

Review

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Article

Current state of Dementia Management Within the South African Public Healthcare system: A Scoping Review

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Abstract

Background: Dementia is a primary cause of disability and dependence among older adults worldwide, with cases increasing most rapidly in low- and middle-income countries. In South Africa, the ageing population faces growing dementia needs, but current management systems remain fragmented and under-resourced. **Aim:** To review and summarise how dementia is currently managed in South Africa, covering its prevalence, causes, diagnosis, treatment, care, and the health system and policy responses. **Methods:** We conducted a broad review in accordance with established methods and reporting guidelines. We searched both published and unpublished sources from 2000 to 2024 across multiple databases and websites. Two reviewers independently screened and extracted data. Findings were summarised in text and organised into topic-based tables. **Results:** Twelve studies and relevant grey literature were included. Among adults aged 60 and older, the prevalence of dementia ranges from approximately 8% to 12%. This highlights the need for additional resources to improve dementia management. Expanding screening programs, notably in underserved areas, could help guarantee equitable access and earlier detection. Key risk factors include age, vascular disease, female sex, low educational attainment, poverty, and rural residence. Most screening and diagnosis occur in urban specialist settings, and common tools (e.g., MMSE, 10/66 battery) are not well validated for South Africa's diverse populations. Dementia care is inconsistent: medication is available in specialist centres, but community and primary care programs are limited. Most ongoing care is provided by families and NGOs. There is no national dementia strategy, and policy integration is weak. **Conclusions:** Currently, dementia in South Africa is often undiagnosed, care is not equally accessible, and primary health care has a limited role. Most support comes from families and NGOs. In rural areas, caregivers face major challenges, balancing daily responsibilities with caring for relatives with dementia, often without professional help. The following steps are to establish national monitoring, adapt screening tools for all cultures, integrate dementia into primary health care, increase caregiver support, and develop a national dementia plan.

Keywords: dementia; South Africa; scoping review; primary health care; dementia management; policy; LMIC

1. Introduction

Dementia is a condition that gets worse over time and affects memory, behaviour, and daily abilities, making it hard for people to live on their own and enjoy life. It is one of the main reasons older people become disabled and need help, and it is becoming a bigger health issue around the world. The World Health Organisation (WHO) says more than 55 million people have dementia worldwide, with about 10 million new cases each year. By 2050, this number could reach nearly 150 million, largely because people are living longer and surviving other long-term illnesses (International, n.d.).

Importantly, more and more dementia cases are happening in low- and middle-income countries, which are expected to have about 70% of all cases by the middle of the century (World Health Organization, 2012). This creates major problems for health systems that already have few resources, many other health issues to address, and social inequalities. In many of these countries, dementia is often not noticed, not diagnosed, and not managed well. Care is often uncoordinated, there are insufficient specialists, and families provide most of the care. (Mbilini et al., 2024)

South Africa is a good example of these problems. More people are living longer, and there are more older adults, along with high rates of long-term illnesses like high blood pressure, diabetes, and stroke, which increase the risk of dementia. Even with these changes, South Africa's health system has largely focused on infectious diseases and care for mothers and children, paying little attention to long-term brain conditions associated with ageing. As a result, dementia is not a regular part of primary health care, long-term disease management, or national plans for older people (Kalula, Petros & De Jager, 2023). This emerging population shift may pose economic challenges, as the increased prevalence of dementia can lead to greater demands on the health care system and associated costs (Kobayashi, Glymour, Kahn, Wagner, Tollman, & Berkman, 2024). Estimating future cost burdens associated with dementia care could strengthen the case for early investment in dementia treatment, potentially drawing interest from treasury and planning departments.

Dementia brings many challenges that go beyond just getting a diagnosis. It also involves long-term care, supporting caregivers, and making sure that health and social services work together. Good dementia care means identifying it early, providing routine check-ups, delivering emotional and social support, and supporting caregivers, all within a well-organised health system. But in South Africa, dementia is often found late, usually by specialists, and sustained care is limited. Diagnosis and treatment vary across regions, with substantial differences between cities and rural areas and between provinces.

Screening and diagnosis make dementia care even harder. The most common tests, such as the Mini-Mental State Examination (MMSE) and the 10/66 Dementia Battery, have not been well validated among South Africans who speak different languages or have low reading skills. This means that people may be misdiagnosed or missed. In response to these challenges, a pathway for co-creating culturally adapted screening tools has been proposed. This entails collaborating with local communities, healthcare professionals, and researchers to develop and validate tools customised to South Africa's diverse population. By consulting stakeholders during design and testing, these tools can be refined to improve accuracy and availability, thereby enabling earlier detection and reducing reliance on specialists, who are scarce and often unavailable in rural or low-income areas.

Because there is no full public system for dementia care, families and non-governmental organisations (NGOs) are the main providers of long-term care for people with dementia in South Africa. Most family caregivers are women, and they often have little training, money, or time off, which causes a lot of stress and financial problems. Caregiver strain is not merely a social issue or a health outcome that should be measurable and addressable within the health system. Treating caregiver burnout as a legitimate health indicator can help unlock dedicated funding for caregiver support, thereby ensuring equitable service delivery. (Carries et al., 2023) NGOs help by raising awareness, advocating for people with dementia, and supporting caregivers; however, their support is not available everywhere, is mostly concentrated in cities, and depends on funding that is not always stable. This means that whether someone receives care depends not only on their health needs but also on where they live, their income, and whether their family can provide unpaid care.

Even though dementia is becoming a bigger problem and there are many challenges, it is not a main focus in South Africa's national policies. There is no national plan or strategy dedicated solely to dementia, and it is only a small part of other health and ageing policies. This lack of focus makes it hard to plan, allocate resources, train staff, and ensure dementia care is delivered effectively. Matching these gaps with South Africa's commitment under the WHO Global Action Plan on the Public Health Response to Dementia 2017–2025 could spur decision-makers to respond more urgently (World Health Organisation, 2017). The same problem is observed in many other low- and

middle-income countries, underscoring the importance of collecting local evidence to improve health systems.

Even though some studies have looked at how common dementia is, what causes it, or what caregivers go through in South Africa, the research is scattered and mostly focused on certain areas. There has been little work that brings together how these factors, e.g., how common dementia is, what causes it, how it is treated, how care is provided, and what policies exist, work together to shape dementia care. We need a review that examines the whole system, not just the numbers, to understand how dementia is identified, managed, and organised in South Africa's health system.

