These examples reflect behaviour that provide support to the older adult rather than suggestive of elder abuse.

Table 4: Carer quotes in response to probes related to the CASE items. The themes represent examples of out-of-scope interpretations of the concept 'out-of-character'.

<Insert Table 4 here>

Care experiences and risk of elder abuse in South Africa

Carers shared a range of experiences considered when responding to the CASE that were in-scope of the intended meanings.

Care responses were grouped as (1) pacify and evade; (2) forced to be rough; and (3) recipient of aggression and violence. For example, when being met with aggression, some carers were able to pacify behaviour by evading conflict or simply walking away: *"In the beginning my dad was very aggressive. But you can't get aggressive back at*

him, doesn't help the situation. Just walk away" (RJENG0026, 62 year old female, English).

Unmanaged dementia symptoms made carers feel that they themselves are vulnerable to aggression and violence (e.g., being hit, shouted at, things thrown at them). For example, a carer shared that when locking the front door before bedtime, her sister living with dementia would react violently: *"It is very hard. When she says she wants to go outside, she uses even a knife or beat the door hard wanting to leave" (HMRJXH0027, 60 year old female, isiXhosa).*

Some carers felt 'forced to be rough' to get cooperation to complete tasks, for example: *"I am a patient person...[but] sometimes I need to be aggressive for some things to happen" (HMRJXH022, 57 year old female, isiXhosa).*

Many carers shared their experiences of being recipients of violence and aggression. In some cases, carers revealed that their care experiences can be characterized as reciprocal violence: *"Yes, she is bullying and bossy so I would end up being rough with her" (HMRJXH023, 60 year old female, isiXhosa).*

Other challenges to care include time and financial constraints. Caring in a context without adequate support made carers feel that they '*can't do what is really necessary or what should be done'* (CASE question 5). For example, the realities of juggling multiple roles and responsibilities place significant constraints on time to meet all care needs: *"My mom need[s] mental stimulation. We don't have the time and capacity to give this to her. She needs to be talked to. I have children, husband, no real time.*

(RJENG0021, 42-year-old female, English). Carers were doing their best, in the absence of being able to afford formal support: "*This is often due to finances. Good care is expensive in South Africa. [We] need care that is responsive to what the person needs" (RJENG0022, 42-year-old female, English).*

Reactions to binary response options

Participants found it challenging to express their experiences caring for a person living with dementia as binary (Y/N) and instead responded using terms such as 'sometimes' (most common), 'not often', 'a little', 'a lot' or 'rarely'. A simple 'yes' or 'no' restricted their experiences to absolutes, when they viewed their experiences as fluid and varying in frequency. This is especially relevant in the context of dementia care as experiences vary considerably over time and with the progression of the condition, while the CASE does not provide a time frame for experiences (e.g., in the past year). The 'yes' or 'no' responses were perhaps experienced as confrontational, making participants reluctant to respond with 'yes' to questions that they find rings with some degree of truth, but not as an absolute indication of their everyday or more recent experience and changing circumstances. Participants reflected on this difficulty and suggested the use of scaled response options, for example: *"Use options like 'sometimes', it's a more accurate reflection of what actually happens" (RJMSENG0024).* Another said: *"It's very difficult to just say yes or no to these questions if dealing with dementia. Dementia-person happens on a spectrum, not just yes or no. It happens on a spectrum, one should be able to rate it on a spectrum" (RJENG0022, 42 year old female, English).*

DISCUSSION

We set out to cross-culturally adapt two screening tools - the EAST and CASE for their cultural appropriateness across two regions (and 4 languages) in South Africa. As part of the overall validation process, the findings suggest that these tools are suitable for use in South Africa but require some adaptations.

This study highlights a need for contextualizing the EAST to a common understanding of elder abuse to address the broad range of out-of-scope interpretations, and minimize responses related to general experiences of being unhappy or unsafe. Our findings also show that the EAST has potential as a community screening tool for elder abuse, but in its current form, does generate false positives when screening across all 4 languages tested. We also show that care experiences and risk for elder abuse vary greatly among participants, and with minor adjustments, the CASE can be a suitable tool to screen for risk across these 4 languages in South Africa.

