

**A SYSTEMATIC REVIEW TO DETERMINE WHETHER ANY VALIDATED DEMENTIA SCREENING
TOOLS EXIST FOR USE IN PALLIATIVE CARE POPULATIONS IN SUB-SAHARAN AFRICA.**

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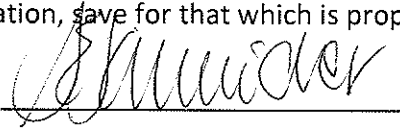
Please grant my visitors tolerance for my confusion,
Forgiveness for my irrationality and the strength
To walk with me into the mist of memory
My world has become.

Please let them take my hand and stay awhile,
Even though I seem unaware of their presence.
Help them to know how their strength
And loving care will drift slowly
Into the days to come just when I need it most.
Let them know when I don't recognize them That I will. . .
Keep their hearts free from sorrow for me,
For my sorrow, when it comes,
Only lasts a moment, then it's gone.
And finally, please let them know,
How very much their visits mean,
How even through this relentless mystery,
I can still feel their love.

Plagiarism Statement

I, Suzanne Eva Schneider, know the meaning of plagiarism and declare that all of the work in the dissertation, save for that which is properly acknowledged, is my own.

Signature: _____

A handwritten signature in cursive script, appearing to read 'Suzanne Schneider', is written over a horizontal line.

Date: 25th August 2014

DEDICATION AND ACKNOWLEDGEMENTS

I dedicate this dissertation to my beautiful and amazing daughter Claudia, who fills my life with meaning and purpose.

Thank you for your love, support, understanding and the many sacrifices made to complete this journey.

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1. DEFINITIONS OF TERMS AND ABBREVIATIONS

TERM	MEANING
HIV	Human Immunodeficiency Virus
WHO	The World Health Organisation
DLB	Dementia with Lewy Bodies
ADI	Alzheimer's Disease International
LMIC	Lower Middle Income Countries
GBD	Global Burden of Disease
D.A.S.A.	The Dementia Association of South Africa
OECD	Organisation for Economic Co-operation and Development
UNAIDS	United Nations Programme on HIV & AIDS
AIDS	Acquire Immunodeficiency Syndrome
ADC	AIDS Dementia Complex
DSM-IV	The Diagnostic and Statistical Manual of Mental Disorders
HAD	HIV-Associated Dementia
IHDS	The International HIV Dementia Scale
ART	Anti-Retroviral Treatment
MMSE	Mini Mental State Examination
SBT	Short Blessed Test
PRISMA	Preferred Reporting Items for Systematic Reviews
UCT	University of Cape Town
CD4 Count	A glycoprotein predominantly found on the surface of helper T cells. In humans it is a receptor for HIV, enabling the virus to gain entry into its host. A CD4 count is performed to determine the number of T-helper lymphocytes per cubic millimeter of blood
HAND	HIV-Associated Neurocognitive Disorder
GPCOG	General Practitioner Assessment of Cognition
MIS	Memory Impairment Screen

TERM	MEANING
RUDAS	Rowland Universal Dementia Assessment Scale
MoCA	Montreal Cognitive Assessment
SA	South Africa

2. **ABSTRACT**

2.1. Context

Do any validated dementia screening tools exist for use in palliative care populations in sub-Saharan Africa?

Around the world populations have increased life expectancies. The tendency to develop dementia increases with age. By 2040, it is projected that more than 80 million people worldwide will suffer from dementia.

Effective and validated dementia screening tools are used for screening and identifying people with dementia at an early stage, allowing for the possibility of earlier intervention. Validated tools are used internationally, but there is a need to determine if such tools have been validated for use in a sub-Saharan African palliative care population, which presents with the distinct challenges of literacy, language and culture. There is also a high incidence of HIV in sub-Saharan Africa, with a concomitant high prevalence of HIV-associated dementia.

Sub-Saharan Africa therefore needs a unique, validated dementia screening tool for use in a palliative care population.

Dementia causes a high burden of suffering for patients, their families, and communities. There is a similarity between many of the symptoms of cancer and dementia, although patients with dementia have a longer life expectancy. Palliative care is the cornerstone in the management of cancer patients and is therefore clearly ideal for people suffering from dementia. The World Health Organization, in their publication: "Palliative Care for Older People: Better Practices", state that people who suffer from dementia are in urgent need of improved palliative care services

2.2. Aim

The aim of this systematic review was to identify validated dementia screening tools, and of those tools, to determine, specifically, whether they had been validated in a palliative care population in sub-Saharan Africa.

This was done by following 3 objectives:

1. To identify which validated dementia screening tools are available.
2. To identify and isolate those tools which have been validated in sub-Saharan Africa.
3. To determine from those tools validated in sub-Saharan Africa, which have been validated in a palliative care population.

To clarify, the aim of the study was to identify the validated tools, for dementia screening in sub-Saharan Africa, in a palliative care population. This study did not endeavor to conduct an in-depth analysis of the psychometric properties of the identified tools.

2.3. Methods

The EBSCO, PUBMED, SCOPUS, Medline, Psych INFO, CINAHL and Africa-Wide Information databases were searched to identify dementia screening tools. The comprehensive search strategy focused on search terms in the categories of dementia, screening tools and sub-Saharan Africa.

Included were all tools used to screen dementia in an adult population, provided the tools met one of the following validity criteria: face validity, or content validity, or concurrent validity as well as internal consistency. An abstract had to be available. The tool had to be peer reviewed, for use with human subjects, and in English. Exclusion criteria for the validated tools were: grey literature and the screening of children.

2.4. Results

Stage 1 was to identify validated dementia screening tools internationally using the electronic databases listed above under methods. This search identified 116 articles written on global dementia screening tools. Stage 2 was performed on the same electronic databases to determine if any tools had been validated in sub-Saharan Africa. This search identified 8 articles on dementia screening tools validated in sub-Saharan Africa. The 3rd stage was to determine if any of the dementia screening tools from stage 2 had been validated in a palliative care population. In stage 3, 3 articles were identified all pertaining to the same dementia screening tool. The International HIV Dementia Scale (IHDS) was the only validated dementia

screening tool found that had been validated in sub-Saharan Africa in an HIV population but not in a palliative care population. HIV can be seen as being included in a palliative care population.

2.5. Conclusion

No validated tool was identified for the broad-based screening of dementia in sub-Saharan Africa in a palliative care population.

The IHDS has been validated for use in screening for HIV-associated dementia in this region. This tool can still be used in the HIV population, but the author is of the opinion that the IHDS, as a screening tool for dementia, is not adequate in the general palliative care population.

In the current clinical setting, the international gold standard tool for dementia screening, the Mini Mental State Examination (MMSE), is regularly used, and despite certain limitations associated with its use in the sub-Saharan Africa setting, the author recommends its continued use.

The author recommends that the MMSE be revalidated for use in the sub-Saharan Africa palliative care population.

Key words: dementia, screening, validated, palliative, population, sub-Saharan Africa

3. Introduction

The global prevalence of dementia is growing and this condition therefore requires validated screening tools for standardized diagnosis. Sub-Saharan Africa presents with unique challenges of a socio-economic, educational and linguistic nature as well as a high prevalence of HIV-associated dementia and therefore this region would require a tool validated for these specific challenges.

This research addresses the following question:

Do any validated dementia screening tools exist for use in palliative care populations in sub-Saharan Africa?

3.1. Definitions of Dementia

The World Health Organization in their report: Dementia: A Public Health Priority – Geneva 2012, define dementia as: A syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behavior and the ability to perform everyday activities (1).

Dementia is an acquired syndrome of decline in memory and at least one other cognitive domain such as language, visuo-spatial or executive function that is sufficient enough to interfere with social or occupational functioning in an adult (2). Prince et al define dementia as a clinical syndrome caused by neuro-degeneration, characterized by inexorably progressive deterioration in cognitive ability and capacity for independent living (3).

Dementia is recognized by Birch et al as a progressive terminal illness for which there is no cure (4). Life expectancy after onset can vary anything between 2 to 15 years with the end stage lasting 2 to 3 years (4). This condition more typically affects older people and contributes significantly to disability and dependence (3).

According to the Alzheimer's Association, there are different types of dementia that have been categorised as follows: Alzheimer's disease, Vascular dementia, Dementia with Lewy bodies (DLB), Mixed dementia, Parkinson's disease, Frontotemporal dementia, Creutzfeldt-Jakob

disease, Normal pressure hydrocephalus, Huntington's disease and Wernicke-Korsakoff syndrome. Cullen et al report on four sub-types of dementia, which are "characterized by different patterns of impairment" (5). Alzheimer's disease presents initially with intermittent verbal and non-verbal memory impairment followed by judgment dysfunction (5). Vascular dementia is characterised by patients who tend to be considerably more impaired than patients suffering from Alzheimer's disease (5). Frontotemporal dementia patients usually have worse letter fluency and executive function than a patient with Alzheimer's disease although their memory performance is usually better (5). In Lewy body dementia the patient suffers from many dysfunctions such as attention, visuo-spatial abilities, letter fluency, mental tracking and abstract reasoning (5).

3.2. Epidemiology Global

Prince et al estimated that in 2010, 35.6 million people lived with dementia (3). They projected that numbers would almost double every 20 years to 65.7 million in 2030 and 115.4 million in 2050 (3).

The World Health Organization (WHO) in their report on Global Dementia determined through internationally varying estimates that between 2% and 10% of all cases of dementia start before the age of 65, with prevalence doubling in five-year increments after the age of 65 (6).

The World Health Organization (WHO) stated in their fact sheet number 362 from April 2012 that the following key facts are evident regarding dementia:

1. "It is a syndrome in which there is deterioration in memory, thinking, behavior and the ability to perform everyday activities."
2. "Although dementia mainly affects older people, it is not a normal part of ageing."
3. "Worldwide, 35.6 million people have dementia and there are 7.7 million new cases every year."
4. "Alzheimer's disease is the most common cause of dementia and may contribute to 60 – 70% of cases."
5. "Dementia is one of the major causes of disability and dependency among older people worldwide."

6. "Dementia has physical, psychological, social and economic impacts on caregivers, families and society."

From a regional basis, in 2010 Western Europe had the greatest prevalence of dementia with 7 million sufferers, East Asia had 5.5 million, South Asia 4.5 million and North America has 4.4 million (3).

On a country-to-country basis, China in 2010 was the country with the largest number of dementia sufferers of 5.4 million followed by the USA with 3.9 million, India with 3.7 million, Japan with 2.5 million, Germany with 1.5 million, Russia with 1.2 million, France with 1.1 million, Italy with 1.1 million and Brazil with 1 million (3).

Alzheimer's Disease International (ADI), quoted in the World Health Organization Report on the Global Prevalence of Dementia 2012, commissioned a panel of experts to review all available epidemiologic data of the global prevalence of dementia in order to reach a consensus estimate of prevalence in each of the 14 World Health Organization regions (3, 7). Their estimates were that 24.3 million people aged 60 years and over were living with dementia in 2001 of which 60% lived in lower middle income countries (LMIC) (3, 7). They predicted an annual increase of 4.6 million new cases and estimated that numbers would nearly double every 20 years to 81.1 million by 2040 (3, 7). Data collection from Europe, North America and the developed Asia-Pacific countries was broad, data from China and India was considered to be too variable for a consistent overview (3, 7). ADI noted a dearth of studies from Latin America, Africa, Eastern Europe, Russia and the Middle East (3, 7). However, the tendency noted from the limited data available from the few LMIC studies, was that the prevalence of age-specific dementia was found to be lower in developing countries than in developed ones (3, 7).

Eleven of the 21 World Health Organization Global Burden of Disease (GBD) regions had good coverage of prevalence of dementia studies (7). Western Europe had the highest at 61 studies; East Asia had 34 studies (7). These made up the bulk of available data (7). The Asia Pacific Region had 22 studies, North America had 13 and Latin America had 11 studies (7). Reasonable coverage was found in South Asia with 7 studies, South-East Asia with 5 studies and Australasia had 4 studies (7). Five regions were sparsely covered (7). The Caribbean had 4 studies, Central

Europe also had 4 studies, North Africa / Middle East had 2 studies and Eastern Europe had 1 study (7).

Western sub-Saharan Africa had 2 studies (7). Southern sub-Saharan Africa had only 1 study (7). Central and Eastern sub-Saharan Africa and Central Asia yielded no eligible studies (7).

Wimo et al estimate that in 2009, there were 14 million people aged 60 years and over suffering from dementia in the Organization for Economic Co-operation and Development (OECD) countries, which accounted for more than 5% of the population in that age group (8). France, Italy, Switzerland, Spain and Sweden had the highest prevalence, with estimates of 6.3% to 6.5% of the population aged 60 years or older having dementia (8). The prevalence rate was only about half these rates in some emerging economies including South Africa, Indonesia and India, although this in part reflects fewer detected cases (8).

3.3. Epidemiology Sub-Saharan Africa

The Joint United Nations Programme on HIV and AIDS (UNAIDS) stated in their HIV report of 2009 that East and Southern Africa are the global areas most heavily affected by the HIV epidemic (9). Nations Online 2012 and UNAIDS Report on the Global Aids Epidemic 2012 states that even though only 15.2% of the world's populations live in Africa, in 2011 - 69% of people living with HIV and 70% of all AIDS deaths occurred in Sub-Saharan Africa (10). Southern Africa is the region with the highest incidence with at least 10% of the populations of Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe being infected (10).

In contrast UNAIDS reported that HIV prevalence in West and Central Africa in 2009 was comparatively low, with the adult HIV prevalence estimated at 2% or under in 12 countries (Benin, Burkina Faso, Democratic Republic of the Congo, Gambia, Ghana, Guinea, Liberia, Mali, Mauritania, Niger, Senegal, and Sierra Leone) (9). Cameroon had the highest prevalence of HIV at 5.3%, followed by Central African Republic 4.7%, Côte d'Ivoire 3.4%, Gabon 5.2% and Nigeria 3.6% (9).

