Elder abuse in South Africa: Measurement, Prevalence and Risk

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Declarations

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I declare that this thesis is my original work and that neither the whole work nor any part of it has been, is being, or will be submitted for another degree in this or any other university. Ethical approval was obtained from Human Research Ethics Committee (HREC) of the Faculty of Health Sciences at the University of Cape Town for the duration of the study, reference no. HREC 692/2019 (sub-study of HREC021/2019).

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(1) Jacobs, R., Schneider, M., Farina, N., du Toit, P., Docrat, S., Comas-Herrera, A. and Knapp, M. (*submitted 30 June 2022, under review*). Dementia in South Africa: a situational analysis. Dementia (special issue). [See Part I of Chapter 2, sub-study 1].

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I have no conflict of interests to declare.

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ABSTRACT

Abuse towards older people is a global public health and human rights concern and considered a hidden pandemic due to underreporting. It has been estimated that 1 in 6 people aged 60 and older have experienced abuse at some point, with World Health Organization estimating that only 4% of cases are reported. Often older adults do not recognise their situation as an abusive one or may be reluctant to disclose because the abuser is a family member, often an adult child for which the older person feels responsible for. People living with dementia and older persons with significant health concerns are especially vulnerable to elder abuse, with estimates showing that 2 in every 3 people living with dementia have experienced some form of abuse. Rigorous data on the extent of the problem globally is limited, with studies often excluding the self-report of older adults with cognitive impairment, such as dementia. Lack of disclosure may therefore be amplified in people living with dementia with limitations in insight, recall or communication skills. These realities keep elder abuse hidden, while often relying on the self-report of perpetrators to disclose abuse.

Screening and identifying elder abuse, especially amongst people with cognitive impairments, are complex. Very little research is published on elder abuse in South Africa, with a complete absence of prevalence estimates, routine reporting, or monitoring and surveillance of issues relating to elder abuse. From the limited data available, elder abuse in South Africa is a serious concern. In South Africa older persons are now, more than ever, expected to manage households, rear children, and financially support their entire household with their pensions. This shift in role makes them especially vulnerable to the impact of the country's high rates of poverty, unemployment, and crime, especially within the home environment. These structural and social determinants of violence are poorly understood in the context of elder abuse. In particular, there is a serious lack of local evidence that supports the understanding, risk, and measurement of elder abuse in South Africa. This study therefore proposed to address these gaps through four sub-studies designed to describe the landscape of elder abuse in South Africa. These sub-studies had the following aims:

1. To provide a situational analysis on current service provisions for dementia and elder abuse for older adults, including people living with dementia and their families (sub-study 1).

2. To cross-culturally adapt the Elder Abuse Screening Tool (EAST) and the Caregiver Abuse Screen (CASE) in South Africa, to detect self-reported abuse and risk of abusing from older persons' and potential perpetrators' perspectives (sub-study 2).

3. To examine the nature of self-reported elder abuse using the Elder Abuse Screening Tool (EAST) to generate evidence on the prevalence, predictors, and perpetrators of abuse (sub-study 3).

4. To estimate the prevalence and predictors of risk of abusing using the Caregiver Abuse Screen (CASE) amongst household informants, including carers for people living with dementia (sub-study 4).

Sub-study 1: "Dementia in South Africa: a situational analysis"

This study comprises of two parts. Part I presents a situational analysis that was conducted in three phases: (1) a desk review guided by a comprehensive topic guide which included the World Health Organization's (WHO) Global Dementia Observatory indicators; (2) multi-sectoral stakeholder interviews to verify the secondary sources used in the desk review, as well as identify gaps and opportunities in policy and service provisions and (3) a SWOT-analysis examining the strengths, weaknesses, opportunities and threats in current care and support provisions in South Africa. Findings highlight the gaps and opportunities with current service provisions and show how structural factors create barriers to diagnosis, support and care. These barriers to diagnosis, care and support create risk for elder abuse and neglect as families and people living with dementia are largely unsupported by formal, community-based services. Part II expands this analysis and provides a closer look at the insights gained from stakeholders interviewed and reports on the status of elder abuse support provisions in South Africa. We found that, like in the case of dementia services, support provisions for elder abuse are poor. While there is a lack of data on the nature and extent of the problem, experts agree that underreporting is a big problem, and that people living with dementia are at greater risk of elder abuse that may include extreme forms of violence.

Sub-study 2: "Cross-cultural adaptation of the EAST and CASE screening tools for elder abuse in South Africa"

We tested the cultural appropriateness of the EAST (Elder Abuse Screening Tool) and the CASE (Caregiver Abuse Screen) in two regions (Western Cape and Limpopo) and four languages in South Africa (English, Afrikaans, isiXhosa and Northern Sotho (Sepedi)), using a cognitive interviewing methodology. 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. Older persons' fear, knowledge and experience of crime also showed that strangers may deliberately use deception to

build trust and abuse. Further validation is needed to determine suitable scoring and use by health and social care practitioners.

Sub-study 3: "Prevalence, perpetrators, and predictors of self-reported elder abuse in South Africa: findings from a household survey"

Informed by the cognitive interviews in sub-study 2, the adapted EAST was used in a household survey to screen 490 older people for self-reported elder abuse across two areas, Cape Town (Western Cape) and Dikgale (Limpopo). One in ten older adults screened positive for abuse, of which financial abuse was most common. Perpetrators of elder abuse were most often a non-family member with whom the older adult had a relationship with. Higher prevalence of self-reported abuse was strongly predicted by higher levels of the respondent's own functional impairment. This is one of the first studies that explore the relationship between dementia, functional impairment, and elder abuse at a community level in South Africa.

Sub-study 4: "Risk of elder abuse in South Africa: a survey of household informants"

Within the same household survey, we screened informants of the older adults using the CASE. We found that risk of elder abuse was very high, with half of participants screening positive for abusive dispositions toward an older person. Carers of people living with dementia were four times more likely to be at risk of abusing compared to carers of people free of dementia. However, our multivariate model showed that more severe psychological and behavioural symptoms and increased carer burden are the main associations with elder abuse in this population. Supporting carers to manage stress and reduce burden includes the effective management of neuropsychiatric symptoms and has potential to reduce risk for elder abuse.

Overall, the findings of this study showed that elder abuse and risk of abusing is high in South Africa, with perpetrators often being a non-family member with whom the older person has a personal relationship with, or a family member. It provides an important contribution to the available evidence base on elder abuse in a low-or-middle-income country like South Africa and gave insight into understanding elder abuse in context to support targeted efforts to reduce risk of abuse and provide adequate services for older adults, including people living with dementia.

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List of abbreviations

ASA	Alzheimer's South Africa
EAST	Elder Abuse Screening Tool
CASE	Caregiver Abuse Screen
DIMAMO	Demographic Health Research Surveillance Site, University of Limpopo
GDO	Global Dementia Observatory
LTC	Long-Term Care
MHPF	Mental Health Policy Framework and Strategic Plan
NDOH/DOH	National Department of Health
NDSD/DSD	National Department of Social Development
NGO	Non-Government Organisation
NHI	National Health Insurance
SAHRC	South African Human Rights Commission
SANC	South African Nursing Council
STRIDE	Strengthening Responses to Dementia in Developing Countries
SWOT	Strengths, Weaknesses, Opportunities and Threats
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

1.1 Background

Elder abuse is a serious public health concern that results in death, traumatic injury, pain, and negative mental health outcomes including depression, stress, and anxiety (WHO, 2017a). As the world's population ages rapidly, countries face the challenge of meeting the growing health and social care needs of older adults who may face a gradual decrease in physical and mental capacity and increased risk of disease as they approach end-of-life (WHO, 2022). World Health Organization (WHO) estimates that between 2015 and 2050, the world's population of older adults aged 60 years and over will double from 12% (1.4 billion) to 22% (2.1 billion), with 80% living in low-or-middle income countries (WHO, 2017a, 2022). With the increase in the number of older persons[1] globally, the number of elder abuse and neglect cases are also expected to increase with devasting consequences to health and well-being of older adults, including societal costs (Pillemer et al., 2016).

With over 60 million people in South Africa, older persons comprise 9.2% of the population, of which 6.2% are 65 years and older (StatsSA, 2022). Most older persons in South Africa are female (69.1%), with a national growth rate of 2.1% for the period 2020-2021, post-pandemic (StatsSA, 2022). Provinces with the highest concentration of persons 60 years and older include the Eastern Cape (11.6%), Western Cape (10.7%) and the Northern Cape (10.1%), while Kwazulu-Natal (8.1%) and Mpumalanga (8.2%) have the least (StatsSA, 2022). South Africa is a country with twelve official languages, with a myriad of cultures and belief systems. Spirituality plays a big role in most families, where majority South Africans identify themselves as Christian (86%), with the remaining identifying as Ancestral, Tribal or other Traditional African religions (5%), Muslim (1.9%), or Hindu (0.9%) (StatsSA, 2016). However, African Traditional Religions have historically been suppressed or hidden in South Africa, and with the rise of democracy around 1994, have gained recognition (Adamo, 2009). African Traditional Religions vary across the continent and across ethnic groups but have similar characteristics that include the belief of divinities, ancestors or forefathers, good and evil, supernatural powers, an afterlife, and sacrifices (Adamo, 2009). In this context, the origin of misfortune is believed to be *social*, and that 'witchcraft' may be responsible for negative life events

[1] We acknowledge that the terminology used to refer to older persons vary across contexts. For this study, we will use the terms 'older adults', 'older persons', and 'older people' interchangeably.

including tragedies, accidents, illness, social disputes, or extreme weather conditions (Mkhonto & Hanssen, 2018).

Historically, South African cultures value older persons as revered members of the family and broader community. It is common for older persons, particularly older women, to live with their adult children, who in the context of widespread migrant labour practices provide essential child-rearing support to grandchildren and households (Madhavan, *et al.,* 2017). State pensions also provide a valuable source of income, often supporting entire households impacted by poverty and unemployment. Older women, in particular, tend to share their pensions with family members, or pool this income to support household needs, health and wellbeing of adult children and grandchildren (Ralston, *et al.,* 2015). Therefore, the role of older persons in South African households position them as valuable sources of stable income and reproductive labour, providing opportunities that support well-being and active ageing[2] but also vulnerabilities to exploitation and abuse.

1.1.1 Defining elder abuse, risk, and prevalence

In line with World Health Organization (WHO), the South African Older Persons' Act (no.13 of 2006) defines elder abuse as "…*any conduct or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress or is likely to cause harm or distress to an older person"* (Government Gazette, 2006). This definition includes broad types of abuse that can be physical, emotional, sexual, or financial, that are intentional, reflect neglect or a combination (WHO, 2018). Elder abuse occurs within a relationship where key elements such as dependency, caregiver burden, stress and pathology, environmental stressors, socio-cultural factors, and learnt abusive behaviours create and sustain abusive situations (Downes et al., 2013; Momtaz et al., 2013). Elder abuse also occurs when older adults are targeted *because* of their age and assumed vulnerability, where the establishment of a relationship of trust (including engagements by strangers) is deliberate with the intention to deceive, exploit and abuse (Goergen & Beaulieu, 2013; Jackson, 2016). For these reasons, conceptualisations of elder abuse are complex. Understanding of what constitutes abuse is informed by values and norms that influence behaviours that vary across culture, context and time (Momtaz et al., 2013), and abuse is manifested differently across contexts (Moon & Benton, 2000). These local idiosyncrasies and cultural interpretations of behaviours make

[2] Active ageing*:* A philosophy that promotes the full participation of older persons in their societies, decision-making and keeping them in their families and communities for as long as possible (Jordan, 2009).

it hard to define the parameters of elder abuse definitively, and results in broad definitions across the globe. These broad definitions challenge effective responses to abuse, especially where less reported types of abuse are not understood or recognised, or where new types of abuse are still in the process of evolving (e.g. the development of cybercrime, online fraud, and social media scams). Broad definitions pose a challenge to the recognition and response to elder abuse, while directly affecting the accuracy and relevance of its measurement.

As definitions vary across the globe, risks of elder abuse also vary across contexts. Widely accepted risk factors for perpetration of elder abuse include high levels of care burden, poor social support, carer depression and psychopathology, substance abuse, and caregiver health status (Downes et al., 2013). For older adults, risk factors for experiencing abuse include their functional dependence status, physical and mental health, and cognitive impairment (Pillemer et al., 2016). Cognitive impairment, including dementia, compromises an individual's ability to recognise as well as disclose abuse and therefore poses greater difficulty in detecting the presence of abuse (Downes et al., 2013).

Underreporting of elder abuse is a global problem, with the WHO estimating that 1 in 6 people aged 60 and older have experienced abuse at some point, with only 4% of cases reported (WHO, 2016). People living with dementia are at increased risk of elder abuse, with global estimations indicating that 2 out of 3 people living with dementia have been abused (WHO, 2016).

1.1.2 Defining dementia as risk for elder abuse

Dementia is a broad term used to describe a collection of symptoms generated by progressive and neurodegenerative conditions that are characterised by a decline in mental ability, memory loss, and executive functioning that are severe enough to impede daily functioning (Alzheimer's Association, 2019; WHO, 2019). Globally, it is estimated that there are over 57 million people currently living with dementia, and with people living longer, it is expected to increase to 152.8 million by 2050 (Nichols et al., 2022a). Dementia prevalence is less established in low-or-middle income countries, with estimations for the four Sub-Saharan regions ranging between 2 to 4% (Prince et al., 2013). While dementia is not a 'natural' part of ageing, it is an associated risk and is characterised by the progressive loss of functioning in cognition, social ability, and behaviour (Downes et al., 2013). Onset is gradual and often goes unnoticed and characterised by memory-related issues including forgetfulness, not recognising familiar places, and losing track of time (WHO, 2019). As the condition progresses, symptoms become more pronounced affecting the individual's behaviour, functioning, communication, and increasing the need for assisted self-care and support (Downes et al., 2013; WHO, 2019). Later stages of dementia require increased assisted self-care and the person

increasingly has trouble recognising family and friends (WHO, 2019). Dementia affects each individual differently depending on type, severity, coping strategies and available support.

Caring for someone living with dementia is physically, emotionally, and financially demanding and intensifies as the disease progresses to severe stages. Caring also involves making medical decisions and providing support for end-of-life care. Dementia often exceeds the care demands of other conditions (Prince et al., 2015), carers are at greater risk of developing poorer health outcomes themselves, including anxiety and depressive symptomatology, maladaptive coping, and caregiver burden (Cooper et al., 2007). Unmanaged symptoms of dementia (especially aggression from care-recipients) are believed to act as 'triggers' of reciprocal violence by carers (Downes et al., 2013). Studies have shown that carers who expressed fears of becoming violent were more likely to be caring for someone with aggressive symptomatology (Baharudin et al., 2019; Downes et al., 2013). These realities amplify caregiving stress and the quality of the relationship between carer and care-recipient, and are linked to a greater risk for elder abuse and neglect (Campbell-Reay & Browne, 2001).

1.1.3 Elder abuse in South Africa

There are no national monitoring and reporting of the prevalence and nature of elder abuse in South Africa. A review of available studies on elder abuse also found very little research published in South Africa (Kotzé, 2018). Two studies directly assessed elder abuse and focused on the epidemiology of sexual assault among older women in the Mthatha area (Meel, 2017), and the prevalence and predictors of elder abuse in Mafikeng (Bigala & Ayiga, 2014). The epidemiological study on sexual assault in Mthatha (Eastern Cape province) was done retrospectively from 2,579 rape case hospital records and found high rates of sexual abuse among women aged 65 years and older (i.e., 17,1/10,000 in 2007 to 40/10,000 women in 2009) (Meel, 2017). The Mafikeng study (North-West province) was a multi-stage, randomised household survey of 506 older adults aged 60 years and older, that found a high prevalence of self-reported elder abuse (>60%) (Bigala & Ayiga, 2014). To date, the Mafikeng study was the only attempt to estimate prevalence of elder abuse in the South African context, and relied on a constructed composite measure of abuse indicating whether the older person respondent had 'ever experienced abuse' (Bigala & Ayiga, 2014). In the absence of high-quality and more recent data, an alternative approach is to infer prevalence of elder abuse through studies that indirectly capture underlying domains. For example, in Mpumalanga province, more than half (50.7%) of older adults surveyed (n=900) were vulnerable to financial losses due to theft or mugging (Makiwane & Kwizera, 2006).

South Africa is considered one of the most dangerous and violent countries, with the third highest crime rate in the world (i.e. 76.86/100 000) (World population review, 2023). While very little is published about elder abuse and crime against older persons in South Africa, housebreaking and robbery are the most common types of crime experienced in households, with consumer fraud having increased significantly by 373.3% between 2018/19 and 2019/20 police (StatsSAb, 2019). Individual crime levels in South Africa are also underreported, with property crime at 38%, robbery at 42%, assault at 42%, and fraud at 26% being reported to the police (StatsSAb, 2019). Fear of crime and multiple victimisation is pervasive in South Africa, with older persons experiencing higher levels of fear than their younger counterparts (Fry, 2017). Ageing in South Africa is characterised by social determinants like poverty, social exclusion and the impact of high unemployment and crime (SAHRC, 2015). Although the South African Human Rights Commission has launched an investigation into the systemic complaints in the treatment of older persons (SAHRC, 2015), response to these issues has been slow. The promotion of human rights for older persons therefore remains threatened by widespread crime and violence.

1.1.4 Screening for elder abuse in South Africa

There are no validated or culturally adapted measures available to screen for elder abuse in South Africa, and Africa more broadly (Fang & Yan, 2018). As showed previously, local studies relied on measuring elder abuse indirectly through quality of life measures (Makiwane & Kwizera, 2006), or creating a composite measure asking respondents if they ever experienced abuse (Bigala & Ayiga, 2014). Although these studies provide valuable insight to a phenomenon severely under-studied in South Africa, they lack scientific rigor in detecting abuse and have not demonstrated the cultural appropriateness of their measures in identifying potential abuse, or risk of abuse in a multi-lingual and multi-cultural context like South Africa. Firstly, there is a need to use valid tools sensitive enough to predict risk of abuse, support the detection of risk and abusive experiences, and provide a basis to facilitate early intervention (Gallione et al., 2017). Secondly, there is a need to cross-culturally adapt these tools within the contexts of South Africa as local understandings and interpretations have implications for accurate measurement beyond that which one-way translations can offer (Beaton et al., 2000).

Globally, there are various tools developed and validated across contexts to measure elder abuse (e.g. Neale et al., 1991; Reis & Nahmiash, 1995, 1998a, 1998b; Schofield & Mishra, 2003; Yaffe et al., 2008). For this study, two tools have been selected for translation and cross-cultural adaptation, namely the Elder Abuse Screening Tool (EAST) and the Caregiver Abuse Screen (CASE). The EAST was developed in South Africa through a collaboration between the National Department of Health

(NDOH) and the WHO to support professionals in detecting self-reported elder abuse, and support protection services in targeting appropriate interventions (NDOH, 2011a). With no evidence available on the tool being tested or validated, the EAST was originally designed for screening elder abuse in South Africa, and deemed a contextually relevant and appropriate tool to adapt and test for use in this study. The EAST is however reliant on the self-report of abuse, which may be problematic in people living with dementia as their recall ability and their capacity to disclose abuse may be compromised as the condition progresses. Therefore, we wanted to also understand carers' perspectives and screen for risk of elder abuse among household informants who know the older adult best and provide care and support to their older adult. The CASE is a non-confrontational tool that screens for risk of abusing amongst carers (Reis & Nahmiash, 1995). It was selected for its non-blaming questions and its potential to circumvent the challenge of potential perpetrators not disclosing abuse for fear of self-incrimination. The CASE has been validated across various contexts, including assessing risk of elder abuse amongst carers of people living with dementia (Melchiorre et al., 2017). The EAST and CASE have never been cross-culturally adapted or tested in South Africa.

1.1.5 Social determinants of risk of elder abuse in South Africa

Characterised by widespread poverty and unemployment, South Africa is considered one of the most unequal countries in the world (The World Bank, 2018). The need to migrate for work, together with the high prevalence of HIV/AIDS has shifted the roles of older adults to providing care for their missing or ill adult children, and/or raising and providing for their grandchildren (Kotzé, 2018). Families dependent on migrant labour practices for income therefore become entirely dependent on the older adults' reproductive labour to support households and child care while adult children are away to work. Old age pensions are often the only stable source of income supporting entire households, while a lack of income and financial resources for younger people in South Africa has resulted in older persons becoming targets for financial abuse and exploitation.

Socio-cultural factors have also been linked to greater risk of violence and abuse against older persons. Like other African countries, women in South Africa (especially black women) are particularly vulnerable to allegations of 'witchcraft' that result in extreme violence, being burned, assaulted, and violently killed (Kalula & Petros, 2011; Kotzé, 2018; Mkhonto & Hanssen, 2018). Although research on these killings are limited, a few studies link 'witchcraft' allegations to economic motivations such as confiscating property from elderly women (Kotzé, 2018). Allegations of 'witchcraft' has also been linked to dementia, where symptoms such as confusion, memory loss, and mood alterations have been understood as being 'bewitched' or 'cursed' (Khonje et al., 2015), increasing risk of violence against people living with dementia. These risks and social determinants

of violence are poorly understood in a context of elder abuse in South Africa, with limited information available on how these factors specifically affect persons living with dementia.

1.2 Rationale and overall study aims

Research on elder abuse in low-or-middle income countries, including South Africa, is limited (Kotzé, 2018), with serious gaps in available research on older persons at risk of abuse, especially people living with dementia. South Africa has not established elder abuse prevalence and risk conclusively, and to date have a poor knowledge base on elder abuse and dementia to inform priority setting for adequate health and social care responses to provide support and protection to older persons. This study therefore responds to these gaps and generates evidence through the following broad aims:

1. To provide a situational analysis on current service provisions for dementia and elder abuse for older adults, including people living with dementia and their families.

2. To cross-culturally adapt the EAST and CASE screening tools in South Africa, to detect self-reported abuse and risk of abusing from older persons' and potential perpetrators' perspectives respectively.

3. To examine the nature of self-reported elder abuse using the EAST to generate evidence on the prevalence, predictors, and perpetrators of abuse.

4. To estimate the prevalence and predictors of risk of abusing using the CASE amongst household informants, including carers for people living with dementia.

See flowchart of study design in Figure 1 below:

SUB-STUDY 1: Situational analysis on dementia and elder abuse in South Africa

Purpose:
To identify current and future needs; and inform priority setting for strengthening service provision, care, protection and support.

OUTCOMES

South Africa needs contextually appropriate ways to **measure** and understand elder abuse;

SUB-STUDY 2:
CROSS-CULTURAL ADAPTATION of the Elder Abuse Screening Tool (EAST) and Caregiver Abuse Screen (CASE)

Outcome:
Culturally relevant tools to screen for elder abuse risk in South Africa (i.e. both older adult and carer perspectives).

Urgent need for **data** on prevalence to inform priority setting setting for health, social care, and support services.

SUB-STUDY 3:

PREVALENCE, PREDICTORS, AND PERPETRATORS of self-reported elder abuse.

Outcome:
Generated evidence to understand the nature of self-reported abuse (i.e. from older persons' perspective).

Identify **risk factors** for elder abuse to inform priority setting for health, social care, and support services.

SUB-STUDY 4:

PREVALENCE AND PREDICTORS OF RISK OF ABUSING older adults and people living with dementia

Outcome:
Generated evidence to understand risk of abusing (i.e. from carers' perspective).

Figure 1: Flowchart of study design

1.3 Study design methodology

This study was nested within the STRIDE project (i.e., *Strengthening responses to dementia in developing countries, see www.stride-dementia.org)*, an international study funded by the Global Challenges Research Fund (GCRF) (2017-2022) and led by the London School of Economics and Political Sciences (LSE). South Africa was one of seven participating middle-income countries that also included Brazil, India, Indonesia, Kenya, Jamaica, and Mexico. This study on elder abuse was nested within the South African component, where my full-time responsibilities as the research officer on the project included the bulk of the planning and coordination of research activities, doing as well as overseeing qualitative and quantitative data collection, data cleaning, analyses, write up and dissemination for the overall South African and doctoral components. My involvement was thus at all stages of the research process. Given that the STRiDE project was a team effort, I use the plural of 'we/our' to reflect this team effort.

The study aims will be addressed in four sub-studies that describe the landscape of elder abuse in South Africa across four chapters. Each sub-study (chapter) will provide details about its design and methods, including selected materials and tools, participants, procedures, and analyses. This section provides a broad overview of the study design and overall methodology for the four sub-studies:

1.3.1 Sub-study 1: Situational analysis

Aim: To provide a situational analysis on current service provisions for dementia and elder abuse for older adults, people living with dementia and their families in South Africa.

The study presented in Chapter 1 consisted of two parts, where Part I presents evidence on the available service provisions in health, social care, and support for older adults, including people living with dementia and their families. Part II provides a closer examination of the status of elder abuse support provisions in South Africa. To address both parts, this study consisted of three phases of data collection, including a desk review, multi-stakeholder interviews and a SWOT-analysis (i.e., strengths, weaknesses, opportunities and threats). Evidence was collected using a topic guide (Comas-Herrera et al., 2021), and analysed to describe the status of services available to older persons, including people living with dementia and their families, in relation to dementia and elder abuse.

1.3.2 Sub-study 2: Cross-cultural adaptation of elder abuse screening tools

Aim: To cross-culturally adapt the EAST and CASE screening tools in South Africa, to detect self-reported abuse and risk of abusing from older persons' and potential perpetrators' perspectives.

The EAST and CASE was cross-culturally tested and adapted for its appropriateness to use in South Africa across two regions (Limpopo and Western Cape) and four languages (English, Afrikaans, isiXhosa and Northern Sotho) using a cognitive interviewing methodology.

1.3.3 Sub-study 3: Prevalence, predictors and perpetrators of self-reported elder abuse

Aim: To examine the nature of self-reported elder abuse using the EAST to generate evidence on the prevalence, predictors, and perpetrators of abuse.

Nested within the STRIDE household survey, the adapted EAST was used to screen older adults 65 years and older for *self-reported abuse*. The survey was done in the Dikgale, Limpopo Province, and Cape Town, Western Cape Province, areas in English, Afrikaans, isiXhosa and Northern Sotho (Sepedi). Households were selected using randomisation techniques suited to each of the regions and included the formal measurement of various health and well-being components, including dementia and severity, neuropsychiatric symptoms, social engagement, recall ability, elder abuse, and functional impairment status.

1.3.4 Sub-study 4: Risk of abusing older adults and people living with dementia

Aim: To estimate the prevalence and predictors of risk of abusing using the CASE amongst household informants, including carers for people living with dementia.

Also nested within the STRIDE household survey described in sub-study 3, the adapted CASE was used to screen for *risk of abusing* amongst household informants that were defined as a household member that knew the older adult best, spent at least 4 hours a day together, and provided care and support to the older adult where needed. Formal measurement of various health and well-being components for this sub-study included dementia and severity, neuropsychiatric symptoms, care burden and need, living and relationship status, social engagement, elder abuse, and functional impairment status.

1.4 Chapter layout

This study is presented across six chapters, each with an introduction, methodology, results, discussion, limitations, recommendations, and conclusion section. References and appendices listed as Chapter 7 and 8, respectively. Study chapters (2-6) are summarised as follows:

Chapter 2: Dementia and elder abuse in South Africa: A situational analysis

This chapter is divided into two parts. The first (Part 1), presents the evidence from the three phases of data collection (desk review, multi-stakeholder interviews, and SWOT-analysis), linking the lack of

current service delivery to a greater risk of elder abuse and neglect. The second (Part 2) section expands on these findings and provides a closer examination of elder abuse, identifying current and future needs to inform priority setting for strengthening service provision, care, protection and support.