Reducing false-positive screening of abuse

When administering the EAST across the four languages, most questions were interpreted within scope of intended meanings. Where interpretations were out-of-scope, participants often screened positively for elder abuse (i.e., scored as experiencing abuse), when in fact they were sharing general (non-abusive) experiences that caused emotional distress or harm (e.g., death of a close friend, divorce, power-dynamics at their workplace). The EAST in its current form is hence vulnerable to generating out-of-scope interpretations and false positives. This could be avoided by including verification prompts to limit false positive responses, and for further verification of this tool. Out-of-scope and false-positive responses were also noted in the CASE (question 2) where carers felt they were acting ‘out of character’ when they were in fact supporting the family member living with dementia. This was not a consistent finding

for all CASE questions, and a slight adjustment in wording is recommended to strengthen this particular question (see recommendations for CASE section below).

Role of dependency in screening for elder abuse

A key element missing from the EAST relates to determining whether there is a *dependency* relationship that may generate power dynamics between the older person and a possible carer or, for example, another household member. According to social exchange theories of elder abuse, dependence of an older adult on the abuser (or vice versa) increases risk of abuse (Momtaz et al., 2013). The EAST in its current form does not screen for this power relation between an older adult and others that potentially distinguishes general negative social experiences from abusive ones within a dependency relationship. For example, asking a question about whether the older adult depends on someone else for shopping suggests an abusive dynamic (neglect) when this assistance is denied, compared to an older adult that is self-reliant and simply being denied a social favour. Therefore, it is proposed that a screening question be added to the EAST to distinguish between general negative social interactions and abuse (see recommendations for EAST section below).

Crime and elder abuse

Crime was a recurring theme in responses for ten of the twelve questions posed by the EAST, with examples of participants (1) being fearful of becoming a victim of general crime; (2) knowing another older person in the community that was a victim; and (3) having had an experience of being a victim themselves. These fears and experiences shared by participants were all perpetrated by strangers rather than family or people they have a relationship with. Definitions of elder abuse from the WHO and the South African Older Persons' Act both articulate that the context of abuse falls

within a relationship where there is an 'expectation of trust' between the older adult and perpetrator (Older Persons Act, 2006; WHO, 2019a). This speaks to a contention in elder abuse literature where defining elements of *trust* are debated, arguing that strangers could be in a 'trusting relationship' with an older adult under certain circumstances (Jackson, 2016). In fact, for some types of abuse to occur (for example property offences or financial exploitation), building trust with the intention to betray this trust is a key element for the offence to be successful (Goergen & Beaulieu, 2013; Jackson, 2016). Examples of strangers' deliberate use of deception to build trust with the motivation to exploit or harm is evident in this study, such as (1) where a salesperson builds trust to convince the older adult to sign documents that unknowingly authorizes a purchase in a furniture store; and (2) where a young man was 'helping' an older person at the ATM to gain proximity in order to rob him under the threat of violence (see Table 3). Arguably these offences fall within the conceptualization of elder abuse, especially when older adults are targeted for exploitation or violence because of their age and assumed vulnerability to ward off attacks (physically, psychologically, financially, sexually). Elder abuse by strangers is acknowledged by the judicial system in Canada, for example, where criminal cases receive harsher sentences if the crime is proved to be age-related with an implication of vulnerability (Goergen & Beaulieu, 2013). As such, age is not automatically an indicator of vulnerability, but perhaps playing into ageist beliefs.

Despite South Africa having one of the highest crime rates in the world (i.e. six times higher than the global average) (Peden et al., 2002), very little is known and published about elder abuse and crime against older persons. Despite this gap in evidence, fear of crime is well documented internationally (e.g. Lorenc et al., 2012;

Tandogan & Ilhan, 2016), with feelings of insecurity and vulnerability to crime found to increase with age (Hanslmaier et al., 2018; Scarborough et al., 2010). Fear of crime has also been linked to negative impacts on health and wellbeing, with avoidance behaviors restricting freedom of movement outside the home (Lorenc et al., 2012). This study showed that fear, knowledge, and experience of crime has been a recurring theme across participant narratives. Understanding how these elements of elder abuse intersect not only has implications for the health and well-being of older adults, but also for screening and measurement, research methodologies, as well as social or legal interventions suitable for South Africa.

Vulnerability of caring in isolation

This study highlights that caring for a family member without formal support is a common occurrence in South Africa. This 'caring in isolation' not only promotes incidents of abuse when carers attempt to meet the needs of the older adult but can also lead to the carer feeling victimized by the older person.