According to the World Health Organization, “HIV-associated dementia is an AIDS-defining illness, with a prevalence of 15–30% in untreated populations, presenting with neurocognitive impairments (forgetfulness, poor concentration and slowed mental processing), emotional disturbances (agitation, apathy), and motor dysfunction” (11). AIDS Dementia Complex (ADC) is a common complication of late stage HIV-1 infection (11). The high incidence of ADC and HIV in Southern Africa correlates to a significant causal factor of dementia in sub-Saharan Africa (11).

The World Health Organization in their report: Dementia: A Public Health Priority – Geneva 2012, found that the HIV epidemic is concentrated in younger people in low-income countries, particularly in southern and eastern Africa (1). They also found that rural and less developed sites had a low prevalence of DSM-IV dementia (1). However, milder dementia in LMIC countries may be under-detected because of low awareness, high levels of support routinely provided to older people, and unwillingness to report failings (1).

The Dementia Association of South Africa (D.A.S.A.) report that dementia affects 5% of the population, or one in 20 people, from the age of 65 (12). This increases to one in 5 people, or 20% of the population over the age of 80 (12). There are however diagnosed and documented cases of early –onset dementia before the age of 65 (12).

Furthermore D.A.S.A. report that a new case of dementia arises every seventy seconds in the developed world, and they estimated that by 2040 the amount of people with dementia will have risen from the 24, 3 million people currently affected to 81, 1 million (12).

3.4. Clinical Dementia in Sub-Saharan Africa

Paddick et al reported a prevalence of DSM-IV dementia of 6.4% of older adults living in the rural Hai district of Tanzania (13).

In Western sub-Saharan Africa the overall prevalence of dementia in the ≥60 year age group, is 2.07% (3).

Ineichen found that of 100 reviewed studies of dementia; very few had been carried out in Africa, and of those found the majority came from reviews of small hospitalized samples (14).

However he found a recent series of studies from Ibadan, Nigeria, where consistently low rates for dementia were found (14).

George-Carey et al state that in adults older than 50 years in Africa, the prevalence of dementia is estimated to be about 2.4% translating to 2.76 million dementia sufferers in 2010 (15). Of those about 2.10 million if they live in sub-Saharan Africa (15). Females aged 80 and over had the highest prevalence (19.7%) with little variation between regions (15). The most prevalent cause of dementia was Alzheimer Disease (57.1%) followed by vascular dementia (26.9%) (15). Alzheimer's in Action state that approximately 750 000 people in South Africa currently have dementia (16).

3.5. Screening for HIV-Associated Dementia (HAD)

Robbins et al in their study: Screening for HIV-Associated Dementia in South Africa: Potentials and Pitfall of Task-Shifting, found that HIV-associated dementia is a common cause of dementia below the age of 40 (17). In high income countries, they found the prevalence estimate to be as high as 10% in HIV patients, but state that South Africa with the worldwide majority of people living with HIV has insufficient knowledge about HAD sufferers (17). This is of concern because in South Africa more than 1 million people living with HIV may be at risk of HAD (17). In South Africa HAD is not routinely assessed in the overburdened and under resourced Healthcare clinics (17).

HAD is diagnosed through a comprehensive neuro-psychological evaluation and neurological examination (17). There are not many neuro-psychological screening tests for HAD in South Africa which are translated, normed and which are culturally validated in this diverse population which has 11 official languages, a high level of illiteracy and a low level of academic achievement (17). All of these variables are known to negatively affect neuro-psychological test results (17).

A pilot study was done on The International HIV Dementia Scale for validation purposes for its use in HIV positive populations in South Africa (18). Although the sensitivity was 88% and the

specificity was 50%, no firm conclusions were determined but the need to conduct a larger study was identified to validate the International HIV Dementia Scale (IHDS) (18).

Joska et al administered the IHDS to 96 HIV-positive individuals not receiving antiretroviral treatment (ART) in South Africa (19). They found that HIV positive individuals showed increased impairment on the IHDS and on a range of neuropsychological tests when compared to HIV-negative controls, but that individuals with HAD who performed poorly on tests of executive function did not always correspondingly screen poorly in the IHDS (19). They concluded that the IHDS may have limited application as a screening tool for HAD, for South Africans affected with HIV, and that the International HIV Dementia Scale needs to be refined in further research (19).

3.6. The Interface and Relevance of Dementia in Palliative Care

The World Health Organization define palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (20). The World Health Organization state that people live for many years after the onset of symptoms of dementia (20). With appropriate support, many can and should be enabled to continue to engage and contribute within society and have a good quality of life (20).

Hughes et al state that care of dementia sufferers deteriorates progressively at the end of life and it appears that they do not gain access to specialist palliative care services (21).

Dementia disease progression is often characterized with periods of plateau interspersed with acute illness which causes a decrease in mental and functional status to a lower level (22). Therefore the incorporation of palliative care and a suitable care plan, as the disease progresses, can be beneficial to the patient and the family (22).

With an aging population, the prevalence of dementia is expected to increase, creating a unique set of challenges for patients, caregivers and healthcare providers (23). The goal of palliative medicine is to provide comfort for patients suffering from any life threatening or life limiting illness, including dementia (23). Palliative care is holistic and has an individualized

approach (23). This approach should be taken for each patient and family member involved in the care of the patient (23). It is of utmost importance to keep in mind the patient's goals of care and quality of life at all times (23). Advanced care planning is particularly important for patients with dementia (23). By reviewing the natural progression of dementia, and anticipating common issues early in the disease process, physicians can help patients and caregivers navigate complex future decisions (23).

The World Health Organization in their report: Dementia: A Public Health Priority – Geneva 2012 report that in the LMIC regions of Africa, Asia and Latin America older people are rarely cared for in formalized institutions (1). The long-term care remains a family responsibility, because many families cannot afford institutionalized care and there are relatively few state-funded facilities (1).

3.7. The Interface and Relevance of Palliative Care for People Living with HIV

Help the Hospices, supported by the Open Society Institute – International Palliative Care Initiative, published an article called “What does Palliative Care Have to do with HIV and AIDS?” The article affirms that Palliative Care is highly recommended for people living with HIV for the following reasons (directly quoted):

1. “Palliative care will improve the quality of life of people living with HIV by addressing physical, psychological, social, legal and spiritual issues.”
2. “Palliative care supports the affected person with antiretroviral therapy adherence by means of identification and treatment of symptoms associated with antiretroviral therapy.”
3. “People living with HIV experience pain and other symptoms that affect their quality of life throughout all the stages of the disease including depression, fatigue and anxiety.”
4. “Palliative care addresses the need for the provision of emotional and social suffering.”
5. “HIV presents itself with comorbidities such as cancer, hepatitis and cardiovascular disease.”
6. “Palliative care supports the family members and carers looking after the affected person.”
7. “People living with HIV have a higher incidence of mental health problems including HIV related dementia.”

8. "Towards the end of the disease palliative care will provide end of life care and subsequent bereavement support."

According to The World Health Organization, palliative care forms an essential part of an all-inclusive care and treatment plan for people with HIV due to the variety of symptoms they can experience and symptoms that often go untreated and undetected. It is the aim of palliative care to relieve such symptoms that may result in the unnecessary suffering of the person and their family affected by HIV.

3.8. Screening for Dementia

Cohen and Swerdlik define a screening tool as "an instrument or procedure used to identify a particular trait or constellation of traits at a gross or imprecise level, as opposed to a test of greater precision used for more definitive diagnosis or evaluation" (24).

A screening tool can also be defined "as a measure to evaluate cognitive or 'thinking' functions such as memory, concentration, visual-spatial awareness, problem solving, and counting and language skills." (25).

Screening for dementia means utilizing recognized screening tools for diagnostic purposes.

Lischka et al in a Systematic Review of Tools Predicting the Development of Dementia identified the following screening tools for diagnostic purposes (26):

- Alzheimer Disease Assessment Scale Cognitive Subscale (ADAS-cog) (Rosen, Mohs, & Davis, 1984)
- Benton's Visual Retention Test (BVRT) (Benton, 1965)
- Cambridge Cognitive Examination (CAMCOG) (Roth et al., 1986)
- Cognitive Capacity Screening Examination (CCSE) (Jacobs, Bernhard, Delgado, & Strain, 1977)
- Isaacs Set Test (IST) (Isaacs & Kennie, 1973)
- Standardized Mini-Mental State Examination (S-MMSE) (Molloy, Alemayehu, & Roberts, 1991)

- Addenbrooke's Cognitive Examination Revised (ACE-R) (Mioshi, Dawson, Mitchell, Arnold & Hodges, 2006)
- Chinese Abbreviated Mild Cognitive Impairment Test (CAMCI) (Lam et al., 2008)
- Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) (Jorm & Jacomb, 1989)
- Memory Impairment Screen (MIS) (Buschke et al., 1999)
- Mini Mental State Examination (MMSE) (Folstein et al., 1975)
- Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2003)
- Revised Hasegawa's Dementia Scale (HDS-R) (Imai & Hasegawa, 1994)
- Short Test of Mental Status (STMS) (Kokmen, Naessens, & Offord, 1987)

The five tools which Lischka et al determined to be the best screening tools in terms of test accuracy, predictive ability and comprehensiveness are (26):

1. The memory section of the CAMCOG (comprising the orientation and memory subscales of the full CAMCOG)
2. CCSE
3. CAMCI
4. The ACE revealed good predictive ability and test accuracy only
5. ACE-R (good comprehensiveness only)

Malmstrom et al (27) in Informant-Based Dementia Screening in a Population-Based Sample of African Americans report that brief cognitive tests, such as the Mini Mental State Examination (MMSE) and the Short Blessed Test (SBT), are commonly used to screen for cognitive impairment, including dementia (27).

There are many complexities surrounding the use of dementia screening tools. Dr Jill Phillips in her report for Alzheimer's Australia states that barriers exist to timely diagnose and manage dementia (28). Dr Phillips identified factors in the systemic, patient/carer, and General Practitioner settings that can influence the diagnosis of dementia (28). Patient/carer factors include their perceptions of and understanding about dementia and aging and a lack of insight into declining abilities (28). People who live alone may not recognize their declining cognitive

abilities (28). General Practitioner factors include time constraints, recognizing minor cognitive changes in patients which could be the signs of early dementia, negative ideas of dementia, limited access to referring specialists, the possible negative consequences of diagnosing dementia, the challenge of communicating the diagnosis of dementia and the responsibility of auxiliary issues such as legal, advance planning and financial (28). Systemic factors include the lack of efficient communication to detect and manage dementia and the conceptualization that dementia is not considered a chronic condition (28). Stress, anxiety and fatigue are possible causes that could affect the performance of a patient who is being screened (28).

3.9. Why Screen for Dementia

Lischka et al state that early detection of dementia guides front-line health care practitioners in planning further clinical evaluations and in determining treatments (26).

The World Health Organization in their report: Dementia: A Public Health Priority – Geneva 2012, find that dementia is one of the major causes of disability in later life, accounting for 11.9% of the years lived with disability due to a non-communicable disease (1). In both high-income and lower middle income countries (LMIC); it is the leading cause of dependency (need for care) and disability among older persons (1).

Furthermore, the report states that especially in LMIC countries the impact of dementia is poorly understood, resulting in a lack of policy direction, programme development, and in inappropriate allocation of funding (1).

Chang & Silverman propose that an early diagnosis of Alzheimer's Disease/Dementia would allow patients to benefit from drug and non-pharmaceutical therapies which may improve memory or delay memory decline (29).

Henry Brodaty from the University of New South Wales together with Lee-Fay Low, Louisa Gibson & Kim Burns list the following ten reasons for screening of dementia (30):

Reversible causes need to be identified, the relief to know what has been wrong, for legal planning, for financial planning/protection, for medical planning and general treatment, for life

planning, work and driving, for relations with family, and for prescribing medication for cognition (30).

Perceived benefits from an appropriate & competent screening is that a correct diagnosis is made thereby ensuring correct treatment as well as a correct palliative care plan being drawn up to suit the patients' needs. It creates a sense of understanding the patients' position thereby creating a platform for an empathetic and holistic approach to patient, family and carer.

3.10. Why Screen for Dementia in a Palliative Care Population

According to the Wilson-Junger criteria for appraising the validity of a screening programme, the following criteria are recommended:

1. "The condition should be an important health problem that has been detected at an early stage and with the history of the condition well understood."
2. "The commencement of treatment at an early stage will be of more benefit than at a later stage with adequate health services provision available."
3. "The costs should balance the benefits with the risk on a physical and psychological level being minimalistic."

In palliative care all life limiting and life threatening diseases can be seen as important health problems that benefit from early screening, diagnosis and treatment, therefore having a dementia screening tool in this population can be of great benefit, thereby ensuring that the person suffering from such a disease is cared for from the onset with a holistic approach.

3.11. A Personal Perspective on the Importance of this Study

The author comes from a nursing background, having spent the last 5 years in a management position at a Hospice, and currently in a facility for the elderly which includes a dementia unit. Particularly from a management perspective, knowledge and information is of vital importance. In particular, planning, based on statistics and numbers, is an essential part of management so that provision can be made for:

- Correct staffing ratio
- Correct therapeutic environment
- Formal and informal training of staff
- Ensuring sufficient facility capacity
- Early diagnosis to facilitate forward planning
- Ensuring the delivery of excellent palliative care

The Mini-Mental State Examination (MMSE), although not validated in a palliative care population in sub-Saharan Africa, is a gold standard tool which the author has used in both the Hospice and her current working environment. The author is of the opinion that the tool is more easily administered in her current working environment, a care facility for the elderly catering to affluent well educated patients. Her previous experience of using this tool in a Hospice setting catering to the general palliative care population of South Africa, was deemed unsatisfactory by the following factors; language limitation, education levels - in particular it was noted in those patients coming from poorer socio-economic backgrounds that difficulties were experienced in performing aspects of the test that were not necessarily related to their ability to perform the test but rather due to a lack of basic education and literacy e.g. spelling the word “world” backwards, counting from 100 backwards in sevens, and creating a sentence with a noun and a verb.

