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Challenges among informal caregivers of people living with motor neuron disease in South Africa

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Background: Motor neuron disease (MND) is a progressive and fatal neurodegenerative condition that is increasingly impacting individuals and their families globally. Despite being relatively rare, prevalence is rising because of an ageing population, with significant socio-economic consequences, particularly in countries with fragmented healthcare systems, financial challenges, and limited resources and skills. Family members often assume the caregiving role, leading to substantial caregiver burden in a context where support is lacking.

Objectives: Against this backdrop and given the scarcity of research on MND within South African communities, this study aimed to investigate the challenges experienced by caregivers of individuals with MND.

Method: We adopted an exploratory and qualitative approach to gain an in-depth understanding of lived experiences. Semi-structured interviews were conducted with 17 informal caregivers of MND patients across South Africa.

Results: The data, transcribed and analysed using thematic analysis, revealed insights into caregiver burden. The objective burdens were physical and financial strain, the impact on caregivers' social environments, and difficulties with healthcare services. The subjective burdens were perceived loss of love and self, guilt, and emotional impact.

Conclusion: These findings underscore the profound emotional, social, physical and financial burden of informal caregiving for individuals with MND, and highlight the urgent need for improved support systems, policy responses and greater societal awareness.

Contribution: There is a need for further research focused on intervention development and policy reform to alleviate caregiver burden and enhance support services, grounded in caregivers' lived experiences.

Keywords: motor neuron disease; informal caregiver; informal care; caregiver burden; lived experiences; thematic analysis; South Africa.

Introduction

Motor neuron disease (MND), or amyotrophic lateral sclerosis (ALS), is a debilitating neurodegenerative condition characterised by the degeneration of upper and lower motor neurons, leading to progressive muscle loss and eventual death (Hobson et al. 2016). Symptoms include muscle weakness, impaired mobility, speech difficulties and swallowing challenges. Median survival ranges from 2 years to 5 years, though some individuals live significantly longer (Hobson et al. 2016; Verber et al. 2019).

The incidence of MND increases after age 40, with typical onset in the early 60s (Bäumer, Talbot & Turner 2014; Lerum, Solbrække & Frich 2016). As life expectancy continues to rise because of advancements in healthcare, the number of individuals affected by MND is expected to grow. Globally, MND cases are projected to increase by 69% by 2040, with Africa expected to experience a sharper rise of 116% (Arthur et al. 2016; United Nations Department of Economic and Social Affairs 2022). In South Africa, those aged 60 and older may comprise 15.4% of the population by 2050 (Gallant 2017; Solanki et al. 2019). This demographic shift, coupled with limited data, raises concerns about an increase in age-related illnesses such as MND. Henning et al. (2021) identified 203 new MND cases in the Western Cape between 2014 and 2018, indicating a growing concern.

Despite the complexity of care required, there is currently no cure for MND, and management depends heavily on multidisciplinary teams. In low-resource settings, such care is often inaccessible, placing the burden on families for caregiving (Bäumer et al. 2014; Orrell & Guiloff 2020). Informal caregivers, usually relatives, often provide around-the-clock support with minimal professional assistance (Thrush & Hyder 2014). They face significant challenges, including insufficient medical, social and financial support, leading to strain on their well-being (Breen et al. 2007; Kipp et al. 2007).

South Africa's public healthcare system remains under severe strain, hampered by budgetary constraints, staff shortages, poor infrastructure and long waiting periods (Gallant 2017; Harris et al. 2011). While private healthcare offers more comprehensive services, it is unaffordable for most, exacerbating healthcare disparities.

Consequently, informal caregiving remains central to MND care in the country.

Informal caregivers of individuals with MND face a multitude of burdens that are well-documented in international literature but are underexplored in low- and middle-income countries. The psychological burden is particularly severe. In a review of 51 studies, Thrush and Hyder (2014) found that 73% reported psychological distress as the most common caregiving burden, while Trail et al. (2003) found that caregivers scored significantly higher on depression scales than the patients they cared for.