Unmanaged behavioral symptoms of dementia (e.g. aggression) are often found to act as 'triggers' for reciprocal violence in care-dyads and increasing carer burden, stress and therefore abuse (Downes et al., 2013). Financial constraints in providing holistic care drives feelings of inadequacy and anxiety to meet the older adult's needs, which are known risks associated with elder abuse (Downes et al., 2013). In South Africa, these vulnerabilities are amplified in a context of widespread poverty, lack of knowledge about dementia, and restricted access and availability of support services. Caring for a family member living with dementia often leads to stigmatization and social isolation (Jacobs et al., 2022; Marais et al., 2006; Mkhonto & Hanssen, 2018), as well as restricted daily activities, reduced employment and increased financial burden

(Gurayah, 2015). These realities therefore drive stress reactions among carers and increase risk of elder abuse.

Recommendations for the EAST and CASE

The cognitive interviews from this study have highlighted essential adaptations required to the EAST and CASE, before they can be utilized in a South African context. The following amendments to the EAST are proposed:

(1) Screen for relationships of dependency, for example: Question 1: *Are you currently relying or dependent on anyone for meeting your basic needs such as shopping, preparing meals, feeding, dressing, bathing and/or personal hygiene?*

(2) Adjust wording for question 4 (*Has anyone in the last two months touched you in ways you did not want*) in Afrikaans to directly translate to 'touch' instead of 'affected by' (for example: *"Het enigiemand in die afgelope twee maande aan jou gevat op maniere wat jy nie wou hê nie?"*).

(3) Include a preface statement to provide a basic understanding of what is defined as elder abuse, to provide a context for the questions.

(4) Use verification probes for each question to strengthen the sensitivity and specificity in test performance (internal validity).

(5) Scoring of the EAST: The EAST in its current form has no guidance on scoring for risk of elder abuse. A population-based sample can provide data to develop scoring.

The following amendments to the CASE are proposed:

(6) For the use of the CASE in South Africa, it is recommended that a rating response (e.g. 'never', 'rarely', 'sometimes', 'very often', and 'always') be used

to facilitate participation and elicit responses in a non-blaming, non-threatening manner – in line with the original purpose of the CASE (Cohen, 2011).

(7) To potentially address false-positive screening of risk of elder abuse (i.e., 'yes' response to questions when participant interpretations are actually out-of-scope), it is recommended that question 2 is reworded as follows: *"Do you often feel you are being forced to act out of character or do things to your [_____] that you feel bad about?*

Limitations

There are however several limitations to consider. First, although the four languages tested are dominant in the two provinces tested, the tools will need to be culturally adapted in other areas (and languages) for local idioms and understandings of elder abuse. Second, participants were selected purposively to meet the study criteria for carers and older adults. This sampling strategy was effective in including carers of persons living with dementia but limited by the representativeness of the areas and languages tested. Third, whilst we recommend the inclusion of a preface statement defining elder abuse, its usefulness needs to be established. Fourth, psychometric validation was outside the scope of this study and therefore such evidence is needed to ascertain the appropriateness of adopting either screening tool, in addition to developing a suitable scoring algorithm. Exploration of how these tools complement each other in establishing an accurate picture of elder abuse, and what is the optimum threshold to screen positive for elder abuse is particularly important. Finally, we need to be vigilant about the ramifications of false-positives of either screening tool, particularly when used by health and social care professionals. At this stage, the tools should not be seen

as definitive means of identifying elder abuse, but rather as a means to stimulate discussion and further exploration of elder abuse.

Conclusion

The findings of this study show that the questions in the EAST and CASE are generally well understood and reflect a culturally appropriate and relevant reality, but that adaptations of both measures are necessary for use in South Africa to ensure accurate contextualization of the participants' responses. The use of the EAST and CASE are complementary and can potentially be used together when taking care to administer them individually and privately to encourage honest responses. Where cognitive impairment is suspected or known, reliance on the CASE alone may provide a reasonable screening of risk for abuse, to prompt further investigation.