By looking closely at how dementia is currently managed, this review answers global calls, especially from the WHO, to improve how health systems deal with dementia in low- and middle-income countries. The goal is to provide useful ideas on policies and practices, to integrate dementia into primary health care, to develop screening and care methods that align with local cultures, to provide greater support to caregivers, and to develop a national dementia plan for South Africa. These lessons can also help other countries confronting similar changes.

To summarise, the rising number of dementia cases, research focused on only a few areas, not enough screening and diagnosis, heavy dependence on family care, and lack of a clear policy all show that dementia is not well managed in South Africa's health system. While some studies provide useful information on the prevalence of dementia, its causes, and the challenges caregivers face, there has been little work that brings these pieces together to present a comprehensive picture. We need a comprehensive review that examines how dementia is diagnosed, managed, and supported in South Africa, and identifies what needs improvement. This review does so by carefully examining all available evidence to guide policy, practice, and future research.

What makes this review novel is that it examines the entire dementia care system in South Africa, rather than focusing solely on numbers or individual issues. Rather than focusing exclusively on the prevalence of dementia, its causes, or caregivers' experiences, this review synthesizes information on how dementia is detected, managed, and supported within the health system (Kalula & Petros, 2024).

This review is important for three reasons. First, it highlights major problems in the health system, including insufficient diagnosis, unfair access to care, weak links to primary health care, and overreliance on families and NGOs. Second, by comparing South Africa with other low- and middle-income countries, the review offers ideas that can help other places confronting similar changes. (Mfene & Pillay, 2024) Third, it synthesizes scattered research into clear, useful recommendations, including developing improved screening tools, strengthening primary health care, supporting caregivers, and creating a national dementia plan. (Ngcobo, 2026)

Overall, this work shows that a scoping review can do more than collect information—it can also assess the effectiveness of current dementia care systems and help improve health systems. (Health system description and assessment: a scoping review of templates for systematic analyses, 2024)

Aim

To examine and synthesise evidence on the current state of dementia management in South Africa.

Objectives

1. Describe the current epidemiological profile of dementia in South Africa: Prevalence rates of dementia in different regions.
2. Examine key biological, social, and structural determinants shaping the current dementia burden: the frequency of identified determinants in affected populations.
3. Assess the current state of screening, diagnostic, and case-finding practices: Number of screenings conducted and diagnostic correctness rates.
4. Describe existing treatment, clinical management practices, and care pathways: Availability of treatment options as well as adherence to care guidelines.
5. Examine the roles of health system actors, NGOs, and caregivers in the current dementia management landscape: Level of involvement and services provided by each actor.

6. Identify gaps and offer practical suggestions for strengthening dementia management: Number of implemented recommendations and their impact on dementia management.

Research Questions

1. What is currently known about the burden and geographic distribution of dementia in South Africa?
2. What determinants shape current patterns of dementia risk and vulnerability?
3. How is dementia currently identified, diagnosed, and managed within the South African health system?
4. What care pathways and support mechanisms are currently available for people living with dementia and their caregivers?
5. How do policy, governance, and organisational arrangements influence the current state of dementia management?
6. What gaps and system weaknesses characterise current dementia management, and what opportunities exist for improvement?

2. Methods and Materials

2.1. Study Design

This study used a scoping review to synthesize information on how dementia is currently managed in South Africa, including its prevalence, causes, detection, and treatment, and on how the health system and policies respond. A scoping review was chosen because information on dementia in South Africa originates from multiple sources and is not always complete or well organised. Scoping reviews are useful for answering broad questions, identifying what information exists, and identifying where more research is needed. Unlike systematic reviews, scoping reviews do not combine results numerically or assess the effectiveness of treatments. Instead, they provide an overview to inform policy, practice, and future research. Systematic reviews usually focus on a narrow topic and require many similar studies, which is not the case for dementia management in South Africa. The review followed a five-step process: (1) setting the research questions; (2) finding relevant studies; (3) choosing which studies to include; (4) organising the data; and (5) putting together and sharing the results. This method is widely used in public health research and is effective for integrating information from different fields. Subsequent improvements, such as clarifying the rules for including studies and for team-based decision-making, further strengthened the review.

To guarantee transparency and reproducibility, the review was reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines (Tricco et al., 2018). The PRISMA-ScR checklist guided reporting of eligibility criteria, search strategies, study selection processes, and data charting methods, and a PRISMA-ScR flow diagram documented the identification, screening, eligibility, and inclusion of sources. Importantly, the scoping review approach permitted the inclusion of both peer-reviewed and grey literature, such as government policy documents, organisational reports, and non-governmental organisation publications. Inclusion of grey literature is recommended in scoping reviews examining health systems and policy contexts, particularly in low- and middle-income countries, where critical evidence may not be captured in academic journals alone (Peters et al., 2015; Tricco et al., 2018). This approach strengthened the review's capacity to characterise the real-world context of dementia management in South Africa.

Overall, this study design enabled the review to synthesize diverse types of information, providing a comprehensive picture of how dementia is identified, managed, and addressed in South Africa and identifying where improvements are needed in policy, practice, and future research.

2.2. Identification of Relevant Studies

A thorough, organised search was conducted to find information on how dementia is managed in South Africa. The search sought evidence across multiple areas, including studies on the prevalence of dementia, its treatment, the health system, caregiving, and policies. Online databases such as PubMed, Scopus, Web of Science, and African Journals Online (AJOL) were used to identify research published from January 2000 to December 2024. This period was selected to encompass recent changes in South Africa's health system. To ensure that all important information was found, other sources, such as Google Scholar, government and organisational websites, and reports from groups such as Dementia SA and the South African Department of Health, were also searched. To support reproducibility and aid future researchers, the core Boolean search strings used are listed below:

- ("dementia" OR "Alzheimer's disease" OR "cognitive impairment") AND ("South Africa" OR "Limpopo" OR "Mpumalanga" OR "Gauteng" OR "Western Cape" OR "KwaZulu-Natal" OR "Eastern Cape" OR "Free State" OR "North West" OR "Northern Cape")

This concise listing facilitates the easy replication of search parameters, supporting cumulative scientific research. The search terms were developed systematically, using terms related to dementia and the names of South African provinces. Special search words like "AND" and "OR" were used to make the search more accurate. The reference lists of the studies were also checked for additional useful sources. Using multiple sources is important for reviews like this, especially in countries where not all information is available in large databases.