Chapter 3: Cross-cultural adaptation of the EAST and CASE screening tools for elder abuse in South Africa

This chapter examines the complexities in detecting elder abuse in community settings and presents the findings of our cross-cultural adaptation of the EAST and CASE, using a cognitive interviewing methodology. We show how these tools have the potential to screen for risk of experiencing (EAST) or perpetrating (CASE) abuse from both carer and older adult perspectives and provide suggestions on how out-of-scope interpretations of the questions asked can be mitigated.

Chapter 4: Prevalence, perpetrators and predictors of self-reported elder abuse

This chapter fills a critical gap in the evidence base for elder abuse in South Africa, and presents evidence on the prevalence, perpetrators and predictors of self-reported elder abuse. Adjusting for participants with dementia's recall ability, this study provides a unique contribution by including the participation of people living with dementia, and older persons in general.

Chapter 5: Risk of perpetrating elder abuse in South Africa: A prevalence study using the Caregiver Abuse Screen (CASE)

Using the Caregiver Abuse Screen (CASE) in assessing risk of abusing amongst carers, this chapter provides evidence on the prevalence and predictors of risk of abusing older adults. We show how carers of people living with dementia are more likely to be perpetrators of abuse compared to carers of older adults without dementia. We also show how a range of associated factors that increase risk of abusing, that include both carer and older adult characteristics.

Chapter 6: Discussion

This chapter provides a discussion on the key findings from the four sub-studies and reflects on the implications of these for research and practice. We also discuss the strengths and limitations of this study and reflect on how our findings contribute to the global measurement of elder abuse.

Chapter 7: Conclusions and recommendations

This chapter brings together the main issues raised by this study. We provide recommendations to inform priority setting to strengthen health and protection responses for older adults and people living with dementia in South Africa. In this final chapter we call for action to strengthen systems

that support the recognition and reporting of elder abuse, health promotion, service and policy development. The chapter concludes with recommendations to further develop elder abuse theory in South Africa and evidence-based practices, through the integration of surveillance and evaluation efforts of elder abuse across sectors.

References and Appendices are provided at the end of the thesis.

CHAPTER 2: DEMENTIA AND ELDER ABUSE IN SOUTH AFRICA: A SITUATIONAL ANALYSIS

This chapter consists of two parts presenting a situational analysis of dementia and elder abuse in South Africa. Part I presents the evidence on current service provisions for people living with dementia, and how deficits in the health and social care systems may pose greater risk for elder abuse and neglect. This part combines three sources of information (desk review, multi-stakeholder qualitative interviews, and a Strength, Weaknesses, Opportunities and Threats [SWOT] -analysis) to inform priority setting for the strengthening of services for older persons in South Africa and decreasing risk for elder abuse and neglect. This part has also been submitted for publication and is currently under review[3]. Part II expands on the insights gained from stakeholders interviewed and provides a closer examination of the status of elder abuse support provisions in South Africa.

2.1 PART I: Dementia in South Africa: a situational analysis

2.1.1 Introduction

It is important to understand the landscape of available care and support for older persons, people living with dementia and their families to strengthen its responses to dementia in South Africa. Despite limited or absence of regional and national data, the Global Burden of Disease (GBD) forecasts a 181% increase in dementia prevalence between 2019 (241,937) and 2050 (680,045) for South Africa (Nichols et al., 2022b). As populations age and people live longer, the need for care and support increases as the prevalence of chronic conditions increases. Older persons in South Africa are defined as 60 years and older and comprise 9.15% of the population (i.e. 5.5 million people) (StatsSA, 2021), and projected to increase to 15.4% in 2050 and 27.8% in 2100 (United Nations, 2015). With competing public health concerns and social care priorities such as HIV/AIDS, gender-based violence (GBV) and poor early childhood development (ECD), dementia and long-term care (LTC) for older persons have not received adequate attention in South Africa. The lack of research and policy focus on geriatric health and dementia (Lloyd-Sherlock, 2019) has significant consequences for health and social care system preparedness. There is a growing need for culturally appropriate responses to support 'ageing-in-place' or 'active ageing', promoting the protection and

[3] Part I is under review and is presented in this chapter, with minor adaptations in terminology for this thesis.

inclusion of older persons in daily living and decision-making at home and within communities (Jordan, 2009).

This part presents a situational analysis of existing provision of healthcare, social care and support for older persons, people living with dementia and their families in South Africa. Situated against the current and future needs for this population group, it is intended that this situational analysis provides an evidence base to inform priority-setting for strengthening responses to dementia in South Africa.

Evidence was generated via three phases: (1) a desk review guided by a comprehensive topic guide (Comas-Herrera et al., 2021) and including WHO's Global Dementia Observatory indicators (WHO, 2017b); (2) multi-sectoral stakeholder interviews to verify secondary sources used in the desk review, and identify gaps and opportunities in policy and service provisions; and (3) a *SWOT* analysis in current care and support provision for older persons and their families in South Africa. The purpose of this chapter is to present key findings from these three phases, with an emphasis on the insights derived through stakeholder interviews; the full desk review and SWOT-analysis can be accessed elsewhere (see Jacobs, *et al.,* 2022a).

2.2 Methodology

Nested within the STRiDE project (*Strengthening responses to dementia in developing countries*), this study was funded by the UK Research and Innovation's Global Challenges Research Fund (GCRF) that aimed to contribute to improving dementia care, management and support for people living with dementia and their families (see https://stride-dementia.org/).

2.2.1 Phase 1: Desk Review

A desk review was conducted following a detailed topic guide developed by STRiDE investigators. It covered ten 10 areas: (1) overall country context (population, demography); (2) health system; (3) LTC system; (4) policy context; (5) dementia awareness and stigma; (6) epidemiology and information systems for dementia; (7) the dementia care system; (8) unpaid care and other informal care; (9) social protection; and (10) dementia research (see Comas-Herrera et al., 2021). The topic guide also included WHO's Global Dementia Observatory (GDO) indicators and resulted in a detailed, in-depth situational analysis of care and support arrangements for older persons in South Africa. The full situational analysis includes a SWOT analysis to inform other dimensions of the STRiDE project, modelling the current and future costs for each participant country (see www.stride-dementia.org/).

Evidence sourced for the desk review included official government policies, legislation and reports, country-specific statistical releases, academic peer-reviewed journal publications, grey literature, and institutional reports obtained through university and/or public repositories. The desk-review was additionally guided by an overall cross-country desk-review guide (Comas-Herrera et al., 2021). In cases where official sources were not available, we included media and organisational websites and available online resources.

2.2.2 Phase 2: Multi-stakeholder engagement

Phase 2 focused on multi-sectorial stakeholder consultations with key decision-making and topic experts, and experts by experience (i.e., people living with dementia and their carers). We conducted in-depth, semi-structured interviews with stakeholders from (a) the public healthcare sector; (b) the social care and support sector; (c) government officials; (d) civil society and non-governmental organisations (NGOs); (d) traditional healing; (e) the private LTC and support sector; and (f) people living with dementia and their carers.

a) Topic guides

Semi-structured interview topic guides were generated separately for decision-making and topic experts and for experts by experience, *a priori.* Following completion of Phase 1, these topic guides were adapted for relevance to both the interviewee(s) and the identified gaps in the evidence base. Broadly, the interviews with experts by experience included questions about their experiences of and perspective on diagnostic and care services, social support and care and elder abuse. Interviews with decision-makers and topic experts were tailored to their experience with and expertise on dementia, where questions broadly focussed on (i) health services; (ii) prioritisation concerning detection and management; (iii) data and surveillance; (iv) awareness and prevention; (v) LTC services; (vi) policy prioritisation, development, and progress; and (vii) elder abuse. The final topic guide(s) are available in Appendix 1.

b) Participant recruitment

A total of 12 stakeholders were interviewed across six predefined sectors, namely health, social care, ageing and civil society, traditional healing, LTC, and experts by experience. We purposively selected stakeholders to include both national and provincial level officials, and across geographic regions. People living with dementia and their carers were included as experts by experience because they have personal experience in seeking help and accessing services and provide valuable insight to the experiences of dementia care service users. We recruited participants in collaboration with

members of the STRIDE South African Advisory Group (SAAG)[4] or identified via information freely available on official government websites. We used snowballing techniques, asking enrolled participants to share our project information letter with their contacts. For inclusion, stakeholders were required to have a minimum of two years' experience in their sector. Experts by experience were included if they had received a formal diagnosis of dementia or have been living with or caring for a person diagnosed with dementia for at least two years.

c) Procedure

Stakeholders were interviewed virtually to accommodate COVID-19-related restrictions with face-to-face contact. Interviews ranged between 40 and 90 minutes and were led by one interviewer (RJ or MS) and either one or two co-interviewers (RJ, MS, PDT, or SD). One interview was done jointly because a person living with dementia and carer felt most comfortable to be interviewed together. Informed consent was obtained from all participants, with precautions taken to explain information letters and consent forms verbally, via a virtual platform. The consent process was documented either digitally (where both audio and visual recordings of the consenting procedure were transcribed verbatim and filed securely and separately to the interview content); or via signed consent forms returned to the researchers via email.

d) Analysis, rigor and reflexivity

All interviews were digitally recorded (audio and visual), transcribed verbatim for quality and analytic purposes, and entered into NVivo 12 (NVivo, 2022). Inductive thematic analysis was conducted to interpret the complexity and richness of the information collected, and sorted into dominant themes (Nowell et al., 2017; Thomas, 2006). The PhD candidate analysed the transcripts following Braun and Clarke's (2006) approach to thematic analysis, in the following steps: (1) familiarising with the data; (2) generating first-level codes; (3) identifying themes; (4) reviewing themes; (5) refining themes; and (6) generating the findings and report (Braun & Clarke, 2006). Our study employed various strategies that determine the validity of qualitative, inductive analysis such as peer debriefing, member-checking, triangulation and thick description (Creswell & Miller, 2000). The PhD candidate led on the coding, with debriefing discussions with co-interviewers. Follow-up discussion with participants (member-checking) allowed for the validation of interpretations as well

[4] SAAG: This group included representatives from the National Department of Health, National Department of Social Development, Alzheimer's South Africa (ASA), the South African Older Persons' Forum, the South African Human Rights Commission, academics and researchers and people living with dementia and carers.

as enhancing the positionality[5] of participant insights, especially when presenting information on traditions, beliefs, and cultural practices (as researchers are situated outside of the cultural belief systems that participants described). We include detailed narratives (thick description) to provide readers with an understanding of the context of the account and make decisions about the transferability of findings to other similar conditions (Creswell & Miller, 2000).

e) Ethical considerations

Precautions were taken by the lead interviewers, including myself, to ensure participants living with dementia understood the purpose and expectations of the study (Lee, 2010), retained and engaged with the information to make a decision, and that they were able to clearly communicate that decision (Gilbert et al., 2017). People living with dementia and their carers in this study were existing service users of our NGO partner, Alzheimer's South Africa (ASA), a national organisation with offices in 8 of the 9 provinces in South Africa. An ASA social worker, and co-author on the submitted paper, provided support to participants with dementia and their carers during the interviews. No people with severe dementia and without capacity to consent were interviewed. Special precautions to de-identify stakeholder narratives were taken to protect the anonymity and confidentiality of participants and the specific organisations they represent. Participants are positioned in terms of the broader sector they represented.

2.2.3 Phase 3: SWOT analysis

We performed a SWOT analysis to further inform priority-setting and identify weaknesses and threats to provide insight to managing risks that undermine priorities (Gurel & Tat, 2017). Four steps were followed: (1) collect data and information (desk review); (2) critically evaluate data and sort factors across the four SWOT components; (3) populate the SWOT matrix, categorising factors as they relate to the health system, LTC, economic context, political context, legal and social protection context, and cultural and societal context; and (4) incorporate inputs from the multi-stakeholder interviews (Docrat, Lorenz, et al., 2019). Factors were listed in four-quadrant SWOT tables.

[5] *Positionality* - a concept that acknowledges the context in which identity, understanding, and world views are influenced by factors such as race, class, gender, sexuality and ability (Dictionary.com, 2018).

2.3 Findings

2.3.1 Phase 1: Desk review findings

a) Healthcare system

South Africa's health system is divided into two sectors: public and private. The public sector offers free healthcare for 84% of the population (Mahlathi & Dlamini, 2015) who cannot afford private medical insurance and the out-of-pocket payments. Public health services are rationed by queuing systems and long waiting lists. Despite active redresses by government, the health sector is still characterised by unequal access to services and resources (including human, financial and technological), with an urban bias despite most of the population (64.7%) living in rural areas (Mahlathi and Dlamini, 2015; South African Government, 2017; Competition Commission SA, 2018). State sources estimate that rural populations are serviced by only 12% of doctors and 19% of nurses in the country (NDOH, 2011b), with an estimated 79% of physicians in the private sector (Rawat, 2012). Access to private medical care is contingent on having medical insurance, which few South Africans can afford (16%) (Mahlathi and Dlamini, 2015; StatsSA, 2019). Escalating private sector rates are the result of an unregulated pricing environment, lack of integrated care models and solo practices that incentivise practitioners to provide more services than needed through their own activities and through referral for further investigations and hospitalisation (Competition Commission SA, 2018).

There are no dementia-specific services at the primary healthcare level, with fewer than ten geriatricians and five geriatric psychiatrists (Kalula & Petros, 2011) to serve the entire country of over 5.5 million older persons (StatsSA, 2021). The poorest South Africans live furthest from healthcare facilities (Mclaren et al., 2013), with time and travelling costs to the nearest centre posing significant barriers to access and health (Fusheini & Eyles, 2016). Diagnostic pathways for dementia are weakened by common misperceptions amongst primary healthcare staff that dementia is a natural part of ageing, not requiring referral for further assessment, diagnosis and management of care (Kalula et al., 2010; Kalula and Petros, 2011; Jacobs et al., 2022). Therefore, most people living with dementia in South Africa remain undiagnosed and cared for without professional or other formal support. South Africa has standard treatment guidelines for the pharmacological management of dementia (Emsley et al., 2013; NDOH, 2020), but the public sector has a general shortage of available pharmaceutical supplies (South African Government, 2017).

South Africa is a multi-cultural country with twelve official languages and a myriad of customs, beliefs, and practices. Traditional healing among some cultures is a way of life, with diseases,

misfortune, and especially mental or emotional conditions understood as being social in origin (Mkhonto & Hanssen, 2018). Traditional healers often live amongst the people in communities, speak the local languages and provide a rich source of support for the whole family (Audet et al., 2017). Cultural beliefs play an important role in understanding dementia, where symptoms are often viewed with suspicion and fear, and where stigma sends families into hiding and avoiding help-seeking (Mkhonto & Hanssen, 2018; Mukadam & Livingston, 2012).

b) Social care and Long-term care (LTC) sector

Social care and support services, including LTC, vary greatly across South Africa. Access to LTC services is largely limited to those who can afford out-of-pocket payments as medical insurance companies do not support LTC and residential care services. Available LTC services (including home care, residential care facilities, respite care) are skewed towards the private sector with many being unregistered with the Department of Social Development as required (Mahomedy, 2017).

Community-based services for people living with dementia are limited and based within the NGO-sector, with two dementia-specific NGOs in South Africa: Alzheimer's South Africa (national coverage), and Dementia-SA (Western Cape province). Government relies heavily on the NGO sector to provide psychoeducation and support to people living with dementia and their families, and to link service users to home-based care, counselling groups and legal advice. There are no nationally representative data available in South Africa on caregiving arrangements specific to dementia care, although a small study in Cape Town showed that 79% of persons living with dementia were cared for at home either by a spouse or an adult child (Kalula et al., 2010).

c) Policy environment

South Africa currently has no national dementia policy or health plan. The Department of Social Development (DSD) is the custodians of the *Older Person's Act* (no.13 of 2006) that broadly promotes the rights, protection and care provision for older persons and ageing in general, while the *Older Person's Programme* is responsible for coordinating services to older persons and includes awareness, educational, communication programmes, and residential care services (Jordan, 2009). The Older Person's Act recognises the State's responsibility for developing home-based care and providing information, education and counselling services, and includes care for Alzheimer's disease and other dementias (amongst other conditions) (see section 11 (2)(c) of the Older Person's Act, p.13*)* (Government Gazette, 2006). The *Older persons' programme* (Jordan, 2009) and the *Protocol on management of elder abuse* (DSD, 2010) were established by the Department of Social Development to support the development of a 'self-reliant society' that empowers and protects

older persons, while promoting their well-being, safety and security (Jordan, 2009). Current policies support services for older persons and are embedded in an *'active ageing'* philosophy that promotes the full participation of older persons in their societies, decision-making and keeping them in their families and communities for as long as possible (Jordan, 2009). The shadow side of this philosophy is that the absence of adequate community-based support services for dementia locates care primarily within the family, where women often adopt care roles without support, and result in excessive burdens (Lloyd-Sherlock, 2019).

South Africa has strong policy support for moving toward universal healthcare through the development of the National Health Insurance (NHI). The objective of the NHI is to provide quality healthcare regardless of a person's economic status and ability to contribute to the fund (NDOH, 2017). However, despite these plans for redress of widespread inequality in South Africa, implementation of the NHI has been slow, with unclear funding modalities and lack of plans for how this scheme will be fully implemented and sustained. In 2013, the National government adopted the Mental Health Policy Framework and Strategic Plan (MHPF) (2013-2020) that promotes an integrated care model for mental health in South Africa, supporting the decentralisation of primary care to home- and community- based services (NDOH, 2013). However, like the NHI, these policies are largely 'dementia-invisible' with no provisions articulated for dementia care and support services for persons living with dementia and their families. South Africa faces many challenges with policy implementation and corruption across a wide range of sectors. An evaluation of the health system costs of mental health services and programmes in South Africa showed that (i) despite the national policy agenda promoting the decentralisation of services, 86% of mental health service costs remain directed at inpatient services, with the majority of this spending occurring within specialised psychiatric hospitals, (ii) significant disparities exist between provinces on resource allocations, and (iii) there is limited evidence of community-based reforms being initiated (Docrat, Besada, et al., 2019).

2.3.2 Phase 2: Stakeholder interviews

a) Stakeholder characteristics

The 12 stakeholders interviewed shared their views and experiences from multiple roles. For example, two participants were interviewed in their capacity as a representative for their sector but also had personal experience with caring for a parent living with dementia. Table 1 provides a description of these stakeholders and their multiple roles and experiences. The numbers in the 'Interviewed' column reflect the number of interviews covering that role perspective. Stakeholders

were from five of the country's nine provinces: Gauteng, Free State, Kwazulu-Natal, Western Cape, and the Eastern Cape provinces.

Table 1: Stakeholders characteristics

Sector	Stakeholder	Interviewed	Sex (F, M)
Experts by experience	Person living with dementia	2	(2F, 0M)
	Carer of person living with dementia	3	(1F, 2M)
Health	Clinician, Geriatric medicine	1	(1F, 0M)
	Occupational therapist	1	(1F, 0M)
Traditional healing	Traditional healer	1	(1F, 0M)
Long-term care	Academic	3	(2F, 1M)
	Care home management	1	(0F, 1M)
Ageing, social care, and support	Ageing and civil society	1	(0F, 1M)
	National Department of Social Development	2	(2F, 0M)
	Provincial Department of Social Development	1	(1F, 0M)
	Non-governmental/non-profit organisation	3	(2F, 1M)

b) Thematic map of stakeholder interviews

The multi-stakeholder interviews largely corroborated the findings of the desk review and provided valuable insight to existing diagnostic services, post-diagnostic support, socio-cultural factors, and LTC and support provisions in South Africa. Findings showed how these fragmented systems largely leave people living with dementia and their families with poor diagnostic, referral and support outcomes, and at risk of elder abuse and neglect. Figure 22 provides a thematic overview of these findings.

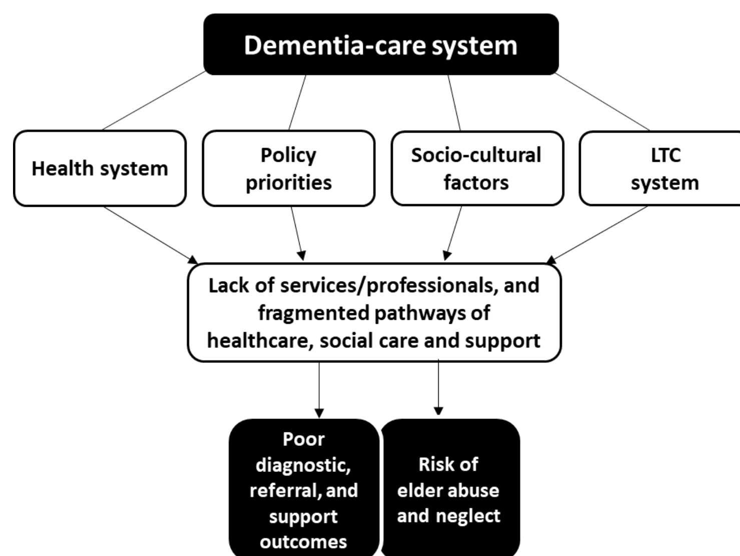

Figure 2: Thematic map of stakeholder interviews

c) Access to diagnostic services

There are many factors influencing access to a dementia diagnosis in South Africa. Referral and diagnostic pathways were described as fragmented, with no specific dementia services at primary healthcare level. Variations in the medical training of primary healthcare doctors and nurses were highlighted as a serious gap in the health system, affecting the identification, diagnostic capacity, and management of dementia.

For example, training nurses on dementia is not prioritised, with reluctance from both nursing schools and the regulating nursing council to include geriatrics in the curriculum:

> *"… for nurses to train in geriatrics, we have tried that, but they say that, that has to be on a postgraduate level, and they are not sure about how much intake there would be…Nursing and geriatric training is a national issue which, over many years, we have tried to motivate for it, but the nursing council haven't really agreed to have it incorporated. We worked together with the Department of Health, the geriatric sector, to try and talk to the nursing council, but for some reason they seem not to have room for that up to now…" (Participant 11, Clinician, Public health service).*

Nurses were seen as the backbone of the South African public healthcare system. The low prioritisation of geriatrics and dementia training in nursing curricula limits the availability of a critical healthcare resource for people living with dementia. One carer shared about the devasting effect of dementia being unacknowledged in a healthcare setting. Her mother was admitted to hospital after experiencing a stroke and, despite informing nurses that her mother had dementia, she found her mother restrained because staff were unable to manage her behaviour. She was discharged without notifying the family (or doctor). She was lost and tried walking home over 13 kilometres before being found:

> *"I found my mother [restrained] with bandages after she had a stroke. Legs and arms…And the next week she got discharged without the nurse consulting the doctor. So, she walked…being disorientated and not knowing who she was…her feet had blisters and she fell over the bridge from [suburb name], trying to get to [name of suburb she lives in]. And people that recognized her, brought her home…" (Participant 10, Carer and Healthcare professional).*

A clinician described how the skill and knowledge of qualified general practitioners (GPs) differ since medical training and exposure to geriatrics vary considerably across the country. Some also believe

that nothing can be done for someone with dementia. These factors therefore preclude the identification of dementia and referring patients for formal assessment and diagnosis:

> *"…at the community level regarding health services…there's not much specific in the management of dementia…What is unfortunate is that the medical schools within the country, not all of them have any exposure to geriatrics at all, so probably only half the medical schools, so that some practitioners finished their training without much exposure to how older people differ [and] their management differs from younger adults. So unfortunately, it's not just the layperson, it's even the qualified practitioner…for them to say, 'maybe this is dementia, probably this needs a further referral'…or if they decide to say 'oh, you know what can be done about it anyway'? 'What's the point of me referring?' So that's how it is that not everybody is picked up and not everybody…finds it essential or necessary to refer someone on for further assessment" (Participant 11, Clinician, Public health sector).*

Participants living with dementia confirmed this reality and shared their experiences with private GPs that dismissed dementia based on their (younger) age. The first participant described a long journey of yo-yoing between a series of general practitioners and neurologists with poor outcomes:

> *"Then we went to this neurologist [Dr A]. And…he said that…he suspected that I have early onset dementia, Alzheimer but he wasn't sure…he just suspected. I went back to work. Then, I went back to the GP and…suggested that I see [Dr B, another neurologist]. I went to him, and he then diagnosed me…I think it was a year after he diagnosed me, I went to the GP, the first GP and then he said no, I'm too young and he doesn't think so. So, he made[me] go off all the tablets…which I did…I carried on working…he didn't believe me because of my age…he thinks I should go off all the tablets and carry on with my life. And then that's when I went back to Dr B [2nd neurologist] and I said to him what the GP said…And he said he can do is do all the tests and things again. Which he did. And then apparently, he sent a new report back to the GP to say you know, that this is the situation. I then left that GP I didn't go back to that GP again" (Participant 4, Person living with dementia).*

Delays in diagnosis and help-seeking were evident. An experienced clinician linked delayed help-seeking to beliefs of dementia as 'natural ageing', also creating risk for elder abuse when families cannot cope with advanced care needs and when changes in behaviour is not understood as a symptom of dementia:

> *"But what we see mostly is that, even for those[families] who are knowledgeable, they don't feel the need of referring someone in the early stages. So, you find that the only time they*

are prompted to seek any help is when some behavioural or some either feeding or incontinence or something has developed that they are having challenges to cope with, at that point then that's when they feel, 'I think we need help'. So, in the early stages when it's…mild things that they can manage…families don't feel they need to consult anyone about it mostly in the early stages it's regarded as 'this happens when you get old… sometimes there is no understanding of certain behaviours, you know this might be due to dementia. Unfortunately, abuse might even set in at that point because they…cannot live with this change, the challenge" (Participant 11, Clinician, Public health sector).

Even when awareness and understanding of dementia are good, the reality is often that there are no services available to refer patients to, adding to the belief amongst practitioners that nothing can be done to support people living with dementia:

"…family members who have the knowledge, they will say something like 'I live in the Eastern Cape, do you know anyone in this area who can see my mother or my father…who can give a proper assessment? We think she has dementia.' So that is a well-informed family, but then they don't have a service to go to" (Participant 11, Clinician, Public health sector).

All participants agreed that current responses to dementia in South Africa are inadequate and that there is a need for awareness amongst the general public, as well as education and training on dementia for healthcare staff. One participant summarised these views and talked about the inadequacy of current responses to dementia, noting how education and training are critical tools for awareness and understanding:

"…firstly, I think there needs to be a general societal awareness…community clinics in all the areas that have staff that are equipped to see the early warning signs, to start doing some psychoeducation around healthy ageing…we're not even out of the starting blocks in many respects of people understanding dementia…I'm not talking about in rural remote areas. I'm talking about urban areas. I'm talking about educated people…basic understanding in the community is still lacking. There's lots of misconceptions…that escalates people's fear...in rural and remote settings there's lots of suspicion around symptomatic behaviour of dementia patients. I think services are completely inadequate." (Participant 6, Ageing, Social Care and Support sector).

d) Post-diagnostic support

While there remain many barriers to a timely diagnosis for people living with dementia, as described above, a further challenge (if a diagnosis is obtained) is inadequate post-diagnostic support in South Africa.

One of the main challenges reported by experts by experience in this study was that after diagnosis, there was no information or support on how to manage dementia beyond pharmacological responses. One couple shared their post-diagnostic experience in the private sector:

> *"…she's[neurologist] never even sat with me. When we came there, I said to [husband's name], what now? What now? I think if you are there for the time with your doctor, whose given you this thing [diagnosis], surely you would like…[to be] more clearer about things which didn't come from my neurologist." (Participants 1, Person living with dementia).*

Post-diagnostic support is, however, offered in pockets by healthcare staff that have more understanding of dementia. A clinician reflected on a strength of the public (tertiary) health system where patients are linked to their community practitioners to co-manage care when re-entering the community:

> *"…we advise families to consult the practitioner who sees them so that we can get full medical background. Also, the reason why we insist that there should be a practitioner involved in the community is that the management has to be bi-directional. After assessment we need to send them back to somebody in the community who can co-manage…we do refer family members to contact [NGO name] to join the groups to support families [and] the patients themselves." (Participant 11, Clinician, Public health sector).*

Medications that support dementia symptom management are not freely available and come at a considerable cost. The minority who can afford medical insurance and/or out-of-pocket payments are able to secure long-term use of medications via private pharmacies:

> *"There's three that's quite expensive…but the medical aid is quite good. But the last three months of the year we normally had to pay out of[pocket], then the fund is finished" (Participant 1, Carer).*

For the majority of South Africans that rely on free public health services, dementia largely goes unmanaged:

> *"Cholinesterase inhibitors are not on the code for the public healthcare services. So…we do inform them about their availability in the private pharmacies. But again, due to cost most of the people we see, they are on old age pensions and their families cannot afford to buy those medications for year in, year out...there are so many demands on that income…the public healthcare sector has a list of medications that's on code that you are permitted to use, there has been over the years motivation to include the cholinesterase inhibitors on the public service code, but because of the costs and the and they are not 100% effective, there has*

been resistance to include those on codes, saying it would be very costly nationally…" (Participant 11, Clinician, Public health service).