Elder abuse is complex and measuring it in the South African context is challenging when older persons' fear and experiences of crime and violence perpetrated by strangers and familiar people alike, are framing a reality of risk and vulnerability. Further research on elder abuse and vulnerability in the context of pervasive crime in South Africa is needed, with special attention to methodology, measurement and the development of targeted intervention responses that considers both perpetrator and victim characteristics. Although not representative of all family carers for people living with dementia in South Africa, evidence from this study shows that carers themselves are recipients of violence and aggression and, in the absence of support, reciprocate with aggression. Risk for elder abuse in these cases reflects a reality in South Africa that is characterized by a lack of resources (social, financial) and inaccessible dementia support services for persons living with dementia and their families. We need to be cognizant of not 'villainizing' family carers as abusers, whilst ensuring that individuals

are protected from abuse. Our understanding and attempts to identify and measure elder abuse in South Africa must therefore be sensitized to these realities that support risk, and frame appropriate responses that promote early detection, intervention and support.

Declaration of interest

No conflict of interest to report.

Ethical statement

This study has ethical approval from the University of Cape Town's Human Research Ethics Committee (HREC reference 692/2019).

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Data availability

The nature of data in this study is qualitative, and at higher risk for identifying participants if raw data is openly shared. For further information, please contact the corresponding author.

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Table 1: Demographic information for carer and older adult participants

	Older adults	**Carers**	**Total**
Sex	11F; 8M	17F; 3M	39
Missing information	*0*	*3*	*3*
Age range	63-79	35-78	
(mean; SD)	(69.75; 5.08)	(61.58; 10.89)	
Total	**19**	**23**	**42**

Table 2: Narrative evidence of out-of-scope interpretations for EAST (n=19)

EAST no.	Question	In-scope	Out-of-scope	Out-of-scope (%)	Themes	Narratives of Out-of-scope interpretations (examples)
1	**Are you afraid of anyone in your family, home, institution or community that you are living in?**	18	1	5%	Work	*"No. Thought of people I worked with as a leader. Some came drunk to work. They were problematic at work…" (LMRJSEP02).*
2	**Has anyone in the last two months hurt or harmed you?**	16	3	16%	Death of friend	*"Yes. A very good friend of mine passed away. He hurt me. He pulled me a dirty. He left me alone. He was my inspiration…I'm at this age where being hurt is not being hurt physically but emotionally" (RJENG002).*
					Work	*"Yes. Sometimes you hire a person and make promises that he will come 3 times a week. First week he complies. Second and third week he doesn't come to work and gives funny excuses. Fourth[week], month end, he comes because he wants to get paid. I thought of the person we had agreed to help each other but let me down by not honouring our agreement" (LMRJSEP02)*
3	**Has anyone in the last two months forced you to do things that you did not want to do?**	17	2	11%	Work	*"yes, at work they made me do things I don't want to do, it's work-related. Power-plays. Not popular when I refuse to do the work" (RJAFR0002)*
4	**Has anyone in the last two months touched you in ways you did not want?**	17	1	5%	Rude (translation error)	*"Yes. Someone was rude and behaved rudely" (RJAFR0005)*

EAST no.	Question	In-scope	Out-of-scope	Out-of-scope (%)	Themes	Narratives of Out-of-scope interpretations (examples)
5	**Has anyone in the last two months scolded or sworn at you or threatened you?**	18	1	5%	Driving incident	*"Sometimes when you're driving, someone is driving in a negligent way, reckless and the other person is getting upset and threaten this person" (RJENG003).*
6	**Has anyone prevented you from getting food, clothes, medication, spectacles, hearing aids and / or medical care?**	18	1	5%	Eye drops	*"Yes. Said it was too early for me to buy eye drops at the chemist with a prescription…" (LMRJSEP02)*
7	**Are you left alone a lot, locked up, not allowed to socialise or has anyone been prevented from visiting you?**	19	0	0%	-	-
8	**Has anyone ever failed or refused to help you take care of yourself when you needed help?**	15	4	21%	Divorce	*"Yes. Thinking of my divorce" (RJAFR0001)*
					Household chores	*"Yes. My grandchildren that are cheeky and not wanting to do anything at home" (HMRJXH003)*
					Household repairs	*"Yes. Asked someone to come to fix my house. Came once and never came back" (LMRJSEP03)*
					Go to shop	*"Someone I wanted to send to the shops and would refuse" (HMRJXH005)*
9	**Has anyone made you sign papers that you did not understand or did not want to sign?**	19	0	0%	-	-
10		16	3	16%	Lost wallet	*"Lost wallet once" (RJAFR0004).*