Financial hardship is another persistent challenge. Many caregivers reduce work hours or leave employment entirely, increasing economic vulnerability. The burden is compounded by the high cost of care – estimated at $69 475 annually per ALS patient in the United States (Gladman & Zinman 2015) – and the lack of public support systems in countries such as South Africa, where only 17.2% of the population have access to medical insurance (Statistics South Africa 2019). Social isolation also emerges as a significant concern. Aoun et al. (2012) found that most MND caregivers provide over 12 h of care daily, often at the expense of relationships and social well-being. Physical demands of caregiving – including assisting with mobility, managing equipment and coping with disrupted sleep – contribute to fatigue, illness and even elevated mortality risk, particularly among older caregivers (Fredman et al. 2010).

Despite these intersecting challenges, caregivers in resource-limited settings remain largely invisible in healthcare planning and unsupported in practice (Malakoane et al. 2020). Understanding these layered burdens is essential to designing interventions that support both patients and those who care for them.

It is within this context that the current study seeks to explore the multifaceted burdens – psychological, social, physical and financial – experienced by informal caregivers of MND patients in South Africa. To the best of our knowledge, this study represents the first qualitative inquiry of its kind focused on South African caregivers aged 18 and older, offering vital insights into a critically understudied area of care.

Research methods and design

Participants

The study included 17 informal caregivers of people living with MND, all of whom identified as white people. The sample was predominantly female (95%), aged 31–76 years (median: 53). Most (94%) cared for male recipients and had a direct familial tie, including wives ($n = 10$), daughters ($n = 2$), a sister, a husband, a granddaughter, and two women who were in a relationship with the patient.

Regarding marital status, 11 were married or in a relationship, 4 were widowed and 2 were single. Employment varied: 7 were employed, 3 self-employed, and 7 unemployed. 14 participants had children while caregiving.

Caregiving duration ranged from 7 months to 4 years (average: 2 years, 2 months). At data collection, 76.5% were still actively caregiving, while 23.5% had completed their role because of the care-recipient's death.

Interviews

Interviews were conducted online because of caregiving demands, with one held in person. Interviews lasted 45 to 90 min, were recorded digitally and transcribed verbatim.

A semi-structured format was used. The first section invited participants to share their caregiving experiences, from diagnosis to daily challenges, while the interviewer ensured focus and opportunity for emotional expression.

The second section addressed predefined topics such as emotional and physical burden, financial strain, social support, coping mechanisms and healthcare experiences. The guide was refined throughout to support comprehensive data collection. While it provided structure, interviews remained flexible to capture individual perspectives.

Data analysis

The analysis followed a systematic approach, beginning with familiarisation through re-reading transcripts and revisiting recordings. Braun and Clarke's six-step thematic analysis method was applied (Braun & Clarke 2006). In the initial phase, we generated codes by identifying key concepts. These were grouped into broader themes, which were reviewed and refined through multiple analysis rounds. Redundant or irrelevant themes were discarded. In the final phase, themes were applied to the full dataset and validated by revisiting transcripts to ensure accurate representation of caregiver experiences. This process resulted in a refined set of themes presented in the final report.

Ethical considerations

Ethical clearance to conduct this study was obtained from the Psychology Departmental Ethics Screening Committee (DESC) and the Health Research Ethics Committee of Stellenbosch University (No. S23/04/089). Because of the study's sensitive nature, ethical protocols ensured participant well-being and confidentiality. Distressed participants were offered immediate termination of interviews and referred to no-cost support services, including Lifeline and the South African Depression and Anxiety Group (SADAG). Follow-up support was provided when consented to. Participants were informed that pseudonyms would be used in all outputs, and detailed information was given regarding recording, transcription and data access procedures.

Results

To interpret the patterns of caregiver burden identified in the data, we applied Hoenig and Hamilton's (1966) framework of Objective and Subjective Burden of Care.