Participants frequently expressed a need for multi-disciplinary, home-based services for people living with dementia:

> *"Dementia is a challenge, it's not just the medical part…Its a multi-disciplinary management that is lacking. Especially in the public service…if someone is very confused, you take them out of their home to see a day hospital for how many hours and maybe be told that sorry we have run out of medication, or we don't have…I think those are the challenges that there isn't much provision of people going out to people's homes and manage them there. Everyone has to come and line up with everybody else. And for someone who is disoriented, that wait, I mean it's a challenge to sit there with lots of people, a lot of noise going on…someone with dementia can't filter out [or] block out things so to them [it]is an experience. They go home then they are worse off than they were before. So, we don't have community services that support people within their homes." (Participant 11, Clinician, Public health service).*

As a culturally diverse country, many families seek support from the health system as well as faith-based or spiritual communities, and traditional healing. These pathways of care are not mutually exclusive and reflect the complexity of help-seeking behaviour in South Africa.

e) Socio-cultural factors: Traditional healing vs. Western medicine

Accessing traditional healers is an important help-seeking resource. One participant summarised how traditional healers are often the first port of call for many families, and especially for older persons:

> *"…they [older persons] will start by getting a traditional healer before the western medicine and sometimes things go well, and sometimes things don't go well and when people are too sick, as traditional healers, there are things we can heal and there are things we can't heal. And that's why we have to really understand" (Participant 10, Traditional healer).*

Therefore, for dementia awareness and understanding to be meaningful, it is critical to understand how traditional healing approaches include the family system in their consultations (where western medical approaches tend to focus on the individual/disease). Family systems reflect generational norms that are conflicting and create friction within families about care pathways to follow. Insights from a traditional healer with experience and training in dementia illustrated how (often juxtaposed) western and traditional practices could bridge gaps between these 'worlds' to serve the needs of

people living with dementia and their families (irrespective of where they access the care pathway first):

> *"…our [Western, medical] care is not family-centred. It's looking at individuals, it's not looking at the whole family…But the traditional healers would talk to a person and the whole family…it's the family that is suffering and that our [western] care or help that we get, is not family centred. Because the person lives within the family and the family lives within the community…The most important thing is communication with the families, to also say this is how dementia presents itself. So, when you see the symptoms in your family, please go to the clinic or come to [place's name]" (Participant 10, Traditional healer).*

Often dementia is confused with an ancestral calling[6], a belief where ancestors call an individual through spiritual means to become a traditional healer. A traditional healer explained this phenomenon in comparison to dementia and argued that there are key differences on how ancestral callings manifest that would help traditional healers make choices about their response (i.e., a ritual versus a referral to a primary healthcare system):

> *"…a person with ancestral calling will get a repeating or consistent dream. It's like watching a movie when things are happening, and you are able to tell that story. But once you go to a person with dementia, they tell you 20 stories in one story…that's why if you are [a]traditional healer you must listen very carefully…You can't on that first instance say that [the] person has an ancestral calling…this person must…come to you for maybe four times for you to actually ascertain if it's an ancestral calling or it's related to an intellectual or psychiatric illness and to be able to refer…It's very rare when people are older that they get ancestral calling. It can happen. But it doesn't happen a lot. So, most of the time it's dementia. But you can't just diagnose without considering the stories" (Participant 10, Traditional healer).*

It is critical that health staff and traditional healers understand the full patient history, and what is consumed or ingested, especially if prescribing treatment responses. Participants noted that it was common when visiting a medical facility for patients to hide that they consulted a traditional healer,

[6] Ancestral calling: Understood as an 'unusual perceptual experiences' where ancestors are believed to call on an individual to become a traditional healer. Manifestations of callings are understood as prophetic dreams, feelings and sensations, mental disturbances, somatic symptoms and/or serious illness (van der Zeijst et al., 2021)

for fear of judgement. People are reluctant to reveal that they may be using alternative interventions before, or alongside pharmacological interventions prescribed by health practitioners:

> *"If they go to a traditional healer, they get asked why did you go there? If the person goes to see a traditional healer sometimes it's seen as a crime when they go to the western doctors. So, they have to hide that they've gone to a traditional healer. So there's no understanding…people get scared to reveal where they've been, where they've sought help…" (Participant 10, Traditional healer).*

Traditional healing and the needs of families are important considerations when strengthening *culturally acceptable* responses to dementia. The narratives presented above shows that there are many valuable and under-used resources like primary healthcare nurses, doctors and traditional healers that can be drawn on to strengthen *acceptable* responses to dementia in South Africa. Support of families is critical, with an emphasis on long-term care and support provisions.

f) Long-term care and support provisions

Participants interviewed from the social care and long-term care sectors described dementia care in South Africa as largely family-centred, where the dominant culture in caring for older persons is situated within families and their larger communities:

> *"…a residential facility...that's the last resort and it depends also on the culture of the older persons. You know as [black] Africans, most older persons would want to remain in their homes and taken care of by their families," (Participant 9, Social care sector).*

Specialised dementia LTC services are skewed to the (largely unaffordable) private sector. Community-based services are therefore critical to support families caring for people living with dementia. Unregistered facilities respond to this growing need for LTC provisions in communities, as family members desperately try to balance employment with meeting care needs. Stakeholders talked about their challenges with the mushrooming of unregistered, often predatory, care facilities that do not comply with minimum norms and standards of care for older persons:

> *"…some of our older persons or the families end up taking an older person to an unregistered facility because a registered facility, you'll find that the waiting list…they will tell you we don't have space until maybe another older person dies. So, it's quite a challenge in terms of space. And that is why we have a lot of mushrooming residential facilities which are not registered which do not even comply [to norms and standards]. They would close one here…and after some few weeks they would open in another area. So, it's a money making [enterprise]. I think they are making money out of older persons because family members*

become frustrated. If I'm the only one looking [after] and there's no other person who can take care of my mom. I would look for an alternative…The need is there." (Participant 9, Social care services sector).

Stakeholders recognised the need for community-based services but explained that current services were fractured and severely threatened by a failing funding model, even before the COVID-19 pandemic. The needs of older persons were simply not a priority for the country:

"You know what, I don't think it's the pandemic. It talks to the priority of the country, we have to start there…services to older persons unfortunately is very critical, but it has never been on the top of the agenda of the country…That's why it's so unfunded both at National[level] and at provinces, because provinces are struggling to increase their funding to NGOs, not because they don't want to, but because there are no funds available. The funds are not increasing at all. If you look at the ECD, they have a lot of money. They have that what we call the grants straight from Treasury so that they can be able to top up when they have [to]. If you look [at] gender-based violence [GBV], everybody's talking about it. Everybody is contributing towards GBV. Everybody is funding even the donors. But when you go to older persons is like 'why should we waste money?' as if you are over 60 then you don't have a life anymore. So funding is it's quite a challenge. And we normally say it's because it lacks a political buy in. They don't see it as an important service. Unfortunately. We can't fund our organisation[s] properly." (Participant 7, Ageing, Social Care and Support sector).

Formal care in South Africa is expensive and unaffordable to most of the population who need long-term care solutions. One participant argued that dementia care is broader than medical understanding and approaches to the condition, and that there is a need to 'de-medicalise' care in South Africa to make it more accessible to families that need this type of long-term support:

"We are too prone to think that you <u>nurse</u> people who have dementia…you don't nurse them, you <u>care</u> for them. All caring for someone with dementia takes [is] common sense, compassion, and a bit of an innovative aspect in their approach. I think in this country the biggest problem we have is that it's [dementia care] over-medicalised and over-legalised…it adds hugely to the costs…and most of the costs involved in those kind of fees [care services] relate to professional salaries and wages. Not the ordinary carers. It's the highly paid registered nurses…you just need ordinary people with common sense and compassion. The very wealthy…can afford these huge fees - the majority of our population can't." (Participant 3, Long-term care sector).

Despite the critical need for formal carers to support service provision in the broader long-term care system (i.e., beyond institutions and including home/community services), there is no formal career path or appropriate salary structure in place to ensure the availability of relevant care workers to promote philosophies of 'ageing in place' that encourage the participation of older persons and promote their quality of life in their communities for as long as possible:

> *"…carers in our country are one of the most underappreciated professions and under paid. These people take the responsibility of that older person on their shoulders. They're the primary contact in many instances for that older person and that the scales on which they are paid are simply horrendous. I don't know if in fact there is really career pathing for people that wants to take up a career in caring for people with Alzheimer's and dementia, but also whether there is accredited training for care workers…" (Participant 5, Ageing sector, Civil society).*

Families with unmet home-care needs are struggling to manage care when a care facility is not an option. Participants noted that unsupported families with long-term care needs are ideal environments for elder abuse and neglect to flourish:

> *"I don't think institutionalisation is necessarily the future. We don't have the resources as a country to build more residential care facilities, [or] to provide more subsidies. Subsidies are not adequate [in]most cases, which is why, as a result of covid-19 also, many of the residential care facilities have opted to close. If you have a person with dementia in a residential care facility, and that facility closes, where does that older person go? Most likely back to family. And that can be an ideal recipe for abuse and neglect…sometimes people just don't have the capacity to deal…and they try to make do…sometimes it's just an issue of desperation…if there's nowhere to send grandma that has dementia and you can hardly deal with your children, now you have to deal with an older person as well, [and] you don't really know dementia...How do you deal with that? (Participant 5, Ageing sector, Civil society).*

2.3.3 Phase 3: SWOT-analysis

Despite strong policy support for decentralised care to home- and community-based services, the healthcare system in South Africa is still skewed to hospital-centric models of care, with low readiness to integrate mental healthcare and dementia at community levels. Provision of home- and community-based services for people living with dementia rests heavily on a struggling NGO-sector, which, through inadequate funding from the State, is unable to meet the demands for care and

support. Unregistered care facilities respond to these community needs for care and support. However, these facilities' lack of compliance to prescribed norms and standards, that guide the appropriate care and support of older persons in South Africa (DSD, 2011), increase risk of elder abuse and neglect to older persons in need of care (including people living with dementia). The NHI does not articulate any specific objectives for mental health and dementia-related services but, with further development, could offer the opportunity to integrate plans for the scale-up of health- and long-term care services for people living with dementia. Despite strong policy support for the 2013-2020 Mental Health Policy Framework, now expired, there was no budget allocated to its implementation. This reflects a common threat to policy and implementation in South Africa, leaving older persons, including people living with dementia and their families, unsupported at a structural level, within their homes, and communities.

The SWOT-matrix provides further findings for the *healthcare system* (Table 2), *social care and LTC-system* (Table 3) and the *policy environment* (Table 4).

Table 2: SWOT analysis of the healthcare system

<table>
<tr><th colspan="2">HEALTHCARE SYSTEM</th></tr>
<tr><th>STRENGTHS</th><th>WEAKNESSES</th></tr>
<tr><td>

Free primary healthcare in public sector, access to hospital care is only free for those who do not have the means to pay for these services.
Strong policy support (Mental Health Policy Framework 2013-2020) for an integrated care model that decentralises primary care to home- and community-based services.
South Africa is moving towards providing universal health coverage through the development of a National Health Insurance (NHI) scheme to provide all South Africans (as well as legal residents) quality healthcare regardless of whether they are employed and able to contribute monetarily to the fund.
Specialized healthcare services available in the existing private sector, i.e., general as well as dementia specific.
Standard Treatment Guidelines for Dementia exist for the private and public sector.

</td><td>

Inequality and urban-bias in access to care services, resources (human, financial and technologies) between provinces.
Overburdened healthcare system shouldering the needs of 84% of the population.
The prevalence of dementia in South Africa has not been established conclusively.
Inconsistent supply of medical products and health technologies in the public sector.
The private healthcare is unaffordable to most South Africans, and characterised by
(i) an unregulated pricing environment.
(ii) healthcare expenditure that is driven by medical practitioners (i.e., via their own practice or via referral for further investigation), and as result
(iii) a supply-induced demand that reflects a lack of competition in the market of medical scheme administrators.
Very few geriatricians and geriatric psychiatrists in South Africa, and 79% of physicians work in private sector.
Gerontology was removed by the South African Nursing Council (SANC) from its specialist training curriculum, and despite being urged by the South African Human Rights Commission (SAHRC) to reconsider has not been restored to nursing curriculums.
Lack of awareness and understanding of Dementia among healthcare staff (perceptions of dementia as ‘natural ageing’ and ‘nothing can be done’).
Weak diagnostic pathways for dementia leads to delayed (or no) diagnosis, with unmanaged symptoms increasing risk of elder abuse and neglect.

</td></tr>
</table>

OPPORTUNITIES	THREATS
• Opportunity to integrate plans for health service scale-up for persons living with dementia into the National Health Insurance (NHI) drive informing the future health system of the country. • Secure funding for the health sector that would support provinces purchasing more specialised services from the private sector. • Formalisation of integrated care models for community-based care (Mental health policy framework, MHPF) provides an opportunity to integrate mental health (inclusive of dementia-specific needs/care) at community healthcare levels. • National mental health investment case underway with opportunities to identify interventions for dementia care to be scaled-up in the short, medium, and long term. • Increasing calls for nationally representative prevalence data for dementia. • Understanding and training on dementia for health staff and traditional healers can strengthen referral pathways, diagnosis, and support for people living with dementia and their families.	• No National Dementia Health Plan or mandate to guide inter-sectoral and multi-disciplinary management of dementia. • Poor diagnostic and referral pathways along continuums of care. • Heavily hospital-centric models of care. • No dedicated budgets available for the implementation of mental health policy. • Shortages in human- and financial resources. • Limited awareness and knowledge of dementia at (macro) structural levels. • High levels of structural-, internalised and public stigma that limit help-seeking behaviour and delay diagnosis (or no diagnosis). • Low level of health-system readiness to integrate mental healthcare and dementia at community levels. • Lack of understanding of culture and traditional practices (such as traditional healing) promote the non-disclosure of full patient histories, placing people living with dementia at risk of mismanagement of health conditions. • Weak capacity for management and implementation of the national Mental Health Policy Framework (2013-20) especially at the provincial and district levels. • NHI implementation has been slower than expected.

Table 3: SWOT analysis of the social care and long-term care (LTC) system

<table>
<tr><th colspan="2">SOCIAL CARE AND LONG-TERM CARE (LTC) SYSTEM</th></tr>
<tr><th>STRENGTHS</th><th>WEAKNESSES</th></tr>
<tr><td>• LTC systems are available in the form of residential care facilities for older persons in the public sector.
• Non-profit/non-governmental organizations offer community-based dementia care services, including:
o Providing support and training to care for persons living with dementia,
o Monitoring their well-being and
o Linking to services such as respite care, home-based care, support groups, counselling, and legal advice services.
• There is currently a shift from emphasizing the funding of State care homes, to more community-based care.
• There are over 1000 long-term care facilities for older persons across the South African private sector.</td><td>• These are no dementia-specific care centres in the public sector.
• Long term care facilities are not equally distributed across the 9 provinces; skewed to urban areas. Demand for these services is beyond that which the public sector can cater for, and long waiting lists are significant barriers.
• Challenge of unregistered facilities that do not comply to the minimum norms and standards for care of older persons (only about 415 long-term care facilities that are officially registered with the Department of Social Development).
• The South African government relies heavily on the services of NGOs to make up for the deficits in care provisions for older persons but is dependent on a failing funding model.
• Community-based services (NGO's) are offered at a cost to families (based on assessment of affordability) but are largely still biased to urban areas despite redresses.
• Long-term care services including community-based services, home-care and residential care is not supported by medical insurance companies.
• Shift toward funding community-based care has been slow; the bulk of long-term care is still focused on the funding of residential care facilities and relying on family care (unsupported) within the home.
• Unsupported families and carers increase risk factors for elder abuse and neglect.</td></tr>
<tr><th>OPPORTUNITIES</th><th>THREATS</th></tr>
<tr><td>• Increased calls for intersectoral working and the establishment of intersectoral forums in the provinces.
• Opportunity to integrate LTC service provision needs for persons living with dementia with the National Health Insurance (NHI) drive.
• With current attention on the LTC sector emerging from the COVID-19 pandemic, opportunity to professionalise the training, registration, and accreditation of carers.</td><td>• Social care and support services dependant on a failing funding model, where community-based services are not adequately funded by state departments.
• Predatory, unregistered facilities pose risk of elder abuse and neglect to older persons in need of care, including people living with dementia.
• Shortages of trained LTC workforce in dementia care.
• Lack of specialist skills, e.g., shortage of Geriatricians and geriatric psychiatrists in South Africa.
• Lack of specialist training opportunities in South Africa: e.g., Geriatric Nurses' specialist training qualifications removed from SANC (nurses are the backbone of an integrated care model in South Africa).
• Lack of funding for in-service training, and professional development for nurses and carers for people living with dementia.</td></tr>
</table>

Table 4: SWOT analysis of the policy environment

<table>
<tr><th colspan="2">POLICY ENVIRONMENT</th></tr>
<tr><th>STRENGTHS</th><th>WEAKNESSES</th></tr>
<tr><td>• Public and private-sector support for the Mental Health Policy Framework (MHPF).
• Strong policy support for National Health Insurance (NHI).
• Policy support for the empowerment and protection of older persons (Department of Social Development, DSD):
(1) Older Person's Act (no.13 of 2006): Although it does not deal with dementia in detail, it refers to dementia as a consideration for community-based programmes (see section 11(2)(a), p.7); and services at residential facilities (see section 17(b) and (d), p.9) (Government Gazette, 2006).
(2) Older Person's Programme was established to support the development of a self-reliant society that empower and protect older persons, promoting their well-being, safety, and security.
(3) Protocol for management of elder abuse (2010): Guide for inter-disciplinary and intersectoral response to elder abuse and neglect.
• Philosophy of 'active aging' or 'ageing in place' that promotes the full participation of older persons in decision-making, societies and keeps them within the family and community setting for as long as possible.</td><td>• Despite political will displayed and policy support for MHPF and NHI, these developments are 'dementia-invisible', and have now expired (2013-2020).
• No dementia-specific national document, policy, or plan for South Africa.
• Despite the national level mental health policy framework, provincial level capacity for implementing the mental health policy is weak.
• High levels of corruption and difficulties with implementing national policies across a wide range of sectors.
• Lack of political will or appetite to financially support services for Older Persons and people living with dementia in South Africa.
• Policies inadvertently promote discourses that locate responsibility of care primarily within the family, which often have a negative impact on the economic outcomes of the family (exacerbated by widespread poverty, inequality, and unemployment). Family carers are often women who has to quit a job to provide unpaid care services to ailing family members.
• Despite policy support protective services against elder abuse and neglect (Older person's Act no.13 of 2006 and the Protocol on management of Elder Abuse, 2010), there are no guidelines or measures to support the detection of elder abuse and neglect for persons living with dementia and their families.</td></tr>
<tr><th>OPPORTUNITIES</th><th>THREATS</th></tr>
<tr><td>• National Health Insurance (NHI): State commitment (political will) to provide accessible, quality healthcare for all.
• Mental Health Policy Framework and Strategic Plan (2013-2020)</td><td>• No specific objectives for mental health service provision within the NHI.
• Unclear how the NHI will be funded, and mental health services supported.
• No budget allocated to the implementation of the MHPF.
• Inadequate funding model supporting community-based services (care, support, protection) for people living with dementia and their families.</td></tr>
</table>

2.4 Part I: Discussion on dementia in South Africa

The desk review, stakeholder interviews and SWOT analysis provided an in-depth situational analysis of available care, support and treatment provisions for older persons, people living with dementia and their families in South Africa. We presented the findings from three phases which showed the current provisions for dementia diagnosis, post-diagnostic services, LTC and support, and the role of traditional healing and culture in dementia care in South Africa. Interviews and quotes from stakeholders provide nuance and context to a complex and fragmented system, while the SWOT analysis provides a summary of the factors to inform priority setting (strengths and opportunities), as well as to identify risks to achieving these priorities and goals (weaknesses and threats).

We found that dementia diagnostic services were highly fragmented at primary healthcare level, and that most General Practitioners and nurses were not formally trained in geriatrics and dementia. Training in geriatrics and gerontology is limited across the country, with only eight geriatricians registered in 2010 (Lloyd-Sherlock, 2019). In the outcomes of the '*Investigative hearing into the systemic complaints relating to the treatment of older persons*', the South African Human Rights Commission (SAHRC) urged the South African Nursing Council (SANC) to reinstate gerontology as a requirement in nursing curriculums (SAHRC, 2015), with no response to date.

Experts by experience and public health participants indicated that there are various factors (other than training) that delay diagnosis, including stigma and beliefs that 'nothing can be done' or 'you're too young'; and the unavailability of care and support services to which to make referrals. Most people in South Africa rely on the public sector for free healthcare (Mahlathi & Dlamini, 2015). Another study highlighted that existing health structures do not support the management of dementia, with structural stigma resulting in a 'dementia-blind' healthcare system that negatively impacts both help-seeking behaviour and the health system's preparedness to meet the needs of people living with dementia and their families (Jacobs et al., 2022).

Carers that feel supported are less likely to abuse care recipients (Serra et al., 2018). Our findings suggested that there might be a link between delayed help-seeking and diagnosis, unmet home- or community-based support needs, and the risk for elder abuse. As dementia and functional dependence increase, the family's ability to cope and provide adequate support is diminished in a context where no formal support services are accessible. Lack of post-diagnostic support, high levels of care burden, and poor knowledge of how to care for someone living with dementia are known risk factors for elder abuse and neglect (Downes et al., 2013). These realities are amplified in a country characterised by widespread poverty, crime, inequality and unemployment (The World Bank, 2018) and emphasise the need for adequate diagnostic and post-diagnostic support and care.

Existing community-based care services are urban-biased and divided across two tiers: (1) private, profit-based care that is accessible only to the minority who can afford it; and (2) the non-governmental sector (NGO) that is non-profit, severely underfunded and resource-constrained (Prince et al., 2016). The NGO sector is currently the only source of dementia-specific care and support for the majority of South Africans who cannot afford private care. Therefore, most people living with dementia live at home and are supported by an unpaid, informal carer who is (usually) a female family member (Lloyd-Sherlock, 2019). Despite the government's reliance on the NGO sector for care and support, our study showed that these essential community-based services are grounded on a failing funding model where the need substantially outweighs investment by the State. The large number of unregistered facilities reflect the magnitude of this unmet need at community level, leaving people living with dementia and their families unsupported and at risk of isolation, increased financial hardship, as well as elder abuse and neglect.

Our study has shown that the family system is an important resource in health decision-making, support and the care of people living with dementia. Like many other countries in Africa (WHO, 2013), traditional healing is often the first port of call for many, and an important source of support for families at community level. It is vital that people feel safe to inform health staff about treatments accessed, especially when using traditional substances in conjunction with pharmacological interventions. Health staff sensitisation and understanding of traditional practices are important to understand patient histories holistically, and crucial to create safe spaces for families to communicate freely. While the integration of biomedicine and traditional healing approaches is gaining attention in other contexts, a study in Malawi showed that there are important barriers that prevent mutual respect and collaboration (Lampiao, Chisaka & Clements, 2019). They found that traditional healers were generally more enthusiastic than medical practitioners to collaborate, with biomedical practitioners being more reluctant to refer patients to traditional healers for lack of trust, and concerns about traditional methods being unregulated and unstandardised. However, despite their differences in approaches and practices (and beliefs about the role each other play), biomedical practitioners and traditional healers share an important motivation to improve patient care and promote a healthy society (Lampiao, Chisaka & Clements, 2019). As in Malawi, South African health professionals and traditional healers share a similar motivation for patient well-being and broader community health, that provides an opportunity for collaboration between these practices. Our findings highlight that education and training are powerful tools for dementia awareness and could potentially bridge the often juxtaposed western and traditional healing practices. Traditional healers, together with trained general practitioners and primary health nurses, are largely unused resources for the identification, referral, and management

of dementia. This study suggested that, with training, traditional healers can distinguish between signs and symptoms of dementia versus an ancestral calling and that, in bridging the gap between these 'worlds' (western and traditional), South Africa can strengthen responses to dementia in culturally acceptable ways.

2.4.1 Limitations

Our study is not without limitations. While a SWOT-analysis provides a simple, low-cost method to comprehensively integrate data to identifying strategies for improving services, analysis is inherently biased by the data used and subjective. Secondly, our SWOT-analysis and desk review was limited to three main systems (i.e. healthcare system, social care and long-term care systems, and the policy environment), and could be extended to include other aspects such as the country's socio-cultural belief systems, the legal system, and available social protection systems. Thirdly, the findings are derived from a small number of stakeholders, with different backgrounds and expertise. The fact that there were common themes despite the heterogeneity in the sample, nevertheless, strengthens the likelihood that these experiences are commonplace, and this is further confirmed from data collected in other components of the study. However, our interviews do not represent dementia stakeholders from all backgrounds and regions, and as such we should be cautious about assuming generalisability. Selection bias may also lead to certain views being more prominent in the study, thus confirmation of findings in a larger cohort would be beneficial. We had limited participation from the health sector because of unanswered applications for formal permission to interview national health government officials (in part due to their increased workload during the COVID pandemic). It is therefore important to note the timing of data collection – the heart of the COVID-19 pandemic – when the health sector was largely unavailable and involved in managing the national health crisis and people were feeling the effects of even more limited access to healthcare. Data collection during the pandemic has also restricted any community engagement activities to identify and recruit a broader stakeholder group that includes neighbourhood organisations and community-based stakeholders. These limitations therefore predetermined sample size, without data saturation reached. A larger heterogenous sample of stakeholders is needed. We adopted a pragmatic solution of completing a dyadic interview with a person with dementia and their carer. Whilst this helped make the person with dementia feel more at ease, it is important to consider that interview responses may have been influenced by the presence of a family member within the room. Our selection of participants did not include other sources of informal support offered by, for example, religious institutions and other community-based organisations that are not ageing or dementia-specific. Finally, we also acknowledge that our understanding of participant experiences is limited to the explanations of cultural beliefs provided by the stakeholders themselves.

2.5 Conclusion on the situational analysis of dementia

Our findings provide an important contribution to inform priority-setting for health, social care, and support services and to highlight gaps and opportunities within current provision for people living with dementia and their families in South Africa and potentially also in other low-or-middle-income settings. We have shown how structural factors (weaknesses and threats) create barriers in accessing a timely diagnosis, post-diagnostic support and care. We have also shown how current structures locate dementia care within households that are, for the most part, unsupported, and thereby fuelling known risk factors for elder abuse and neglect. Post-diagnostic support described by our stakeholders living with dementia tended to centre around pharmacological interventions. We need more research to explore the contributions that non-pharmacological approaches can make to support care practices at family and community level.

There is an urgent need to prioritise adequate responses at policy, structural and community levels as the general unavailability of services drive stigmatising beliefs that 'nothing can be done' for people living with dementia. This study highlighted an opportunity to support broader employment initiatives by developing career pathways for formal carers and in doing so, strengthen community structures to support 'ageing in place'. Supporting people living with dementia is everyone's responsibility and cuts across sectors, disciplines, and traditions. Ageing in South Africa is hard for older persons and people living with dementia. There is an urgent need for intersectoral policy responses to support the strengthening of current health, social care, and support systems so that people living with dementia and their families can live and age well.