2.3. Eligibility Criteria

Eligibility criteria were defined upfront, to ensure transparency and consistency in study selection, in accordance with PRISMA-ScR guidance (Tricco et al., 2018). Studies and documents were included if they,

- Focused on dementia or cognitive impairment;
 - Were conducted in South Africa or included South Africa-specific analysis;
 - Addressed at least one aspect of the current state of dementia management, including:
 - ✓ prevalence or incidence;
 - ✓ biological, social, or structural determinants;
 - ✓ screening or diagnostic practices;
 - ✓ treatment, care pathways, or service delivery;
 - ✓ caregiving, community, or organisational roles;
 - ✓ policy, governance, or health system responses;
 - Employed quantitative, qualitative, or mixed-methods designs, or constituted relevant grey literature (e.g., policy documents, organisational reports);
 - They were published in English between 2000 and 2024.
- Records were excluded if they,
- They were not specific to South Africa and lacked disaggregated South African data.
 - Were narrative reviews, editorials, opinion pieces, or case reports without empirical or policy relevance;
 - Focused exclusively on biomedical or laboratory aspects of dementia without relevance to management or health systems;
 - Lacked sufficient methodological or context-related detail to inform the review objectives.

2.4. Study Selection Process

The study selection process followed a two-stage screening approach, consistent with best practice for scoping reviews (Levac et al., 2010; Tricco et al., 2018). All identified records were imported into a reference management system, and duplicates were removed before screening. In the first stage, titles and abstracts were independently screened by two reviewers against the eligibility criteria. Records that clearly did not meet the inclusion criteria were excluded at this stage. In the second stage, full texts of potentially eligible records were retrieved and independently assessed by the same reviewers for final inclusion. Discrepancies at either stage were resolved through discussion and consensus, with reference to the review objectives and eligibility criteria.

The selection process was documented using a PRISMA-ScR flow diagram, detailing the number of records identified, screened, excluded, and included at each stage. A total of 356 records were identified through databases (PubMed, Scopus, WoS, AJOL). An additional 22 records were identified through grey literature. After removing duplicates, 300 records remained for screening. Of these, 273 were excluded based on title and abstract reviews. This left 27 full-text articles, of which 15 were excluded for failing to meet the objectives. Ultimately, the final scoping review included 12 studies. (Experiences and practices of caregiving for older persons living with dementia in African countries: A qualitative scoping review, 2022, pp. 1-9) While these precise figures may appear straightforward, they point to inherent challenges and divisions within South African dementia management research, revealing a scarcity of comprehensive evidence on the topic (see the PRISMA flow diagram in Figure 1).

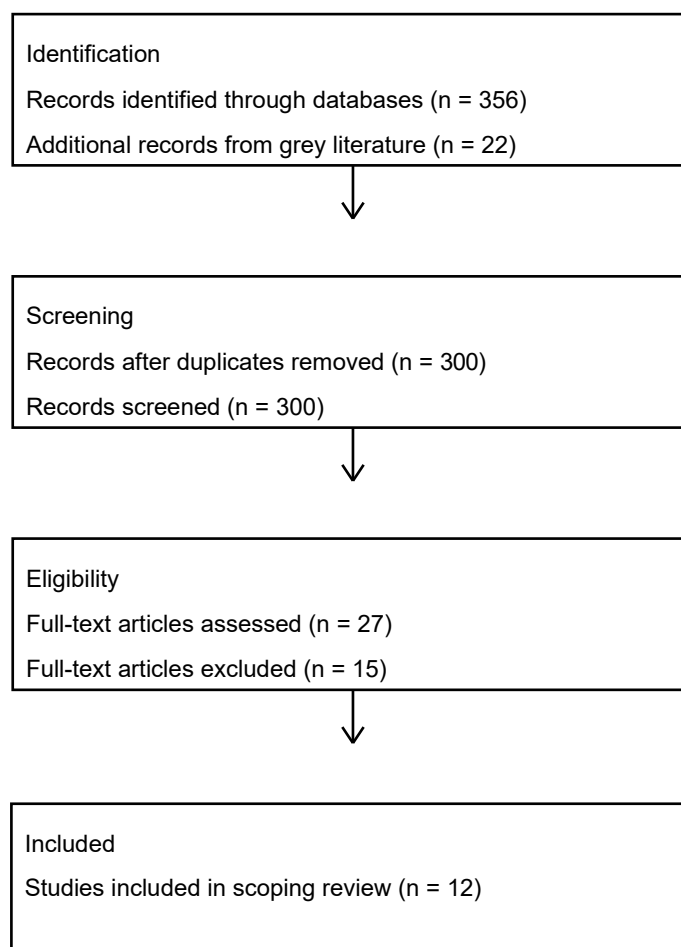


Figure 1. PRISMA flow diagram.

This open reporting improves reproducibility and allows readers to assess the comprehensiveness of the search and selection process (Tricco et al., 2018). (al., 2018)

2.5. Data Charting

Data from included studies were extracted using a structured data charting form, developed iteratively and piloted on a subset of studies to guarantee consistency and relevance (Arksey & O'Malley, 2005; Levac et al., 2010). The charting form captured the information as shown in Table 1 below:

Table 1. Characteristics of included studies.