Lack of knowledge about motor neuron disease

A notable challenge reported by informal caregivers was their limited understanding of MND, compounded by broader community ignorance. For many, the initial diagnosis brought confusion and uncertainty. Participants described the disease as *very confusing* and caregiving as *new territory* that they had to navigate with little preparation. Several stressed the absence of formal instruction, saying they themselves:

> '… literally had to learn everything'. (P1, 63, female)
>
> '… there's no textbook on how to care for an MND patient, especially one on life support.' (P1, 63, female)

Most caregivers relied on trial and error to manage complex needs; only one had the rare chance to attend a workshop. This knowledge gap contributed significantly to emotional distress, with one caregiver describing the experience as:

> '… becoming numb with the realisation that I really don't know how to do this … what am I doing right, what am I doing wrong?' (P2, 70, female)

Communication challenges with care recipients heightened feelings of isolation.

Beyond personal knowledge gaps, caregivers highlighted public misunderstanding of MND as a major obstacle.

One caregiver stated:

> '… people are sympathetic but not really understanding because there's not much knowledge about what this is.' (P3, 31, female)

Another participant described difficulties with institutions, yet staff often failed to accommodate these limitations, explaining that:

> '… when you have MND, you can't sign, and you can't speak.' (P4, 48, female)

Misidentification of MND as other, more familiar conditions, such as multiple sclerosis, further demonstrated the widespread lack of awareness and contributed to caregiver frustration.

Participants strongly emphasised the need for increased public and professional education regarding MND. These narratives illustrate not only the practical difficulties associated with caring for an individual with MND but also the urgent need for greater societal awareness, professional training and systemic support to meet the unique demands of MND caregiving.

Loadshedding

Another challenge experienced by informal caregivers of individuals with MND in South Africa was the persistent issue of loadshedding. Loadshedding, often experienced in developing countries as a result of limitations in electricity generation capacity, involves scheduled power outages that disconnect large sections of the grid, leaving households without electricity for extended periods (Oluwasuji et al. 2020). For MND caregivers, this disruption posed life-threatening risks because of patients' dependence on electricity-powered medical equipment. One such device is the bilevel positive airway pressure (BiPAP) machine, a non-invasive ventilation system essential for supporting the breathing of MND patients. During outages, BiPAP machines become inoperable, triggering intense anxiety and panic among caregivers. One caregiver recalled:

> 'He used to get suffocated with the BiPAP when the power went off. I'd be at the chemist and just freak out, calling home to make sure they'd taken it off in time.' (P5, 76, female)

The psychological burden of these outages was considerable, leaving caregivers in a constant state of hypervigilance and fear. Even attempts to mitigate these risks by using inverters were often insufficient. One caregiver explained:

> 'The inverter with all the machines only lasts under 2 h, but loadshedding can go on for six.' (P6, 49, female)

This unpredictability compounded psychological distress, forcing caregivers to manage both the physical consequences of outages and the ongoing emotional strain of being constantly on alert.

Caregivers unanimously felt that solar power was the only sustainable solution, offering reliable electricity and much-needed peace of mind amid the ongoing energy instability.

Difficulties with medical staff

Caregivers of individuals with MND expressed deep frustration and emotional exhaustion over interactions with medical professionals. A common theme was a lack of empathy, guidance and understanding. Doctors were often described as blunt and uncommunicative, with little regard for the emotional impact of a terminal diagnosis. One caregiver recounted the doctor's detached delivery:

> 'It is a terminal disease and he probably has 8 months to 5 years to live [before ending the consultation, leaving the family to] go and google this disease.' (P7, 49, female)

Another likened the experience to being:

> '… dropped in the middle of the ocean and left for the sharks.' (P1, 63, female)

Such encounters heightened distress and isolation.

Nurses, too, were often untrained in MND care, adding to caregivers' burdens. Participants described having to guide staff on basic procedures, such as preventing pressure sores or communicating with non-verbal patients.