2.6 PART II: Status of current support provisions for elder abuse

This section focuses the situational analysis on current service provisions for elder abuse in South Africa and includes reflections from the stakeholder interviews described in Part I. For this component, interviews about elder abuse were focused on the views and experiences of service providers and not experts by experience. No older adults with abuse experience were interviewed for this sub-study. Due to the nature of elder abuse, this content may be disturbing to the reader but were included to provide supporting evidence of the realities faced by older adults in South Africa. This section examines the status of elder abuse in South Africa, identifying current and future needs to inform priority-setting for strengthening service provision, care, protection, and support.

2.6.1 Status of elder abuse in South Africa

There is currently no formal surveillance and monitoring of elder abuse in South Africa. Participants (interviewed as stakeholders) working in civil society, non-profit organisations (NPOs), and the

government sector agree that elder abuse is a human rights and public health concern that does not receive enough attention, with huge evidence gaps to support current assumptions. Despite these gaps, stakeholders agreed that the most common type of abuse relates to financial exploitation and emotional abuse of older adults, especially during the COVID-pandemic period:

> *"…Abuse in terms of financial, those are reported. Emotionally yes, like during COVID…I think we received a lot of emotional abuse cases…especially during COVID [pandemic], emotional and financial…those were the major cases or high cases that were reported…It's the pandemic, [impact of pandemic]hits everybody. Financially it was strained for everyone. So, in case an older person has money and there's this other one who's abusing substances, she would definitely demand an older person to give even if the other person says 'I don't have money'. So, she would just torment an older person until the older person maybe gives up and then gives money…if you are soft target then they would do whatever they want with you (Participant 9, Social care services sector).*

Older persons do not receive the needed care and support from family or household members, while their pensions and reproductive labour make them targets for exploitation:

> *"This granny has tenants at the back and it's the tenants that looks after this granny when she has her own children that won't come see her. The abusing of the grant is major, but also they're abused emotionally where they look at the grandkids and the people can go out and do whatever, enjoy themselves. We also had a granny who had a stroke, staying in a shack, staying with her daughter's children…she got sick and her daughter said she can't share her mother in her house with her husband and asked a friend to take her mother. And when we wanted to follow up, the granny was sent to the Eastern Cape. So, we don't have contact with her, I'm concerned…because she's not nearer to health facilities and she just had a stroke. So, when the daughter couldn't cope with her mother, she sent her to the Eastern Cape (Participant 10, Occupational Therapist).*

While acknowledging the lack of data on elder abuse in South Africa, our stakeholders raised serious concerns about extreme forms of violence against older persons, especially people suspected of living with dementia:

> *"…one concerning issue for me specifically in relation to dementia and Alzheimer's disease is the effect it has on rural communities and the correlation between abuse of older persons accused of witchcraft, or being possessed, as a result of the disease and the case of abuse*

and killings of older persons that are seen as witches because of the behavioural issues that goes along with the disease. Well, my understanding of it is that due to a lack of awareness of the disease, and because of certain cultural practices, older persons that that have the disease are seen as witches and persecuted. We just had a case two months ago of an older person in the Eastern Cape that was tortured and killed by community members, including [supported by] the chief of that specific area because she was behaving erratically. She had dementia. And awareness in those communities…this is a disease that they're completely unfamiliar with and they see the older persons as being possessed…and are persecuted as a result. This is a definite problem." (Participant 5, Ageing sector, Civil society).

This participant goes on to report that despite the lack of formal data and surveillance (and not really knowing how big of a problem this is), this extreme violence against older persons suspected to be living with dementia is visible:

"Well, I don't know about [existing]statistics on that but it's important or it happens often enough for the department to take note of this. Like with abuse in communities, much of it is unreported. We can relate those two killings of those two older persons directly to witchcraft because the community gave evidence of that, but in many other cases, you know the older person would be killed but the collaborating evidence that it's related to witchcraft would not necessarily be forthcoming…I believe, is also under-reported" (Participant 5, Ageing sector, Civil society).

2.6.2 Under-reporting of elder abuse

Participants reflected on what drives under-reporting of elder abuse in South Africa. For the social care sector, some of the main issues were related to both community and professionals' reluctance to formally report cases. Reluctance amongst families and professionals was reportedly motivated by three main factors: (1) the awareness of their own rights and ability to identify an abusive situation; (2) the discomfort associated with talking about elder abuse; and (3) unclear reporting structures and processes to follow:

"We know abuse…it's a taboo. Other family members wouldn't be free to report, that's not a positive thing to really report. But then if provinces or older persons become aware that this thing should not happen to me, they should be free to report, even if it's not a nice thing or a positive thing to do. It was a challenge, provinces were not reporting as expected and we would even remind [people]. Others do not know what to do because maybe [there are]

updates but that particular counterpart doesn't filter through what's the latest, they might not even know because the information did not reach them." (Participant 9, Social care services sector).

Another challenge related to professionals' skills in adequate report writing and supporting the legal proceedings with the needed evidence to ensure proper judicial processes can be followed:

> *"I think there's a lot of it to be done to empower our social workers. Even the reports that they write, when the case is presented at court…they need to be empowered on the writing skills because a person will just write a report but not substantiate, the report wouldn't even have substance, not refer to any legislation, it doesn't have facts. So, I think there's a need to train our social workers. Currently our social workers are not specializing so you will be working with children, older persons, everybody. So, you just become 'Jack of all trades', but not a master of anything. (Participant 9, Social care services sector).*

Older adults themselves are reluctant to report abuse. Despite measures put in place to safeguard testimonies from direct contact with the perpetrator, older adults fear confrontation and direct contact with the perpetrator, and keep the abuse hidden for feelings of shame:

> *"Although with the Department of Justice now, cases will be held on camera…So older persons were afraid to even confront or being confronted in a court of law. So, the older person would say that I'd rather die than go to court. They don't want people to know about their situation, so you know it's age and also about your dignity" (Participant 9, Social care services sector).*

A register of perpetrators convicted of elder abuse has been an issue of contention since its mandate in the South African Older Persons' Act (no.13 of 2006) came into effect in 2010. While the register is in place and legislated, it is criticised for not being fully functional for over a decade since its inception as described by a participant involved in the ageing sector:

> ***"****The issue, especially that's concerning in relation to abuse is the political will, to be honest. Because if there was sufficient political will, we wouldn't still sit with a situation where that elder abuse register has not yet been finalized. They're still working on it. There was a discussion in 2010 about this. There was a discussion with the sector, but so far not much has progressed. I understand the challenges…But not enough has been done. The register is legislated, and I think the register is in place, but the register is not functioning yet. There's certain IT issues in certain provinces in relation to the abuse, there's many issues because of access, IT issues of provinces, of not being able to put offenders on the register and apparently developing a register is quite costly exercise and not all the funds have been*

allocated in different provinces, to be able to do that." (Participant 5, Ageing sector, Civil society).

These challenges were echoed by the social care and protective services sector, while being hopeful to see significant progress that includes the development of an electronic Elder Abuse Register:

"The Electronic Abuse Register is currently under review…Previously it was manually done and currently for the past three years [the sector has been] busy with an electronic abuse register whereby they would just send those forms electronically for [the sector] to access…currently [the sector] is working with Its [information technologists] to ensure that the system is [developed]…[and] training provinces on the utilization of the new abuse register…to ensure that the system is running" (Participant 9, Social care services sector).

2.6.3 Lack of adequate support and protective services for elder abuse

Currently there are no specific organisations that specialise in the provision of support services for elder abuse. A participant summarises the need for services that include places of safety, a national helpline[7], and data to understand the magnitude of elder abuse in South Africa:

"Well, good supportive situation would be…places of safety for the people. I mean…there's centres for abused women and children. There isn't really, in South Africa, centres for abused older persons…so I think that is something that that is quite needed. A national helpline system. Because people are abused, who do you call? If you're in a rural village in the Eastern Cape who you going to call? You're going to call the police? And the policeman is most likely unsensitised about elder abuse and think you're complaining too much. There's nobody that they can contact. There's no helpline…we'd like to see a national organisation or national helpline specifically dealing with abuse of older people. I think that's much needed, whether it's run by government or whether it's run by NPOs [non-profit organisations]…And we need those types of statistics and I think organisation like that could go a long way in getting us…more accurate statistics on the prevalence of abuse (Participant 5, Ageing sector, Civil society).

While the lack of capacity of state services and facilities is a serious problem, current protective services include the removal of the older adult where possible. A participant argues that despite the

[7] At the time of this interview, there was no national helpline for many years and this was considered a critical gap in services to older persons. A NGO (TAFTA) recently launched a national helpline for elder abuse end November 2022.

motivation for removal being in the interest of the older adult's safety, and that there are genuine environmental conditions that indicate that removal is the best option, the current system uproots and disrupts the individual already afflicted by abuse, while the perpetrator goes largely unaffected:

> *And we always say, you know, we always remove a victim rather than removing their perpetrator, yeah, so the person would remain to abuse other people. It can't. It was supposed to be him [perpetrator] being removed. Taken to either prison or to a rehabilitation [centre]…" (Participant 9, Social care services sector).*

2.6.4 Shared responsibility in responding to elder abuse

Participants advocated for the sharing of responsibility across sectors and communities in responding to the needs of older adults to prevent, protect and achieve justice against elder abuse in South Africa:

> *"I think we can win the battle against abuse. It should not be the responsibility of one department. If it means a community member has to report, if the family has to report, it should not be something taboo as it currently is… also our social workers. If they can realize that not reporting or maybe manually or electronically not punching [capturing] that information you are also not helping because we wouldn't have the statistics of what is happening, so that appropriate intervention can be done within that particular community…" (Participant 9, Social care services sector).*

Inter-departmental, multi-sectoral responses were identified as important starting points to strengthen support services for elder abuse:

> *"I was just thinking that you know, the police services should also have an extensive list of social workers in the area or residential care facilities where one can take this older person to. I mean the simple fact is that if a person is a police officer and they don't care or are not sensitive to the needs of their own elderly in their own community, their own grandfather, it's very unlikely that they would extend a hand of help in their setting. This is maybe part of a broader problem in that older persons are seen that they have had their lives, and they are [a] burden on society and I think this is the attitude of many of the police officers in our country, and that needs to change. And maybe one of the ways that it can change is by creating a structured directive. A national directive from the Police Commissioner with regards to situations of abuse, situation of and older persons suspected of having Alzheimer's and dementia, how to treat this, what to do, what to do with a victim like that, who to phone, who to call you know." (Participant 5, Ageing sector, Civil society).*

2.7 Part II: Discussion on elder abuse

The status of current support provisions for elder abuse in South Africa is poor. While there is a lack of data on the nature and extent of the problem, stakeholders agree that elder abuse is a big concern with financial and emotional abuse being the most reported. Under-reporting is a serious problem with both community and systemic roots. Stigma and fear of facing the perpetrator drive the hidden nature of abuse at community level, while unclear reporting structures and processes deter professionals from filing formal reports. These challenges are echoed globally, where elder abuse often goes unreported by older adults themselves because (1) they feel embarrassed and ashamed; (2) worry about getting the abuser in trouble because the abuser is often a family member or their adult child; (3) fear retaliation or losing care and support should they disclose; or (4) due to a cognitive impairment are unable to recognise or disclose abuse (Pang, 2000; WHO, 2016). Furthermore, the practice of removing abuse survivors from their homes (to protect them from further abuse), uproots the individual that is already traumatised, and perhaps serves as a perverse incentive to not report. Other systemic barriers to detecting and reporting include a lack of knowledge and capacity amongst health and social care professionals to adequately respond to elder abuse (Schmeidel et al., 2013). Nurses and doctors often believe that identifying and responding to elder abuse is outside their scope of practice, while social workers rely on referrals from these healthcare practitioners to provide the necessary service responses (Schmeidel et al., 2013).

Older persons in South Africa face various forms of exploitation and abuse that include extreme forms of violence, including homicide. While rigorous data on this phenomenon currently does not exist, people living with dementia are believed to be especially vulnerable to harmful cultural beliefs that could result in violent attacks and homicide. These threats are largely directed at women (Kalula & Petros, 2011; Mkhonto & Hanssen, 2018), with some research suggesting that allegations of witchcraft are used as a strategy to confiscate property from older women (Kotzé, 2018).

2.8 Conclusion on the situational analysis of elder abuse

This section provided an important addition to our general situational analysis of current care and support provisions for older adults in South Africa. We have shown that, like in the case of dementia services, support provisions for elder abuse are very limited or non-existent. Community and systemic factors drive the undetected and under-reported nature of elder abuse in South Africa while stigma, lack of dementia awareness, financial exploitation, and harmful beliefs may increase elder abuse risk and extreme forms of violence against older adults and people living with dementia. These realities reflect a need for awareness and education on how to identify and respond

appropriately to suspected abuse and imminent threats of violence. Protection services should be multi-disciplinary and inter-sectoral, that is adequately resourced with clear roles and responsibilities, and unambiguous referral pathways. Adequately addressing the needs of older adults and people living with dementia is a shared responsibility that should be evidence-driven and supported by sustainable funding models. South Africa needs contextually appropriate ways to measure and understand elder abuse, gather data on prevalence, and examine risks to inform priority setting for health, social care, and support services for older persons and people living with dementia. Responding to these gaps is critical for strengthening responses to the health and well-being of older persons in South Africa, so they can live with dignity and greater quality of life. These gaps are addressed in the remaining chapters.

CHAPTER 3: Cross-cultural adaptation of the EAST and CASE screening tools for elder abuse in South Africa

3.1 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).

3.1.1 The 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.

3.1.2 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 for risk of abusing by family members, potential perpetrators, or

available healthcare and support providers, becomes critical in detecting possible 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). Despite these challenges, studies have found that carers for people living with cognitive and physical impairments are more open to reporting their frustrations, abusive behaviours and neglect (Beach et al., 2016). All perpetrators are not equal and range in culpability from pre-meditated, 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.

3.1.3 Elder abuse screening tools

Elder abuse screening tools seek to (1) identify risk factors for 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. 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 specialised 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. This exclusion disempowers people living with dementia and prevents them from having a voice in matters that concern their well-being.

3.1.4 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 accessible government reporting systems

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. 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 twelve 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).

South Africa needs culturally appropriate screening tools that aim to promote the detection of elder abuse at community level. This component of the overall study therefore set out to cross-culturally adapt two elder abuse screening tools, each from the perspective of the older adults and carers[8], respectively. Our investigation focused on the content *respondents* considered when answering questions. This allowed us to gain insight into their interpretations of questions, understanding of concepts, and appropriateness of response option selection. 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.

3.2 Methods

3.2.1 Study objective

To cross-culturally adapt and cognitively test the appropriateness of the Elder Abuse Screening Tool (EAST)[9] and the Caregiver Abuse Screen (CASE) for use in South Africa across four languages, English, isiXhosa, Afrikaans, and Northern Sotho (Sepedi).

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[8] 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.

[9] 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).

3.2.2 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 World Health Organization (WHO) and the South African National Department of Health (SADoH) in 2008:

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 facilitate genuine 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 ($\alpha = .86$) and strong correlations with known risk factors of abuse such as carer burden and dealing with dementia-related behavioural 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 ($\alpha = .84$) (Pérez-Rojo et al., 2015), Iran ($\alpha = .86$) (Sakar et al., 2019), and Pakistan ($\alpha = .88$) (Khan et al., 2020). Box 1 lists the original CASE questions below (full testing version in Appendix 2):

Box 1: Caregiver abuse screen (CASE)

1. Do you sometimes have trouble making (_____) control his/her temper or aggression?
2. Do you often feel you are being forced to act out of character or do thing you feel bad about?
3. Do you find it difficult to manage (_____)'s behaviour?
4. Do you sometimes feel that you are forced to be rough with (_____)?
5. Do you sometimes feel you can't do what is really necessary or what should be done for (____)?
6. Do you often feel you have to reject or ignore (_____)?
7. Do you often feel so tired and exhausted that you cannot meet (______)'s needs?
8. Do you often feel you have to yell at (_____)?

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 healthcare 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. While the EAST was developed specifically for South Africa, there is no evidence available on the extent to which it is used to screen for elder abuse in research, or in a public service context. Box 2 lists the original EAST questions (full testing version in Chapter 4):

Box 2: Elder abuse screening tool (EAST)

1. Are you afraid of anyone in your family, home, institution or community that you are living in?
2. Has anyone in the last two months hurt or harmed you?
3. Has anyone in the last two months forced you to do things that you did not want to do?
4. Has anyone in the last two months touched you in ways you did not want?
5. Has anyone in the last two months scolded or sworn at you or threatened you?
6. Has anyone prevented you from getting food, clothes, medication, spectacles, hearing aids and / or medical care?
7. Are you left alone a lot, locked up, not allowed to socialise or has anyone been prevented from visiting you?
8. Has anyone ever failed or refused to help you take care of yourself when you needed help?
9. Has anyone made you sign papers that you did not understand or did not want to sign?
10. Has anyone taken money, valuables (ID, bank card) or any other things that belong to you without your permission, or against your will?
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?
12. Have you have ever been placed in shackle[s], tied up, or locked up in confined spaces?

3.2.3 Setting

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. Northern Sotho 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.

3.2.4 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 (i) referrals by dementia-specific non-government organisations (NGOs), such as Alzheimer's South Africa (ASA) and Dementia-SA; (ii) snowballing; and (iii) self-referrals recruited via flyers circulated on existing community-safety neighbourhood WhatsApp groups or circulated through existing contacts.

3.2.5 Procedure

The following process was conducted to prepare the tool by translating and culturally adapting it for appropriate use in the South African setting.

a) 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.

b) 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* methodology was followed, where in-depth interviews were used to identify difficulties experienced by respondents when answering questionnaires. Cognitive interviewing examines the construct validity of survey questionnaires as they identify the content respondents consider that inform their responses to questions (Miller et al., 2014). This methodology was used for the purpose of testing questions for their wording and interpretation in relation to the questions original meaning; and to test the equivalence of translations across cultural contexts (Miller et al., 2014). 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 how respondents interpreted them (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 to determine a respondent's interpretation of the questions.

Where participants felt comfortable with a digital recorder present, interviews were audio-recorded for quality purposes. The recordings were used to complement the notes and were not transcribed. Interviews were conducted at places of convenience for participants and included seniors' centres, luncheon clubs or participants' homes. Space limitations within homes and other venues are common realities in South Africa, and where interviews were conducted in shared spaces, care was exercised to ensure it was not within listening distance of others in the vicinity. A social worker from Alzheimer's SA or Dementia-SA was available for referrals in each of the research settings to provide support if needed. All interviews were conducted in the preferred language of the participant, with the PhD candidate (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.

3.2.6 Analysis

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

- Step 1: Collecting narratives via individual interviews.
- Step 2: Synthesizing narratives into detailed summaries to capture specific events and experiences considered when responding to each item.
- 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).
- 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.
- 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 as these guided the final adaptation of the instruments. We provide analysis on in-scope interpretations that give context to participants' experiences and help build an understanding of what elder abuse comprises. We 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').

3.2.7 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. I (RJ) the PhD candidate, led the analysis. I am a South African researcher with good insight into different South African cultures. I had no personal experience with elder abuse. As such, my own experiences of the culture may influence coding and interpretation. To address this, the developing themes were reviewed by my co-authors, MS (South Africa) and NF (UK).

3.2.8 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 (as applicable). At the time of the interviews, carers of persons living with dementia were attending (or had already been supported by) local support groups run by a social worker from Alzheimer's South Africa (ASA) or Dementia-SA. Participants were screened informally for capacity to consent during the consent process, and people who showed clear evidence of not being able to follow the consenting process and give consent were not included. Individual consent was obtained in writing, while safeguarding the identities of participants and anonymizing data.

3.3 Results

3.3.1 Demographic information

A total of 42 participants were interviewed across the four languages, with participants recruited until data saturation was 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, while carers ranged between 35 and 78 years with almost half (11 of 23) being 60 years and over (see Table 5). 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 5: 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**

3.3.2 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.

a) 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 6 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. Refer to Figure 33 for common themes identified when probing responses to the EAST questionnaire by older adults. The themes represent major out-of-scope experiences described by the older adults. There were no out-of-scope interpretations noted for questions 7, 9, 11 and 12.

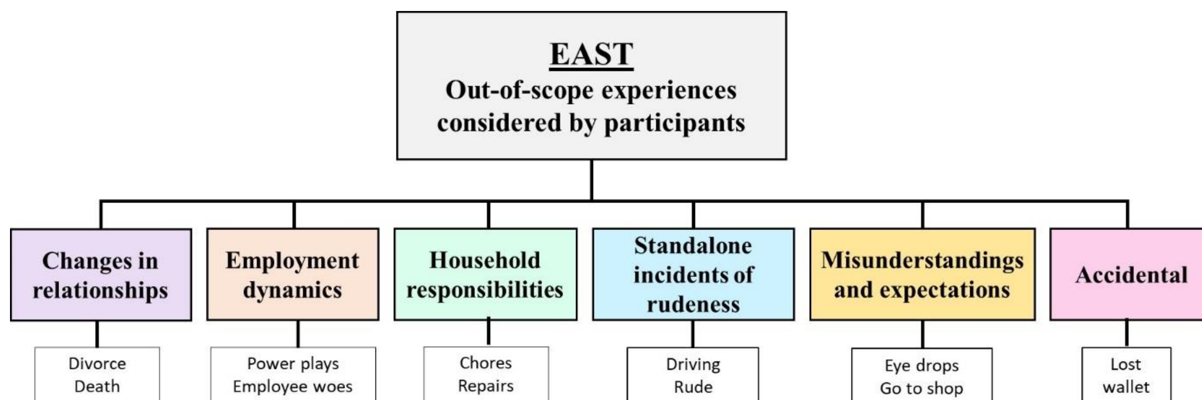

Figure 3: Thematic map of out-of-scope responses of older adults to the EAST

b) *Participants' fear, knowledge, and experiences of crime*

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 7 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. Refer to 4 for common themes identified from older adults when probing responses to the EAST. The themes represent crime-related experiences shared by older adults.

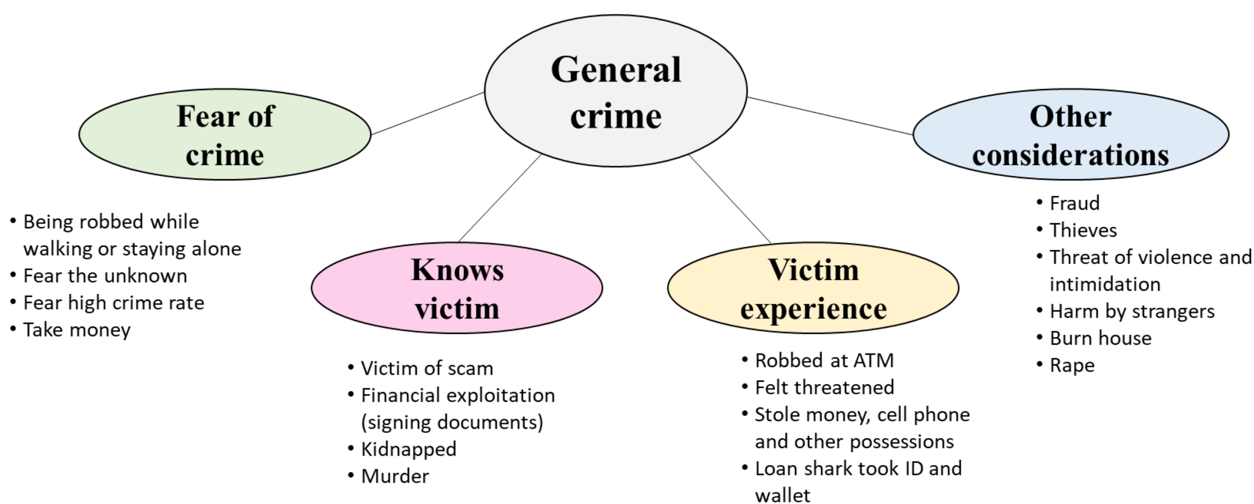

Figure 4: Thematic map of older adults' responses to the EAST that represent crime-related experiences

Table 6: Out-of-scope interpretations from older adults' response to the 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)*
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		15	4	21%	Divorce	*"Yes. Thinking of my divorce" (RJAFR0001)*

EAST no.	Question	In-scope	Out-of-scope	Out-of-scope (%)	Themes	Narratives of Out-of-scope interpretations (examples)
	Has anyone ever failed or refused to help you take care of yourself when you needed help?				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	**Has anyone taken money, valuables (ID, bank card) or any other things that belong to you without your permission, or against your will?**	16	3	16%	Lost wallet	*"Lost wallet once" (RJAFR0004).*
					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 7: 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.

Sub-theme	EAST Question no.	Narratives
Fear about crime	**E1**	*"If you walk or stay alone and someone comes 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).*
	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)*

Sub-theme	EAST Question no.	Narratives
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).

c) 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.

d) EAST Response options

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

3.3.3 The Caregiver Abuse Screen (CASE)

Analysis across all four 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 from in-scope interpretations that reflect care-experiences and risk of elder abuse in South Africa.

a) Out-of-scope interpretations of the CASE

When asked if they "often feel if they are being forced to 'act out of character' or do things they feel bad about", carers' 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 8). These examples reflect behaviour that provide support to the older adult rather than suggestive of elder abuse.

Table 8: Carer responses to the CASE that represent examples of out-of-scope interpretations of the concept 'out-of-character'

Concept interpretations	Sub-theme	Narratives (examples)
'Out of character'	**Shifting roles and responsibilities**	*Dementia sets a different set of rules for life. There's a new norm that is out of character. You do things that you never thought you had to do. Example, she wets herself so you do your mother's personal cleaning…" (RJENG0022).*
	Managing hygiene needs	*When you're in a situation you're quite embarrassed about and don't know what to do about, like an incontinence situation. Something that's embarrassing to you. You are not yourself in at moment" (RJENG0026)*
	Confronting family	*"I'd rather do something out of character than get into a difficult situation. For me [out of character] would be to step in to do something about a situation where family is not treating her right" (RJAFR0021).*

b) *Care experiences and risk of elder abuse in South Africa*

Carers shared a range of experiences considered when responding to the CASE questions that were in-scope relative to the intended meaning (see 5).

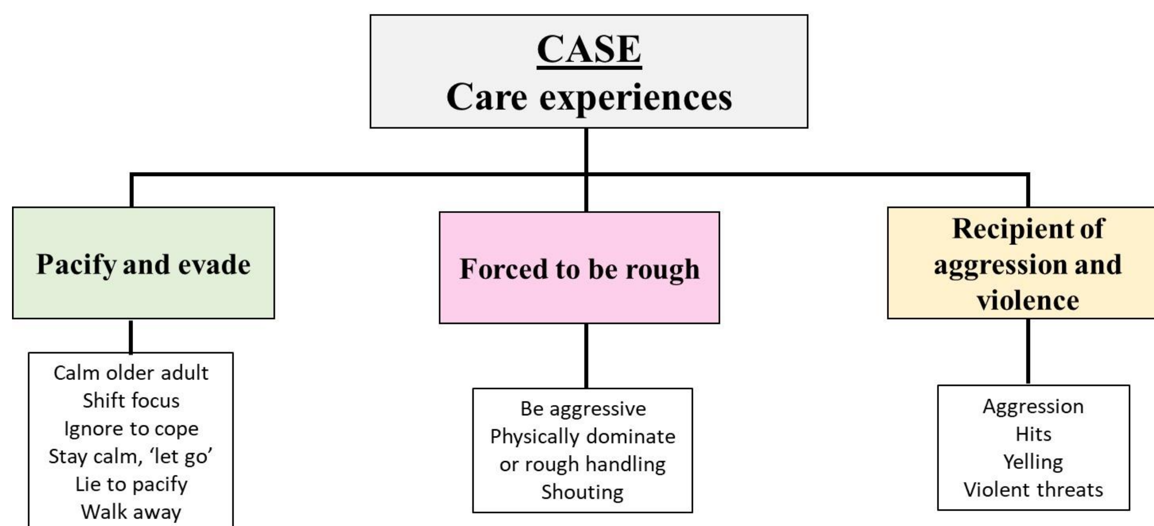

Figure 5: Themes of carer responses to the CASE that represent in-scope care experiences

Care responses were grouped as (1) pacify and evade; (2) forced to be rough; and (3) themselves recipient of aggression and violence (see Appendix 3 for supplementary table for expanded listing of themes and narratives). 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).*

c) Reactions to binary response options

Participants found it challenging to express their experiences caring for a person living with dementia as binary using Yes/No responses 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, and 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).*

3.4 Discussion on cross-cultural adaptation of the EAST and CASE

We set out to cross-culturally adapt two screening tools - the EAST and CASE - across two regions (and 4 languages) in South Africa. From this adaptation process (an important component of a full 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 four languages tested. We also show that care experiences and risk for perpetrating elder abuse vary greatly among participants, but that, with minor adjustments, the CASE can be a suitable tool to screen for this risk across these four languages in South Africa.