De Jager et al., 2017	Population-based cross-sectional study	Rural Limpopo	Adults ≥ 60 years	Epidemiology; Diagnosis	Dementia prevalence estimated at ~11%; underdiagnosis common; strong association with age and vascular risk factors; highlights lack of routine screening in PHC
Kobayashi et al., 2019	Longitudinal cohort (HAALSI)	Limpopo (Agincourt)	Adults ≥ 40 years	Epidemiology	Incidence ~2–3% per annum; dementia burden projected to rise substantially with ageing population
Kobayashi et al., 2021	Longitudinal cohort analysis	Limpopo	Older adults	Determinants	Dementia risk strongly associated with low education, poverty, vascular disease, and rural residence
Van der Poel & Pretorius, 2009	Diagnostic validation study	Western Cape	Older adults with low literacy	Screening & Diagnosis	10/66 protocol feasible but literacy and language pose diagnostic challenges; need for culturally adapted tools
Ssonko et al., 2023	Retrospective clinical record review	Urban memory clinic (Western Cape)	Patients attending specialist clinic	Diagnosis; Management	Diagnoses occur late and are specialist-centred; limited continuity of care and follow-up
Mahomed & Pretorius, 2022	Qualitative interviews	Gauteng & Western Cape	Family caregivers	Caregiving; Service delivery	Heavy reliance on unpaid family care; high caregiver burden; minimal formal support or respite services
Glymour et al., 2024	Mixed-methods implementation study	Rural Mpumalanga	Older adults & PHC staff	Screening; Health systems	Digital and task-shifted diagnostic approaches show

					promise in low-resource PHC settings
Schneider et al., 2024	Modelling & secondary data analysis	National	National population	Epidemiology; Policy	Dementia burden projected to increase sharply; current health system not prepared for scale of need
Alzheimer's Disease International, 2019	Global report (grey literature)	Includes South Africa	People living with dementia & caregivers	Policy; Caregiving	Highlights stigma, lack of national dementia plans, and reliance on informal care in LMICs
Dementia SA, n.d.	Organisational reports (grey literature)	National (NGO services)	People with dementia & caregivers	Service delivery; Caregiver support	NGOs provide awareness, education, and support but coverage is uneven and funding-dependent
WHO, 2017	Global policy framework	Global (LMIC focus)	—	Policy; Health systems	Recommends national dementia strategies, PHC integration, caregiver support, and surveillance
WHO, 2021	Global strategy (UN Decade)	Global	—	Policy: Healthy ageing	Emphasises integrated care for older people, community-based services, and caregiver support

Data charting was conducted primarily by the lead reviewer (author), with cross-checking by a second reviewer (librarian) to guarantee accuracy and completeness. This repeated charting process allowed refinement of categories as familiarity with the literature increased, consistent with scoping review methodology (Levac et al., 2010).

2.6. Data Synthesis and Reporting

Because the studies were very different, the results were described rather than quantified. The results were grouped by topic, with a focus on how dementia is managed across different levels of the South African health system. The review synthesized information from studies on the prevalence of dementia, clinical research, caregiver experiences, and policy documents to provide a comprehensive overview. To translate these findings into concrete policy changes, decision-makers should consider how these topics can inform new actions and health policies. Summary tables were used to make the information clearer and easier to compare. Rather than assessing treatment effectiveness, the review focused on patterns and gaps and their implications for the health system, offering useful ideas for policy, practice, and future research. This aligns with the primary objective

of scoping reviews and supports global efforts to improve dementia care in low- and middle-income countries.

2.6. Risk of Bias and Reduction Strategies

In accordance with established guidance for scoping reviews, a formal risk-of-bias or quality appraisal of individual studies was not undertaken (Arksey & O'Malley, 2005; Tricco et al., 2018). Scoping reviews are designed to map the breadth and nature of available evidence rather than to assess the effectiveness of interventions or to produce pooled effect estimates. Nevertheless, potential sources of bias inherent in the included evidence and within the review process were carefully considered and addressed through methodological safeguards. Several sources of bias were identified within the existing dementia literature in South Africa:

- *Geographic bias*: Much of the epidemiological evidence is concentrated in a limited number of provinces, particularly Limpopo and Mpumalanga, through cohort studies such as HAALSI. This limits national representativeness and may underestimate regional variability in dementia burden and service availability.
- *Selection bias*: Many studies rely on community-based cohorts or clinic-based samples, which may exclude institutionalised individuals, people with advanced dementia, or persons unable to access healthcare services, leading to underestimation of disease burden and care needs.
- *Measurement bias*: Widely used cognitive screening and diagnostic tools (e.g., MMSE, 10/66 protocol) have limited validation for multilingual and low-literacy populations. This may result in misclassification, underdiagnosis, or differential measurement error among population groups.
- *Publication bias*: Peer-reviewed literature tends to report positive or novel findings. At the same time, routine service delivery challenges and unsuccessful interventions are more likely to appear in the grey literature or remain undocumented.
- *Policy and reporting bias*: Government and organisational documents may emphasise planned programmes rather than actual implementation, potentially overstating system capacity.

Likely biases associated with the review process itself have also been considered:

- *Search bias*: Although multiple databases and grey literature sources were searched, it is possible that some relevant unpublished or non-indexed materials were missed.
- *Language bias*: Only English-language sources were included, which may have excluded relevant materials published in other languages.
- *Reviewer bias*: Interpretation of qualitative and policy evidence may be influenced by reviewer judgment.

Multiple strategies were implemented to minimise bias and enhance the rigour and transparency of the review, namely,

- Multiple bibliographic databases and grey literature sources were searched, and reference lists of included studies were hand-searched to maximise coverage.
- Inclusion and exclusion criteria were defined a priori and applied consistently throughout the screening process.
- Titles, abstracts, and full texts were independently screened by two reviewers (an author and a librarian); discrepancies were resolved through discussion and consensus.
- Data extraction was carried out using a structured charting form that was piloted and refined iteratively, reducing the risk of bias in data capture.
- The study selection process was documented using a PRISMA-ScR flow diagram, and findings were synthesised thematically in accordance with the stated objectives and research questions.
- Findings from epidemiological studies, qualitative research, clinical reports, and policy documents were synthesised to provide a balanced, systems-level perspective and reduce excessive reliance on any single evidence source.

The presence of geographic concentration, measurement limitations, and reliance on observational and descriptive studies means that findings should be interpreted as indicative of system-level patterns and gaps rather than as precise national estimates or causal relationships. (Russ, Batty, Hearnshaw, Fenton, & Starr, 2012) Nonetheless, by clearly documenting these limitations and incorporating diverse evidence sources, the review provides a robust and credible synthesis of the current state of dementia management in South Africa, suitable for informing policy, practice, and future research priorities.

3. Results

The findings of this scoping review are presented in accordance with the objectives and research questions, focusing on how dementia is currently identified, managed, and supported within the South African health system. A total of twelve peer-reviewed studies, together with relevant grey literature, met the inclusion criteria. The evidence base comprised population-based cohort studies, clinic-based reviews, qualitative caregiver studies, and policy and organisational documents [De Jager et al., 2017; Kobayashi et al., 2019; Mahomed & Pretorius, 2022; Schneider et al., 2024] (see details in Table 1).