EAST no.	Question	In-scope	Out-of-scope	Out-of-scope (%)	Themes	Narratives of Out-of-scope interpretations (examples)
	Has anyone taken money, valuables (ID, bank card) or any other things that belong to you without your permission, or against your will?					
					Divorce	*"Yes. Stole my gold, with the divorce she took things that wasn't hers" (RJAFR0001)*
11	**Do you feel not properly cared for because others are using your money or possessions against your will or because you have to pay for other people's needs?**	19	0	0%	-	-
12	**Have you have ever been placed in shackle[s], tied up, or locked up in confined spaces?**	19	0	0%	-	-

Table 3: Narratives of participants' fear, knowledge, and experiences of crime

Sub-theme	EAST Question no.	Narratives
Fear about crime	**E1**	*"If you walk or stay alone and someone come and may harm you, don't like it" (MSENG001)*
		"I fear the unknown. Breaking in here, my fear is about the crime in this country" (RJAFR0004)
	E4	*"They would push me to do something that I dislike, example someone wanting to take away my money without my permission" (HMRJXH005)*
	E11	*"I worry a person forcefully stealing my money or withdrawing it without my permission" (HMRJXH002)*
Knows a victim	**E9**	*Someone in a furniture store was forced to sign without purchasing but furniture was brought into the house. Insurance papers and from sellers who claim you have to sign [to prove that they spoke to you] even if you're not buyers. Older people experience these because they can't read what is written" (LMMSSEP05)*
	E10	*"…there are many fraudulent activities that people come into contact with that, others may end up in jail. Some get into trouble because of a simple signature. Tie yourself up, binding yourself to something" (LMRJSEP02)*
	E12	*"Someone was once kidnapped, and money was withdrawn from his account. He got murdered after the wife stopped the card. A pensioner" (LMMSSEP05)*
Victim experience	**E4**	*Thought of people I meet on the road. The one's robbing people using magic. It's usually a group of people, some will touch you and the other will come claiming to help and the others will be pretending to be police" (LMRJSEP02)*
	E5	*I felt threatened by gardener, he was asking for money. I felt unsafe" (RJAFR0003).*
	E8	*"Money yes. My friend's son is a 'tik-kop'[meth addict], he stole money from me. And my friend wouldn't help me get my money back from his son. He was my friend but he was protecting his son" (RJAFR0007).*

Sub-theme	EAST Question no.	Narratives
	E10	*"…someone stole my phone 2 years ago, stole it out of my car" (RJENG003).*
		"Loan shark taking my wallet and ID due to [me] owing them" (HMRJXH002).
		"Yes. Mugged by a group of boys. One touched me, the other came pretending to help, took me to the others who were pretending to be police. They demanded bank card and pin or they'll kill me" (LMRJSEP02)
	E11	*"Yes. They take my stuff" (HMRJXH003)*
Other crime-related content	**E1**	*I understand that it is asking if there is someone troubling me. Maybe break into my house or fight me" (LMRJSEP03)*
		No. [thinking of] a thief, attacker" (LMMSSEP05).
	E3	*"Being forced to sign for example, in politics [forced to go] voting. It's about doing things without your willingness" (LMMSSEP05)*
		"Someone demanding you to give him/her your belongings or rape. Forcing you to give them your belongings. Thought of meeting a person in a mall and the person forcefully takes your belongings" (LMRJSEP05)
	E5	*"Thought about people who take other people's belongings, lying to people and being fraudulent to take what belongs to them" (LMRJSEP02)*
		"Tell you they will burn your house, break in or kill you" (LMRJSEP03)
		"Telling you they will kill you" (LMRJSEP05)
		"Threatening with a knife for example, with harm. Shouting in a loud voice. The elderly experience these more than the younger" (LMMSSEP05)
	E7	*"No. May find that the person has problems with the memory. They lock him up because if he goes out, he might get lost or other people will trouble him with questions, teasing him, and strangers may also harm the person" (LMRJSEP05)*
	E10	*"An abusive person like a robber or a family member" (HMRJXH005)*
		thought of thieves, maybe they want to withdraw your money from the bank…forcing you to give them something that belong to you or stealing from you" (LMRJSEP03).