3.4.1 Reducing false-positive screening of abuse

When administering the EAST across the four languages, most questions were interpreted within scope relative to the intended meaning. Where interpretations were out-of-scope, participants often screened positively for experiencing 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).

3.4.2 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).

3.4.3 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, with examples such as (1) a salesperson built trust to convince the older adult to sign documents that unknowingly authorized a purchase of furniture; 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 (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 a consequence of, or led by ageist beliefs.

Despite South Africa having one of the highest crime rates in the world (World population review, 2023), 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 behaviours 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.

3.4.4 Vulnerability of caring in isolation

This sub-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 behavioural 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 in the carer's ability 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), 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.

3.4.5 Recommendations for the EAST and CASE

The cognitive interviews for testing the performance of the questions 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' (revised Afrikaans text: "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) and reduce false positives.

(5) Include a new item related to being a *victim of crime by a non-family/community member*, with prompts to provide contextual information about whether they believe the crime was (a) *because of their age;* or (b) whether they have been a *victim of general crime more than once.*

(6) 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. This is presented in the next chapter.

The following amendments to the CASE are proposed:

(7) 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).

(8) To potentially address false-positive screening of risk of perpetrating 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 <u>to your</u> [care recipient] that you feel bad about?" (The underlined <u>'to your'</u> is the added text).

3.4.6 Limitations

There are several limitations to consider. First, although the four languages tested are dominant in the two provinces wher the testing occurred, 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. Using screening tools in isolation and without further investigation pose dangers of people identified through false positives being prosecuted and added to the elder abuse register (once established). It is therefore important that health and social care practitioners and the criminal justice system understand the limitations of screening tools, and that a positive screen for elder abuse risk (using the EAST and/or CASE) necessitates further investigation of context, evidence, and support needs of both the older adult and the alleged perpetrator.

3.5 Conclusion on cross-cultural adaptation of the EAST and CASE

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 perpetrating 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.

CHAPTER 4: Prevalence, perpetrators, and predictors of self-reported elder abuse in South Africa

4.1 Introduction

Detecting elder abuse in multi-cultural communities is complex. Globally there is little consensus on what constitutes elder abuse (Roberto, 2016), while screening tools rarely consider how cultural diversity mediates understandings and manifestations of abuse (Brijnath et al., 2020). The South African Older Persons' Act (no.13 of 2006) defines elder abuse very similarly to World Health Organization (WHO), as "*…any conduct or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress or is likely to cause harm or distress to an older person"* (Government Gazette, 2006). This definition broadly specifies elder abuse types as physical, psychological or emotional, sexual, financial, and neglect (WHO, 2018).

Elder abuse research is less established in low-or-middle-income countries (LMICs) (Dong, 2015), like South Africa. Limited evidence suggest that older adults generally feel unsafe in their homes and their communities, while women especially feel at greater risk of violence and abuse (Lloyd-Sherlock et al., 2018). Existing studies show that most perpetrators are a family member or spouse, someone the older person lives with, and/or someone that provides daily assistance (Amstadter, et al., 2011). Perpetrators are also heterogenous as a group and found to vary across types of abuse (Jackson, 2016). If a person is a physical abuser, they tend to have a history of crime (police record) and/or substance abuse, whereas emotional abusers are often someone the older adult relies on for care and support (Amstadter, et al., 2011). Other predictors of experiencing elder abuse include a family history of violence, high stress, and social isolation (Campbell-Reay & Browne, 2001; Gurayah, 2015; Raggi et al., 2015). Risk of abuse also increases where the older adult has significant health concerns, including functional dependence and cognitive impairment such as dementia (Pillemer et al., 2016). While problems with recall and communication associated with dementia can prevent the self-reporting of abuse, from the carer perspective, providing care and support in isolation and without psychoeducation on how to support people living with dementia, can increase stress, carer burden, and abuse (Downes *et al.*, 2013). To date there has been no national prevalence studies on elder abuse in South Africa (Kotzé, 2018), with two localised studies suggesting that rates are high (>60%) (Bigala & Ayiga, 2014; Meel, 2017). However, within a South African context it is unclear what the most common forms of abuse are, who are common perpetrators, and what risk factors for abuse are. Understanding the role of dependency, dementia, and functional impairment in risk for elder

abuse will enable health and social care systems in South Africa to identify those most at risk and put strategies in place to strengthen protective services for older adults in need of support. This study therefore examines the prevalence, perpetrators, and predictors of elder abuse in a household survey across two regions in South Africa.

4.2 Materials and methods

4.2.1 Design

The elder abuse screening tools were nested within a household survey that collected data estimating the prevalence, social impact and cost of people living with dementia in South Africa. All tools were forward and back translated into four languages, i.e., English, Afrikaans, isiXhosa, and Northern Sotho, and then cross-culturally adapted for use in the two South African regions. The cross-cultural adaptation of these measures are described and published elsewhere (see Farina et al., 2022). The cross-cultural adaptation of the EAST and CASE tools was described in Chapter 3.

4.2.2 Setting

The adapted Elder Abuse Screening Tool (EAST) described below was included in the STRIDE-household survey in the Cape Town and Dikgale areas, South Africa. Cape Town is predominantly an urban, coastal setting in the Western Cape province, while Dikgale contrasts as a predominantly rural, land-locked site within the Limpopo province. The Western Cape province has an estimated 7,113,776 million people in 2021, of which 6.9% are 65 years and older (StatsSA, 2021). The Limpopo population is estimated at 5,926,724 million people, with 374,425 (6.13%) people 65 years and older (StatsSA, 2021).

4.2.3 Participants

Older adults were aged 65 years and older at the time of the interview and participated in the STRIDE household prevalence survey between October and December 2021. The survey included two interviews per household, one with the older adult and one with a household informant 18 years or older and who knew the older adult best. Participants were screened for capacity to consent during the consent process, and people who showed clear evidence of not being able to follow the consenting process and give formal consent were not included. Screening for capacity to consent was based on four questions: (1) Are participants able to understand the purpose of the study; (2) retain information long enough to make a decision; (3) able to weigh up information to make a decision; and (4) are participants able to communicate their decision? Where participants did not have capacity to consent, their informant/primary carer was asked to complete a consultee

declaration form where they indicated that to the best of their knowledge of the older person's wishes, that they would want to participate or not. This study only focuses on the data collected from the older adult (see Chapter 5 for sub-study on informants and potential abusers). Participants had to be fluent in at least one of the four languages, English, Afrikaans, isiXhosa, or Northern Sotho.

4.2.4 Sampling strategy

Different sampling strategies were employed to ensure the most appropriate method was used for the population information available at the time of the survey. The strategies for Cape Town and Dikgale are described below, with an initial target of 400 households per site.

4.2.5 Cape Town sampling strategy

The City of Cape Town is a metropolitan municipality divided into 115 wards (Wikipedia, 2022), using the latest census (2011) and Community Survey (2016) data to provide information about population size, age, sex, and income. To select wards, a proportionate to population size (PPS) technique (Cheung, 2014) was used. Wards were stratified according to low-, middle- and high-income strata and then randomly selected within each stratum to identify 3 low, 3 middle, and 2 high income wards across the City of Cape Town (8 wards in total). Maps were printed for each ward and divided into sub-areas for dwelling counting to update the population size estimates for each ward. This exercise was especially relevant to include informal household structures such as shacks, 'wendy[10]' houses or any kind of backyard dwelling used for living purposes. The total estimated number of dwellings for each ward was calculated and then divided by 50 to obtain the interval between each dwelling selected for recruitment. The interval was then applied to select 50 households per ward using systematic random sampling to search for eligible households. Since there was no sampling frame of eligible households for recruitment in Cape Town, a door-knocking strategy supported the identification of eligible participants and guided the recruitment and replacement of participant households. This entailed visiting the selected household to complete a short eligibility screening questionnaire that included questions about total household membership, number who are 65 years and older, available informant, willingness to participate, reasons for refusal, if a revisit is needed, contact details, proposed appointment for the interviews, and outcome of interview.

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[10] *Wendy house* – a temporary structure that resembles a garden shed that is commonly used as a living space or home.

4.2.6 Dikgale sampling strategy

A total of 14 villages in the Dikgale area were included in the survey. These villages are small and form part of a health research demographic surveillance site called DIMAMO (see https://saprin.mrc.ac.za/nodes.html) , an ongoing partnership with the University of Limpopo (UL). These villages are relatively homogenous in terms of socio-economic status and provided a representative sample typical of the South African rural context. Households are surveyed annually, with updated population information available for each dwelling across the 14 villages. The DIMAMO database therefore provided an ideal sampling frame to select eligible households for recruitment, using simple randomisation to target households with a person 65 years or older at the time of the recruitment across the 14 villages.

4.2.7 Screening procedure

Participants were interviewed at their homes in a space where they felt comfortable, using mobile devices and capturing data on REDcap (Harris et al., 2009). Limitations in space and privacy, especially in informal dwellings and overcrowded household structures, were navigated by interviewing participants: (1) outside the home or in a private space (e.g., garden or veranda); (2) not within hearing distance of other household members, especially in busy households; and (3) skipping the tool (proceeding with the other STRIDE tools) and resuming later when passers-by or household members had vacated the interview space.

4.2.8 Elder abuse screening tool (EAST)

The EAST was originally developed in a collaboration between the South African National Department of Health (NDOH) and the World Health Organization (WHO) (NDOH, 2011), for all healthcare workers at healthcare facilities (e.g. clinics, community health centres, luncheon clubs and residential care) to screen and identify possible elder abuse. The tool aims to identify self-reported elder abuse, including physical, sexual, financial, psychological/emotional abuse, and neglect. It consists of 12 screening questions directed at persons 60 years and older. The EAST was adapted, as described in Chapter 3 (herein referred to as the adapted EAST) by adjusting the wording to maximise in-scope interpretations of elder abuse. In-scope interpretations are when the respondent understands and interprets the question as intended. It also included verification prompts for each of the original questions (labelled east1 – east12 in Table 9) to assess the congruency of participant responses with the definition of elder abuse. To better understand the nature of the abuse, the interviewer also noted *who was involved* in the elder abuse example provided. This addition was for research purposes, and not intended as a core item for the EAST.

The adapted EAST also includes a new item related to being *victim of crime committed by a non-family/community member* (*east10gc*). Additional contextual information is collected in the form of the older adult's *dependency status* (*east0*), whether they believe the crime was *because of their age* (*east10age*) and if they have been a *victim of general crime more than once* (*east10multi*). It is important to note that *east0* (i.e. *"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?")* screens for self-reported dependency, and unlike the other EAST questions, does not in itself suggest abuse and therefore handled differently (see analysis section).

For this study, we used the adapted EAST to collect community-level data to identify possible elder abuse at a household level. We scored the EAST the same as for the Elder abuse suspicion index (EASI) (Yaffe et al., 2008), a similar tool. As such, each 'yes' response was given a score of 1 (min = 1, Max=13). For screening purposes, a single affirmative response was deemed as the person being at risk of elder abuse. The EAST was nested within the *STRIDE Older Adult Toolkit* that also collected extensive data on the history, functional status, health, and cognitive status of older adults and household informants (see Appendix 4 for instruments in STRIDE Older Adult Toolkit) (Farina et al., 2022). The measures included for analysis in this study are described below.

Table 9: The Adapted Elder Abuse Screening Tool (EAST) tools and variable names

PREFACE
Now I am going to ask you questions about how you are treated at home and how others who you have a relationship with, treat you and make you feel. There are no right or wrong answers, some of these questions may not be relevant to you but we ask everyone the same questions. Please remember, these questions refer only to interactions you have with people that you have some form of relationship with or with whom you have an expectation of trust, for example: a family member, your spouse, your child, your grandchild, a caregiver/someone who cares for you, a neighbour, to name just a few. I will ask a question and you can respond by choosing 'Yes', 'No', 'Don't know' or 'I'd rather not say' to describe how those you trust or care for you, treat you or make you feel.

Item	Question	Verification prompt
[east 0]	**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?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 1]	**Are you afraid of anyone in your family, home, or community that you are living in?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 1_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 1_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household 2, Family member who does not live in same household

Item	Question	Verification prompt
		3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 2]	**Has anyone in the last two months hurt or harmed you?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 2_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 2_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household 2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 3]	**Has anyone in the last two months forced you to do things that you did not want to do?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 3_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 3_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household 2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 4]	**Has anyone in the last two months touched you in ways you did not want?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 4_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 4_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household

Item	Question	Verification prompt
		2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 5]	**Has anyone in the last two months scolded or sworn at you or threatened you?** 0, No	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 5_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 5_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household 2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 6]	**Has anyone prevented you from getting food, clothes, medication, spectacles, hearing aids and / or medical care?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 6_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 6_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household 2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 7]	**Are you left alone a lot, locked up, not allowed to socialise or has anyone been prevented from visiting you?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 7_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse

Item	Question	Verification prompt
		2, Yes - Meets definition of elder abuse
[east 7_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household 2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 8]	**Has anyone ever failed or refused to help you take care of yourself when you needed help?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 8_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 8_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household 2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 9]	**Has anyone made you sign papers that you did not understand or did not want to sign?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 9_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 9_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household 2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 10]	**Has anyone taken money, valuables (ID, bank card) or any other things that belong to you without your permission, or against your will?**	0, No 1, Yes 777, Don't know 999, I'd rather not say

Item	Question	Verification prompt
[east 10_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 10_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household 2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 10gc]	**Has your money, valuables, or any other things taken by a stranger(s)/non-family/community member(s) where you were the victim of a general crime?**	1, Yes 0, No 777, Don't know
[east 10age]	**Do you think you were targeted due to your age?**	1, Yes 0, No 777, Don't know
[east 10multi]	**Has this happened more than once?**	1, Yes 0, No 777, Don't know
[east 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?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 11_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 11_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household 2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[east 12]	**Have you have ever been placed in shackle[s], tied up,or locked up in confined spaces?**	0, No 1, Yes 777, Don't know 999, I'd rather not say
[east 12_example]	**Would you be comfortable to give an example?**	0, No 1, Yes - Does not meet the definition of elder abuse 2, Yes - Meets definition of elder abuse
[east 12_who]	**Who did the example involve? Tick all that apply:**	1, Family member who lives in the same household

Item	Question	Verification prompt
		2, Family member who does not live in same household 3, Non-family member who you have a personal relationship with (e.g. neighbour, friend) 4, Non-family member who is in a position of power (e.g. police, doctor, paid carer) 6, Other
[easthelp]	**Do you wish to receive further help from a Social Worker?** *If the answer is "no", the older person should be given contact details where to get help should he/she change his/her mind at a later stage.*	1, Yes 2, No

4.2.9 Measures to identify predictors of elder abuse

Measures completed by both older adults and informants under the STRIDE project were used to identify predictors of elder abuse. Descriptions of these measures and how they were cross-culturally adapted are provided elsewhere (Farina et al., 2022). Demographic predictors used include age, sex, and educational attainment. Older adult measures used include:

- ***World Health Organization Disability Assessment Schedule*** **(WHODAS 2.0)** (12 items) was used to measure functional impairment (Üstün et al., 2010)
- The ***10/66 Short Schedule*** (Stewart et al., 2016) was used to identify participants with possible dementia. While diagnosis is not clinically confirmed in this study, this algorithm is validated and suitable for identifying dementia at community level in epidemiological studies. The outcome of the 10/66 algorithm was included as a binary variable in this study where each older adult was either *free of dementia* or had *dementia*.
- The ***Lubben Social Network Scale (LSNS-6)*** (Lubben et al., 2006) (6-items), was used to measure social engagement (network and isolation);
- A dichotomous, self-reported item (*east0*) screening for self-reported ***dependency***: *"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?"*

Measures completed by the informants about their older adult household member include:

- A shorter version of the 12-item ***Neuropsychiatric Inventory Questionnaire (NPI-Q)*** (Kaufer et al., 2000), that focused on the severity of neuropsychiatric domains; and
- The ***Dementia Severity Rating Scale (DSRS)*** (Clark & Ewbank, 1996), a 12-item questionnaire that assesses the severity of dementia.

Lastly, we used an indicator called *Insight into memory impairment* to measure the cognitive ability of older adults to recall their experiences (recall ability for elder abuse). This is novel in the measurement of elder abuse, where we hypothesise that less insight (i.e., less recall ability) shows a decreased likelihood to report elder abuse. This is a composite variable consisting of both informant and older adult data on perceived memory impairment. For the older adult, we used the Geriatric Mental Schedule (GSM), an older adult self-report on subjective memory complaints) (Copeland et al., 1986) and extracted: (1) memory impairment, (2) forgetting where they put things; and (3) forgetting names of friends and family. Each of these items were dichotomised (1 = impairment and 0 = no impairment) and summed to a max of 3. For the informant, we used four items from the Community Screening Interview for Dementia (CSI-D): (1) their perception of the older adult's memory impairment, (2) forgetting where they put things, (3) forgetting names of friends, and (4) forgetting names of family members. We merged forgetting names of friends and names of family to correspond with the GSM. Once we had three informant items, these items were also dichotomised (1 = impairment and 0 = no impairment) and summed to a max of 3.

We then subtracted the *perceived memory impairment* from older adults from that of informants', creating this new variable where higher scores indicate poorer *insight into memory impairment* (mean=0.14, SD=1.2, min= -3, max=3). This calculation is similar to that reported by Vogel and colleagues (Vogel et al., 2004).

4.2.10 Analysis

We used the data collected from the verification prompts of the adapted EAST to recode verified responses for EAST items, against the standard definition of the South African Older Persons' Act and the WHO of what constitutes abuse. For example, positive screens for items were calculated by adding 'yes' responses of the participant on the question asked, with corresponding 'yes' responses on the verification prompt that the interviewer completed to indicate whether the example provided by the participant meets the definition of elder abuse (see Table 9). Participants screening positive for elder abuse were those who had a verified 'yes' response to 1 or more items on *east1-12*, while non-abused groups were those who responded 'no' or had provided examples that do not meet the definition of elder abuse (verified by interviewers).

Sample size (n) and valid percentages (%) were reported for descriptive data on sample characteristics, including individual item responses and overall prevalence of the adapted EAST. Odds ratio was used to estimate risk of abuse. We also reported the internal consistency for the adapted EAST items (Cronbach's α). As a guide, a value over 0.6 was considered having acceptable internal consistency (Taber, 2018). The strongest predictors of elder abuse were identified through

binary logistic regression, using a two-phased approach: (1) Univariate logistic regression to identify significant factors; and (2) multivariate logistic regression of statistically significant factors from the first phase being entered alongside age, sex and education. Univariate analysis included self-reported elder abuse as dependent variable (0=no abuse, 1=elder abuse), self-reported dependency (*east0*), functional impairment (WHODAS 2.0), dementia status (10/66 algorithm), dementia severity (DSRS), neuropsychiatric index (NPI-Q), social engagement (LSNS-6), and insight and recall ability (i.e., insight to cognitive impairment) as predictor variables. Variables in the model were retained if they were statistically significant ($p<0.05$).

To explore the common types of abuse experienced, we conceptually grouped items (see Table 11), namely, emotional/psychological, financial, sexual, and physical abuse and neglect (National Institute on Aging, 2020; WHO, 2018). In some instances, individual items were assigned to multiple groups (e.g. *east4* screens for both physical and sexual abuse).

All analysis was done using SPSS 26 (statistical package for the social sciences, https://www.ibm.com/support/pages/downloading-ibm-spss-statistics-26), reporting sample size (*n*) and valid percentages (%) to adjust for missing values.

4.3 Results

4.3.1 Sample characteristics

This study included 490 households, with older adult participant ages ranging between 65 and 101 (M=74.6; SD=7.5). Participants were predominantly female (66.2%, n=309) and were screened in English (19%, n=93), Afrikaans (9.4%, n=46), isiXhosa (12.9%, n=63), and Northern Sotho (58.7%, n=288). Most participants had primary level schooling or higher (57.3%, n=269). Significant differences were found in educational attainment between males and females, where men were more likely to have higher level of educational attainment (OR = 1.53, 95%CIs 1.03 to 2.27). Although many participants were retired (63.5%, n=298), a small group of older adults were still economically active with paid work ranging from full-time (2.2%, n=10) to part-time work (3%, n=14). The dementia status was only available for 408 participants due to data (n= 82) required to successfully run the 10/66 short algorithm being missing. A total of 14.5% (n= 59) (unweighted) participants were identified as having dementia. Participants with dementia had a dementia severity rating of mild (n=51, 87.9%), moderate (n=5, 8.6%), and severe (n=2, 3.4%), see Table 10.

Table 10: Sample characteristics (N=490)

Sample characteristics	Mean (SD)	N (%)
Age *(n=489)*	74.6 (7.5)	
Sex *(n=467)*		
Female		309 (66.2%)
Male		158 (33.8%)
Language *(n=490)*		
English		93 (19%)
Afrikaans		46 (9.4%)
Xhosa		63 (12.9%)
Northern Sotho		288 (58.7%)
Educational attainment *(n=469)*		
No schooling		66 (14.1%)
Some schooling		134 (28.6%)
Primary		161 (34.3%)
Secondary		54 (11.5%)
Tertiary		54 (11.5%)
Employment status *(n=469)*		
Paid, full-time salaried		5 (1.1%)
Paid, part-time, salaried		7 (1.5%)
Paid, full-time, unsalaried		5 (1.1%)
Paid, part-time, unsalaried		7 (1.5%)
Unemployed, looking for work		14 (3%)
Unemployed, not looking for work		98 (20.9%)
Housewife/husband, full-time		35 (7.5%)
Retired		298 (63.5%)
Dementia *(n=408)*		
Free of dementia		349 (85.5%)
Dementia		14.5% (59)
Dementia severity* *(n=58)*		
Mild		51 (87.9%)
Moderate		5 (8.6%)
Severe		2 (3.4%)
**Note: Dementia severity reported here only for participants who were identified to have dementia according to the 10/66 short algorithm.*		

4.3.2 Adapted and original EAST responses

When calculating the EAST scores based on the use of unverified (original EAST) responses versus the scores using the verified (adapted EAST) responses, we found that the unverified use of the EAST estimated a prevalence that was twice as high (19.3%; 95%CIs 15.8 to 23.1) compared to the verified prevalence estimate (reported below, see 4.3.3). For purposes of this study, the adapted EAST (using the verified responses, i.e. *east1-12*, listed in table 11) had acceptable internal consistency (Cronbach's $\alpha = 0.64$).

4.3.3 Prevalence

In this survey, we found that 10.4% (95%CIs = 7.8 to 13.5) (n= 50) of participants screened positive for elder abuse based on the adapted EAST. While elder abuse was reported more by women

(64.4%, n=29) than men (35.6%, n=16), differences were not significant (OR=1.13, 95%CIs 0.59 to 2.15). Table 11 shows reported elder abuse for each of the EAST questions.

Table 11: Frequencies of verified self-reported elder abuse for EAST (n=50)

Item	EAST Question	N (%)	Theoretical link
East1	*Are you afraid of anyone in your family, home, or community that you are living in?*	11 (22%)	Emotional / psychological
East2	*Has anyone in the last two months hurt or harmed you?*	13 (26%)	Emotional / physical / sexual
East3	*Has anyone in the last two months forced you to do things that you did not want to do?*	1 (2%)	Emotional / physical / sexual
East4	*Has anyone in the last two months touched you in ways you did not want?*	3 (6%)	Sexual, Physical
East5	*Has anyone in the last two months scolded or sworn at you or threatened you?*	14 (28%)	Emotional / psychological
East6	*Has anyone prevented you from getting food, clothes, medication, spectacles, hearing aids and / or medical care?*	1 (2%)	Neglect
East7	*Are you left alone a lot, locked up, not allowed to socialise, or has anyone been prevented from visiting you?*	0 (0%)	Emotional / psychological
East8	*Has anyone ever failed or refused to help you take care of yourself when you needed help?*	3 (6%)	Neglect
East9	*Has anyone made you sign papers that you did not understand or did not want to sign?*	3 (6%)	Financial
East10	*Has anyone taken money, valuables (ID, bank card) or any other things that belong to you without your permission, or against your will?*	11 (22%)	Financial
East10gc	*Has your money, valuables, or any other things taken by a stranger(s)/non-family/community member(s) where you were the victim of a general crime?*	23 (46%)	Financial
East11	*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?*	2 (4%)	Financial
East12	*Have you have ever been placed in shackle[s], tied up, or locked up in confined spaces?*	0 (0%)	Physical
**Please note: East0 ("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?") screens for self-reported dependency, and unlike east1-12, a positive screen on east0 does not in itself suggest abuse, and is not included in these calculations of self-reported abuse.*			

The most common reports of elder abuse aligned to questions of financial (n = 39, 78%) and emotional abuse (n=25, 50%). Of concern is that almost half (46%, n=23) of all positive screens for elder abuse involved *money, valuables, or any other things taken by a stranger(s)/non-family/community member(s) (east10gc)*. Of those participants who screened positive for this question (*east10gc*), 44.4% (n=8) *believed they were targeted because of their age* (*east10age*) and 38.1% (n=8) said that this happened more than once (*east10multi*). Questions that reflect neglect, sexual and physical abuse were less frequently reported (see Table 11).

4.3.4 Perpetrators

Of all instances of reported abuse, *non-family member where there is a personal relationship* (29%, n= 18), *family member living in the same home* (26%, n= 16) and a *family member not living in the same home* (24%, n=15) were the most common perpetrators. Other perpetrators involved were reported as *non-family member in a position of power* (11%, n=7) and *other* (10%, n=6) (see Table 12).

Table 12: Perpetrators involved in self-reported elder abuse (% of responses, n=62)

Perpetrators involved in elder abuse	***n***	***%***
Non-family member where there is a personal relationship	18	29%
Family member living in the same home	16	26%
Family member not living in the same home	15	24%
Non-family member in a position of power	7	11%
Other	6	10%

4.3.5 Predictors of self-reported abuse

We found that dementia status and severity, neuropsychiatric symptoms, insight into memory impairment (recall ability), and social network and engagement were not associated with elder abuse (see Table 13). Functional impairment was the only significant factor, and remained robust even after adjusting for age, sex and education (see Table 14). The Nagelkerke r^2 model fit statistics were 0.05 (Cox & Snell $r^2=0.02$).

Table 13: A series of univariate logistic regression models, with risk of elder abuse (adapted EAST, screen positive) as the dependent variable.