Table 1. Characteristics of included studies

Author (Year)	Province/Setting	Study Design	Sample Size	Population	Key Focus
De Jager et al. (2017).	Limpopo	Longitudinal cohort (HAALSI)	>5,000	Adults ≥40 years	Cognitive decline, dementia prevalence
Kobayashi et al. (2019).	Mpumalanga	Longitudinal cohort	~3,500	Adults ≥45 years	Dementia incidence
Kobayashi et al. (2021).	Mpumalanga	Cross-sectional	~1,400	Older adults	Risk factors
Glymour et al. (2024).	Mpumalanga	Mixed methods	~4,000	Rural adults	Diagnostic innovation
Van der Poel & Pretorius (2009).	Free State	Pilot study	200	Older adults	10/66 dementia tools
Ssonko et al. (2023).	Western Cape	Clinic-based	150	Memory clinic patients	Diagnosis and treatment
Mahomed & Pretorius (2022).	Gauteng	Qualitative	25	Caregivers	Care experiences

The majority of studies were population-based and concentrated in the rural provinces of Limpopo and Mpumalanga, with limited representation from other regions (De Jager et al., 2017; Kobayashi et al., 2019; Kobayashi et al., 2021; Glymour et al., 2024).

3.1. Current Epidemiological Profile of Dementia in South Africa

Available evidence indicates that dementia is a major and growing public health burden in South Africa, although epidemiological data remain regionally limited. Population-based cohort studies conducted primarily in Limpopo and Mpumalanga provinces report dementia prevalence estimates ranging from approximately 8% to 12% among adults aged 60 years and older, with incidence rates of approximately 2–3% per annum in longitudinal follow-up (De Jager et al., 2017; Kobayashi et al., 2019). National modelling studies project a substantial increase in the number of people living with dementia in the coming decades, driven by population ageing and the rising burden of non-communicable diseases (Schneider et al., 2024). However, robust epidemiological data are available from only a small number of provinces, limiting the ability to generate nationally representative estimates and obscuring potential regional variation in dementia burden (De Jager et al., 2017; Kobayashi et al., 2021).

Table 2. Current profile of dementia in South Africa.

Province	Data Source	Age Group	Prevalence (%)	Incidence
Limpopo	HAALSI	≥60 years	~10%	Not reported
Mpumalanga	HAALSI	≥60 years	~12%	2.5% per year
Western Cape	Clinic-based	≥60 years	Not generalisable	Not reported
Gauteng	Qualitative	Older adults	Not available	Not available
Other provinces	–	–	No data	No data

Solely robust epidemiological data were available for Limpopo and Mpumalanga, highlighting major provincial inequities in dementia surveillance (De Jager et al., 2017; Kobayashi et al., 2019; Schneider et al., 2024).

3.2. Determinants Moulding the Current Dementia Burden

Across included studies, dementia risk was determined by a mixture of biological, social, and structural determinants. Advanced age and vascular comorbidities, including hypertension, diabetes, and stroke, were consistently associated with increased dementia risk (De Jager et al., 2017; Kobayashi et al., 2021). Female sex was associated with higher observed prevalence in some cohorts, showing both biological factors and differential survival patterns (Kobayashi et al., 2021). Social determinants featured prominently. Low educational attainment, poverty, and rural residence were repeatedly associated with enhanced vulnerability to dementia and poorer access to diagnostic and care services (Kobayashi et al., 2021; Schneider et al., 2024). Qualitative evidence additionally emphasised the role of stigma, limited dementia awareness, and low health literacy in delaying help-seeking and diagnosis (Mahomed & Pretorius, 2022) (see Table 4 for details).

Table 3. Key risk factors and determinants of dementia in South Africa.

Domain	Factors Identified	Evidence Source
Biological	Advanced age, female sex, vascular disease	HAALSI cohort
Social	Low education, poverty	Population-based studies
Contextual	Rural residence, stigma	Qualitative studies
System-level	Limited services, late diagnosis	Multiple studies

3.3. Current State of Dementia Management in South Africa

Primary Health Care and Service Integration

Primary health care (PHC) is not yet systematically used for dementia case finding and ongoing management (Mahomed & Pretorius, 2022).

Table 2. Dementia management at the primary healthcare level.

Screening	Not routine	Missed early diagnosis	Mahomed & Pretorius (2022)
PHC training	Limited	Low detection and confidence	Mahomed & Pretorius (2022)
Care pathways	Absent	Delayed referrals	De Jager et al. (2017)
Continuity of care	Weak	Episodic management	Mahomed & Pretorius (2022)

Screening, Diagnostic, Case-Finding Practices, and access to specialists

The review identified substantial constraints in current screening and diagnostic practices. Cognitive assessment tools such as the Mini-Mental State Examination (MMSE) and the 10/66 Dementia Diagnostic Protocol were most commonly reported in both research and clinical contexts (Van der Poel & Pretorius, 2009; De Jager et al., 2017). However, these tools have limited validation in South Africa's multilingual, low-literacy populations, eliciting concerns about misclassification and underdiagnosis (Van der Poel & Pretorius, 2009; Glymour et al., 2024). Diagnostic services were concentrated in urban, specialist, and tertiary care settings, including memory clinics and specialist

outpatient services (Ssonko et al., 2023). In contrast, routine dementia screening was rarely conducted in primary healthcare facilities, and primary healthcare workers reported limited training in recognising and managing dementia (Mahomed & Pretorius, 2022). Referral pathways were described as lengthy and fragmented, often resulting in diagnoses at advanced stages of disease (Glymour et al., 2024). Table 5 has details.

Table 5. Diagnostic capacity for dementia.

Diagnostic sites	Urban tertiary centres	Rural exclusion	Glymour et al. (2024)
Screening tools	Poorly adapted for low literacy	Underdiagnosis	Van der Poel & Pretorius (2009)
Referral systems	Complex and delayed	Late diagnosis	Glymour et al. (2024)
Specialist availability	Limited	Long wait times	Ssonko et al. (2023)

Treatment/clinical management practices and care pathways

Evidence on dementia management revealed a fragmented and inconsistent care environment. Pharmacological treatments were available in some specialist public-sector and private-sector settings but were not uniformly accessible across provinces or levels of care (Ssonko et al., 2023). Dementia was rarely managed as a chronic condition within structured care pathways, and continuity of care was limited. Non-pharmacological interventions, including cognitive stimulation, psychosocial support, and structured caregiver education, were underdeveloped within the public health system and were largely limited to NGO-led or small-scale initiatives (Mahomed & Pretorius, 2022). Multidisciplinary approaches to dementia care were rarely reported, showing broader constraints on health system capacity (see Table 6).