The IHDS has been validated in a HIV population which can be understood to include palliative care, however, from the author’s experience in her current setting, this tool is also of limited applicability because frail elderly patients often battle to perform some of the more motor based tasks as a result of their physical constraints, e.g. a patient suffering from severe arthritis will have difficulty performing the motor speed and psychomotor speed components of the IHDS.

The author wanted to find a validated tool which would be applicable for use across the board in a palliative care setting specifically for use in sub-Saharan Africa. Such a tool would enable the early diagnosis of dementia, and this would allow for improved planning and therefore ensure optimal palliative care.

The tool identified, or if necessary adapted or created, should be simple to administer by nursing staff and should take into account the variations in language, education, and socio-economic background of patients falling under palliative care in sub-Saharan Africa.

3.12. What is Validation

Validation of screening tools can be based on the following criteria ⁽³¹⁾:

1. Face validity simply reflects that the investigators' assessment of the screening tool sufficiently matches the variables being tested for.
2. Content validity is a theoretical concept based on judgments conferred by professionals in that the content of the screening tool accurately examines and reflects those aspects that are intended to be measured.
3. Criterion validity compares one set of measures with another which is already accepted as valid (gold standard). There are two types of criterion validity namely concurrent validity and predictive validity. Concurrent validity denotes an independent corroboration that the screening tool is measuring what it is intended for. Predictive validity determines whether the screening tool can predict future changes in key variables in expected directions.
4. Construct validity corroborates that the screening tool measures the primary concept it claims to measure through how the screening tool is predicted to perform and through observing to see whether the data supports the hypothesis. Convergent validity and discriminant validity are the two elements that make up construct validity.
5. Precision validity indicates whether a screening tool can detect small changes in a test feature.
6. Responsiveness to change validity indicates that changes which occur in individuals or populations over time will be reflected through altered results.
7. Sensitivity validity refers to diagnosed cases (e.g. a person with dementia) that score positive on a relevant screening tool.
8. Specificity validity measures the likelihood of correctly detecting a non-affected person (e.g. a person who does not have dementia) through use of a screening tool.

3.13. The Importance of Local Validation

There are current screening tools that have been developed in first world settings but their applicability and validity to the sub-Saharan African setting have not been substantiated yet.

Deficiencies in current screening tools that have been identified by healthcare workers & the author whilst working in a palliative care population include:

1. Aspects that do not allow for differences in patient's levels of literacy
2. Language
3. Numerical skills
4. Level of education
5. Cultural beliefs
6. Socio-economic conditions
7. Inappropriate terms of reference e.g. memorizing words that are not part of the patient's language, culture or level of education.

Sub-Saharan Africa presents with its own unique set of circumstances that makes use of an internationally validated tool complicated. It is important to have a validated dementia screening tool for use in sub-Saharan Africa which is appropriate to the population found in this region. The challenges in sub-Saharan Africa are of an educational, linguistic, and socio-economic nature, which differ from those found internationally. Also, there is a high prevalence of HIV-associated dementia.

Validity refers to the extent to which a tool actually measures a trait (31). A validated dementia screening tool should be validated for the targeted population as well as setting (31). Validity is important because a validated tool proves to measure what it claims to measure in a specific population (31). A validated tool correctly identifies a patient who has dementia and thereby reduces the waste of limited resources on those who do not need intervention (31). One is more likely to get the desired outcome when using a validated tool in the target population group (31).

3.14. What do we know currently in Sub-Saharan Africa

The prevalence of dementia is estimated to be very low in the 4 sub-Saharan African regions (3).

Prince et al found one good quality study performed in sub-Saharan Africa, which greatly influenced the low estimated prevalence of dementia (3). When only a few studies are available, or when the studies are small, or when they were conducted a long time ago, or when they are of poor methodological quality, a low generalizability is conferred (3).

Robbins et al state that “there is an urgent need for valid, reliable, and simple-to-use screening tools for HIV-associated dementia in South Africa...” (17).

Singh et al found that a larger study is needed to validate the International HIV Dementia Scale (IHDS) in South Africa (18).

4. Aim and Objectives

This study is a systematic review. The specific aim is to identify available validated dementia screening tools, and of those to determine whether they have been validated in a palliative care population in sub-Saharan Africa. This study is not a meta-analysis as it does not aim to compare the findings from a series of studies to assess the clinical effectiveness of the tools.

It is important to have a working understanding of those tools which were finally identified and deemed applicable for use within the parameters of this study, but it is important to clarify that the aim of this study was specifically to identify validated tools, rather than to compare the clinical effectiveness of the tools.

The objectives are:

1. Identify which validated dementia screening tools are available.
2. Determine and identify those tools which have been validated in sub-Saharan Africa.
3. To determine of those validated in sub-Saharan Africa, which have been validated in a palliative care population.

4.1. Aim

To identify existing dementia screening tools validated for use in a Sub-Saharan Africa palliative care population.

To contribute to the peer reviewed evidence base, with the further intention of assessing the situation from a clinical perspective so that this information can guide the sub-Saharan African regions approach to dementia screening with particular emphasis for palliative care populations.

5. Method

For this study six definitions are necessary:

1. Dementia: “a life limiting and incurable illness, characterised by progressive deterioration of a patient’s usual cognitive abilities with a functional decline severe enough to interfere with daily life” (22).

In this study the term dementia includes HIV related dementia, and excludes those forms of dementia caused by head-injuries, brain tumours and young-age onset dementia.

2. Palliative care: The World Health Organisation defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (20).

3. Palliative care population: There is an increasing ageing population in the world. The disease patterns in the last years of life also change. Many more people die from serious chronic disease than from acute illness (32). The World Health Organisation in their report Better Palliative Care for Older People recognises that life expectancy has increased with many people living past 65 years of age and into very old age (32). With the ageing process needs change and quality care is imperative requiring geriatric and palliative expertise to ensure support of the patient and their family (32).

The palliative care population is expanding to include all people of any age that are nearing the end of their life be it due to life limiting diseases, life threatening diseases, ageing, frailty or a wider range of diseases such as HIV.

4. Hospice care: The National Hospice and Palliative Care Organization provide the following definition of hospice care: “The focus of hospice relies on the belief that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so. Hospice is built around the key concept that the dying patient has physical, psychological, social, and spiritual aspects of suffering. Hospice is a philosophy, not a specific place.... The core structure of hospice includes an

Interdisciplinary team that ... provides access to a wide range of services to support the primary caregiver, who is responsible for the majority of the patient care.”

5. Sub-Sahara Africa: "Political definition of "Major regions", according to the UN" refers to Sub-Saharan Africa as a geographical term encompassing the area of the African continent which lies south of the Sahara. The following countries form part of sub-Saharan Africa: Africa, Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cape Verde, Central African Republic, Chad, Comoros, Congo, Cote d'Ivoire, Democratic Republic of the Congo, Equatorial Guinea, Eritrea, Ethiopia, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mozambique, Namibia, Niger, Nigeria, Rwanda, Soa Tome and Principe, Segegal, Seychelles, Sierra Leone, Somalia, South Africa, Swaziland, Togo, Uganda, United Republic of Tanzania, Zambia and Zimbabwe.
6. Adult: The Children's Act 38 of 2005 determines that the age of majority is 18 ⁽³³⁾. For the purpose of this study adulthood will be any person 18 years and older.

6. Study Design

The design and reporting of this systematic review follow the best practice guidance by PRISMA (34).

The term PRISMA refers to Preferred Reporting Items for Systematic Reviews and Meta-Analyses which are increasingly utilised in systematic reviews (34). The use of PRISMA has superseded QUORUM because PRISMA aims to contain both systematic reviews and meta-analyses (34). PRISMA covers general concepts and topics which are relevant to any systematic review, not only those which aim to summarise the benefits and harms of healthcare interventions (34).

A flowchart of the stages of the review process in all searches was done according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (34).

The systematic review will be conducted in three stages, corresponding to Objectives 1 – 3. In Stage 1, available validated dementia screening tools will be identified.

In Stage 2, the retained articles from stage 1 will be subjected to a second screen to determine which ones have been validated in sub-Saharan Africa.

In Stage 3, the retained articles from stage 2 will be subjected to a further screen to determine if the tools validated in sub-Saharan Africa have been validated in a palliative care population.

6.1. Search Strategy

The search strategy used was: a keyword specific search of the following databases was conducted.

6.1.1. Databases

Seven electronic databases were searched: EBSCO, PUBMED, SCOPUS, Medline, CINAHL, PsycINFO and Africa-Wide Information. All databases were taken from inception date or either 1950 to September 2013. All databases searched used the same keywords as described in tables below.

Other sources were: Google Scholar for accessing hard copies of the tools which appeared in the journal articles and or studies, hand searching of relevant journals, correspondence with experts in the field, and of particular benefit was email correspondence with Professor John Joska who is a co-author of the IHDS study which was the final identified study found, reference lists of identified studies and relevant review articles, and Google Search to locate additional validation articles relating to identified tools.

6.2. Analysis of the Validated Dementia Screening Tools

This study is a systematic review. A meta-analysis is not appropriate because the aim of the study was specifically to identify a validated dementia screening tool for use in a palliative care population in sub-Saharan Africa and not to compare the effectiveness of various screening tools.

In a meta-analysis review, data from two or more randomised controlled trials is combined, generally to assess the clinical effectiveness of a healthcare intervention. This study is not to assess the clinical effectiveness of the tools; it is to identify specific, validated tools.

Comparable to the systematic study conducted by Selman et al regarding The Measurement of Spirituality in Palliative Care and the Content of Tools Validated Cross-Culturally: a systematic review; where nine validated spirituality measuring tools were identified in a in a cross-cultural palliative care population (35), this systematic review aimed only to identify validated dementia screening tools in a palliative care population in sub-Saharan Africa.

This systematic review identified 116 articles in the stage 1 search and these were analysed according to the following criteria:

Traceable reference, year of study, country of study, study setting & population, name of the dementia screening tool, language of the tool, version of the tool, number of items in the tool, and importantly, the validation of the tool.

From this, a data extraction table was developed to identify those studies which were validated in a palliative care population in sub-Saharan Africa. So firstly, the studies in which the screening tools were validated were analysed to determine if they were conducted in sub-

Saharan Africa, and those falling in other regions were extracted. The studies were then further analysed for their use in a palliative care population which in this study included people nearing the end of their life as a result of a life limiting disease and or a life threatening disease, and those tools not validated in a palliative care population were extracted.

The final study was carefully analysed to ensure that it complied with the study parameters.

6.3. Stage 1

6.3.1. Aim

The aim of this systematic review is to identify validated dementia screening tools and of those to determine whether they have been validated in a palliative care population in sub-Saharan Africa.

6.3.2. Objective 1,

To identify validated dementia screening tools available.

6.3.3. Method

A search for global dementia screening tools was conducted on Pubmed, Scopus and EBSCO using the following keywords: (elder* OR geriatric* OR senior* OR confus* OR cognitive impairment OR palliat* OR disorientat* OR dementia OR capacity neuro cognitive deficit) AND (valid* dementia screen* tool* OR dementia screen* tool*). See table 1. The articles found on the databases were analysed. Duplicates were removed. A further knockout was done on the title and the abstract and not applicable articles were eliminated. The remaining articles formed Search 1.

Correspondence and consultation with authors of journal articles identified in Stage 1 guided this author to additional articles not found in the data base search, or through a manual search in the UCT library.

Some full text journal articles identified in the search stages, where only the abstract was available, had to be accessed through inter-library loans and this was arranged by a UCT librarian.

The articles were examined to determine which of the found tools had been validated, and those which were not found to be validated were eliminated.

6.3.4. TABLE 1
KEYWORDS FOR STAGE ONE

Group 1 Dementia	Group 2 Screening tools
<ol style="list-style-type: none"> 1. Elder* OR 2. Geriatric* OR 3. Senior* OR 4. Confus* OR 5. Cognitive impairment OR 6. Palliat* OR 7. Disorientat* OR 8. Dementia OR 9. Capacity OR 10. Neuro cognitive deficit 	<ol style="list-style-type: none"> 1. Valid* dementia screen* tool* OR 2. Dementia screen* tool*

6.3.5. Search strategy

The search strategy followed a standardized format designed for Medline and adapted for the other databases used. The search strategy for all the databases used two groups of terms combined with AND: “dementia,” AND “screening tools”.

6.3.6. Inclusion/Exclusion Criteria

Inclusion criteria included: 1. Tools reported to include any of the following aspects of validity: face, content, criterion, construct, precision, responsiveness to change, sensitivity and specificity, 2. Tools that are used to screen dementia in an adult population, 3. Articles where the abstract was available, 4. Peer reviewed literature, 5. Human subjects and 6. Studies reported in English.

Exclusion criteria in the literature review were personal opinions, editorial and case studies, grey literature and the screening of children.

6.4. Stage 2

6.4.1. Aim

The aim of this systematic review is to identify validated dementia screening tools and of those to determine whether they have been validated in a palliative care population in sub-Saharan Africa.

6.4.2. Objective 2

To determine whether the tools identified in stage 1 have been validated in sub-Saharan Africa.