One caregiver recalled a nurse asking her to spell *'motor neuron'* to look it up online. Misperceptions about patients' cognition were common, with staff sometimes treating patients as *'stupid'*, despite their being cognitively intact. One caregiver shared how her sister, unable to speak, mouthed that she was hungry, only for nurses to *'laugh and walk away'*. These dismissive and dehumanising interactions fostered mistrust.

In one instance, a caregiver's concerns were dismissed until she reminded staff:

> 'You're not dealing with a dog that you wheel into theatre … She's a human being with feelings and emotions.' (P6, 49, female)

Another participant described the experience as *'very robotic'* and lacking support, comfort and empathy.

Perceived loss

Caregivers reported that MND profoundly disrupted spousal relationships, replacing emotional intimacy with clinical responsibility. Many described the painful shift from partner to caregiver, feeling *'cut off'* and emotionally estranged. Fleeting moments of normalcy were overshadowed by caregiving demands:

> 'You get a bit of normal when socialising, but then it's back to the daily grind.' (P8, 55, female)

Several participants noted that caregiving consumed their identity, creating role confusion and exhaustion. One explained:

> 'Some days you're a caregiver, some days a friend, and some days maybe a partner – but it's difficult.' (P7, 49, female)

Intimacy eroded under the weight of daily care tasks:

> 'When you're dealing with poop and stuff, it does change things.' (P8, 55, female)

This burden extended to caregivers' sense of self, with grief over lost interests and identities. One said:

> 'I've lost interest in things I used to love … too many balls to juggle.' (P6, 49, female)

Another added:

> 'I don't even get half an hour a day to myself.' (P9, 60, female)

Former hobbies and self-care were sacrificed, leading to personal depletion:

> 'I don't feel like I'm 100% anymore.' (P3, 31, female)

Collectively, these accounts highlight the psychological burden of caregiving: loss of intimacy, identity erosion, and ongoing emotional and physical strain, compounded by limited support.

Physical burden

Informal caregivers experienced significant physical strain, mainly because of disrupted sleep and constant nighttime caregiving demands. Many described waking up hourly to assist with basic needs, leaving them exhausted during the day. One caregiver shared:

> 'I'm literally awake every hour checking on him.' (P1, 63, female)

Balancing work and caregiving compounded this fatigue:

> 'By the time I drive an hour in traffic and start the evening routine, then I'm further drained.' (P10, 38, female)

In addition to fatigue, caregivers experienced physical strain from lifting and assisting their loved ones, often leading to back and neck problems. One caregiver noted:

> 'I neglected my own health because of my husband's illness.' (P5, 76, female)

Poor posture over time aggravated these issues:

> 'My head is always tilted because I have to maintain eye contact or observe him.' (P1, 63, female)

Some participants received medical warnings about potential long-term health impacts, including autoimmune diseases, because of a lack of rest. Despite this, finding time for self-care or medical attention was challenging. One caregiver explained:

> 'I've had a bad knee for 2 years … I was more concerned about him.' (P5, 76, female)

While one male caregiver reported becoming fitter because of the physical demands, the overall toll on caregivers' health and well-being was considerable. One concluded:

> 'By the time I go to bed, there's nothing left.' (P10, 38, female)

Social burden

Caregivers of individuals with MND experienced significant social burden, marked by isolation, strained relationships and emotional fatigue. All participants reported a decline in social life because of caregiving demands.

Even brief moments of socialisation were overshadowed by guilt and anxiety. One caregiver shared:

> 'I always felt guilty because you didn't know how much time you had left with them.' (P5, 76, female)

While another said:

> 'It was difficult to socialise and pretend to be happy … It was more torture for me than enjoyment.' (P6, 49, female)

Many described increasing isolation, both practical and emotional. One participant explained:

> 'I literally go to Spar, go to the chemist … and I'll come home. So I don't actually interact with anybody really.' (P11, 70, female)

Others withdrew socially for extended periods:

> 'I didn't do anything for the 1st year because I cared for him on my own with the kids' help.' (P10, 38, female)

Time constraints and exhaustion left caregivers without energy or opportunity to engage socially.