Table 6. Treatment/clinical management practices and care pathways.

Pharmacological care	Available in select clinics	Limited public access	Ssonko et al. (2023)
Non-pharmacological care	Minimal structured support	Poor quality of life support	Mahomed & Pretorius (2022)

3.5. Roles of Health System Actors, NGOs, and Caregivers

The review repeatedly demonstrated that family caregivers form the backbone of dementia care in South Africa. Unpaid family members, predominantly women, predominantly provided care and reported high levels of emotional, physical, and financial strain (Mahomed & Pretorius, 2022). Formal caregiver training, respite services, and psychosocial support were limited. Non-governmental organisations played a critical compensatory role, particularly in dementia awareness, caregiver education, advocacy, and support services (Alzheimer's Disease International, 2019; Dementia SA, n.d.). However, NGO services were unevenly distributed, often urban-biased, and donor-dependent, limiting sustainability and coverage (Mahomed & Pretorius, 2022).

Table 8. Role of NGOs in dementia management (with citations).

Awareness	Public education	Urban bias	Alzheimer's Disease International (2019)
Caregiver support	Support groups	Limited reach	Mahomed & Pretorius (2022)
Training	Skills development	Sustainability challenges	Alzheimer's Disease International (2019)
Service delivery	Gap-filling	Donor dependency	Mahomed & Pretorius (2022)

Care provision largely falls on unpaid family caregivers, who face stress, isolation, and burnout (Mahomed & Pretorius, 2022) (see Table 7).

Table 7. Caregiving and local support landscape.

Caregivers	Mostly unpaid family	High burden	Mahomed & Pretorius (2022)
Training	Minimal	Caregiver stress	Mahomed & Pretorius (2022)
Respite services	Rare	Burnout	Mahomed & Pretorius (2022)
Community support	Uneven	Social isolation	Alzheimer's Disease International (2019)

Across all domains, the evidence highlighted persistent system-level gaps, including the absence of a national dementia strategy, weak integration of dementia into primary healthcare, limited workforce capacity, and fragmented coordination between health and social sectors (World Health Organisation, 2017; Schneider et al., 2024). Collectively, the findings depict dementia management in South Africa as largely reactive, specialist-centred, and informal, placing significant responsibility on families and NGOs while leaving substantial unmet needs within the public health system. This begs the question: which crucial services will remain underfunded or neglected if the development of an integrated national strategy continues to be delayed? Through quantifying what is forfeited through inaction, there is an opportunity to catalyse greater cross-sector collaboration and mobilise resources more productively (see Table 8 for details).

Table 8. Policy and governance environment context of dementia management.

National strategy	Absent	Lack of coordination	WHO (2017)
Policy integration	Weak	Dementia marginalised	WHO (2017)
Intersectoral action	Limited	Fragmented services	Schneider et al. (2024)
Dedicated funding	Minimal	Under-resourcing	Schneider et al. (2024)

4. Discussion

This scoping review synthesised evidence on the current state of dementia management in South Africa, integrating epidemiological, clinical, caregiving, organisational, and policy perspectives. The findings show that dementia is a growing and predictable public health challenge, yet current management stays fragmented, inequitable, and heavily reliant on informal care. By coordinating the discussion with the objectives, this section interprets the findings in relation to health system performance, equity, and policy relevance, carrying implications for South Africa and other low- and middle-income countries (LMICs).

Interpreting the Current Epidemiological Profile

The review confirms that dementia prevalence and incidence in South Africa are considerable and increasing, with estimates comparable to, or exceeding, those reported in other LMIC settings (De Jager et al., 2017; Kobayashi et al., 2019; Schneider et al., 2024). However, the epidemiological evidence is geographically concentrated, with most data derived from cohorts in Limpopo and Mpumalanga, thereby limiting national representativeness. This pattern indicates broader challenges in LMICs, where surveillance systems for age-related conditions remain underdeveloped (Kalaria et al., 2008; World Health Organisation [WHO], 2017). The limited availability of nationally representative data constrains effective planning and the allocation of funding. Without routine surveillance integrated into national health information systems, dementia remains largely invisible in policy prioritisation. These findings underscore the need for nationally coordinated dementia surveillance, either through dedicated surveys or by integrating it into existing demographic and health surveillance platforms.

Determinants and Structural Disparities Shaping Dementia Risk

The evidence emphasises dementia as a condition determined by life-course and structural determinants, including low educational attainment, poverty, rural residence, and high vascular disease burden (Kobayashi et al., 2021; Schneider et al., 2024). These determinants intersect to produce inequitable patterns of risk and access to care, underscoring the need to view dementia through a social determinants of health and health equity lens. The strong association between vascular risk factors and dementia supports global calls for integrated prevention strategies linking dementia with non-communicable disease (NCD) prevention and control (WHO, 2017). In South Africa, where hypertension and diabetes prevalence are high, dementia prevention could be strengthened by embedding cognitive health within existing NCD programmes. Failure to handle these upstream determinants risks continuing inequities and increasing long-term care demands.

Screening and Diagnostic Practices as System Bottlenecks

A central finding of this review is the weakness of current screening and diagnostic practices, particularly at the primary healthcare (PHC) level. Reliance on tools that are not adequately validated for multilingual and low-literacy populations contributes to underdiagnosis and delayed care (Van der Poel & Pretorius, 2009; Glymour et al., 2024). Concentration of diagnostic capacity in urban specialist centres further exacerbates inequities, leaving rural populations underserved. These problems mirror those seen across LMICs, where specialist-centred diagnostic models are poorly aligned with population needs (Kalaria et al., 2008). Task-shifting, simplified screening tools, and digital decision-support innovations have demonstrated potential in low-resource settings and could be adapted for South Africa (Glymour et al., 2024). Strengthening PHC capacity for early identification is essential for shifting dementia care from reactive to proactive management.