Univariate analysis					
	b	**Exp(B)**	**LCI**	**UCI**	**p**
10/66	0.26	1.30	0.55	3.10	0.55
WHODAS	0.05	1.05	1.02	1.08	<0.001
East0	0.34	1.40	0.75	2.64	0.30
NPI	-0.06	0.94	0.82	1.08	0.41
Insight	-0.13	0.88	0.68	1.14	0.33
LSNS-6	-0.01	0.99	0.93	1.05	0.64
DSRS	0.03	1.04	0.99	1.09	0.15

10/66 *– 10/66 Short Schedule (dementia algorithm)*
WHODAS *– World Health Organization Disability Assessment Schedule 2.0*
East0 *– The Adapted Elder Abuse Screening Tool (self-reported dependency item)*
NPI *– Neuropsychiatric Inventory Questionnaire*
Insight *– Insight into memory impairment (recall ability)*
LSNS-6 *– Lubben Social Network Scale (LSNS-6)*
DSRS *– Dementia Severity Rating Scale*

Table 14: Multivariate logistic regression analysis, with risk of elder abuse (adapted EAST, screen positive) as the dependent variable.

Multivariate analysis					
	b	**Exp(B)**	**LCI**	**UCI**	**p**
Age	-0.02	0.98	0.93	1.03	0.35
Sex	0.004	1.00	0.50	2.04	0.99
Education	-0.29	0.75	0.38	1.49	0.41
WHODAS 2.0	0.05	1.05	1.02	1.08	<0.01
Constant	*-0.81*	*0.45*			*0.68*
***WHODAS** – World Health Organization Disability Assessment Schedule 2.0*					

4.4 Discussion on prevalence and predictors of elder abuse

This study aimed to determine the prevalence of self-reported elder abuse for older adults across two regions in South Africa and examined the potential perpetrators and predictors of elder abuse. We found that 1 in 10 older adults screened positive for self-reported abuse, with most perpetrators being either a non-family member where there is a personal relationship, or a family member. In the previous chapter, the EAST was cross-culturally adapted for the purposes of screening for elder abuse in this context, and accounts for how cultural, and geographical diversity may mediate the presentation of abuse. In this sub-study, we showed that the understanding of elder abuse varied with interpretation, and that without verification, reports of abuse were higher. Irrespective, self-reported elder abuse was high at 10.4%, but significantly lower than reported in a previous study within South Africa which did not use verification (e.g. 64.3% men and 60.3% women) (Bigala and Ayiga, 2014). However, our estimations are in line with global prevalence studies that report the pooled prevalence for self-reported elder abuse at 10% (Ho, et al., 2017) and 15.7% (Yon, et al., 2017).

Responses linking to financial and emotional/psychological abuse were most reported, with less reported abuse for questions that reflect neglect, physical and sexual abuse. We also found that many demographic (e.g., age) and health (e.g., dementia status) factors were not associated with reports of abuse. There was also no association between reporting abuse and older adults' insight into memory impairment, highlighting that lack of insight within the present sample was not associated with fewer reports of abuse. It also shows that potential underreporting (in this sample) may be less due to factors related to cognitive impairment, and perhaps have more to do with factors related to fear of disclosure and reporting of abuse. Fear of disclosure is well-documented globally where older adults do not report abuse because of feelings of shame, being worried about getting the abuser in trouble (as this is often their adult child), and the fear of retaliation (or loss of

support) by the perpetrator (Pang, 2000; WHO, 2016). Stigma and non-disclosure were also reported by stakeholders in our situational analysis in Chapter 2. We showed that older adults in South Africa were reluctant to report abuse because, despite measures put in place in the judicial system to protect testimonies, older adults feared direct contact or confrontation with the perpetrator and as result do not report abuse (see Part II in Chapter 2). In the current sub-study however, only functional impairment of older adults was statistically associated with elder abuse.

Whilst the majority who reported abuse in this sample were women (64.4%), they were not at greater risk of abuse than men (35.6%). This could be because of the small sample size of people who reported abuse (n=50), and the smaller percentage of male participants sampled (33.8%) in comparison to female participants (66.2%). While there are mixed findings globally on the gendered nature of elder abuse (Yon et al., 2017), there are some studies in other LMICs countries that show older women to be at higher risk than older men (Hagh et al., 2021; Jeon et al., 2019; Nair et al., 2021). Elder abuse prevalence at a national level has never been established in South Africa, although a previous study in the Mafikeng area (North West province) showed that slightly more older *men* (64.3%) than women (60.3%) reported abuse (Bigala & Ayiga, 2014). These differences can be accounted for by inconsistencies in measurement and untested understandings of elder abuse in community settings. The Mafikeng study asked older adults 'whether or not they perceived they were ever abused', creating a composite variable of 'ever experienced abuse', and specific follow up questions to determine type (Biyala & Ayiga, 2014). While this Mafikeng study provided insight into elder abuse where no data were previously available, it did not use a formal measure to screen for abuse, nor verified responses to determine if responses constitute elder abuse rather than negative social experiences instead, as shown in Chapter 3.

As expected, we found that elder abuse was strongly associated with the older adult's functional status. Functional impairment is a known risk factor for elder abuse (Downes et al., 2013; Sathya & Premkumar, 2020) and linked to increased dependence and vulnerability as impairment progresses (Roberto, 2016). However, the association might be more complex. Factors associated with increased dependence such as cognitive impairment (Roberto, 2016) and dementia (Downes et al., 2013) are identified risk factors for elder abuse globally. However, within the present study perceived dependence, dementia caseness, and dementia severity failed to reach statistical significance. There does appear to be a high level of uncertainty of the true effect within our sample based on the wide confidence intervals for some of these variables, and that our regression models do not tell us whether the types of abuse experienced differs between demographic groups. While further investigation is needed, understanding the link between functional impairment and increased risk of abuse can inform the strengthening of health and social care systems by

introducing, for example, targeted screening by health- and social care professionals, and increasing the accessibility of interventions. Prevention efforts could include the promotion of healthy ageing policies and the prevention of functional impairment through addressing modifiable risk factors throughout the lifespan, such as smoking, malnutrition, alcohol use, hypertension, and diabetes (WHO, 2019).

Age and sex were not associated with self-reported abuse, highlighting that prevention responses may need to be universal, and not targeted at women alone. While education is a known predictor for many modifiable risk factors for functional impairment (Litke, et al., 2021), we found that education was not significantly associated with self-reported abuse in our sample. However, strengthening responses to education in South Africa may address known risks for functional impairment, and therefore also reduce risk of elder abuse.

In line with previous studies (Fang & Yan, 2018; Roberto, 2016), older adults typically knew their abuser. Financial and emotional abuse related examples were commonly cited. However, unlike other forms of abuse where the perpetrator had a personal relationship with the older adult, almost half of abuse reports were related to valuables taken by a stranger/non-family/community member (i.e. a new item added the EAST as result of our cross-cultural adaptation process). Our results therefore indicate that older adults are typically victimised by people that intentionally build trust to deceive and financially exploit them. In part, this could reflect the realities of South Africa having one of the highest crime rates in the world (i.e. 76.86/100 000) (World population review, 2023) and that older adults are often targets for crime and exploitation (Lloyd-Sherlock et al., 2018). The violation of this ‘expectation of trust’ is key in defining elder abuse (Older Persons Act, 2006; WHO, 2019), and is central to the vulnerability of older adults in their homes and communities where they are often targeted for their pensions (Lloyd-Sherlock et al., 2018). Emotional or psychological abuse was the second most common items reported. This form of abuse is often the hardest to recognise, even by older adults themselves, for example when older adults feel threatened, intimidated, and unsafe, or when their mobility is unduly monitored or restricted. Emotional or psychological abuse is a significant predictor of identifying negative mental health outcomes like depression and anxiety in older adults, as well as functional impairment (Cisler et al., 2012; Roberto, 2016).

4.4.1 Strengths and limitations

A strength of the adapted EAST is its use of verification prompts to frame common understandings of what constitutes elder abuse and verify participant responses to the South African (and WHO’s) definition of elder abuse. This, to our knowledge, is the first study in South Africa to use verification of responses in an elder abuse screening tool and also the first to explore the relationship between

dementia, functional impairment, and elder abuse at community level. Unlike many self-reported screening tools on elder abuse that exclude people with cognitive impairment (Ballard et al., 2019; Gallione et al., 2017; Schofield & Mishra, 2003), another strength of our study was that we were able to include people living with dementia, as their dementia status was determined as an outcome of the study after the questions including the abuse ones were asked. We need to take caution in interpreting reports in elder abuse from people with severe cognitive impairment, as they represent a group prone to poor recall, but also are the most vulnerable. Efforts should be made to not limit the voice of people with severe cognitive impairment but ensure that additional checks are in place to confirm accuracy. Despite finding no association between insight into memory impairment (recall ability) and elder abuse, caution should be taken in assuming that bias does not exist particularly because we had so few cases of severe dementia. Furthermore, this is a cross-sectional study and the predictors identified are associations and we should take caution and contemplate potential reverse causality explanations. A deeper exploration on the psychometrics of the EAST is also needed. Within the study we did not seek to explore the factor structure, however the multi-dimensional nature of elder abuse may not lend itself to being treated as a single construct. Further analysis is needed to understand whether internal consistency is better when treating the measure as being composed of several conceptual factors (e.g. items pertaining to physical abuse). While acceptable internal consistency of the EAST was shown, further analysis is needed to strengthen the future adaptation of the tool to increase its measurement accuracy and reliability. Our sample was limited in size and needs to be extended to allow for more definitive conclusions to be reached.

While the researchers are confident that the adapted EAST provides a good screening tool in detecting elder abuse in South Africa, screening in community settings poses significant challenges for self-reporting and disclosure, especially considering challenges in managing the proximity of the potential abuser during data collection. Interviewers followed strict protocols on managing privacy and confidentiality during screening, however realities such as overcrowded living spaces and fluid movements of members in and around a household are realities that typically shape community level research in South Africa. While elder abuse was found to be high, we suspect possible under-reporting due to the potential proximity of the abuser influencing older adults' disclosure. Our final limitation relates to the very nature of screening for elder abuse in communities, where older adults are screened by a stranger and less likely to disclose abuse if they do not trust the interviewer, the process, or potential consequences of reporting abuse (Brijnath et al., 2020). These realities of community research therefore reflect the hidden nature of elder abuse, and possibly underestimates prevalence.

4.5 Conclusion

This study showed that elder abuse in South Africa is high, with older adults' functional impairment being the strongest predictor of abuse. Financial and emotional abuse were the most typical forms of elder abuse reported, where the perpetrator was usually known to the older adult and/or potentially used deception to build trust to gain access and exploit the older person. This study fills a critical gap in the evidence base for elder abuse in South Africa and demonstrates the utility of the EAST as a promising screening tool for community settings. Our study therefore provides important evidence for South Africa on the prevalence, predictors, and perpetrators of elder abuse. It also extends its relevance to other LMIC contexts by contributing to global evidence on culturally appropriate screening of elder abuse. Screening is not definitive of abuse but a necessary step to start a dialogue with older adults to build rapport, promote trust, and challenge the hidden nature of elder abuse. Detecting elder abuse should not happen in isolation and should be supported with clear processes of investigation to eliminate false positives and, where abuse is confirmed, to refer to protection services that are responsive to the needs of older adults and people living with dementia.

CHAPTER 5: Risk of perpetrating elder abuse in South Africa: A prevalence study using the Caregiver Abuse Screen (CASE)

5.1 Introduction

Elder abuse cuts across class, race, and socio-geographic divides. Risk of experiencing elder abuse increases with longevity (Chalise, 2017) and is often associated with significant health concerns of the older adult such as disability and functional dependence, poor physical or mental health, and cognitive impairment including dementia (Pillemer et al., 2016). Dementia itself is recognised as a risk factor for elder abuse and often linked to a lack of knowledge, skills and support to provide adequate care for someone living with dementia (Downes et al., 2013). Carers who are anxious or depressed are also more likely to report abusive behaviours, especially those who are unsupported, working longer hours and/or experience abuse from their care-recipients (Cooper et al., 2010; Downes et al., 2013). Other known risk factors include the premorbid quality of the relationship between carer and care-recipient, a history of family violence, high stress and care burden, poor social support and isolation, substance abuse, and carer psychopathology (Campbell-Reay & Browne, 2001; Downes et al., 2013; Gurayah, 2015; Raggi et al., 2015).

Problems with recall and communication associated with dementia mask abuse and may prevent people living with dementia from disclosing or removing themselves from abusive situations (Downes et al., 2013). Therefore, where cognitive impairment is suspected, researchers often rely on screening significant others around the individual (including potential perpetrators) (Beach et al., 2016) for behaviours that signal potential abuse. Abusers, for obvious reasons, may conceal the abuse for fear of incrimination. As such, screening for risk of perpetrating abuse may be more effective if done in a non-blaming and non-confrontational manner to facilitate earnest responses (Cohen, 2011; Reis & Nahmiash, 1995). However, all perpetrators of abuse and neglect are not the same and vary in culpability that range from pre-meditated, deliberate acts of violence and exploitation to a genuine inability to meet an older adult's care needs (Jackson, 2016). Some research suggests that carers for people living with dementia are more responsive to disclosing frustrations, and more likely to report abuse and neglect (Beach et al., 2016).

Research on elder abuse in South Africa is extremely limited (Kotzé, 2018), with a lack of studies focusing on contextual conditions that impact the dementia carer experience (Mahomed & Pretorius, 2022). The few South African studies suggest that carers for older adults are predominantly unpaid, female, and unemployed (Lloyd-Sherlock, 2019), with spatial and material resource constraints posing significant safety concerns for people living with dementia (Mahomed &

Pretorius, 2022). Understanding risk of perpetrating abuse in South Africa is important to inform health and social care strategies and strengthen protective services for older adults in need of care and support. This chapter estimates the prevalence of risk of perpetrating abuse among household members who spend considerable time with an older adult (65 years and older) and provide care and support where needed. This sample includes carers providing care and support for someone living with dementia, as we examine known risk factors and potential predictors of abusive behaviours.

5.2 Materials and methods

5.2.1 Design

A household survey estimating the prevalence, social impact and cost of people living with dementia was completed under the STRIDE project in South Africa. The Caregiver Abuse Screen (CASE) was nested within the STRIDE survey's Informant Toolkit (see Appendix 2) and all measures were translated and cross-culturally adapted to four languages (i.e., English, Afrikaans, isiXhosa, and Northern Sotho. Details about this process is described elsewhere (see (Farina et al., 2022) Chapter 3 presents the cross-cultural adaptation of the CASE. Questions were asked about informants' health and well-being, as well as the health and well-being of the selected older adult within the household. While not all older adults in this study needed care, all informants completed the CASE in the context of responding to their experiences with their older adult.

5.2.2 Participants

One older adult aged 65 years or older and one informant (18 and older) were recruited and interviewed separately by two interviewers in each selected household. Findings from older adults screened for self-reported abuse are described in Chapter 4, while this study focuses on the screening of informants for being at risk of abusing an older adult. Informants were selected on the basis that they knew the older adult best, spent at least 4 hours a week with the older adult, and provided care and support where needed.

5.2.3 Setting

The survey was completed across two regions in South Africa. The sample selected for this sub-study was the same as for Chapter 4, where the Cape Town area in the Western Cape province was selected as our predominantly urban site, and the Dikgale area in the Limpopo province our more rural site (refer to Chapter 4 for the sampling strategy).

5.2.4 Caregiver Abuse Screening (CASE) tool

The CASE is a dichotomous (Y/N), 8-item tool that assesses risk of abusing through carefully worded questions that are non-blaming and non-confrontational (Reis & Nahmiash, 1995). This tool is useful for identifying abusive behaviours by asking potential perpetrators themselves, but also has the advantage of identifying *risk of abusing* (i.e., before it happens) (Melchiorre et al., 2017). It is important to note that the CASE, like other screening tools, is not diagnostic but rather suggestive of *risk* and where there is need for further investigation. A CASE score of 1 is suggestive of low risk of abusing, and a score of 4 or more is suggestive of high risk of abusing (Reis & Nahmiash, 1995). For this study, the CASE tool was translated into three languages (in addition to the original English one) – Afrikaans, isiXhosa and Northern Sotho – and cross-culturally adapted (see (Farina et al., 2022), in which in-depth, cognitive interviewing methods were used to ensure the measure was suitable for the South African context (see Chapter 3). Based on the recommendations of this previous work, the CASE was adapted to provide respondents with Likert-type response options (never, rarely, sometimes, very often, always), to capture the nuances in the dementia care experience. The *adapted* CASE was therefore used to screen informants for risk of abusing, but dichotomised responses calculated *post hoc* (i.e. never = 0, rarely to always = 1) to ensure parity with the original measure. The CASE has strong internal consistency across various world contexts (α=0.84 to 0.88) (Khan et al., 2020; Pérez-Rojo et al., 2015; Sakar et al., 2019), including screening carers for people living with dementia in Italy (α=0.86) (Melchiorre et al., 2017).

5.2.5 Other measures

The following measures were used from the STRIDE Informant and Older Adult Toolkits to assess possible predictors of risk of abusing (see Appendix 5 for the full list of instruments including those not used in this study):

- **WHODAS 2.0** (World Organisation Disability Assessment Schedule (Üstün et al., 2010) (12 items): To measure functional impairment;
- **10/66 Short Schedule** (Stewart et al., 2016): To identify older adults with dementia;
- **Dementia Severity Rating Scale (DSRS)** (12 items) (Clark & Ewbank, 1996): Measures severity of dementia symptoms;
- **LSNS-6** (Lubben Social Network Scale) (Lubben et al., 2006) (6 items): Measure of social network size.
- **Neuropsychiatric Inventory Questionnaire (NPI-Q)** (shorter 12 items) (Kaufer et al., 2000): Measures the severity of neuropsychiatric domains.
- **ZARIT-12** (Zarit Burden Inventory Short Form) (12 items) (Bédard et al., 2001): Assesses carer burden.

- STRiDE Informant self-report items on older adult ***care needs*** (1=care needed, 0=no care needed), current ***living status*** (1=living with, 0=not living with), and their ***relationship*** *with older adult* (i.e., 1=family, 0=non-family).
- **Client Service Receipt Inventory (CSRI)** (Chisholm et al., 2000; Farina et al., 2022): Includes the original CSRI and adds items from the 10/66 household survey collects information on participant characteristics, background and measures of costs and service use.

5.2.6 Screening procedure

Screening took place within participants' homes, capturing data on REDcap (Harris et al., 2009) using mobile devices. Interviewers followed strict protocols to preserve privacy, while navigating the realities of fieldwork in communities characterised by informal household structures, space limitations, and overcrowding. The CASE tool was embedded in the STRIDE Informant toolkit (Farina et al., 2022), and when household conditions were not ideal to administer (e.g. passers-by in a busy household), interviewers would continue with other measures and resume screening for risk of abusing when more appropriate. To safeguard confidentiality, informants and older adults were not screened for elder abuse when in hearing distance of each other.

5.2.7 Analysis

Sample size (n) and valid percentages (%) were reported for descriptive data including individual item responses and overall and the prevalence of the CASE. The prevalence of risk of abusing was estimated using the binary scoring of the CASE, dichotomising responses from the *adapted* CASE post hoc (i.e. never = 0, rarely to always = 1) to ensure parity with the original measure. We also reported the internal consistency for the adapted CASE items (Cronbach's α). As a guide, a value over 0.6 was considered the measure having acceptable internal consistency (Taber, 2018) Univariate logistic regression models were developed to understand the relationship between independent variables and risk of abusing (CASE > 0). Independent variables included carer burden (Zarit), functional impairment status of both the informant and older adult (WHODAS 2.0), social network and isolation (LSNS-6), neuropsychiatric symptoms (NPI-Q), and dementia and its severity (DSRS), and *care need* (CSRI), *living status* (CSRI), and *relationship* (CSRI) with their older adult. Significant factors at the univariate level (p<0.05) were then included in our multivariate analysis alongside age, sex and education attainment (*less than primary* vs. *primary and above*). Standardised betas and 95% Confidence Intervals were reported. SPSS 26 software (https://www.ibm.com/support/pages/downloading-ibm-spss-statistics-26) was used for all statistical analyses.

5.3 Results

5.3.1 Sample characteristics

A total of 490 households were surveyed across four languages namely Northern Sotho (58.8%, n=288), English (19%, n=93), isiXhosa (12.9%, n=63), and Afrikaans (9.4%, n=46). Informants were aged between 18 and 96 years of age (M=47.39; SD=18.9) and predominantly female (69.4%, n=334), with most having had primary level education and above (90.9%, n=439). Most informants were either *unemployed, looking for work* (31.7%, n=152) or *retired* (22.3%, n=107), and normally *lived with* their older adult (78.9%, n=378) and were *one of the hands-on carers* involved in care and support (69.5%, n=130). Older adults were most often their parent (38.4%, n=185) or spouse (21%, n=101. (see Table 15).

Table 15: CASE Sample characteristics

Sample characteristics	Mean (SD)	N (%)
Age *(n=481)*	47.4 (18.9)	
Sex *(n=481)*		
Female		334 (69.4%)
Male		147 (30.6%)
Language *(n=490)*		
English		93 (19%)
Afrikaans		46 (9.4%)
Xhosa		63 (12.9%)
Northern Sotho		288 (58.8%)
Educational attainment *(n=483)*		
No schooling		10 (2.1%)
Some schooling		34 (7%)
Primary		176 (36.4%)
Secondary		170 (35.2%)
Tertiary		93 (19.3%)
Employment status *(n=480)*		
Paid, full-time salaried		61 (12.7%)
Paid, part-time, salaried		27 (5.6%)
Paid, full-time, unsalaried		9 (1.9%)
Paid, part-time, unsalaried		16 (3.3%)
Unemployed, looking for work		152 (31.7%)
Unemployed, not looking for work		57 (11.9%)
Housewife/husband, full-time		17 (3.5%)
Student		34 (7.1%)
Retired		107 (22.3%)
Live with the older adult? *(n=479)*		
Yes		378 (78.9%)
No		101 (21.1%)
Older adult is their… *(n=482)*		
Spouse		101 (21%)
Parent		185 (38.4%)
Mother/father-in-law		22 (4.6%)
Sibling		6 (1.2%)
Other relative		70 (14.5%)
Friend		14 (2.9%)
Neighbour		33 (6.8%)
Other		51 (10.6%)
Who were the carers? *(n=187)*		
One of the hands-on carers		130 (69.5%)
Only slightly involved in providing/organising care		31 (16.6%)
One of the main organisational carers		17 (9.1%)
Not at all involved in providing or organising care		9 (4.8%)
Care need of their older adult *(n=483)*		
Does not need care		292 (60.5%)
Occasionally		121 (25.1%)
Needs care much of the time		66 (13.7%)

In these South African data, the *adapted* CASE shows good internal consistency ($\alpha = 0.79$) and was used to determine prevalence of risk of abusing.

5.3.2 Prevalence of risk of abusing

Using the binary scoring, more than half of informants screened positive for risk of abusing (n =236, 51.8%; 95%Cis 47.1 to 56.4) of which 14.3% (n=65, 95%Cis 0.1 to 0.2) were at high risk (i.e., score of 4 or more).

Informants who screened positive for risk of abusing were mostly female (66.9%), with an educational attainment of at least primary level and above (90.7%), and mostly unemployed and looking for work (31.9%) or retired (25.5%). Those who screened positive for risk of abusing were very similar across age ranges, where older adults (34.6%) and youth (34.2%) as carers were identified most frequently. Those who screened positive were also mostly caring for a family member (83%), and more likely to live with the older adult (82.1%) (see Table 16).

Table 16: Characteristics of informants at risk of abusing (n=236)

Informants at risk of abusing	N (%)
Risk of abusing (CASE) *(n=490)*	
Risk of abusing	236 (51.8%)
No immediate risk of abusing	220 (48.2%)
Sex *(n=236)*	
Female	158 (66.9%)
Male	78 (33.1%)
Age range *(n=234)*	
18-34 (Youth)	80 (34.2%)
35–59 (Adulthood)	73 (31.2%)
60+ (older adulthood)	81 (34.6%)
Educational attainment *(n=236)*	
Less than primary	22 (9.3%)
Primary and above	214 (90.7%)
Employment status *(n=235)*	
Paid, full-time salaried	23 (9.8%)
Paid, part-time, salaried	11 (4.7%)
Paid, full-time, unsalaried	5 (2.1.%)
Paid, part-time, unsalaried	9 (3.8%)
Unemployed, looking for work	75 (31.9%)
Unemployed, not looking for work	27 (11.5%)
Housewife/husband, full-time	8 (3.4%)
Student	17 (7.2%)
Retired	60 (25.5%)
Live with the older adult? *(n=234)*	
Yes	192 (82.1%)
No	42 (17.9%)
Older adult is their… *(n=235)*	
Family	195 (83%)
Non-family	40 (17%)

5.3.3 Predictors of being at risk of abusing

We found significant associations between informants who are at risk of abusing and increased *care burden* (Zarit score) or poor *functional status* (WHODAS score). Carers of people living with

dementia were 4 times more likely to be at risk of abusing compared to carers of people free of dementia (OR = 4.3; 95% Cis 2.14 to 8.66). We also found significant associations with their older adult's *need for care*, *neuropsychiatric symptoms*, and *dementia severity* (see Table 17). However, there were no significant associations with *social network,* the *functional impairment* of older adults and whether the informant was *living with* the older adult or a family member (relationship).

Table 17: A series of univariate regression models the for risk of abusing (CASE > 0)

Univariate analysis					
	B	**Exp(B)**	**LCI**	**UCI**	***p***
Care burden (ZARIT-12) *(higher scores=greater carer burden)*	0.15	1.17	1.11	1.22	<.001*
Functional impairment (informants) (WHODAS) *(higher scores=greater impairment)*	0.11	1.11	1.06	1.16	<.001*
Functional impairment (older adults) (WHODAS) *(higher scores=greater impairment)*	0.01	1.01	0.99	1.03	0.21
Social network (LSNS-6) *(higher scores=greater social engagement)*	-0.01	0.99	0.99	1.03	0.59
Neuropsychiatric symptoms (NPI) *(higher scores=greater impairment)*	0.34	1.40	1.20	1.64	<.001*
Dementia (10/66 short diagnostic schedule) *(0= no dementia, 1= dementia)*	1.46	4.30	2.14	8.66	<.001*
Dementia severity (DSRS) *(higher scores=greater severity)*	0.11	1.12	1.06	1.18	<.001*
Care need (CSRI) *(0=no care needed, 1=care needed)*	1.03	2.79	1.87	4.20	<.001*
Living status (CSRI) *(0=no, 1=yes)*	0.31	1.36	0.86	2.20	0.19
Relationship (CSRI) *(0=non-family, 1=family)*	0.25	1.29	0.80	2.06	0.29
**Statistically significant at 95% CI*					
Zarit *– Zarit Burden Inventory Short Form (ZBI-12)* ***WHODAS*** *– World Health Organization Disability Assessment Schedule 2.0* ***LSNS-6*** *– Lubben Social Network Scale (LSNS-6)* ***NPI*** *– Neuropsychiatric Inventory Questionnaire* ***10/66*** *– 10/66 Short Schedule (dementia algorithm)* ***DSRS*** *– Dementia Severity Rating Scale* ***CSRI*** *– Client Services Receipt Inventory*					

Subsequently, we entered all significant variables (above) alongside the informants' age, sex, and educational attainment into a single model. We found that the older adult's *neuropsychiatric symptoms* and informants' *care burden* status were the strongest predictors for risk of abusing (see Table 18. The informant's functional impairment, dementia status, dementia severity and care needs were no longer statistically significant in the model (p>0.05). The Nagelkerke r^2 model fit statistics were 0.35 (Cox & Snell r^2= 0.25).