6.4.3. Method

The set of papers that remained at the end of PRISMA flowchart for stage 1 were used as the basis for stage 2. A search for validated sub-Saharan Africa dementia screening tools was done on Pubmed, Scopus and EBSCO using the set of articles from search 1, stage 1 with the word AND, and with the African countries (Sub Saharan Africa OR Africa OR Angola OR Benin OR Botswana OR Burkina Faso OR Burundi OR Cameroon OR Cape Verde OR Central African Republic OR Chad OR Comoros OR Congo OR Cote d'Ivoire OR Democratic Republic of the Congo OR Equatorial Guinea OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Guinea-Bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Soa Tome and Principe OR Segegal OR Seychelles OR Sierra Leone OR Somalia OR South Africa OR Swaziland OR Togo OR Uganda OR United Republic of Tanzania OR Zambia OR Zimbabwe) as listed in table 2 below. This formed Search 2 and all articles were printed.

The hard copy articles from correspondents and the UCT library were also assessed to determine if they had been validated in sub-Saharan Africa, and those not validated in sub-Saharan Africa were eliminated.

6.4.4. Search Strategy

To take the validated dementia screening tools found in stage 1 and do a new search with AND adding all the African countries listed below = Search 2. See table 2.

6.4.5. TABLE 2

KEYWORDS FOR SEARCH TWO

Search	Country
116 articles from search 1, stage 1, objective 1 combined with AND and the countries as listed in adjacent column.	Sub Saharan Africa OR Africa OR Angola OR Benin OR Botswana OR Burkina Faso OR Burundi OR Cameroon OR Cape Verde OR Central African Republic OR Chad OR Comoros OR Congo OR Cote d'Ivoire OR Democratic Republic of the Congo OR Equatorial Guinea OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Guinea-Bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Soa Tome and Principe OR Segegal OR Seychelles OR Sierra Leone OR Somalia OR South Africa OR Swaziland OR Togo OR Uganda OR United Republic of Tanzania OR Zambia OR Zimbabwe.

6.4.6. Inclusion/Exclusion Criteria

Inclusion criteria included: 1. Tools reported to include any aspect of validity in a sub-Saharan African country, 2. Tools used to screen dementia in an adult population, 3. Articles where the abstract was available, 4. Peer reviewed literature, 5. Human subjects and 6. Studies reported in English.

Exclusion criteria in the literature review were personal opinions, editorial and case studies, grey literature, screening tools that are not validated and the screening of children.

6.5. Stage 3

6.5.1. Aim

The aim of this systematic review is to identify validated dementia screening tools and of those to determine whether they have been validated in a palliative care population in sub-Saharan Africa.

6.5.2. Objective 3

To determine if the tools validated in sub-Saharan Africa have been validated in a palliative care population.

6.5.3. Method

All hard copies generated from stage 2 were screened to determine if they had been validated in a palliative care population in line with definition 3 in the Methods section.

6.5.4. Search Strategy

Each article was accessed, duplications were eliminated, a hard copy was printed and read and thereby each article was evaluated for the inclusion/exclusion criteria.

6.5.5. Inclusion/Exclusion Criteria

Inclusion criteria included: 1. Tools reported to include any aspect of validity in a palliative care population in sub-Saharan Africa, 2. Peer reviewed literature, 3. Human subjects and 4. Studies reported in English.

Exclusion criteria in the literature review were personal opinions, editorial and case studies, grey literature, screening tools that have not been validated, and the screening of children.

7. Results

7.1. Stage 1

7.1.1. Global Dementia Screening Tools

The objective in stage 1 was to identify available validated dementia screening tools found on specialized databases. The Pubmed database yielded 58 results of which 1 was a duplicate, 11 were knocked out by title, and 21 were knocked out by abstract, giving a final total of 25 articles. Scopus returned 21 results of which none were duplicates, 7 were knocked out by title, 3 were knocked out by abstract. From Scopus 11 remained. The EBSCO database includes Africa-Wide Information, CINAHL, MEDLINE and PsychINFO. These produced 126 results of which 31 were duplicates, 18 were knocked out by title, and 15 were knocked out by abstract.

The final EBSCO total was 62 articles.

The total article count from the electronic databases was 98.

Eighteen additional articles referenced in the primary database search were sourced from Google Scholar, hand searching, the reference lists of reviewed articles, Google Search and email communications with authors of journal articles. Although Google is considered to be a generalized search engine, for the purpose of this study it was found to be beneficial in accessing some journal articles and hard-copies of screening tools.

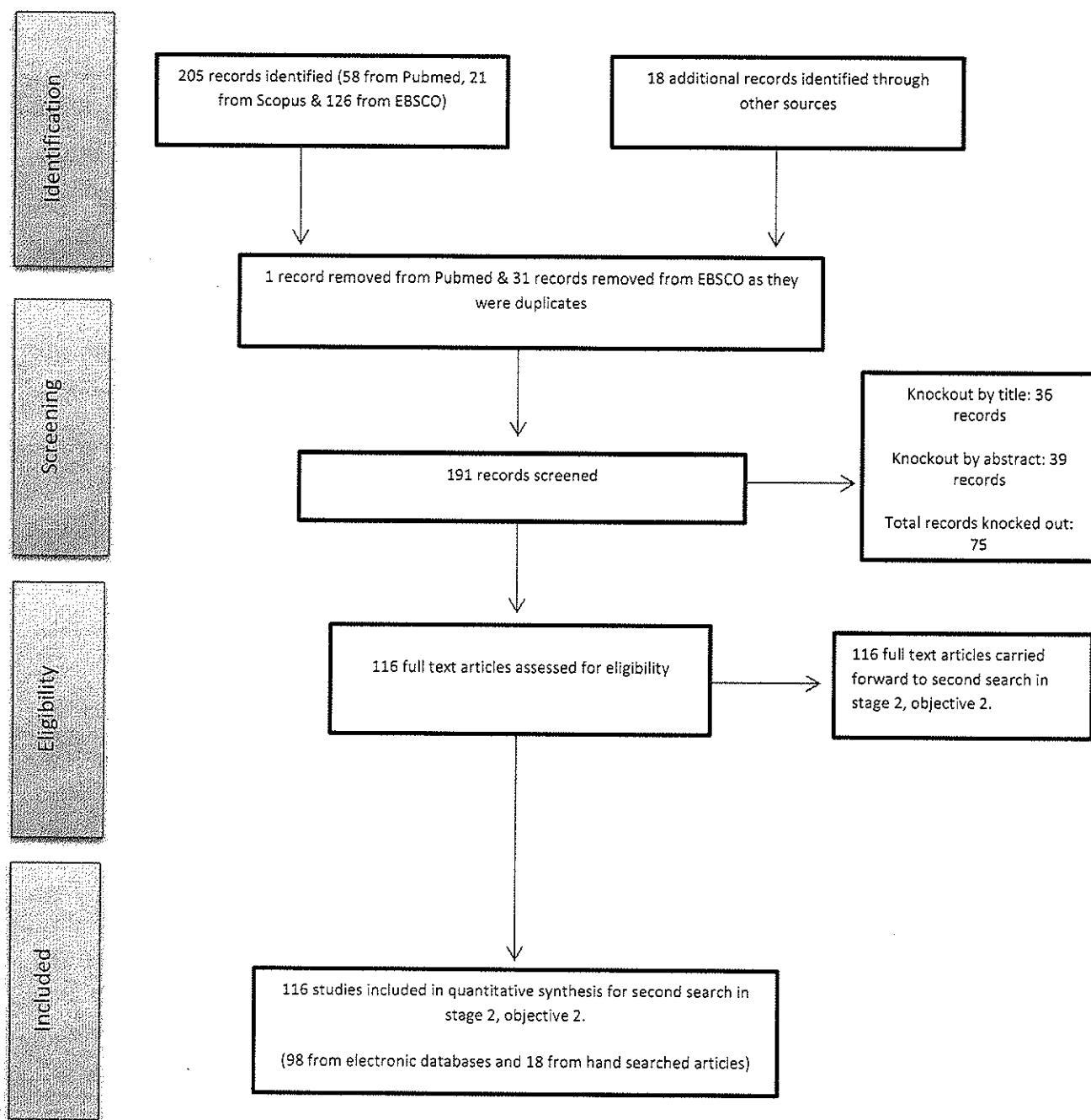
The total article count at this stage was 116 documents.

7.1.2. Results of Stage 1, Objective 1

Objective: Identify which validated dementia screening tools are available

PRISMA 2009 FLOW CHART (34)

October 2013



7.1.3. TABLE 3

SUMMARY OF DEMENTIA SCREENING TOOLS REVIEWED

Alphabetically by Name of Tool

Abbreviation	Name of Tool	Country	Administration Time (min)	Source Ref	Sensitivity (%)	Specificity (%)
ABCS	AB Cognitive Screen	Ontario	3-5	Molloy (5)	79	86
AMT	Abbreviated Mental Test	Australia	5	Hodkinson (5) Brodaty (36)	100	82
ACE-R	Addenbrooke's Cognitive Examination – Revised	UK	16	Mioshi (5)	88	100
AD8	AD8	USA	3 - 5	Yuan-Han Yang (37) Holsinger (38)	85	86
BAS	Brief Alzheimer Screen	USA	<5	Mendiondo (5)	87	99
CAMCOG	Cambridge Cognitive Examination	UK	15 - 45	Nunes (39)	81	88
CDT	Clock Drawing Test	Australia Nigeria	2	Sunderland (5) Brodaty (36)	76	81
CASI	Cognitive Abilities Screening Instrument	Japan USA	15 - 20	Teng (5)	89	90
CAST	Cognitive Assessment Screening Test	USA	15	Drachman (5)	95	88
CCSE	Cognitive Capacity Screening Examination	USA	10 - 15	Kaufman (5)	84	94
CSI "D"	Community Screening Interview for Dementia	Indianapolis	30	Holsinger (38) Boustani (40)	87	83.1
CANS-MCI	Computer-Administered Neuropsychological Screen for Mild	USA	60	Tornatore (41)	76.2	71.9
DQ	Dementia Questionnaire	USA	20 20 - 30	Silverman (5) Holsinger (38) Ellis (42)	92.8	89.5
DemTect	DemTect	Germany	8 - 10	Kalbe (43)	100	92
DECO	Deterioration Cognitive Observee	South Africa	10 - 18	Ritchie (5) Lenger (44)	90	89
FOME	Fluid Object Memory Evaluation	Hong Kong	Not reported	Chung (45) Ho, Shuk-kuen (46)	93	82
GPCOG	General Practitioner Assessment of Cognition	UK	5	Brodaty (5, 36)	85	86

Abbreviation	Name of Tool	Country	Administration Time (min)	Source Ref	Sensitivity (%)	Specificity (%)
HDS	HIV Dementia Scale	USA	Not reported	Sacktor (47)	80	91
HVLT	Hopkins Verbal Learning Test	USA	10	Brandt (5)	96	80
IQCODE	Informant Questionnaire on Cognitive Decline in the Elderly	Australia	10-12	Jorm (5)	90	95
IQCODE-SF	Informant Questionnaire on Cognitive Decline in the Elderly – Short Form	Australia	<10	Jorm (5)	80	82
IHDS	International HIV Dementia Scale	USA South Africa Yaoundé— Cameroon	6 - 8	Sacktor (47) Joska (48) Njamshi (49)	80	57
IST	Isaacs Set Test	France	Not reported	Chopard (50)	74	84
MIS	Memory Impairment Screen	USA	4	Buschke (5) Brodaty (36)	80	96
MAT	Mental Alternation Test	UK	Not reported	Brodaty (36)	95	81
MDS-COGS	Minimum Data Set Cognition Scale	North Carolina	3 - 4	Zimmerman (51)	94	94
Mini-Cog	Mini-Cog	USA	3 - 4	Borson (5, 52) Brodaty (36)	76	89
MMSE	Mini-Mental State Examination	USA	8 - 13	Folstein (5) Brodaty (36)	69	89
MCAS	Minnesota Cognitive Acuity Screen	USA	<20	Knopman (5, 53)	97.3	100
3MS	Modified Mini-Mental State Examination	USA	10 – 15	Teng (5)	86	87
WORLD	Modified World Test	USA	1	Leopold (5)	85	88
Mont	Montpellier Screen	France	6 - 10	Artero (5)	77.3	75.2
MoCA	Montreal Cognitive Assessment	USA	10	Holsinger (38) Luis (54)	96	95
NCSE	Neurobehavioral Cognitive Status Examination (also known as Cognistat)	USA	10-20	Kieman (5)	75	90
R-CAMCOG	Rotterdam Version of the Cambridge Cognitive Examination	Netherlands	10	De Koning (5)	83	78

Abbreviation	Name of Tool	Country	Administration Time (min)	Source Ref	Sensitivity (%)	Specificity (%)
RUDAS	Rowland Universal Dementia Assessment Scale	Australia	Not reported	Brodaty (36)	89	98
SIQ	Short Informant Questionnaire on Cognitive Decline in the Elderly	UK	Not reported	Brodaty (36)	79	82
SASSI	Short and Sweet Screening Instrument	USA	10-15	Belle (5) Brodaty (36)	94	91
S-OMC	Short Orientation Memory Concentration Test (Also known as 6-CIT & Short Blessed Test)	USA	5	Katzman (5) Brodaty (36)	79	100
SPMSQ	Short Portable Mental Status Questionnaire	Nebraska	5	Pfeiffer (5)	74	79
STMS	Short Test of Mental Status	Rochester	5	Kokmen (5) Brodaty (36)	92	91
SIS	Six Item Screener	Indianapolis USA	5	Callahan (5, 55)	88.7	88
TICS-M	Telephone Interview of Cognitive Status – Modified	USA	5 - 10	Breitner (5) Cook (56)	82.4	87
TYM	Test Your Memory	UK South Africa	Not reported	Hancock (57) van Schalkwyk G (58)	73	88
BNCS	The Brief NeuroCognitive Screen	USA	15	Ellis (42)	65	72
ECAQ	The Elderly Cognitive Assessment Questionnaire	Singapore	Not reported	Kua (59)	85.3	91.5
3WR	Three Word Recall	USA	3-4	Kuslansky (5)	65	85
T&C	Time and Change	USA	1	Froehlich (5) Brodaty (36)	63	96
VFC	Verbal Fluency- Categories	USA	3	Isaacs (5)	88	96
WCFT	Weigl Colour-Form Sorting Test	UK	<3	Hobson (60)	83.3	94.1
7MS	7-Minute Screen	Vermont	7-15	Solomon (5) Brodaty (36)	92	96

7.2. Stage 2

7.2.1. Validated Sub-Saharan Africa Dementia Screening Tools

The objective in stage 2 was to determine whether the tools identified in stage 1 had been validated in the 46 countries encompassing sub-Saharan Africa, namely Africa, Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cape Verde, Central African Republic, Chad, Comoros, Congo, Cote d'Ivoire, Democratic Republic of the Congo, Equatorial Guinea, Eritrea, Ethiopia, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mozambique, Namibia, Niger, Nigeria, Rwanda, Soa Tome and Principe, Segegal, Seychelles, Sierra Leone, Somalia, South Africa, Swaziland, Togo, Uganda, United Republic of Tanzania, Zambia and Zimbabwe.