Fragmented Dementia Management and Care Pathways

The review found that dementia management in South Africa is episodic and poorly integrated, with limited continuity of care. Pharmacological treatments are inconsistently available in the public sector and are largely confined to specialist services, while non-pharmacological interventions remain underdeveloped and poorly scaled (Ssonko et al., 2023; Mahomed & Pretorius, 2022). This fragmented care environment reflects the absence of standardised clinical guidelines and chronic care pathways for dementia within the health system. International evidence suggests that integrated, multidisciplinary care models improve quality of life for people living with dementia and reduce caregiver burden (WHO, 2017). Adapting such models to the South African context, through PHC integration and community-based services, amounts to a vital opportunity to strengthen the system.

Reliance on Families and NGOs in the Current Care Model

The findings stress the central role of family caregivers and non-governmental organisations (NGOs) in sustaining dementia care in South Africa. While families grant essential support, the absence of formal training, respite services, and financial assistance places caregivers at high risk of burnout and economic hardship (Mahomed & Pretorius, 2022). This reliance on it reflects a broader pattern in LMICs, in which informal care compensates for limited public-sector services (Alzheimer's Disease International, 2019). NGOs play a vital but uneven role in awareness, advocacy, and caregiver support. However, their dependence on donor funding and limited integration with public health services constrain scalability and sustainability. These findings stress the need for formal recognition and support of caregivers and civil society organisations within national dementia strategies.

This scoping review identified major gaps in dementia management in South Africa, with corresponding priority actions required to strengthen health system responses. By prioritising these gaps based on practicality and effect, decision-makers can be better guided. One approach to this prioritisation is to create a quick-win versus long-haul action matrix. Quick-wins are actions that are both high-impact and readily achievable; these include validating culturally appropriate screening

instruments and scaling task-shifting and digital diagnostic innovations to improve early identification, particularly in rural and underserved settings (Van der Poel & Pretorius, 2009; Glymour et al., 2024). Meanwhile, long-haul actions address pronounced epidemiological gaps, as dementia surveillance is regionally restricted and not nationally representative. Addressing this requires implementing nationally representative surveys and integrating dementia indicators into routine health and demographic surveillance systems to support evidence-based planning (De Jager et al., 2017; Schneider et al., 2024; WHO, 2017). Presenting actions in this staged manner helps overwhelmed readers move from reflection to execution more efficiently.

In terms of service delivery, dementia care is poorly integrated into PHC and chronic disease platforms, with limited availability of structured non-pharmacological interventions. Integrating dementia into PHC, developing standardised clinical guidelines, and scaling evidence-based non-pharmacological and community-based interventions represent crucial measures toward continuity of care (Mahomed & Pretorius, 2022; WHO, 2017). The review also highlighted a heavy reliance on unpaid family caregivers, underscoring the need for formal caregiver support, including community-based training, psychosocial support, and respite services (Alzheimer's Disease International, 2019; WHO, 2021). At the policy level, the absence of a national dementia strategy represents a major structural gap. Developing a coordinated national dementia strategy with dedicated funding and intersectoral governance is critical to address fragmentation and ensure accountability (WHO, 2017; Schneider et al., 2024).

Finally, persistent research gaps necessitate increased investment in longitudinal and implementation research, particularly in rural and underrepresented provinces, to inform scalable and culturally appropriate models of dementia care in South Africa and other low- and middle-income countries (Kobayashi et al., 2021; Kalaria et al., 2008). A defining feature of the current state of dementia management in South Africa is the absence of a dedicated national dementia strategy. Dementia remains poorly integrated into broader mental health, ageing, and NCD policies, resulting in fragmented governance and limited accountability (WHO, 2017; Schneider et al., 2024). International experience demonstrates that national dementia plans are associated with improved coordination, financing, and service development (WHO, 2017). Aligning South Africa's policy response with the WHO Global Action Plan on Dementia and the UN Decade of Healthy Ageing (2021–2030) could catalyse multisectoral action and resource mobilisation.

Consequences for Practice, Policy, and Research

The data show several priority actions: strengthening national surveillance, validating culturally appropriate screening tools, integrating dementia into PHC and NCD programmes, supporting caregivers, and developing a national dementia strategy. Research priorities include nationally representative studies, implementation research on PHC-based care models, and evaluation of community-based interventions. These implications are relevant not only to South Africa but also to other LMICs facing similar demographic and health system changes.

Strengths and Limitations of the Review

A key strength of this scoping review is its systems-oriented focus on the current state of dementia management, rather than limiting the synthesis to prevalence or clinical outcomes alone. Through integrating evidence across epidemiology, determinants, screening and diagnosis, care pathways, caregiving, organisational roles, and policy contexts, the review provides an integrated understanding of how dementia is currently managed within the South African health system. This integrated perspective addresses an important gap in the existing literature, where evidence has often been fragmented and siloed. Methodologically, the review followed established scoping review frameworks and was reported in accordance with the PRISMA-ScR guidelines, thereby enhancing transparency and reproducibility. The inclusion of both peer-reviewed and grey literature is another major strength, particularly given the policy- and systems-focused nature of the review and the likelihood that important evidence in LMIC settings resides outside academic journals. This approach

strengthened the review's relevance for policy and practice. The use of duplicate screening, clearly defined eligibility criteria, and structured data charting further enhanced methodological rigour and reduced the risk of selection bias. Finally, aligning the results, discussion, and recommendations with the explicitly stated objectives improved internal coherence and strengthened the translational value of the findings.

Several limitations should be acknowledged. First, the geographic concentration of available evidence, particularly reliance on studies from Limpopo and Mpumalanga, limits the generalisability of findings to all provinces. This reflects gaps in the underlying evidence base rather than shortcomings of the review itself, but it constrains the ability to draw nationally representative conclusions. Second, the included studies were methodologically heterogeneous, encompassing population-based cohorts, clinic-based studies, qualitative research, and policy documents. While appropriate for a scoping review, this heterogeneity precluded quantitative synthesis and limits causal inference. Third, measurement shortcomings in the primary studies—particularly the use of cognitive screening tools that are not fully validated for multilingual and low-literacy populations—may have contributed to underdiagnosing or misdiagnosing dementia cases. Additionally, the review was restricted to English-language sources, potentially omitting relevant materials published in other languages. Thus, a formal risk-of-bias assessment was not undertaken, limiting the ability to comment on the internal validity of individual studies.