Table 18: Multivariate logistic regression model for risk of abusing (CASE score > 0)

Multivariate analysis					
	B	**Exp(B)**	**LCI**	**UCI**	***p***
Age	0.01	1.01	0.99	1.04	0.23
Sex *(0=female, 1=male)*	0.58	1.78	0.65	4.89	0.26
Educational attainment *(0=less than primary, 1=primary and above)*	0.81	2.25	0.51	10.01	0.29
Care burden (ZARIT-12) *(higher scores=greater carer burden)*	0.12	1.11	1.00	1.24	0.05*
Functional impairment (informants) (WHODAS) *(higher scores=greater impairment)*	0.01	1.01	0.92	1.10	0.87
Neuropsychiatric symptoms (NPI) *(higher scores=greater impairment)*	0.28	1.32	1.09	1.61	0.005*
Dementia (10/66 short algorithm) *(0= no dementia, 1= dementia)*	0.39	1.47	0.38	5.78	0.58
Dementia severity (DSRS) *(higher scores=greater severity)*	0.06	1.06	0.95	1.19	0.32
Care need (CSRI) *(0=no care needed, 1=care needed)*	-0.19	0.83	0.31	2.24	0.71
Constant	*-3.16*	*0.04*			

**Statistically significant at 95% CI*

Zarit *– Zarit Burden Inventory Short Form (ZBI-12)*
WHODAS *– World Health Organization Disability Assessment Schedule 2.0*
NPI *- Neuropsychiatric Inventory Questionnaire*
10/66 *– 10/66 Short Schedule (dementia algorithm)*
DSRS *– Dementia Severity Rating Scale*
CSRI *– Client Services Receipt Inventory*

5.4 Discussion on risk of perpetrating abuse in South Africa

In this study we randomly screened household informants for risk of abusing an older adult. We found that risk of abusing was very high, with half of participants screening positive for abusive dispositions toward an older person. Carers of people living with dementia were 4 times more likely to be at risk of abusing compared to carers of people free of dementia. However, after controlling for covariates, only the severity of older adults' neuropsychiatric symptoms and increased carer burden were associated.

Dementia was significant in our univariate association with carers' risk of abusing, but not in the multivariate model of predictors. This shows that dementia itself may be less pertinent to risk of abusing, but rather the associated comorbidities (i.e. neuropsychiatric symptoms) and increased carer burden. It is widely accepted that neuropsychiatric morbidity in older adults increase risk of elder abuse (Mehra et al., 2019; Nisha et al., 2016; Roepke-Buehler et al., 2015), which in turn have been linked to greater care burden, distress and dysfunctional coping among carers for people living with dementia (Allegri et al., 2006; Cooper et al., 2010; Downes et al., 2013). However, the relationship between neuropsychiatric symptoms and carer burden has been reported to be bidirectional, where symptoms such as anxiety, agitation and aggression places strain on a care-

dyad's relationship, which in turn has a negative impact on neuropsychiatric symptom frequency of the older adult (Isik et al., 2019). However, we caution against drawing final conclusions about the role of dementia and carers' risk of abusing as our sample of people living with dementia was small and will need further investigation. Nevertheless, this current study suggests that we could potentially minimise the risk of perpetrating elder abuse by supporting carers to reduce carer burden. Carer burden for dementia is often associated with anxiety and depression in carers, especially when carer distress is attributed to the caring situation (Campbell-Reay & Browne, 2001; Cooper et al., 2010). Distress among carers include, for example, caring for longer hours, needing greater hands-on care for physical needs of the older adult, and worrying about the well-being and safety of the older adult when wandering off, or getting lost. Supporting carers to manage stress and reduce burden includes the effective management of neuropsychiatric symptoms of the older adult (Isik et al., 2019). Health promotion, education and support *for carers* are as important as supporting the older adult in the prevention and experience of elder abuse, and have been shown to have positive outcomes on carer levels of distress, depression and health (Isik et al., 2019).

While more than half of informants screened positive for risk of abusing in this study, carers of people living with dementia showed significantly higher risk of abusing. Elder abuse in general is often hidden by perpetrators and recipients of abuse themselves, while people living with dementia are especially vulnerable as dementia compromises their ability to defend, or remove themselves from potentially abusive situations, and impairs their ability to seek help (Downes et al., 2013). Therefore, understanding risk of abusing and its predictors, allows for opportunities to guide prevention initiatives and strengthen protective services that include adequate care and support provisions for all older adults who need it.

5.4.1 Limitations

Our study sampled households across two regions and four languages, using randomisation techniques to be as representative as possible. However, South Africa is a multi-cultural and multi-lingual country, and our sample is not representative of all groups and settings. Therefore, our findings cannot be generalised. Furthermore, our model accounts for a modest variance (Nagelkerke $r^2 = 0.35$), suggesting that there may be other variables not included that may affect carers' risk of abusing, for example substance use (WHO, 2016) and a history of family violence (Campbell-Reay & Browne, 2001). While a strength of this study is the use of formal measures to assess multiple risk factors, including dementia at community level, we did not include an assessment of substance abuse behaviours of informants or history of family violence. These factors are strong predictors of

violence and abuse, especially for people living with dementia (Downes et al., 2013), and should be explored in future research.

We also report on 'risk of abusing' versus 'reports of abusing'. While measuring risk of becoming abusive holds value for prevention efforts, it does not provide diagnostic value for elder abuse without proper investigation. Risk of abusing was also assessed by screening a single household member, excluding the risk posed by multiple individuals within the older adult's social network. Lastly, this is a cross-sectional study where the predictors we refer to are statistical associations between risk of abusing and the variables tested. We therefore caution against interpretating these associations in terms of causality.

5.5 Conclusion

This study contributes to the needed evidence-base in South Africa, assessing potential perpetrators of abuse at community level in a non-confrontational, non-blaming manner to understand risk and predictors of elder abuse. Informants most at risk of abusing were female and very similar in age range, with young adults (18-34 years) and older adult carers (i.e., 60 years and older) being most at risk of perpetrating abuse. Those at risk of abusing were either unemployed (looking for work) or retired, while living with and providing some form of care and support to an older adult family member. This study therefore identifies carers most at risk of abusive behaviours towards an older adult or person living with dementia, and highlights where support efforts could be targeted to reduce carer burden and risk of abuse. The relevance of our findings also extends to other low-or-middle income contexts, contributing to a growing knowledge base on elder abuse as a universal public health concern. We have also shown that families struggle with unsupported care needs, that include but are *not* limited to dementia and its associated neuropsychiatric symptoms, as carer burden was a significant contributor to being at risk of abusing. Support for older persons and their families at community level is needed, with clear referral pathways and protective services that are inclusive of individuals who are unable to advocate for themselves or seek help. People living with dementia may be especially vulnerable to exploitation and abuse, but with adequate support within homes and communities, elder abuse could be prevented.

CHAPTER 6: DISCUSSION

This study described the landscape of elder abuse in South Africa and provided (1) an in-depth situational analysis of current service provisions for dementia and elder abuse for older persons, people living with dementia, and their families; (2) the cross-cultural adaptation of the EAST and CASE as screening tools suitable for use across two regions and four languages in South Africa; (3) an estimation of prevalence, perpetrators and predictors of self-reported experiences of elder abuse; and (4) the estimated risk and predictors of abusive behaviours among carers toward older adults, including people living with dementia. The findings are an important contribution to the available evidence base on elder abuse in South Africa (as an example of a LMIC) and provide insight into understanding elder abuse in context to support targeted efforts to reduce risk of abuse and adequate services for older adults, including people living with dementia.

In our situational analysis (Chapter 2), we found that dementia diagnostic services were highly fragmented at primary healthcare level, and that structural factors (such as the lack of a national dementia plan and poor funding models) create barriers in accessing diagnosis, post-diagnostic support and care. Existing health structures were largely dementia-blind and did not support the management of dementia. These blind spots in our health system negatively impacts help-seeking behaviour and the preparedness and responsiveness to meet the growing needs of people living with dementia and their families. We also described how delayed help-seeking behaviour leads to a lack of diagnosis, unmet home-based support needs and risk for elder abuse. As with dementia generally, current support provisions for elder abuse are limited or non-existing. With a complete lack of available data and no routine monitoring and reporting, the status of elder abuse in South Africa is largely unknown. We found that underreporting by both communities and professionals alike is a serious problem, as described by the stakeholders interviewed, with people living with dementia being at greater risk for abuse that include extreme forms of violence. A clear gap exists in the availability of accurate data, and this is what the remainder of the study addressed.

To enable the generation of evidence on prevalence and risk of elder abuse in South Africa, we cross-culturally adapted two tools to screen for self-reported abuse (EAST) and risk of abusing (CASE) (Chapter 3). We adapted the EAST and CASE across two regions and four languages (English, Afrikaans, isiXhosa, and Northern Sotho) and found that with adjustments, the questions on these instruments were generally well understood and suitable for use in South Africa. Through our in-depth cognitive interviewing methodology, we gained insight into what older adults (including people living with dementia) and their carers considered when responding to the EAST and CASE. This informed our understanding of what constitutes elder abuse. We showed how understanding

elder abuse across cultures in South Africa is complex and how unverified screening can lead to false positives. The EAST was especially vulnerable to out-of-scope interpretations (leading to high false positives) and was adapted to include verification prompts used to screen for abuse against the country's definition of abuse. With minor adjustments, the CASE was also found to be suitable for use in South Africa. Carers of people living with dementia felt especially limited by the tool's original binary response options and motivated for a rating scale response instead that allowed to capture their nuanced experiences that vary considerably over time, and the progression of the disease. In addition to the adaptation and testing of the EAST and CASE, we also presented rich content that older persons, people living with dementia, and their carers shared about their experiences with abusive behaviours. We found that self-reported abuse included fear and first-hand experiences of crime where strangers and family potentially used deception to build trust and gain access to exploit and abuse the older person. This finding was consistent with more recent developments in global conceptualisations of elder abuse that include strangers who purposefully gain trust in order to abuse (Goergen & Beaulieu, 2013). Carers also openly shared experiences of caring in isolation, without adequate support, while unmanaged symptoms of dementia led them to feel at greater risk of reciprocal violence (i.e., where symptomatic aggression from the care-recipient triggers aggressive responses from the carer). These dynamics within a dementia care-dyad often drive stress reactions and increase risk of elder abuse (Downes et al., 2013).

The adapted EAST and CASE were then used to screen for elder abuse in a randomised household survey, estimating prevalence of self-reported experiences of abuse and risk of perpetrating abuse. In chapter 4 we showed that self-reported experiences of abuse were high, with 1 in 10 older adults reporting abuse and most perpetrators being either a non-family member where there is a personal relationship, or a family member. Our estimate for self-reported abuse experiences in South Africa is, nevertheless, in line with other meta-analysis studies that report global pooled prevalence between 10% (Ho, et al., 2017) and 15.7% (Yon, et al., 2017). Financial and emotional abuse were the most common types reported, with fewer older adults reporting neglect, physical and sexual abuse in these studies. These findings were consistent with what we found from our multi-stakeholder interviews in the situational analysis (Chapter 2), where experts from the social care services sector indicated that despite serious underreporting, financial and emotional abuse are the most common types of elder abuse across South Africa. Our study therefore supports this global finding and provides statistical evidence of what was previously anecdotally reported by stakeholders (e.g., (Kotzé, 2018; Lloyd-Sherlock, 2018, Penhale and Ayiga, 2018), i.e. that older adults are often targeted because of their age and assumed vulnerability for financial gain. While perpetrators were found to be people the older person has a personal or care relationship with, or

live with, perpetrators have access to isolate and exploit while their physical proximity becomes a key barrier to reporting abuse. Accessible reporting and support structures are needed to breach the 'safety' that silence in an abusive situation provides.

Lastly, this sub-study showed that the functional impairment status of older adults was significantly associated with self-reported abuse. Functional impairment, where meeting the physical needs of the older person is physically demanding on carers, is a known risk factor for abuse and neglect (Downes et al., 2013) and creates a context of vulnerability. Although *age* is not an indicator of vulnerability, our findings show that *functional impairment* exposes older persons to conditions that allows abuse to occur. When unsupported, functional impairment meets the conditions of *vulnerability* by (i) compromising their capacity to defend against abuse; (ii) risk suffering significant harm and lasting effects of abuse; and (iii) weakens their ability to cope with the consequences of abuse (Goergen & Beaulieu, 2013). While our study identified functional impairment as the only factor significantly associated with higher risk of self-reported abuse, this association may be more complex as there were high levels of uncertainty of the true effect of perceived dependence, dementia caseness, and dementia severity within our sample due to wide confidence intervals for some of these variables. Further research is needed to examine these associations more closely and investigate for example whether contextual variables such as poverty and restricted access to resources, neighbourhood safety, or cultural factors and norms about intergenerational relationships, could have mediating effects in understanding the association between functional impairment and self-reported abuse. Other factors that could have a direct impact on the quality of an intergenerational relationship include the mental health of carers themselves, for example substance abuse, anxiety, and depression that when unsupported, increases risk of abuse.

When screening household informants (Chapter 5), we found more than half of participants screened positive for risk of abusing. Carers of people living with dementia were 4 times more likely to report risk of perpetrating abuse. We also showed that while dementia itself may be less of a contributing factor to risk of abusing, the associated comorbidities (i.e., more severe neuropsychiatric symptoms) and their impact on carers (e.g., greater carer burden) increases risk of abusing. People living with dementia may be especially vulnerable to abuse as this condition compromises their ability to defend or remove themselves from potentially abusive situations and impairs their ability to disclose and seek help (Downes et al., 2013). This sub-study highlighted the need for adequate care and support provisions for both people living with dementia and their carers as addressing carer burden could minimise risk of abusing.

There were marked differences between the self-reported abuse of older adults and risk reported by household informants and carers. Interestingly, this was also found in other contexts where older persons disclosed abuse less than their carers reported abusing (Homer & Gilleard, 1990). A more recent meta-analysis across 18 countries showed that a pooled prevalence of self-reported abuse by older adults was 10%, while 34.3% was reported by carers or third parties (Ho et al., 2017). It is important to note that the CASE measures abuse that is both currently happening and situations where abuse is *at risk* of occurring (before it happens). Understanding the differences between reports by older adults themselves and carers were outside the scope of this study but could be explained by the hidden nature of elder abuse and the challenge doing research at household level. For example, the proximity of the abuser during data collection directly affects disclosure, especially to an interviewer who is also a stranger. Furthermore, elder abuse often remains hidden because the older person fears retaliation, or protects the abuser (who is often a close family member) because of fear of getting the family member in trouble (WHO, 2016). With the lack of services such as dedicated NGOs or accessible community-based services that are elder- or dementia-friendly, older persons are isolated, suffering in silence and living in fear. Where limited formal services *do* detect abuse, intervention responses often include the removal of the survivor from their homes, uprooting them from their lives and adding to the existing trauma. Therefore, the impact of disclosure within an unsupported structural environment may in these instances pose a greater threat than living with abuse on a daily basis. Current health and social care systems need reforms that include adequate responses to this hidden problem, while further victimisation from both abuser(s) and formal structures are prevented. Understanding these differences in reporting between older adults themselves and carers may therefore be worth exploring in future research to support services to older adults and people living with dementia, promoting disclosure in self-reported abuse, and targeting responses that support and protect older persons from risk and abuse.

While our study did not directly investigate extreme forms of violence against older persons and people living with dementia such as 'witch-killings', our findings in chapter 5 confirms a link between neuropsychiatric symptoms (often identified as a cause for witchcraft accusations in chapter 2) and risk of abuse. In some cultural contexts in South Africa, the fear of a family member being accused of witchcraft has been shown elsewhere to send families into hiding (Mkhonto & Hanssen, 2018; Jacobs *et al.,* 2022). While families mediate community fears of witchcraft, household pressures and family care needs, an increase in family stress and carer burden, increases risk of abuse within the home. Therefore, a lack of understanding and diagnosis of dementia, unmanaged neuropsychiatric

symptoms, and unsupported care needs increase risk of elder abuse both *inside* and *outside* the home environment.

The evidence generated by these four sub-studies fill critical gaps in South African data. We provided a local knowledge base on prevalence, and culturally appropriate measurement from both older adult and carer perspectives. We also provided evidence on perpetrators and predictors of risk of elder abuse that could inform appropriate responses to intervention, care and support. This project's novelty in South African research on elder abuse was its use of formal measures of elder abuse, dementia and related health and well-being. In our use of verification to frame common understandings of what constitutes local and global conceptualisations of elder abuse (i.e. according to the South African and WHO official definition of elder abuse), this study also contributes to global debates on elder abuse measurement. We demonstrated that the use of participant response verification during screening can standardise an understanding of what is locally and globally accepted as elder abuse, while minimising false positive screening outcomes. Without discounting the distress caused by general negative social experiences and the emotional impact of these (e.g., feeling distressed when a neighbour does not help with home renovations), the verification of responses allows the interviewer to distinguish general negative social experiences from abusive ones and therefore increase the accuracy of screening. Although the application of a standard definition of elder abuse is dependent on the rigorous training and insight of the interviewer, the verification process used in the EAST provides the opportunity to increase accuracy in elder abuse screening by a wide range of people. The results of such screening has the potential to guide official protective services in follow-up investigations, the collection of evidence, and gathering of legal testimonies.

By assessing carers' risk of abusing, we contributed to the global measurement of elder abuse by testing the adapted response options for the CASE. This provided us with the opportunity to expand the assessment of risk to perpetrate abuse and capture the nuanced caregiving experiences of carers (i.e. never, rarely, sometimes, very often, always), while maintaining parity with the original CASE in identifying risk to abuse. These contributions therefore add to the growing body of global knowledge on elder abuse measurement, especially in low-or-middle income contexts like South Africa. However, this study is not without limitations.

6.1 Limitations of the study and recommendations for future research

While we are confident that the EAST and CASE are suitable tools to screen for elder abuse at community level, our study did not include the screening of household members under the age of 18. Young grandchildren often take on caring roles and responsibilities in South Africa, and have been implicated in violence against, and financial extortion of their grandparents (Kotzé, 2018). While assessing risk of abusing for this cohort was outside the scope of this study, estimations of prevalence of abuse and risk of abusing are likely underestimated. Future research should therefore include the measurement of risk for carers younger than 18 (e.g., grandchildren), using tools that have been culturally adapted for this age group. The use of the CASE on younger ages have not been established and remains an area for future study. Risk of abusing at the household level is also underestimated, as this study sample was limited to screening single household informants (excluding other household members in multiple perpetrator scenarios). Expanded samples are also needed to draw more meaningful conclusions on prevalence, predictors and risk of abuse.

Another limitation relates to the cut-off scores used by the CASE. While we captured the nuanced caregiving experiences on a rating scale (i.e., never, rarely, sometimes, very often, always), we estimated risk of abusing in line with the CASE's original dichotomous scoring (never = no; and rarely to always = yes). Future research should therefore benchmark cut-off scores for the rating response options of the *adapted* CASE to interpret risk of abusing as 'low', 'moderate', or 'high' to guide official protective and support service responses and prioritisation for *older adults at risk*, and *carers at risk of abusing*.

While most studies of self-reported abuse exclude people with cognitive impairment, a strength of our design was our inclusion of people living with dementia. However, our sub-sample of people living with dementia was small, with most identifying with mild and less severe dementia. Participants with moderate to severe dementia were therefore under-represented and need greater numbers to draw conclusions about elder abuse prevalence, predictors and risk. Furthermore, people with severe cognitive impairment are prone to poor recall while considered most vulnerable to abuse, thus posing a measurement challenge. Although effort should be made to include the participation of people with severe cognitive impairment, we must ensure that additional measures are in place to verify accuracy. Further validation of the measures beyond internal consistency was outside the scope of this study and should be developed further to include construct, content and criterion-related validity. This study however addressed face validity of the constructs measured and our findings suggest that the questions asked are appropriate and do measure the intended construct.

Lastly, this study provides estimates of prevalence of elder abuse (experience and risk of abusing) based on the self-reported responses to screening tools, without a follow up investigation to confirm elder abuse. Currently, there is no gold standard for measuring elder abuse, while the multi-dimensional nature of abuse may lend itself to several conceptual factors (and not a single construct). For example, confirming elder abuse using police or hospital records would only capture certain aspects of the abuse and further limit confirmation to those cases that are (actually) reported. Despite these limitations, a strength of this study is that the experiences informing participant responses to abuse were verified in relation to the standard definition of elder abuse in South Africa and WHO. While elder abuse was not confirmed via a follow-up investigation, participant's understanding of what constitutes elder abuse in South Africa was verified in a manner feasible to conducting community-based surveys. Therefore, in the absence of a gold standard for measuring elder abuse, this study provides an important contribution towards estimating prevalence of self-reported abuse and risk of abusing in this context.

CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

Elder abuse and risk of abusing older persons and people living with dementia in South Africa are high. Community and systemic factors drive a state of vulnerability for older persons, while unsupported carers and harmful beliefs increase the risk of abuse. Poverty and a lack of adequate community-based support place carers of people living with dementia at greater risk of abusing, while existing health and social care structures create barriers to diagnosis, care and support for older persons themselves. South Africa now has some more reliable data on the prevalence, culturally appropriate measurement, risk for, perpetrators of and predictors of elder abuse.

7.1 Recommendations

In this chapter we provide recommendations for policy, research, and service development for older adults and carers, in need of care and support.

7.1.1 Recognising and reporting elder abuse

This study has shown how community and systemic factors drive the undetected and under-reported nature of elder abuse in South Africa. Our interviews with stakeholders (Chapter 2) described how stigma, lack of dementia awareness, financial exploitation and harmful beliefs increase risk and extreme forms of violence against older adults and people living with dementia. Barriers to identifying and reporting elder abuse are complex and range from older adults themselves hiding abuse out of fear of negative consequences of disclosure, to older adults, carers, and health and social care practitioners not recognising abuse or knowing what to do.

Public education and training are important first steps where communities and health and social care practitioners are trained on elder abuse. Increasing public knowledge about ageism and the rights of older adults in society are important prevention strategies for elder abuse (Hirst et al., 2016). For service providers, training on culturally appropriate screening of elder abuse is needed to provide health and social care practitioners with the tools to identify types of abuse, and to initially assess risk, immediate response needs, and the culpability of perpetrators. As shown in Chapter 3, not all perpetrators are the same (Jackson, 2016), especially when care-dyads need support and education. For example, family carers of people living with dementia have been found to be more responsive to disclosing frustrations, abuse and neglect (Beach et al., 2016) and may respond well to guidance on what to expect with dementia and how to provide appropriate support. Criminalising carers who, with dementia education and training could provide the needed support for a family member, is not a solution. Guidance and ongoing monitoring of the situation may provide a better health outcome for both the older person and the carer. Reporting and referral must therefore

match the needs of the older adult in each situation, and for example, the needs of an unsupported carer. Furthermore, reporting structures need to be clear when legal and criminal justice system responses are required and provide practitioners with unambiguous and efficient referral pathways. Currently, there are no clear service pathways as there are no dedicated NGOs or community-based services for elder abuse in South Africa. Caseloads of social workers from the public sector are excessive, and as shown by our interviews with stakeholders in Chapter 2, their work demands do not allow them to specialise in working with older persons. Therefore, the needs of older persons experiencing abuse are contending with the country's competing priorities such as gender-based violence, early childhood and youth development, HIV/AIDS, and integrating the poverty eradication strategy (NDSD, 2022). Recognising and reporting abuse in the *absence* of available services is problematic and may contribute to maintaining the hidden nature of abuse described above. In the context of mandatory reporting laws in South Africa, case finding needs to be met with capable support and protection services and therefore requires adequate service development for elder abuse.

7.1.2 Service development for responding to elder abuse

Responses to elder abuse should be linked to appropriate home-based and community care services, and/or criminal justice services as required. Stakeholders interviewed in Chapter 2 highlighted the need for dedicated services and programmes for elder abuse, including places of safety as a last resort. While the removal of the older adult may be the best solution in circumstances where the environment poses significant risks to their safety, uprooting the individual may result in secondary trauma (while the alleged perpetrator is largely unaffected). Interventions and protection services should be case-based and person-orientated, while being sensitive to the family context and culture (Kotzé, 2018). Community services should also provide culturally appropriate assistance to older persons and families in need of support (Hirst et al., 2016), and co-develop interventions and community support networks together with locally accepted sources of support like traditional and spiritual leaders, and faith-based organisations (e.g., churches, mosques, etc.). Service development therefore needs to be collaborative, intersectoral, and multi-disciplinary to create a multi-pronged approach in addressing elder abuse. Key stakeholders therefore include (but are not limited to) the National and Provincial Departments of (1) Health; (2) Social Development; (3) Community, Public Safety and Policing; (4) Justice; (5) Public works and Infrastructure; (6) Human settlements; (7) Planning, Monitoring and Evaluation; (8) Treasury; and (9) Civil society (e.g., the South African Older Persons Forum, and the South African Human Rights Commission).

7.1.3 Policy, health promotion and public health strategies

The South African Older Persons Act (no.13 of 2006) adopted a formal definition of and criminalised elder abuse as a punishable offence (Government Gazette, 2006). The country has policy support to protect the rights of older persons and promote their well-being and safety. However, there are no public health strategies in place to guide implementation of these policies in addressing elder abuse, with no guidance or dedicated funding to support intersectoral collaboration efforts. With the supporting legislation such as the Older Persons Act (Government Gazette, 2006), the National Health Act (Government Gazette, 2003) and the National Health Promotion Policy and Strategy (NDOH, 2014), South Africa has historically prioritised the health and well-being of the population. However, these legislative frameworks do not include a focus on elder abuse (or dementia). For a multi-pronged approach to be linked with sustainable funding models, policy and legislative frameworks must support service development and intersectoral programmes for elder abuse. Without a dedicated budget for programmes and services, South Africa cannot effectively respond to elder abuse (and cannot fulfil the mandates of the Older Persons Act or any health promotion strategy).

As shown in this study (chapter 4 and 5), elder abuse was significantly associated with functional impairment, neuropsychiatric symptoms, and increased carer burden. Strengthening health and social care policies to prevent (or reduce the impact of) communicable and non-communicable diseases, can promote healthy ageing and provide the necessary support to individuals and families to maintain functional ability. Preventing elder abuse therefore relies on effective public health strategies that address for example, modifiable risk factors (e.g. lifestyle and nutrition, smoking, alcohol use, etc.), while improving access to diagnostic and support services for older persons and people living with dementia. While this study has identified multiple risk factors for elder abuse in South Africa, promoting healthy ageing provides the opportunity to strengthen multiple protective factors for older persons and their families. Promoting healthy ageing requires a coordinated, multi-sectoral approach (Rudnicka, *et al*., 2020), with the World Health Organization providing strategies and guidelines on developing national programmes for age-friendly communities, combatting ageism, promoting health and well-being, while integrating care, and long-term care (WHO, 2023). Creating age-friendly communities also include the development of safe, accessible physical- and social environments, where older persons feel safe to actively participate in decision-making, and exercise mobility (i.e. economic, social, physical) without fear of crime and violence (WHO, 2023). While these active ageing initiatives evolve over time, there is very little evidence on the adaptation and application of these frameworks in contexts like South Africa (Rudnicka, *et al*., 2020). This study

therefore provides a basic understanding of the landscape of elder abuse in South Africa, to inform policy development that support coordinated responses to promote healthy ageing.

7.1.4 Research and evidence-based practices

While this study filled critical gaps in elder abuse research in South Africa, larger studies are needed to formulate theoretical understandings of indicators, types, risks and protective factors associated with elder abuse. Developing theoretical models of elder abuse provides a framework to guide understanding and actions against elder abuse (Hirst et al., 2016), while providing evidence for policy and service development. We need rigorous data that include routine monitoring and evaluation of the status of health and well-being of older adults in South Africa. Stakeholders across sectors including government, civil society, and NGOs should integrate information systems to develop a surveillance system of elder abuse and health promotion efforts to routinely generate the evidence needed to inform evidence-based practices. The Elder Abuse Register (that falls under the mandate of the National Department of Social Development), is still in process of being digitised and can form part of the spectrum of data monitoring and surveillance required. Routine data collection should include (for example):

- Screening data and elder abuse detection processes.
- Follow up investigation logs.
- Monitoring and supervisions reports of multi-disciplinary assessment teams and case workers.
- Indicators that monitor and evaluate the effectiveness of intersectoral collaboration initiatives.
- Case development data that link inter-governmental databases (e.g., Health, Social Development, Community Safety and the Department of Justice.) to track cases, and criminal case outcomes.
- The Elder Abuse Register (data on convicted perpetrators).
- Monitoring and evaluation of how data in this intersectoral system is used (e.g., Elder abuse register, evidence-base practices, intervention development, etc.).