Pubmed listed the following 4 results:

1. The sensitivity and specificity of subjective memory complaints and the subjective memory rating scale, deterioration cognitive observee, mini-mental state examination, six-item screener and clock drawing test in dementia screening. Ramlall S, Chipps J, Bhigjee A.I and Pillay B.J., *Dement Geriatr Cogn Disord*. 2013;36(1-2):119-35. doi: 10.1159/000350768. Epub 2013 Jul 12.
2. Validity of an interviewer-administered patient health questionnaire-nine to screen for depression in HIV-infected patients in Cameroon. Pence B.W, Gaynes B.N, Atashili J, O'Donnell J.K, Tayong G, Katz D, Whetten R, Whetten K, Njamnshi A.K and Ndumbe P.M., *J Affect Disord*. 2012 Dec 20;143(1-3):208-13. doi: 10.1016/j.jad.2012.05.056. Epub 2012 Jul 27.
3. A brief dementia screener suitable for use by non-specialists in resource poor settings – the cross-cultural derivation and validation of the brief Community Screening Instrument for Dementia. Prince M, Acosta D, Ferri C.P, Guerra M, Huang Y, Jacob K.S, Llibre Rodriguez J.J, Salas A, Sosa A.L, Williams J.D and Hall K.S., *Int J Geriatr Psychiatry*. 2011 Sep;26(9):899-907. doi: 10.1002/gps.2622. Epub 2010 Dec 28.

4. Comparison of the clock test and a questionnaire-based test for screening for cognitive impairment in Nigerians. VanderJagt D.J, Ganga S, Obadofin M.O, Stanley P, Zimmerman M, Skipper B.J and Glew R.H., *West Afr J Med*. 2006 Jul-Sep;25(3):212-8.

EBSCO listed 8 results of which three were duplicates; the remaining 5 were:

1. Screening for HIV-Associated Dementia in South Africa: Potentials and Pitfalls of Task-Shifting. Robbins R.N, Remien R.H, Mellins C.A, Joska J.A and Stein D.J., *AIDS Patient Care STDS*. 2011 Oct;25(10):587-93. doi: 10.1089/apc.2011.0154. Epub 2011 Sep 15.
2. Risk factors for HIV-associated neurocognitive disorders [HAND] in sub-Saharan Africa: the case of Yaoundé-Cameroon. Njamnshi A.K, Zoung-Kanyi Bissek A.C, Ongolo-Zogo P, Tabah E.N, Lekoubou A.Z, Yepnjio F.N, Fonsah J.Y, Kuate C.T, Angwafor S.A, Dema F, Njamnshi D.M, Kouanfack C, Djientcheu V de P, Muna W.F.T and Kanmogne G.D., *J Neurol Sci*. 2009 Oct 15;285(1-2):149-53. doi: 10.1016/j.jns.2009.06.043. Epub 2009 Jul 24.
3. The utility of a rapid screening tool for depression and HIV dementia amongst patients with low CD4 counts - A preliminary report. Singh D, Sunpath H, John S, Eastham L and Gouden R., *Afr J Psychiatry (Johannesbg)*. 2008 Nov;11(4):282-6.
4. The International HIV Dementia Scale is a useful screening tool for HIV-associated dementia/cognitive impairment in HIV-infected adults in Yaoundé—Cameroon. Njamnshi A.K, de Paul Djientcheu V, Fonsah J.Y, Yepnjio F.N, Njamnshi D.M and Muna W.F., *J Acquir Immune Defic Syndr*. 2008 Dec 1;49(4):393-7.
5. A cross-sectional study of quality of life in incident stroke survivors in rural northern Tanzania. Howitt S.C, Jones M.P, Jusabani A, Gray W.K, Aris E, Mugusi F, Swai M and Walker R.W., *J Neurol*. 2011 Aug;258(8):1422-30. doi: 10.1007/s00415-011-5948-6. Epub 2011 Feb 19.

Of the eighteen additional articles mentioned in 7.1.1., only 3 remained which represented sub-Saharan Africa. They were:

1. The International HIV Dementia Scale: a new rapid screening test for HIV dementia, by Sacktor N.C, Wong M, Nakasujja N, Skolasky R.L, Selnes O.A, Musisi S, Robertson K,

McArthur J.C, Ronald A and Katabira E, AIDS. 2005 Sep 2;19(13):1367-74, was included because the study focused on sub-Saharan Africa and in particular Uganda.

2. Validity of the International HIV Dementia Scale in South Africa by Joska J.A, Westgarth-Taylor J, Hoare J, Thomas K.G.F, Paul R, Myer L and Stein D.J, AIDS Patient Care STDS. 2011 Feb;25(2):95-101. doi: 10.1089/apc.2010.0292. Epub 2011 Jan 7, was included because the study was conducted in South Africa on 283 HIV-infected individuals from three primary health care centers. Although this study was not conducted in a formalized palliative care setting, HIV is recognized as a disease which lends itself to palliative care.
3. Normative scores for a brief neuropsychological battery for the detection of HIV-associated neurocognitive disorder (HAND) among South Africans by Singh D, Joska J.A, Goodkin K, Lopez E, Myer L, Paul R.H, John S and Sunpath H, was included as the study was conducted at McCord Hospital in Durban South Africa and used the memory item of the IHDS (doi:10.1186/1756-0500-3-28).

From the remaining 12 studies, 2 were knocked out by abstract: Pubmed articles 2 and 3: "Validity of an interviewer-administered patient health questionnaire-nine to screen for depression in HIV-infected patients in Cameroon; Pence B.W, Gaynes B.N, Atashili J, O'Donnell J.K, Tayong G, Katz D, Whetten R, Whetten K, Njamnshi A.K and Ndumbe P.M" and "A brief dementia screener suitable for use by non-specialists in resource poor settings – the cross-cultural derivation and validation of the brief Community Screening Instrument for Dementia; Prince M, Acosta D, Ferri C.P, Guerra M, Huang Y, Jacob K.S, Llibre Rodriguez J.J, Salas A, Sosa A.L, Williams J.D and Hall K.S."

Ten studies remained. From Pubmed, study 1 was included because it was conducted in South Africa. Study 4 was included because the clock-test is a validated screening tool and the participants were Nigerians. From EBSCO study 1 was included as it was conducted in South Africa. EBSCO study 2 & 4 was included as the International HIV Dementia Scale is a validated tool and the study was conducted in Cameroon. EBSCO study 3 as it was written by a South African doctor and EBSCO study 5 was included as the study was conducted in Tanzania.

The following three additionally sourced articles were included:

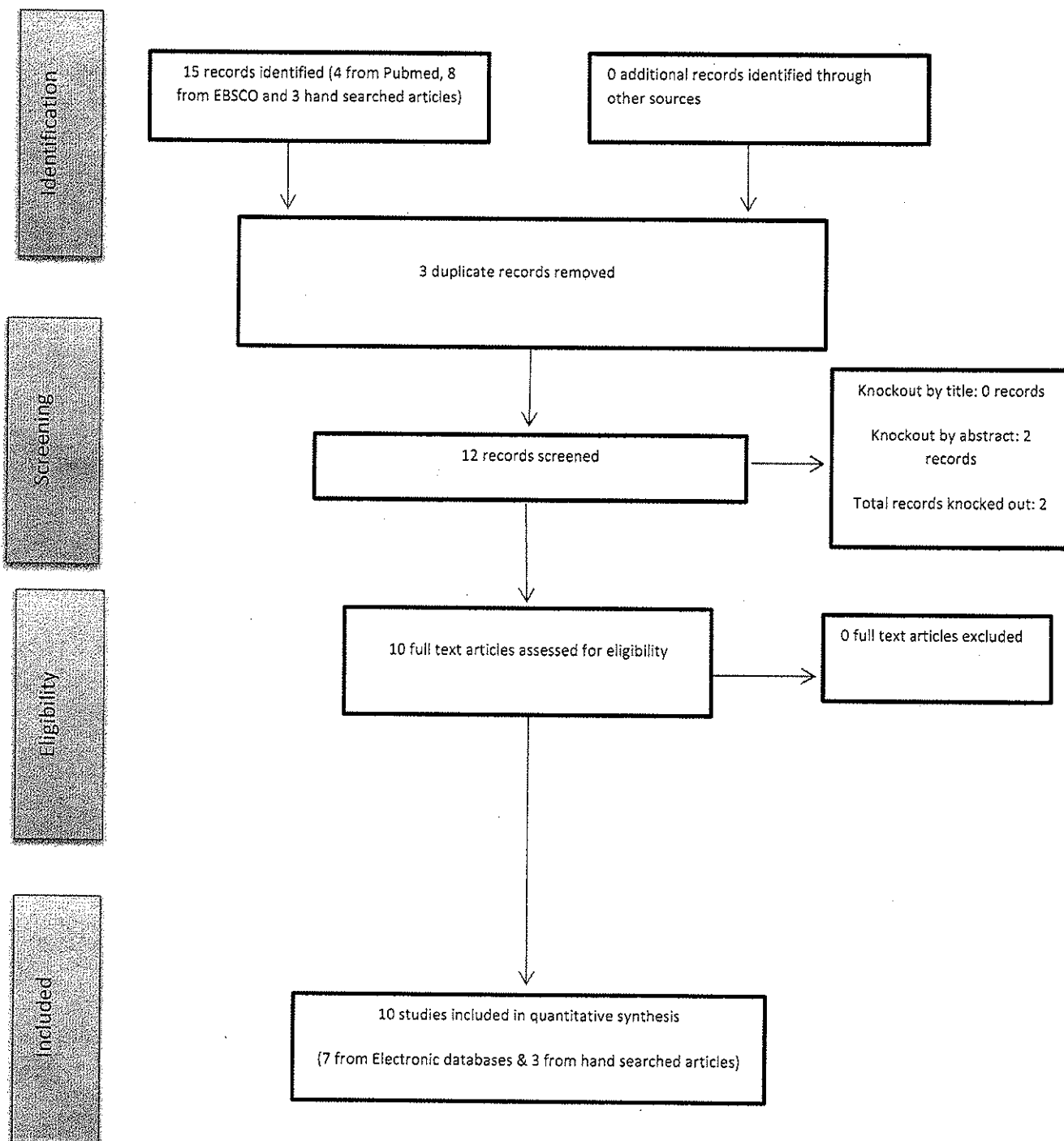
1. The International HIV Dementia Scale: a new rapid screening test for HIV dementia, by Sacktor N.C, Wong M, Nakasujja N, Skolasky R.L, Selnes O.A, Musisi S, Robertson K, McArthur J.C, Ronald A and Katabira E, was included because the study focused on sub-Saharan Africa and in particular Uganda.
2. Validity of the International HIV Dementia Scale in South Africa by Joska J.A, Westgarth-Taylor J, Hoare J, Thomas K.G.F, Paul R, Myer L and Stein D.J, was included because the study was conducted in South Africa on 283 HIV-infected individuals from three primary health care centers. Although this study was not conducted in a formalized palliative care setting, HIV is recognized as a disease which lends itself to palliative care.
3. Normative scores for a brief neuropsychological battery for the detection of HIV-associated neurocognitive disorder (HAND) among South Africans by Singh D, Joska J.A, Goodkin K, Lopez E, Myer L, Paul R.H, John S and Sunpath H, was included as the study was conducted at McCord Hospital in Durban South Africa and used the memory item of the IHDS.

7.2.2. Results of Stage 2, Objective 2

Objective: Determine and identify those tools which have been validated in sub-Saharan Africa

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7.3. Stage 3

The objective in stage 3 was to determine whether the 10 studies identified in stage 2 had reported on tools that had been validated for use in a palliative care population.

EBSCO study 5, "A cross-sectional study of quality of life in incident stroke survivors in rural northern Tanzania. Howitt S.C, Jones M.P, Jusabani A, Gray W.K, Aris E, Mugusi F, Swai M and Walker R.W" was eliminated by title as the target population in the article was stroke patients which are not a palliative care population.

Pubmed study 1, "The sensitivity and specificity of subjective memory complaints and the subjective memory rating scale, deterioration cognitive observee, mini-mental state examination, six-item screener and clock drawing test in dementia screening, by Ramlall S, Chipps J, Bhigjee A.I and Pillay B.J.", was eliminated because the study was conducted in a residential facility for the aged which is not a recognized palliative care population.