Multiple strategies were implemented to reduce these limitations. To address potential publication and reporting bias, the review incorporated extensive grey literature searches and hand searches of reference lists. Duplicate screening and consensus-based decision-making were used to minimise selection and reviewer bias. The inclusion of diverse evidence sources enabled triangulation of findings, lessening reliance on any single study or methodology. Limitations related to geographic concentration and measurement challenges were specifically documented and interpreted cautiously in the Results and Discussion, making sure that conclusions were framed as indicative of system-level patterns rather than precise national estimates. By focusing on patterns, gaps, and system characteristics, rather than effect sizes or causal relationships, the review remained methodologically appropriate and analytically robust.

Despite these limitations, the review provides a credible and policy-relevant synthesis of the current state of dementia management in South Africa. The strengths of comprehensive scope, methodological transparency, and systems-level analysis outweigh the limitations, and the review provides a strong basis for policy development, health system strengthening, and additional research in South Africa and other low- and middle-income country contexts.

5. Conclusion

This scoping review provides a thorough synthesis of the current state of dementia management in South Africa, disclosing a growing and predictable public health burden that is not yet matched by an adequate or coordinated health system response. While available evidence indicates substantial dementia prevalence and incidence, driven by population ageing, vascular risk factors, and social inequities, dementia remains underdiagnosed, unevenly managed, and weakly prioritised within the health system. The review demonstrates that limited epidemiological coverage, weak integration of primary healthcare, specialist-centred diagnostic practices, fragmented care pathways, and heavy reliance on unpaid family caregivers and non-governmental organisations characterise dementia management in South Africa. Screening and diagnostic tools remain insufficiently adapted to multilingual and low-literacy populations, causing delayed diagnosis and inequitable access to care. The absence of a dedicated national dementia strategy and weak policy integration additionally restrict coordinated planning, financing, and accountability.

Although these challenges exist, South Africa has significant opportunities to strengthen dementia management through national surveillance, culturally appropriate screening tools, primary healthcare-integrated care models, structured caregiver support, and multisectoral policy action aligned with the World Health Organisation's Global Action Plan on Dementia and the UN Decade

of Healthy Ageing. By framing dementia as a health system and management challenge rather than solely a biomedical condition, this review offers policy- and practice-relevant insights to inform health system strengthening in South Africa. The findings are also relevant to other low- and middle-income countries undergoing similar demographic and epidemiological transitions, stressing the need for urgent, coordinated, and equity-oriented responses to dementia globally.

6. Recommendations

Based on the synthesis of evidence on the current state of dementia management in South Africa, the following recommendations are presented to strengthen health system responses. These recommendations are relevant to South Africa and transferable to other low- and middle-income countries (LMICs) confronting similar demographic and health system changes. South Africa should establish a nationally representative dementia surveillance system, either via dedicated population-based studies or through integrating dementia indicators into existing demographic and health surveillance systems. Current epidemiological evidence is geographically concentrated and insufficient for national planning. Routine surveillance is essential for estimating burden, monitoring trends, and informing resource allocation (De Jager et al., 2017; Schneider et al., 2024). The World Health Organisation (WHO) identifies surveillance as a core pillar of national dementia responses, particularly in LMICs where dementia remains undercounted (WHO, 2017).

Dementia should be systematically integrated into PHC and chronic disease management platforms, including routine cognitive screening for older adults and clear referral pathways. Specialist-centred models are inequitable and unsustainable. PHC integration enables earlier identification, continuity of care, and enhanced access, especially in rural areas (Mahomed & Pretorius, 2022; Glymour et al., 2024). The WHO and international dementia frameworks emphasise PHC-based models as the foundation of equitable dementia care (WHO, 2017; WHO, 2021).

South Africa should prioritise the development, adaptation, and validation of dementia screening tools suitable for multilingual and low-literacy populations. Current tools, such as the MMSE and the 10/66 battery, are inadequately adapted, leading to underdiagnosis and misclassification (Van der Poel & Pretorius, 2009; De Jager et al., 2017). Culturally appropriate diagnostic tools improve diagnosis accuracy and reduce inequities in LMIC settings (Kalaria et al., 2008; Glymour et al., 2024). Implement task-shifting strategies that enable nurses, community health workers, and allied health professionals to participate in dementia screening, basic management, and caregiver support. Specialist shortages necessitate decentralised care models. Training primary workers improves early detection and reduces service bottlenecks (Mahomed & Pretorius, 2022). Task-shifting is endorsed by the WHO as a cost-effective approach to treating chronic conditions, including dementia, in resource-limited settings (WHO, 2017).

Scale up non-pharmacological interventions, including cognitive stimulation, psychosocial support, and community-based rehabilitation, within the public health system. Non-pharmacological interventions improve quality of life and reduce caregiver burden, although they remain poorly developed and inconsistently available in South Africa (Mahomed & Pretorius, 2022; Ssonko et al., 2023). Global dementia guidelines highlight non-pharmacological care as central to comprehensive dementia management (WHO, 2017; Alzheimer's Disease International, 2019). Introduce structured caregiver support programmes, including training, psychosocial support, respite services, and social protection measures. Heavy reliance on unpaid family caregivers without formal support is unsustainable and increases caregiver burnout and economic hardship (Mahomed & Pretorius, 2022). Caregiver support is a key area of action in the WHO Global Action Plan on Dementia and the UN Decade of Healthy Ageing (WHO, 2017; WHO, 2021).

Strengthen formal partnership between government, NGOs, and community-based organisations to improve service coordination and coverage. NGOs play a key role in dementia care but operate in isolation from the public sector, restricting scalability and sustainability (Alzheimer's Disease International, 2019). Integrated, multisectoral approaches are recommended for dementia care in LMICs to maximise limited resources (WHO, 2017). South Africa should develop and

implement a National Dementia Strategy aligned with the WHO Global Action Plan on Dementia and the UN Decade of Healthy Ageing. The absence of a national strategy undermines coordination, financing, accountability, and long-term planning (Schneider et al., 2024). Countries with national dementia plans present greater policy coherence and service development (WHO, 2017).

Invest in longitudinal, implementation, and health systems research, particularly in under-represented provinces and rural settings, as evidence gaps limit policy responsiveness and modification of care models to local contexts (Kobayashi et al., 2021). Implementation research is essential for translating evidence on dementia into practice in LMICs (Kalaria et al., 2008; WHO, 2021).

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