Research and data collection systems should be integrated across sectors. We need to link evidence-based practices to delivering high-quality care and support for older persons, people living with dementia and their families. Without data and routine surveillance that is based on sustainable funding models, high quality and effective responses to the needs of older persons and their families cannot be achieved.

7.2 Concluding remarks

Adequate responses to support older persons and carers cuts across many systems and is a shared responsibility between sectors. The evidence provided by this study can inform priority setting for health, support and protection services for older adults and strengthen existing responses to move toward prevention efforts. There is an urgent need for intersectoral responses to combat the social and structural determinants of elder abuse, that include both the needs of carers and people living with dementia. Service pathways and access to the justice system for older persons exposed to abuse should be unambiguous and supported by sustainable funding models.

This study systematically addressed the main gaps in the local knowledge base and provided insight into the complexities of elder abuse in South Africa. We also contributed to global debates on elder abuse measurement by cross-culturally adapting two screening tools to measure both self-reported abuse and risk of abusing from the older adult and potential perpetrator perspectives. Our use of verification during screening allowed us to standardise understandings of abuse to local and global definitions, while minimising false positive outcomes.

We provided an initial description of the elder abuse landscape in South Africa and, based on our findings, call for action to develop culturally appropriate ways to intervene, stimulate a targeted response, and learn how to prevent South Africans ageing in fear and without dignity. Access to health, care and support is a human right. Ageing with dignity is a human right. This study paints a bleak reality of the status of older persons in South Africa and shows that we are failing them in achieving their basic human rights.

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APPENDICES

7.3 Appendix 1: Multistakeholder interview topic guides

This topic guide[11] outlines a number of potential questions that could be explored with the different stakeholders in South Africa. It is not to be expected that one interviewee would be asked all of the questions but will depend on the individual's role and expertise and information available from the desk-review performed under sub-study 1 (see FHS015). The interviews are expected to take no longer than 60 minutes and due to compliance to COVID-19 health safety protocols, will be conducted online via Zoom or Skype, or telephonically depending on participants' preference.

Introduction and context setting

- Introduction of the researcher (name, association with the project and organisation)
- Explanation of the study: This study aims to contribute to improving dementia care, treatment and support systems so that people with dementia and their carers can live well without shouldering excessive costs, risking impoverishment and compromising their own health in seven middle-income countries.
- The study is funded by the UK Research and Innovation's Global Challenges Research Fund via the Economic and Social Research Council.
- This interview aims to collect information the situation of dementia policy in [country], how the process of policy making in the context of dementia works in [country], and your views about access to dementia diagnosis, care, treatment and support. We would also be interested in understanding your views of the impact of the COVID-19 pandemic on service provision, as well as your thoughts on elder abuse services for older persons and persons living with dementia within your sector. We would like to hear about your vision for an improved system of care.
- We are interested in your views in your capacity as [stakeholder] on these aspects and would like to have a conversation covering these different aspects.

The interview will be no longer than 60 minutes.

Confidentiality and anonymity

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[11] The topic guide was informed by previous work conducted as part of the Emerald (Emerging mental health systems in low- or middle-income countries) project and informed by questions identified from work by Siddiqi and colleagues (2009) and the WHO (2007):

Siddiqi, S., Masud, T.I., Nishtar, S., Peter, D.H., Sabri, B., Bile, K.M. & Jama, M.A. (2009) "Framework for assessing governance of the health system in developing countries: Gateway to good governance" Health Policy, 90, pp.13-25.

WHO (2007) Everybody's business: Strengthening health systems to improve health outcomes. Geneva: World Health Organization.

With your permission we would like to record the interview with the help of this recording device so that after the interview we can write down what each of us said. We will then transcribe the interview, but we will not include any names or other information that could identify you. Transcribing the information word by word in very important because it would help us to know exactly what you said during the interview. Instead of your name you will be given a code number. After we have transcribed the interview, we will delete the recording.

Consent and withdrawal

- Before we can start the interview, we would like to ask you to read and sign the consent form. This form explains again how we will conduct the interview and what we will do with the information you share with us. By signing this form, you allow us to use the information you share with us for research. The form also outlines that you can withdraw from participating from this interview anytime during this interview. You can also tell us 'I would prefer not to answer this question' if you do not feel comfortable talking about any of the questions we may ask.

[Assumption: participants sign the consent form/ orally consent, otherwise researcher does not start interview]

Do you have any questions before we start?

Are you still happy with having the interview?

STAKEHOLDER: DEPARTMENT OF SOCIAL DEVELOPMENT (DSD)

1. [OPENING]: **What is your role in this position?**
    a. How long have you been working in this position / sector?
    b. How often, if at all, do you deal with issues of older persons and older persons living with dementia in your position? Describe.
2. [DEMENTIA/ELDER ABUSE (EA) SERVICES 1]: **Describe the current provision of services (before COVID-19) for *dementia/elder abuse* in South Africa? Describe what services are currently being provided (in your sector) and what your thoughts are on these services in terms of quality, meeting the needs, etc.**
    a. Examples of services: screening, intervention and protective services, referral- and support services, rehabilitation and reintegration.
    b. Access (i.e. availability, physical accessibility, affordability)?
    c. Structure and quality? (quality monitored? Elaborate)
3. [DEMENTIA/EA SERVICES 2]: **Who/which organisation(s) carry the primary responsibility for these services?**
    a. Who are some of the other role players for these services?
    b. Do services happen in a coordinated (inter-sectoral) manner (e.g. inter-sectoral collaboration between DSD and DoH)? Barriers and facilitators to integrated dementia care?

4. [DEMENTIA/EA SERVICES 3]: **Describe the uptake of these services (in your sector)?**
    a. How are they utilised?
    b. Are there differences across the country?
    c. What are the barriers to uptake?
    d. Do these meet the current need for services?
5. [DEMENTIA/EA SERVICES 4]: **What can be done to <u>prioritise</u> the detection and management of dementia/elder abuse in your sector?**
6. [DEMENTIA/EA COVID-19]: **What was the impact of COVID-19 on dementia/elder abuse services in your sector?**
    a. Challenges and restrictions? Barriers to service delivery? Financial implications?
    b. Measures put in place to overcome these challenges? (continuity of services)
    c. What do you think can be done to ensure continuity of services for future?

7. [DEMENTIA/EA Data, surveillance]: **Based on your experience, are you aware of any data collected for *dementia/elder abuse* <u>within your sector</u>? Describe.** [Verify the existence of the following:]
    a. Decentralised record-keeping at local offices/facilities? (EA offender register and (victim) incidents reported)?
    b. Provincial databases for dementia/elder abuse (offender register and (victim) incidents data)?
    c. National databases for dementia/elder abuse (offender register and (victim) incidents data)?
    d. If these exist, are there any limitations or challenges in collecting this data? How is it utilised?
    e. If these *don't* exist, what has been the challenges/barriers to establishing these? What do you think can be done to develop and adopt a 'culture' of capturing data towards a national surveillance of <u>elder abuse</u>?
8. [DEMENTIA/EA: Awareness and prevention]: **Based on your experience, how would you describe current awareness and prevention efforts of dementia/elder abuse in your sector?** Are there any programmes/interventions targeted at specific groups believed to be especially vulnerable to stigma and abuse? (e.g. women, persons living with dementia, persons living with disabilities?) Describe.

STAKEHOLDER: DEPARTMENT OF HEALTH (DOH)

1. [OPENING]: **What is your role in this position?**
    a. How long have you been working in this position / sector?

b. How often, if at all, do you deal with issues of older persons and older persons living with dementia in your position? Describe.

2. [DEMENTIA/EA SERVICES 1]: **Describe the current provision of services (before COVID-19) for *dementia/elder abuse* in South Africa? Describe what services are currently being provided (in your sector) and what your thoughts are on these services in terms of quality, meeting the needs, etc.**

    a. Examples of services: screening, intervention and protective services, referral- and support services, rehabilitation and reintegration.

    b. Access (i.e. availability, physical accessibility, affordability)?

    c. Structure and quality? (quality monitored? Elaborate)

3. [DEMENTIA/EA SERVICES 2]: **Who/which organisation(s) carry the primary <u>responsibility</u> for these services?**

    a. Who are some of the other role players for these services?

    b. Do services happen in a coordinated (inter-sectoral) manner (e.g. inter-sectoral collaboration between DSD and DoH)? Barriers and facilitators to integrated dementia care?

4. [DEMENTIA/EA SERVICES 3]: **Describe the uptake of these services (in your sector)?**

    a. How are they utilised?

    b. Are there differences across the country?

    c. What are the barriers to uptake?

    d. Do these meet the current need for services?

5. [DEMENTIA/EA SERVICES 4]: **What can be done to <u>prioritise</u> the detection and management of dementia/elder abuse in your sector?**

[COVID-19]: **What was the impact of COVID-19 on elder abuse services in your sector?**

    a. Challenges and restrictions? Barriers to service delivery? Financial implications?

    b. Measures put in place to overcome these challenges? (continuity of services)

    c. What do you think can be done to ensure continuity of services for future?

6. [DEMENTIA/EA Data, surveillance]: **Based on your experience, are you aware of any data collected for: *dementia/elder abuse* <u>within your sector</u>? Describe.** [Verify the existence of the following:]

    a. Decentralised record-keeping at local offices/facilities? (EA offender register and (victim) incidents reported)?

    b. Provincial databases for dementia/elder abuse (offender register and (victim) incidents data)?

    c. National databases for dementia/elder abuse (offender register and (victim) incidents data)?

d. If these exist, are there any limitations or challenges in collecting this data? How is it utilised?

e. If these *don't* exist, what has been the challenges/barriers to establishing these? What do you think can be done to develop and adopt a 'culture' of capturing data towards a national surveillance of elder abuse?

7. [DEMENTIA/EA: Awareness and prevention]: **Based on your experience, how would you describe current awareness and prevention efforts of dementia/elder abuse in your sector?** Are there any programmes/interventions targeted at specific groups believed to be especially vulnerable to stigma and abuse? (e.g. women, persons living with dementia, persons living with disabilities?) Describe.

STAKEHOLDER: NGOs (Non-profit organisations, community-based/faith-based organisations)

1. [OPENING]: **What is your role in this position?**
    a. How long have you been working in this position / sector?
    b. How often, if at all, do you deal with issues of older persons and older persons living with dementia in your position? Describe.

1. [DEMENTIA/EA SERVICES 1]: **Describe the current provision of services (before COVID-19) for *dementia/lder abuse* in South Africa? Describe what services are currently being provided (in your sector) and what your thoughts are on these services in terms of quality, meeting the needs, etc.**
    a. Examples of services: screening, intervention and protective services, referral- and support services, rehabilitation and reintegration.
    b. Access (i.e. availability, physical accessibility, affordability)?
    c. Structure and quality? (quality monitored? Elaborate)

2. [DEMENTIA/EA SERVICES 2]: **Who/which organisation(s) carry the primary responsibility for these services?**
    a. Who are some of the other role players for these services?
    b. Do services happen in a coordinated (inter-sectoral) manner (e.g. inter-sectoral collaboration between DSD and DoH)? Barriers and facilitators to integrated dementia care?

3. [DEMENTIA/EA SERVICES 3]: **Describe the uptake of these services (in your sector)?**
    a. How are they utilised?
    b. Are there differences across the country?
    c. What are the barriers to uptake?
    d. Do these meet the current need for services?

4. [DEMENTIA/EA SERVICES 4]: **What can be done to prioritise the detection and management of dementia/elder abuse in your sector?**

5. [DEMENTIA/EA COVID-19]: **What was the impact of COVID-19 on elder abuse services in your sector?**

    a. Challenges and restrictions? Barriers to service delivery? Financial implications?

    b. Measures put in place to overcome these challenges? (continuity of services)

    c. What do you think can be done to ensure continuity of services for future?

6. [DEMENTIA/EA Data, surveillance]: **Based on your experience, are you aware of any data collected for: *Dementia/elder abuse* <u>within your sector</u>? Describe.** [Verify the existence of the following:]

    d. Decentralised record-keeping at local offices/facilities? (EA offender register and (victim) incidents reported)?

    e. Provincial databases for dementia/elder abuse (offender register and (victim) incidents data)?

    f. National databases for dementia/elder abuse (offender register and (victim) incidents data)?

    g. If these exist, are there any limitations or challenges in collecting this data? How is it utilised?

    h. If these *don't* exist, what has been the challenges/barriers to establishing these? What do you think can be done to develop and adopt a 'culture' of capturing data towards a national surveillance of <u>elder abuse</u>?

7. [DEMENTIA/EA: Awareness and prevention]: **Based on your experience, how would you describe current awareness and prevention efforts of dementia/elder abuse in your sector?** (Determine if there is a lack of awareness, or if it's the case of being aware but not dealing with it? Explore). Are there any programmes/interventions targeted at specific groups believed to be especially vulnerable to stigma and abuse? (e.g. women, persons living with dementia, persons living with disabilities?) Describe.

STAKEHOLDER: OTHER STATE ENTITIES (e.g. South African Human Rights Council, Department of Justice)

1. [OPENING]: **What is your role in this position?**

    a. How long have you been working in this position / sector?

    b. How often, if at all, do you deal with issues of older persons and older persons living with dementia in your position? Describe.

2. [EA SERVICES 1]: **Describe the current provision of judicial/human rights services (before COVID-19) for *dementia/elder abuse* in South Africa? Describe what services are currently being provided (in your sector) and what your thoughts are on these services in terms of quality, meeting the needs, etc.**

    a. Examples of services: screening, intervention and protective services, referral- and support services, rehabilitation and reintegration.

b. Access (i.e. availability, physical accessibility, affordability)?

c. Structure and quality? (quality monitored? Elaborate)

3. [DEMENTIA/EA SERVICES 2]: **Who/which organisation(s) carry the primary responsibility for these services?**

d. Who are some of the other role players for these services?

e. Do services happen in a coordinated (inter-sectoral) manner (e.g. inter-sectoral collaboration between DSD and DoH)? Barriers and facilitators to integrated dementia care?

4. [DEMENTIA/EA SERVICES 3]: **Describe the uptake of these services (in your sector)?**

f. How are they utilised?

g. Are there differences across the country?

h. What are the barriers to uptake?

i. Do these meet the current need for services?

5. [DEMENTIA/EA SERVICES 4]: **What can be done to prioritise the detection and management of dementia/elder abuse in your sector?**

[DEMENTIA/EA Data, surveillance]: **Based on your experience, are you aware of any data collected for: *Elder abuse* (e.g. reported cases vs. convicted cases, human rights for older persons' complaints)? Describe.** [Verify the existence of the following:]

j. Decentralised record-keeping at local offices/facilities? (EA offender register and (victim) reports)?

k. Provincial databases for dementia/elder abuse (offender register and (victim) incidents data)?

l. National databases for dementia/elder abuse (offender register and (victim) incidents data)?

m. If these exist, are there any limitations or challenges in collecting this data? How is it utilised?

n. If these *don't* exist, what has been the challenges/barriers to establishing these? What do you think can be done to develop and adopt a 'culture' of capturing data towards a national surveillance of dementia/elder abuse?

6. [DEMENTIA/EA Detection and management]: **Do you consider elder abuse detection and protective services for older persons a priority within your sector?**

o. Describe understanding of magnitude of the problem (EA), health impact, state- and community responses.

p. Describe the current provision of services for dementia/elder abuse in your sector (e.g. case investigations, intervention and protective services, referral- and support services, rehabilitation and reintegration).

q. Who/which organisations carry the primary responsibility for these services?

r. Describe other role players. Do services happen in a coordinated (inter-sectoral) manner?

s. How are these services accessed? Utilised?

t. Barriers and facilitators to access to protective services?

u. What can be done to prioritise the detection and management of elder abuse in your sector?

7. [DEMENTIA/EA: Awareness and prevention]: **Based on your experience, how would you describe current awareness and prevention efforts of dementia/elder abuse in your sector?** Are there any programmes/interventions targeted at specific groups believed to be especially vulnerable to stigma and abuse? (e.g. women, persons living with dementia, persons living with disabilities?) Describe.

8. [DEMENTIA/EA COVID-19]: **What was the impact of COVID-19 on elder abuse services in your sector?**

v. Challenges and restrictions? Barriers to service delivery? Financial implications?

w. Financial implications: consumables (PPE) and other financial implications?

x. Measures put in place to overcome these challenges? (continuity of services)

y. What do you think can be done to ensure continuity of services for future?

Conclusion:

- Thank you for taking the time to talking to us about your experience. The information you provided is very helpful to our work learning about the dementia care system in South Africa.
- We just want to confirm that all the information you provided will be anonymised and treated confidentially. Please do not hesitate to contact us at a later date if you have any questions.
- Could I please check again that you would be happy with us archiving the interview in a safe place as well as to deposit it with UK Data Service. This will be done to make the information you provided available to other researchers. Before we would store your information with the UK data service we will ensure that there is no information, such as your name or other identifying details in there that could identify you.

7.4 Appendix 2: The Caregiver Abuse Screen (CASE)

CAREGIVER ABUSE SCREEN (CASE)

Purpose: To screen for abuse through multiple sources, for instance, through caregivers, care- receivers, and/or abuse interveners, rather than only through professional reporting. It is designed specifically for community use.

Instructions: Now I am going to ask you questions about your experiences in caring for your [carerrel]. There are no right or wrong answers, some of these questions may not be relevant to you but we ask everyone the same questions. I will ask a question and you can respond by choosing: 'Never', 'Rarely', 'Sometimes', 'Very often', and 'Always' as an option that best describes your experiences in caring for an older adult/for your [carerrel]

Please answer the following questions as a helper or caregiver:

	Never	Rarely	Sometimes	Very often	Always
1. Do you sometimes have trouble making (name of person) control his/her temper or aggression?	●	●	●	●	●
2. Do you often feel you are being forced to act out of character or do things to your (___) that you feel bad about?	●	●	●	●	●
3. Do you find it difficult to manage (___'s) behavior?	●	●	●	●	●
4. Do you sometimes feel that you are forced to be rough with (____)?	●	●	●	●	●
5. Do you sometimes feel you can't do what is really necessary or what should be done for (___)?	●	●	●	●	●
6. Do you often feel you have to reject or ignore (____)	●	●	●	●	●
7. Do you often feel so tired and exhausted that you cannot meet (____'s) needs?	●	●	●	●	●
8. Do you often feel you have to yell at ( )?	●	●	●	●	●

7.5 Appendix 3: Supplementary table with expanded listing of themes and narratives from carer responses to the CASE

Theme	Sub-theme	Narratives
Pacify or evade	Calm older adult	*"Yes. I can calm him quickly. He listens to me. But it's difficult sometimes" (RJAFR0025)*
		"May sometimes get angry at someone shout and swear but am able to calm him down" (LMRJSEP22).
		" I touch her softly and comfort her" (HMRJXH0027)
	Shift focus	*"You can't get them to control it[behavior], just change the subject. They forget completely" (RJENG0022)*
		"Just shift his focus from what he is doing if it is wrong and then he will soon forget" (LMRJSEP22)
	Ignore to cope	*"Yes. Often and usually around supper time. This is when it's 'crazy time'. I have to compartmentalize her out so that I can spend some time with my kids and husband. I initially felt guilty but okay now" (RJENG0022).*
		"Sometimes ignore her. What she says don't make sense. I know if sounds bad but we attach less importance to what she says. She doesn't notice I do this" (RJMSENG0024).
		"yes I ignore her all the time, I just can't deal. Example, she comes into the TV room asks 'what are you guys watching?' she wants to sit and watch TV but wants to sit where her granddaughter is sitting. I know Mother was asking for company but I didn't want to give her mine" (RJENG0021).
		"…sometimes I do feel that way[ignore and reject] but end up feeling like there is no other way" (HMRJXH021).
		"Yes, to just keep quiet sometimes and not respond" (HMRJXH0027)
	Stay calm, 'Let go'	*"It is hard but I just forgive him and let go" (HMRJXH021).*
		I'm used to it and have accepted that he is not doing it deliberately, so I still remain calm" (LMRJSEP22).
		"Yes feel that way, but then you count to 10. And like my colleague at work says, if 10 don't help, just count further" (RJENG0026).
		When he is angry I just remain calm. Listens to the son more than everyone. Easy to calm him down because he easily forgets what happened" (LMRJSEP22)
	Lie to pacify	*When he is angry I keep quiet and not retaliate and then he would end up keeping quiet. He is more like a child so sometimes I would lie to him like a child to make him comply" (HMRJXH021).*
	Walk away	*"She's not physically violent towards us. When dressing her she pushed me away. I left the room rather" (RJMSENG0024)*
		"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).
		"Yes, she hits so I move away from her when she does" (HMRJXH0026)

Theme	Sub-theme	Narratives
Forced to be rough	Aggressive	*"I am a patient person. However, when I get the chance I have to be out of her space, I become very happy. Sometimes I need to be aggressive for some things to happen" (HMRJXH022).*
	Physically dominate or rough handling	*"Once or twice I had to fight her off as she refused me to clean her bed after she soiled her bed. I had to physically dominate and it scared me. Now I squirrel into her room and steal it [dirty linen]. Not something I'm proud of. I recognize this as entirely out of character for both of us" (RJENG0021).*
		"Occasionally, when she doesn't help when I'm trying to clean her. Have to lift her up to clean her or move her" (MSRJENG0023).
		"Yes, sometimes we had to be. Smacked his bum to dress him because he would sit down[instead of lifting]" (RJENG0026).
		"Yes, sometimes when I'm tired, angry and irritable" (HMRJXH021).
		"Yes. I have to, the situation forces me to be" (HMRJXH022)
		"Yes, she is bullying and bossy so I would end up being rough with her" (HMRJXH023).
		"Honestly she was annoying. I remember I had to fight with her to stop her" (HMRJXH0024).
	Shouting	*"Yes sometimes, when he wants to do his own thing then I have to talk loud to him or show him my frown" (RJAFR0024)*
		"Yes, I shout at her when she doesn't want to do it" (HMRJXH0026)
		"Yes. She would take chances if I would be soft to her" (HMRJXH0027).
		"Sometimes. I sometimes do: 'Come now!'. I'm sorry that I shout at her" (RJMSENG0025)
		"Not often but it happens now and again" (RJAFR0023)
		"Only when he's scratching with electrical appliances, it's dangerous" (RJAFR0024).
		"Sometimes yes. When things get too much. Then on the other hand I feel guilty after shouting because he can't help it" (RJAFR0025)
		"…not always. Not all the time" (HMRJXH021).
		"Yes. A lot of times I have to" (HMRJXH022).
		"Yes. I would have to shout at her at times, so that she complies" (HMRJXH023).
		"Sometime I'd be angry and I would need to stop her" (HMRJXH0025)
		"Yes, to make her comply" (HMRJXH0027)
		"Yes. If she does something wrong and you don't reprimand her for it, she may repeat again. She is now like a child and we have to reprimand her as such" (LMRJSEP23)

Theme	Sub-theme	Narratives
Recipient of aggression and violence	**Aggression**	*When she's stressed, her behaviour is out of control. Doing what she loves manages her temper. Behaves well when she's happy" (LMMSSEP22)*
		"Only when she's angry" (LMMSSEP20)
		"She would be angry but I would be able to handle that" (HMRJXH0024).
		"Yes, sometimes she would ask me to close the doors unnecessary, so I wouldn't allow that. I find it hard to control her behavior" (HMRJXH023)
		"Yes. She is easily irritated. Especially when given certain tasks to do" (HMRJXH022)
		He reasons in circles, doesn't get to a point. Goes round in circles and then he fights with me" (RJAFR0023)
		Forceful when it comes to what she wants and throws tantrums if it doesn't happen. Very picky, even with colours" (LMMSSEP22)
	Hits	*"Yes, she hits so I move away from her when she does" (HMRJXH0026)*
		A lot of people would think he's rude. For example, someone comes in that he knows and walked up to him, he was excited to see him and came towards him[visitor] and slapped him[visitor], unintentionally. Now you have to come and explain to this person he's not rude" (RJENG0026).
	Yelling	*Person sits quiet for hours and when asked 'what are you thinking?', she snaps back 'why are you asking?!?'" (RJAFR0021).*
		"Then you give her something she may throw it away and get angry. I just do as they[she] say[s], example you give her a glass of water and she will say the glass is dirty and throw it away. I just fetch another glass and pour the water in front of her. [She] quickly gets impatient and starts shouting, gets angry. I try to satisfy her [as] much as I can to avoid her being angry. Have to be patient" (LMRJSEP21)
		"Sometimes, not always. Like this morning, he doesn't give you a chance to talk, he shouts and says hurtful things" (RJAFR0025)
	Violent threats	*"Yes. 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)*

7.6 Appendix 4: List of instruments in the STRIDE Older adult Toolkit

The STRIDE toolkits consisted of tools that both older adults and informants completed, and a list of tools that were specific to the Older Adult. They are listed below:

	Name	Domain
Older adult and Informant tools	**CSRI** (Client Service Receipt Inventory)	Costs, service use, participant characteristics and background information.
	WHODAS (World Health Organization Disability Assessment Schedule 2.0)	Functional impairment
	CSID (Community Screening Interview for Dementia)	Dementia (older adult and proxy)
	EQ-5D-5L	Health-related quality of life
	WGSS (Washington Group Short Six)	Disability
	Stigma questionnaire (developed by STRIDE and similar to World Alzheimer's Report Stigma survey).	Stigma
Older adult tools	**DEMQOL** (Dementia Quality of Life)	Quality of life
	GMS (Geriatric Mental Schedule)	Memory
	EURO D	Depression
	EAST (Elder abuse screening tool)	Elder abuse

7.7 Appendix 5: List of instruments in the STRIDE Older adult and Informant Toolkits

The STRIDE toolkits consisted of tools that both older adults and informants completed, and a list of tools that were specific to each. They are listed below:

	Name	Domain
Older adult and Informant tools	**CSRI** (Client Service Receipt Inventory)	Costs, service use, participant characteristics and background information.
	WHODAS (World Health Organization Disability Assessment Schedule 2.0)	Functional impairment
	CSID (Community Screening Interview for Dementia)	Dementia (older adult and proxy)
	EQ-5D-5L	Health-related quality of life
	WGSS (Washington Group Short Six)	Disability
	Stigma questionnaire (developed by STRIDE and similar to World Alzheimer's Report Stigma survey).	Stigma
Older adult tools	**DEMQOL** (Dementia Quality of Life)	Quality of life
	GMS (Geriatric Mental Schedule)	Memory
	EURO D	Depression
	EAST (Elder abuse screening tool)	Elder abuse
Informant tools	**NPI-Q** (Neuropsychiatric Inventory Questionnaire)	Neuropsychiatric symptoms
	DSRS (Dementia Severity Rating Scale)	Dementia severity
	OSCARS (Observable Social Cognition Rating Scale)	Social cognition
	Lawton IADL (Lawton Instrumental Activities Daily Living Scale)	Functional ability for daily tasks
	ZBI-12 (Zarit Burden Inventory short form)	Caregiver burden
	CASE (Caregiver Abuse Screen)	Elder abuse

7.8 Appendix 6: Ethics approval letter from the Human Research Ethics Committee (HREC)

This study received ethical clearance from UCT's Faculty of Health Sciences' Human Research Ethics Committee (HREC), ref. no.: 692/2019. See original approval below:

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 650 7260
Email: shakirah.coenraad@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

14 November 2019

HREC REF: 692/2019

A/Prof M Schneider
Alan J Flisher Centre for Public Mental Health
Building B, Room 30
46 Sawkins Road,
Rondebosch
7700

Dear A/Prof M Schneider

PROJECT TITLE: "ELDER ABUSE IN SOUTH AFRICA: MEASUREMENT, PREVALANCE AND RISK" (SUB-STUDY -021/2019) (PHD DEGREE - ROXANNE JACOBS)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 November 2020.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, *Mrs Roxanne Jacobs* will also be involved in this study.

Please also note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC REF in all your correspondence.

Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.

HREC/ref: 692/2019