Pubmed study 4, "Comparison of the clock test and a questionnaire-based test for screening for cognitive impairment in Nigerians. VanderJagt D.J, Ganga S, Obadofin M.O, Stanley P, Zimmerman M, Skipper B.J and Glew R.H", was eliminated because the 54 men and 12 women participants in the study were cared for in a tertiary care center located in Jos, Nigeria. The study does not state if the participants were suffering from life limiting or life threatening disease.

The following two articles from EBSCO were not included as no validity data was established in stage 3:

1. Screening for HIV-Associated Dementia in South Africa: Potentials and Pitfalls of Task-Shifting. Robbins R.N, Remien R.H, Mellins C.A, Joska J.A and Stein D.J. Although the study was conducted on Xhosa speaking black South Africans who were HIV-positive from a medical clinic in the Western Cape region of South Africa, it was recommended to validate the IHDS's performance against a gold standard neurocognitive battery for the detection of HAD among larger samples of Xhosa-speaking South Africans with ART adherence difficulties.

2. The utility of a rapid screening tool for depression and HIV dementia amongst patients with low CD4 counts - A preliminary report. Singh D, Sunpath H, John S, Eastham L and Gouden R. Although it was conducted on 20 HIV-positive, ARV naïve patients at McCord Hospital in Durban, South Africa it was recommended that a larger study is required to validate the IHDS in South Africa.

The following additionally sourced article was not included in stage 3:

1. Normative scores for a brief neuropsychological battery for the detection of HIV-associated neurocognitive disorder (HAND) among South Africans by Singh D, Joska J.A, Goodkin K, Lopez E, Myer L, Paul R.H, John S and Sunpath H; although the study was conducted at McCord Hospital in Durban South Africa it only used the memory item of the IHDS. (Only the memory item of the International HIV Dementia Scale (IHDS) was used in conjunction with the Trail-Making Test (Parts A and B) and the Digit Span Test [Forward (DSF) and Backward (DSB). These two neuropsychological tests can be administered with the IHDS in busy antiretroviral clinics).

EBSCO study 4, “The International HIV Dementia Scale is a useful screening tool for HIV-associated dementia/cognitive impairment in HIV-infected adults in Yaoundé—Cameroon. Njamnshi A.K, de Paul Djientcheu V, Fonsah JY, Yepnjio F.N, Njamnshi D.M and Muna W.F.” was included as the study was conducted on HIV-positive adults in an HIV outpatient clinic.

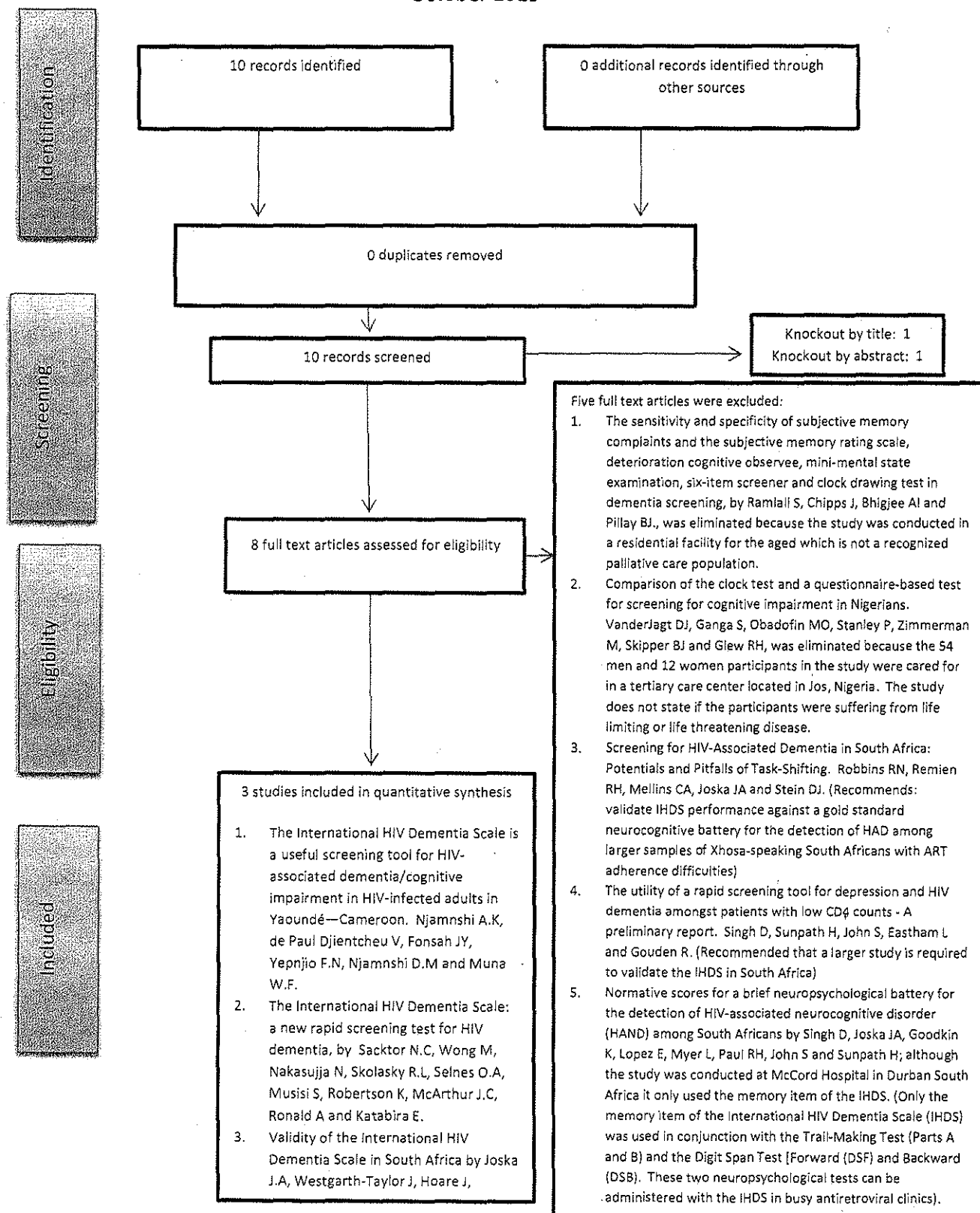
The following two additionally sourced articles from stage 1, objective 1 were included:

1. The International HIV Dementia Scale: a new rapid screening test for HIV dementia, by Sacktor N.C, Wong M, Nakasujja N, Skolasky R.L, Selnes O.A, Musisi S, Robertson K, McArthur J.C, Ronald A and Katabira E, was included because the study focused on sub-Saharan Africa and in particular Uganda.
2. Validity of the International HIV Dementia Scale in South Africa by Joska J.A, Westgarth-Taylor J, Hoare J, Thomas K.G.F, Paul R, Myer L and Stein D.J, was included because the study was conducted in South Africa on 283 HIV-infected individuals from three primary health care centers. Although this study was not conducted in a formalized palliative care setting, HIV is recognized as a disease which lends itself to palliative care.

7.3.1. Results of Stage 3, Objective 3

Objective: To determine of those tools validated in sub-Saharan Africa, which have been validated in a palliative care population

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Stage 3 identified one dementia screening tool represented in 3 articles. The International HIV Dementia Scale has been validated in sub-Saharan Africa although not in a recognized palliative care population. The results of stage 3, search 3 can be seen in table 4 below.

7.3.2. TABLE 4

DEMENTIA SCREENING TOOLS VALIDATED IN SUB-SAHARAN AFRICA FOUND IN SEARCH 3

Name of Tool	Article Name	Publication Journal	Country	Population	Validated in a Palliative Care Population or not
International HIV Dementia Scale (IHDS)	The International HIV Dementia Scale is a useful screening tool for HIV-associated dementia/cognitive impairment in HIV-infected adults in Yaoundé—Cameroon. Njamnshi AK, de Paul Djientcheu V, Fonsah JY, Yepnjio FN, Njamnshi DM and Muna WF.	J Acquir Immune Defic Syndr. 2008 Dec 1;49(4):393-7	Yaoundé—Cameroon	HIV-positive adults used as cases and HIV-negative individuals used as controls. HIV-positive adults followed up in an HIV outpatient clinic were matched to HIV-negative subjects for age and sex and screened using IHDS.	No
	The International HIV Dementia Scale: a new rapid screening test for HIV dementia, by Sacktor NC, Wong M, Nakasujja N, Skolasky RL, Selnes OA, Musisi S, Robertson K, McArthur JC, Ronald A and Katabira E, was included because the study focused on sub-Saharan Africa and in particular Uganda.	AIDS. 2005 Sep 2;19(13):1367-74	Uganda	Sixty-six HIV-positive individuals in the US and 81 HIV-positive individuals in Uganda	No
	Validity of the International HIV Dementia Scale in South Africa by Joska JA, Westgarth-Taylor J, Hoare J, Thomas KGF, Paul R, Myer L and Stein DJ, was included because the study was conducted in South Africa on 283 HIV-infected individuals from three primary health care centers. Although this study was not conducted in a formalized palliative care setting, HIV is recognized as a disease which lends itself to palliative care.	AIDS Patient Care STDS. 2011 Feb; 25(2):95-101. doi: 10.1089/apc.2010.0292. Epub 2011 Jan 7	South Africa	96 HIV-positive individuals who had not received ART and who were attending primary care HIV clinics. The validity of the IHDS was established using a receiver operating characteristic (ROC) analysis.	No

8. Discussion

The aim of this systematic review was to identify validated dementia screening tools available and of those to determine whether they had been validated in a palliative care population in sub-Saharan Africa.

Dementia is a global health priority (6). The prevalence is estimated to double every 20 years (6). Dementia screening tools are a useful primary method in clinical and other settings for making the initial diagnosis of dementia (6).

In stage 1, objective 1, 116 journal articles were identified in which dementia screening tools were discussed. Of these the more commonly used ones are The General Practitioner Assessment of Cognition (GPCOG) as it is a quick efficient test that can make use of informant information as well if it is available, the Mini-Cog which is composed of a three item recall and Clock Drawing Test and is known as an effective routine screening test for use in primary care, The Memory Impairment Screen (MIS) which is a four-item delayed free and cued recall test of memory impairment thereby providing reliable and valid screening for dementia, The Rowland Universal Dementia Assessment Scale (RUDAS) as it is a simple screening tool that tests multiple cognitive domains and appears unaffected by gender, years of education and cultural fairness, The Montreal Cognitive Assessment (MoCA) which is characterized by high sensitivity and specificity for detecting mild cognitive impairment and The Clock Drawing Test which has been suggested to be a useful adjunct to the MMSE as it is quick and simple to use and detects cognitive impairment by testing visuo-constructive ability, executive function and numerical and verbal memory.

Of the identified 51 dementia screening tools listed in Table 3, the Mini-Mental State Examination (MMSE) is one of the most commonly used screening tools and is often used as a gold standard. It assesses skills such as reading, writing, orientation and short-term memory. There is considerable evidence that supports the validity and reliability of the MMSE and it has been popular for more than 30 years (61).

According to Nieuwenhuis-Mark the MMSE has certain advantages and disadvantages (61). In favour of the MMSE is the fact that it is used internationally and has been translated into many different languages, anyone can administer it, there is one score, general cognitive ability is measured, administration time is quick, it is widely available and it is believed that the MMSE's psychometric properties are of a good standard (61). On the negative side, Nieuwenhuis-Mark reports that the "translations into different languages is not always effective, inter-rater reliability may not be stable, the scores can be influenced by the tester as well as the setting, there may be limited differential diagnosis due to heavy reliance on language and memory, scores can be affected by variables such as age and education as norms are not always available in all countries, and in the opinion of General Practitioners it is not quick to administer" (61).

8.1. Global Perspective

Cullen et al state that there is: "(the) lack of robust evidence to support the many screening tests (for cognitive impairment) available" (5). They found that although there are many screening tests, few have been validated for use in their intended populations (5). Also, no universal test exists for cognitive screening and so many specialized tools have been developed (5). Their study focused on 39 tests (5). From these, they found that few had been validated in the target populations for screening (5). Significantly, they found that although there were screens validated for use in particular subtypes of dementia, these tools were not necessarily useful for differential diagnosis (5).

He further states that many of the tests developed so far have concentrated on memory dysfunction, while neglecting aspects such as language, praxis, or executive function and may be based on a "cut-off score" rather than indicating a reference range of dysfunction (5). This method also runs contrary to regular clinical practice where diagnoses of dementia are made on observation and assessment over a period of time (5).

8.2. The Sub-Saharan Africa Perspective

8.2.1. HIV in Sub-Saharan Africa

Only 1 dementia screening tool has been validated in sub-Saharan Africa, namely the International HIV Dementia Scale (IHDS).

HIV-Associated dementia is a common neuropsychiatric complication of AIDS, affecting upwards of 20% of HIV infected individuals (62). This translates numerically into a large patient basis of people suffering from dementia and therefore is the reason why a validated dementia screening tool in sub-Saharan Africa for HIV associated dementia is important (62).

One in three people with HIV/Aids in SA will develop HIV/Aids dementia complex (7). This is a significant problem that needs urgent attention and with a good and reliable assessment method a correct diagnosis will be able to make a difference in the person's life (7).

8.2.2. The Elderly Population in Sub-Saharan Africa

Ramlall et al state that the second largest elderly population in sub-Saharan Africa is found in South Africa (63). In 1996 the population was statistically evaluated to contain 7.1% of people aged 60 years and older (63). This has been projected to increase to 8.4% in 2014 (63). With such high statistical data, there are significant health and economic burdens that are posed by dementia not only on the society at hand but also on the elderly (63). They further report that there were three demographical variables that influenced the performance of the measures used in their study, namely race, age and years of education (63).

An aging population and an increasing population resulting from decreased mortality and morbidity from communicable diseases such as tuberculosis, malaria, and HIV/AIDS will result in an increase in dementia with a concurrent increase in the burden on health services in sub-Saharan Africa (64). Dementia is an incurable disease but early diagnosis means that effective management can begin timeously which will improve the quality of life of dementia sufferers and will also decrease the burden of disease on sufferers, carers and healthcare providers (64).

The elderly in sub-Saharan Africa are often not expected to perform the particular complex functional tasks that similarly aged people in high-income countries carry out (64). Instead, in

sub-Saharan Africa, where the elderly often live in extended families where youngsters are expected to assist in many of the general daily tasks of the home, the cognitive decline becomes less apparent and therefore less of a burden (64).

8.2.3. The DSM-IV Criteria

Different diagnostic systems can yield vastly different prevalence rates (64). For instance the correlation between dementia and education using the 10/66 criteria in rural sub-Saharan Africa could be a genuine effect or it could be the result of an educational bias inherent in the diagnostic instrument (64). The DSM-IV criterion is a recognized international standard for dementia diagnosis although this system too has its own faults (64). Despite these possible faults, the DSM-IV criteria represent an international standard for dementia diagnosis (64). The age-standardized prevalence of clinical DSM-IV dementia was found to be 6.4% (95% confidence interval [CI] 4.9–7.9%) and that of '10/66 dementia' was 21.6% (95% CI 17.5–25.7%) (64). Education was a significant forecaster of '10/66 dementia', but not of DSM-IV dementia (64). The 10/66 diagnostic criteria may however be more appropriate when identification of early and mild cognitive impairment is required and is therefore viewed as the optimal choice (64).

There is a lack of accord of which diagnostic system best suits the populations of sub-Saharan Africa and this hinders the detection of dementia (64). Because different diagnostic systems are used, there are widely varying rates of dementia prevalence; by example, in urban Nigeria the prevalence rates of dementia in the over 65 year old population varies from 2.3% - 10.1% (64).

The current global gold standard of dementia diagnosis is the DSM-IV criteria (64). It is important to note however that this system was developed in high-income countries (64). Questions have been raised regarding its clinical application in developing countries because it requires the presence of a functional impairment for diagnosis to be made (64).

According to Natalie Muth the limitations of the DSM-IV create labels for individual's diagnosed making use of the DSM-IV criteria and this in turn creates the possibility of discrimination and stigmatization toward the diagnosed disease (65). It was found that many of the criteria used to diagnose DSM-IV disorders showed a lack of predictive validity due to the system not being

linked to treatment outcomes in each instance (65). As the criteria were found not always to be reliable the test-retest reliability was influenced (65).

8.3. The Sub-Saharan Africa Palliative Care Setting Perspective

No validated dementia screening tools were found in sub-Saharan Africa in a palliative care population as defined under the methods section point number 3.

The International HIV Dementia Scale has been validated in Uganda by Joska et al on eighty-one HIV positive individuals. Although the scale was not validated in a palliative care setting, HIV can be regarded as a palliative care condition.

In Yaoundé—Cameroon, the IHDS was administered to assess its usefulness at a Day Care Hospital's HIV outpatient clinic, and although this is not a palliative care setting, again HIV can be regarded as a palliative care condition.

9. Conclusion

9.1. What is the State of Evidence?

No single, all-encompassing, validated dementia screening tool was identified for use in a palliative care population in sub-Saharan Africa. The only validated tool identified in this region has been developed for use in HIV-associated dementia. No validated tool was identified for cancer patients and the elderly, a major component of the palliative care population.

A possible reason for the lack of a broadly applicable, validated dementia screening tool in sub-Saharan Africa, apart from the one developed for use in HIV-associated dementia, is that the healthcare approach for the elderly may be neglected in comparison to the huge current focus and financial input into HIV and its associated conditions.

Many screening tools for dementia have been developed in a first world setting but their applicability and validity to the sub-Saharan Africa setting has not been validated in the palliative care population.

This study identified only one tool, namely the IHDS. In 2008, Singh et al conducted a pilot study the IHDS for validation purposes for its use in HIV positive populations in South Africa (18). Although the sensitivity was 88% and the specificity was 50%, no firm conclusions were drawn and it was determined that there was a need to conduct a larger study to validate the International HIV Dementia Scale (IHDS) (18). Joska et al in 2011 subsequently validated the IHDS in South Africa (19).

The IHDS tool consists of the following components:

1. Memory registration (4 word repeated)
2. Motor speed (tap of the first two fingers of the non-dominant hand)
3. Psychomotor speed (hand clenching and 2 hand placements)
4. Memory recall (4 word recall from number 1)

Each component has a score. Patients with a score of ≤ 10 require further evaluation for possible dementia.

Robbins et al found that the IHDS meets the constraints of the South African context, can be administered cross-culturally by non-neurologists, is quick to administer, is not English language proficiency dependent and only requires the use of a timing device (17). The fact that the IHDS is largely motor focused reduces cultural bias but the motor focus predisposes it to being more sensitive in detecting subcortical dementias (17).

The potential risk of bias of the IHDS is noted by Robbins et al who found that in the South African setting there exists a large scale of difference in the training of community health care workers who administer and score the test, and a further discrepancy exists between the abilities of professional health care workers and lay community health care workers in administering the test (17). In particular researchers found that the risk of bias was increased by the community health care workers administering the test, who were seen to be offering subtle forms of encouragement such as head nods or hints, or who had difficulty in assessing the accuracy of the motor tests performed (17).

In the opinion of the author the IHDS has limited applicability. Due to the large motor component the test is more geared towards screening for subcortical dementia. There is a significant risk of bias especially if the test is performed by inadequately trained lay people. There are also practical limitations to administering the test to patients with physical disabilities such as arthritis or muscular atrophy.

Although the only validated tool found in sub-Saharan Africa is in the HIV population, there are internationally recognized gold standard tools such as the Mini-Mental State Examination.

However, this tool in its current state would have limited transferability to the sub-Saharan African region because of factors such as language variations, widely differing levels of education of both administrators and patients, and diverse socio-economic conditions.

9.2. What is the Current Situation Regarding Dementia Screening

Dementia is a progressive life limiting condition with increasing prevalence and complex needs. Palliative care needs of patients with dementia are often poorly addressed.

The wide impairment of mental function in dementia, including memory loss, language impairment, disorientation, personality changes, difficulties with activities of daily living and self-neglect, all indicate that a dementia screening tool for this population would be of great value in order to manage the patient within the holistic realm of palliative care.

In order to palliate people with dementia there needs to be a correct diagnosis thereof. A validated screening tool is the first step towards assisting this process.

While there are many dementia and cognitive impairment screening tests, their application in clinical settings is hampered by a lack of intensive testing and recognized validation in various populations (5).

In a study by Simon et al in which the aim was to facilitate pan-European collaboration to improve patient-reported outcome measures and end-of-life care, it was the recommendations from an international workshop held that a need exists for the standardization of a core set of tools in palliative care (66). The development of numerous scales in palliative care has resulted in a large number of tools being available of which were found to be used inconsistently (66). The international workshop further recommended that a multi-professional approach is required in the further development of tools as well as validation and adaption to a palliative care population (66).

That there are many tests is a reflection of the complexity and variability of cognitive impairment, with specific tools having been created to test for specific areas of impairment (5). A few tests however are recognized for scoring highly on both validity and content (5).

9.3. The Benefits of Screening for Dementia

As dementia is of a prolonged and progressive nature with complex needs, the patient and their family would certainly benefit from what a palliative care organization could offer them.

Palliative care encompasses physical, psychosocial and spiritual needs of a person through planning, treatment and evaluation by a multi-disciplinary team. The importance of diagnosing dementia within this population at an early stage allows the multi-disciplinary team to attend to

the individualized needs of the person as well as their family and enables the person to be assured of quality of life.

The Hospice Palliative Care Association South Africa states that “palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications” (67).

9.4. Limitations of this Study

Firstly, the literature search and data extraction was carried out solely by the author and therefore could be limited from that aspect.

Secondly, the literature search could have missed studies not cited in the target data sources or articles in which it was not clear from the abstract that a dementia screening tool was used, although to minimize this limitation the author corresponded with authors of some of the studies used in this research regarding the existence of additional articles.

Thirdly, professional organisations and quality institutions may have conducted research that has not been published in the scientific literature.

A major limitation identified is that, in the identified studies, there is a significant bias toward HIV-associated dementia with a concomitant paucity of articles regarding old age dementia and dementia caused by life threatening illnesses such as cancer.

A hand search is inherently limited by the searching proficiency of the author despite the intention to be as thorough as possible whilst following the principles as set out by PRISMA.

Any newly published journal articles that have become available since October 2013 will not be included in this study as the database search was conducted in September 2013.

Lastly, although all logical key word choices were covered, it is always possible that the key word choice was not extensive enough.

10. Recommendations

This study has shown a clear need for a validated dementia screening tool that can be broadly administered in a palliative care population in sub-Saharan Africa, a tool which is not only for use in HIV -associated dementia but also for disease progression caused dementia such as cancer and age related dementia.

10.1. The International HIV Dementia Scale

As a starting point there could be further research into the applicability of the IHDS for use in a broader perspective in a palliative care population in sub-Saharan Africa. It has drawbacks in terms of bias and there are challenges with using this tool in a generalized palliative care setting, but it has been validated and it has been used in HIV-associated dementia, and it is ideal for settings where resources may be limited.

The IHDS can therefore be used, either by administering it in its current form in a more generalized palliative care population to test whether the anticipated drawbacks which may occur in the more generalized population are valid, or for the development of a more broadly encompassing tool by further assessing and modifying the existing tool.

It is the author's opinion however that a tool, specific to the challenges of screening for dementia in a palliative care population in sub-Saharan Africa, needs to be developed. It might not be necessary to develop an entirely new tool as there is an internationally recognized gold standard tool, the Mini-Mental State Examination, which could be modified.

A benefit of modifying the existing MMSE is that it would still allow for collaboration with other researchers in the field around the world.

In its current form, some of the tasks included in the MMSE may pose challenges to patients who perhaps do not have the background education and skills needed to complete the tasks. However, it is possible to modify the tasks in such a way that the same cognitive abilities are tested without the need for certain education and linguistic standards, by example where the MMSE asks the patient to spell the word "world" backwards, South African patients could be rather asked to put 5 pictures of the last 5 presidents in backward order.

To further make the MMSE more culturally appropriate, in the component where the test subject is asked to repeat the phrase “no ifs, ands, or buts” it is possible to replace these words with a phrase common to the test population’s culture. Likewise where the MMSE require the test subject to be literate in order to perform written instructions or to write a sentence, the modified version could make use of pictures where the test subject has to follow instructions or verbalize what is seen.

Furthermore, for the MMSE to be applied in the sub-Saharan African setting it would need to be forward/back translated into the languages of intended use.

In conclusion, the author is recommending that an existing gold standard screening tool, the MMSE, needs to be adapted and developed for testing and subsequent use in a palliative care population in sub-Saharan Africa.

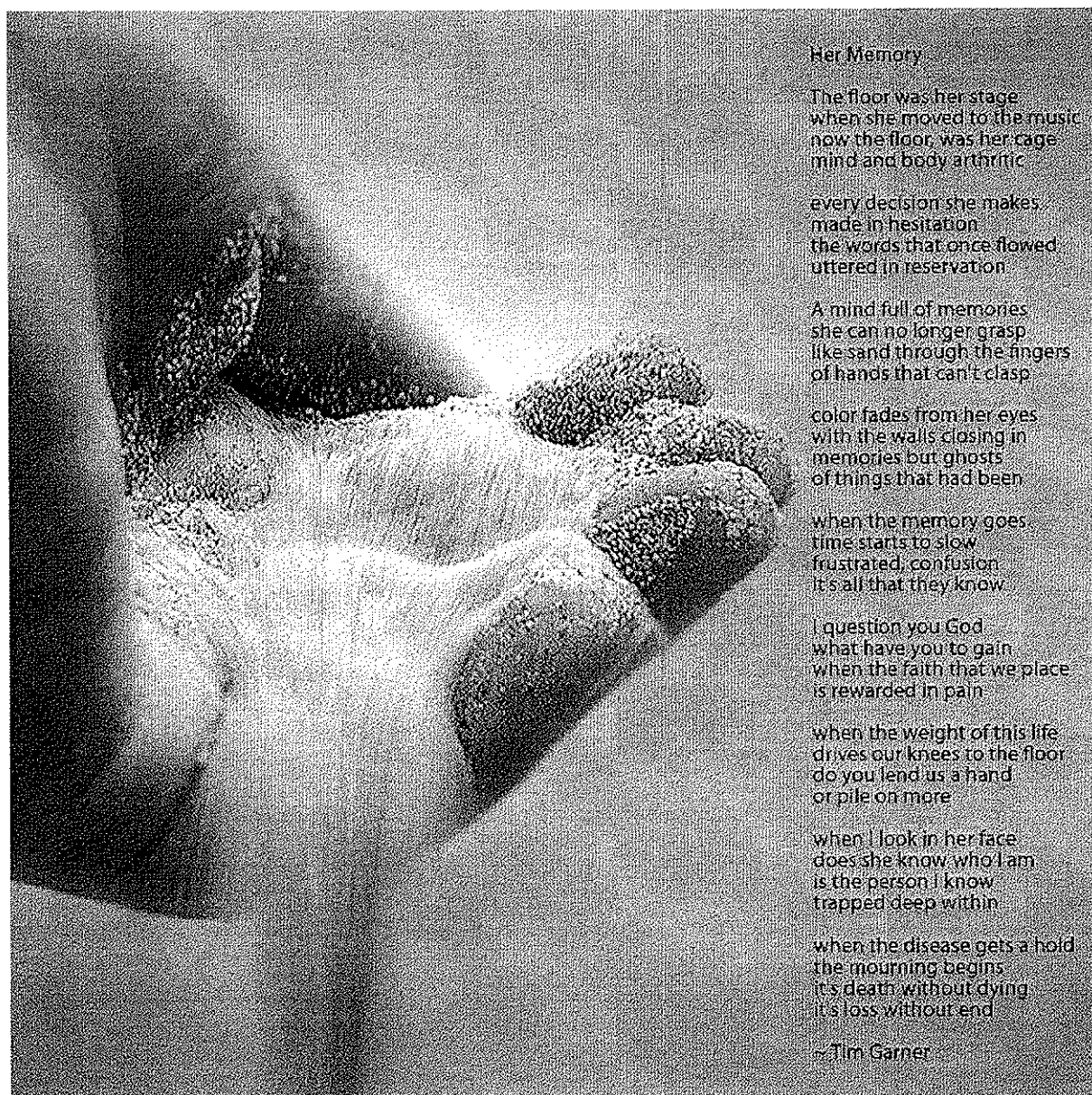
11. Dissemination of Findings

The findings of the study will be disseminated as follows:

- Written dissertation,
- Draft publication for submission to a peer-reviewed journal and
- Submission of an abstract for relevant conference presentations.

12. Funding

A Wolfson International Bursary Grant was awarded from Help the Hospices International Programme, London. They have my sincerest appreciation.



Her Memory

The floor was her stage
when she moved to the music
now the floor was her cage
mind and body arthritic

every decision she makes
made in hesitation
the words that once flowed
uttered in reservation

A mind full of memories
she can no longer grasp
like sand through the fingers
of hands that can't clasp

color fades from her eyes
with the walls closing in
memories but ghosts
of things that had been

when the memory goes
time starts to slow
frustrated, confusion
it's all that they know

I question you God
what have you to gain
when the faith that we place
is rewarded in pain

when the weight of this life
drives our knees to the floor
do you lend us a hand
or pile on more

when I look in her face
does she know who I am
is the person I know
trapped deep within

when the disease gets a hold
the mourning begins
it's death without dying
it's loss without end

~ Tim Garner

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25th August 2014

The Dissertation Committee
University of Cape Town

RE: MPHIL PALLIATIVE MEDICINE

It is with great appreciation that I thank you for appointing an internal examiner to review my dissertation submitted in January 2014 and subsequent decision to allow me to do corrections and not a re-submission.

I wish to thank the examiners for their valuable input, guidance and comments that have helped me to strengthen my dissertation. I believe that my corrected dissertation will meet your approval.

Please find attached my corrected dissertation, corrections list from comments made by all 3 examiners and the signed off corrections form from Professor Richard Harding.

Thanking you once again for allowing me to submit my corrections.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Suzanne Schneider', written in a cursive style.

Suzanne Eva Schneider
schsuz007

Submission of dissertation corrections/revisions - MPhil

Candidate:	Suzanne Eva Schneider
Degree:	MPhil Palliative Medicine
Department:	Family Medicine
Title:	Ms
Supervisors:	Dr Liz Gwyther & Prof Richard Harding

Internal Reviewer (UCT)

	Original dissertation		Corrected/Revised dissertation	
1	Comment 1, pg 1	Note that I did not see a PRISMA checklist included in the thesis, something which may have clarified in which ways the thesis used a systematic review methodology.		I have used the PRISMA flow charts which demonstrate the steps to include / exclude studies as per the PRISMA statement.
2	Comment 2, pg 2	The addition of Stage 4 is both inconsistent and unintegrated in terms of structure, and is very poorly conceived. It does not answer the question the student thinks it answers at all, and does not add anything to the thesis. It should be removed entirely.	Removed	This has been removed from the dissertation. Both external examiners commented on this as well in comment 6 from Julia Blitz and comment 7 from the UK examiner.
3	Comment 3, pg 2	I am not clear why they did a second search during Stage 2. Couldn't the question of geographic scope been answered by reading the studies themselves? A search in the database seems like it might unnecessarily drop articles as compared to a careful read-through.		Stage 2 was to determine if any of the validated tools found in stage 1 were validated in sub-Saharan Africa. Although the database may have dropped articles, I did search other sites and contacted Professors in the field to find all studies pertaining to finding validated dementia screening tools.
4	Comment 4, pg 2	I would recommend that the student and her supervisors respond to both examiners' reports, with the exception of the critique from the first examiner about this not being a systematic review, and that these revisions should be done to the satisfaction of the supervisors.		This has been done.

Examiner 1 – (Julia Blitz – Stellenbosch University)

Original dissertation		Corrected/Revised dissertation		
1	Comment 1, pg 1	The gold standard reference for screening are the USPSTF guidelines, available at http://www.uspreventiveservicestaskforce.org/uspstf14/dementia/dementiasaumm.htm Their finding is that screening for dementia is not recommended in the general population. In this case, the candidate needs to present an argument for why a dementia screening tool needs to be used in this particular population of palliative care patients.		I have included the importance of a screening tool for the palliative care population throughout my dissertation. I have stated that the global prevalence of dementia is on the increase, that dementia sufferers are part of the palliative care population, that being able to screen for dementia at an early stage will aid with the palliative care treatment should the person screen positive for dementia. I will not be referring to the USPSTF guidelines as these relate to the general population and not to the specific palliative care population which is the focus of the research.
2	Comment 2, pg 1	The candidate needs to make a clear argument for why HIV patients can be seen as similar to (representative of) palliative care patients for the purpose of this study. The search results may have been very different if HIV has been used as a search term.	Pg 13	I have added a new point numbered 3.7 and named "The Interface and Relevance of Palliative Care for People Living with HIV" which makes a clear argument as to the relevance between HIV and palliative care.
3	Comment 3, pg 1	The criteria of Wilson and Jungner are still upheld today as classics, the "gold standard of screening assessment", having stood well the test of time. Yet these criteria are not mentioned in determining the usefulness of dementia screening in palliative care patients.	Pg 17	Included. See point 3.10 "Why Screen for Dementia in a Palliative Care Population".
4	Comment 4, pg 2	This review does not have a specific research question – the aim is "to identify validated dementia screening tools..." A literature review is appropriate for achieving this aim.	Pg 3 & 6	"A SYSTEMATIC REVIEW TO DETERMINE WHETHER ANY VALIDATED DEMENTIA SCREENING

				<p>TOOLS EXIST FOR USE IN PALLIATIVE CARE POPULATIONS IN SUB-SAHARAN AFRICA.”</p> <p>The research question is therefore: “Do any validated dementia screening tools exist for use in palliative care populations in sub-Saharan Africa”</p> <p>The statement used at the beginning of the dissertation poses a question namely to determine what tools are available, which ones are validated, which ones have been validated for use in palliative care populations in sub-Saharan Africa.</p> <p>The question is posed on page 3 under point 2.1 and on page 6 under point 3.</p>
5	Comment 5, pg 2	It is unusual to exclude grey literature from a systematic review as the object is to ensure complete sourcing of all relevant literature.		I have excluded grey literature as I needed to identify validated tools. Validated tools have been peer reviewed and their psychometric properties have been established. The use of grey literature would not present me with the correct research I required.
6	Comment 6, pg 2	The study design (page 21) refers to three study stages, however on pages 27 and 42 the candidate refers to stage 4. The purpose of this stage and the method by which the objective of this stage may be reached is not clear.		Removed from the dissertation.
7	Comment 7, pg 2	The stage 2 results do not report which journals the 8 identified articles appeared in.	Pg 38, 39 & 40	Corrected.
8	Comment 8, pg 2	The candidate has missed the validation of the TYM in a South African population (primary care patients): van Schalkwyk G, Botha H, Seedat SJ. 2012. Comparison of 2 dementia screeners, the Test Your Memory Test and the Mini-Mental State Examination, in a primary care setting. Geriatr Psychiatry Neurol 5(2):85-8 doi: 10.1177/0891988712447895.	Pg 37	Corrected.

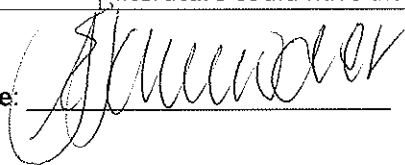
9	Comment 9, pg 2	There is no critical evaluation of the studies that were finally selected, particularly in terms of risk of bias.	Pg 3, 4 Pg 52 & 53	It was not part of the systematic review to analyse the validated tools found and have stated this in the dissertation. Risk of bias has been included.
10	Comment 10, pg 2	There is no summary of the strength of evidence for or against using the tool that the candidate sourced.	Pg 52 & 53	Done.
11	Comment 11, pg 2	In the discussion the candidate seems to use the terms screening and diagnosis interchangeably.		Corrected where required.
12	Comment 12, pg 2	In the conclusion the candidate claims a "definite need" for dementia screening in the palliative care population – however this is not well-substantiated from this study.	Pg 52	The conclusion has been rewritten and amended in totality.
13	Comment 13, pg 2	The recommendations do not come from this study – the candidate has not supplied arguments to back these recommendations.	Pg 57	The recommendations have been rewritten and amended in totality.
14	Comment 14, pg 2	The references are not accurately written, with some dates missing.		This has been amended.
15	Comment 15, pg 2	It is not really acceptable to use Wikipedia as a source.		Removed.
16	Comment 16, pg 2	It is also not acceptable to quote secondary sources.		Under certain circumstances secondary sources are acceptable as it analyses and interprets primary sources. Secondary data is defined by Ann Bowling in Research Methods in Health, as "existing sources of data that could be used for research purposes".

Examiner 2 – (Unknown – from the UK)

	Original dissertation		Corrected/Revised dissertation	
1	Comment 1, pg 1	However, the Wikipedia reference was unnecessary and undermined the academic credibility of the dissertation.		Removed.
2	Comment 2, pg 1	Further inclusion of some critical appraisal would have strengthened the rationale for the study.	Pg 17 Point 3.11 Pg 52	Done.
3	Comment 3, pg 1	The relevance and need for the panel (box) on page 12 however was unsubstantiated and not supported by reference/s. This panel box needs referencing or further explanation regarding the importance of this information related to spirituality or it should be deleted from the study.		Removed.
4	Comment 4, pg 1	The information about validity (page 16) is useful and it also needs to be supported by references.	Pg 19 Pg 20	Point 3.12 – is referenced. Point 3.13 – is referenced.
5	Comment 5, pg 1	The need for a Google search was unclear.	Pg 26	Google scholar is reasonably well accepted and for this reason I included it for the purpose of ensuring that I found required information.
6	Comment 6, pg 1	The need for a Google search was unclear plus the terms “relevant” and “experts” require clarification.	Pg 26 Pg 28 Point 6.3.3 Pg 32	The Google search has been explained above. The terms “relevant” and “experts” indicates the Dr’s & Professor’s I approached in the field of palliative care, geriatrics and mental health, this has been clarified in the dissertation.
7	Comment 7, pg 1	However and unfortunately, in the methods section a fourth objective was added to the study (page 27). This was not specified earlier. This fourth objective is beyond the scope of this review and its inclusion detracted from the dissertation, especially as the findings from this were not consistently presented or discussed in the dissertation.		Fourth objective removed. The reason why I added it was to demonstrate that I did evaluate the sites from which I obtained data. This was done as a “nice to know” for myself and I thought it may be valuable in the dissertation.
8	Comment 8, pg 2	Also, a section regarding analysis is mostly missing from the dissertation. This needed to be specific in the methods section. For example, was meta-analysis going to be used for this review or were narrative approaches going to be used?	Pg 22 Point 4 Pg 26 Point 6.2	It was not part of the systematic review to analyse the validated tools found but have included explanations in the dissertation.
9	Comment 9, pg 2	For example, perhaps the “cross-sectional study of quality of life in incident stroke survivors in rural northern Tanzania” should have been excluded in stage 3 (where the objective		Corrected.

		was to exclude those not used in a palliative care population) rather than stage 2, which focussed on whether the tool had been validated in sub-Saharan Africa.		
10	Comment 10, pg 2	The inclusion of detail regarding analysis should have been included in the dissertation.	Pg 3, 4 & 18	It was not part of the systematic review to analyse the validated tools found but brief explanation has now been included.
11	Comment 11, pg 2	A few references to support the information presented in the discussion were missing (e.g., paragraph 2, page 43).	Pg 47	It has been referenced with reference no. 6.
12	Comment 12, pg 2	Additional thought from the author could have been demonstrated to support their critique of the DSM-IV. Good points were made but further substantiation would have strengthened the dissertation.	Pg 50 Point 8.2.3	I added a few more thoughts but have decided not to continue with too much critique of the DSM-IV as I do not want to distract from the core objectives. I have included the following: "According to Natalie Muth the limitations of the DSM-IV create labels for individual's diagnosed making use of the DSM-IV criteria and in turn creating the possibility of discrimination and stigmatization (63). The group found that many of the criteria used to diagnose DSM-IV disorders lacked predictive validity as the system was not linked to treatment outcomes in each instance (63). The criteria were found to not always be reliable therefore influencing test-retest reliability (63)."
13	Comment 13, pg 2	The author could have also drawn upon other literature regarding the development of palliative care tools to support their conclusions (e.g., Harding JPSM regarding the need to NOT develop any new tools for palliative care but rather to amend existing tools). Drawing upon this additional literature could have aided the conclusions of the study.	Pg 54	Completed.

Student signature: _____



Date: 25th August 2014