Participants also expressed anxiety about emergencies occurring while away, stating:

> 'Nobody will know what to do if there's a crisis.' (P1, 63, female)

Furthermore, asking others for help often provoked guilt:

> 'I just feel that I can't burden everybody every time … It's not fair.' (P6, 49, female)

Physical accessibility also posed challenges with:

> '… not many places are wheelchair friendly.' (P12, 53, female)

Even when socialising was possible, caregivers noted strict time limits:

> 'Everything's got a maximum of 2 h … he gets way too tired after that.' (P4, 48, female)

The combined effects of isolation, fatigue and strained relationships left caregivers feeling detached from their communities. One participant concluded:

> 'It is like we are just left alone to deal with this and make our own plan.' (P7, 49, female)

Financial burden

Participants consistently reported severe financial strain following an MND diagnosis. All care recipients had been employed before diagnosis, and the resulting loss of income placed immense pressure on families. This burden was worsened by the high cost of essential equipment and ongoing medical expenses.

Caregivers highlighted the unaffordability of medication, described as *'exorbitantly expensive'*, alongside specialised equipment required for care. Financial strain was further compounded by emergency medical needs and limited medical aid coverage. One caregiver reflected:

> 'It turns out that my mum saved every penny of her life for her life, in order to facilitate the end of her life. She didn't get to enjoy her money at all.' (P4, 48, female)

Medical aid schemes in South Africa were widely seen as inadequate. Participants reported being denied funding for essential items and services, including communication devices and home-based care. One caregiver remarked sarcastically with frustration:

> 'Communicating with your doctors and your family's a luxury, hmm.' (P6, 49, female)

Participants also expressed a sense of abandonment by the healthcare system and called for policy reform to better support families affected by MND.

Emotional burden

Caregivers of individuals with MND experienced a range of emotional burdens, including anxiety, depression, anger and guilt. Anxiety was constant, driven by fear and uncertainty. One caregiver stated:

> 'Every phone call, you think, is this it?' while another said, 'I dread falling asleep because I'm afraid of waking up and what the next day will bring.' (P11, 70, female)

Depression was also common, with caregivers describing persistent sadness and anticipatory grief:

> 'It's like physically watching your loved one slowly being eaten away.' (P13, 49, male)

Anger and frustration arose as caregivers grappled with life changes. One said:

> 'You want to really give the ***ing universe a finger. ' (P11, 70, female)

While another admitted:

> 'I can really lash out when I'm in an angry state.' (P14, 48, female)

Though mentioned less often, guilt remained a burden. Some participants felt torn between caregiving and other roles:

> 'I often feel guilty because I can't do many activities.' (P14, 48, female)

Others questioned their adequacy:

> 'I just don't think I'm cut out to be a nurse.' (P8, 55, female)

Together, these reflections highlight the psychological toll of caregiving: chronic emotional strain, grief and inner turmoil, underscoring the need for greater emotional support.

Discussion

This study aimed to deepen the understanding of informal caregiving for individuals with MND, aligning with prior research by Kavanaugh, Henning and Mochan (2021). It revealed that caregivers experience diverse subjective and objective burdens shaped by contextual factors. This discussion compares the results with existing literature to enhance caregiving insights.

Circumstantial challenges

Caregiving for individuals with MND is impacted by both the disease's demands and caregivers' personal and environmental circumstances. This study uses 'circumstantial challenges' to describe these burdens. Most participants were women with a median age of 53, similar to international findings (Conroy et al. 2021; Galvin et al. 2018). Younger caregivers balancing work and children reported higher stress, while older, often retired caregivers experienced less burden (Chiao, Wu & Hsiao 2015). Women described more emotional strain, reflecting previous research (Revenson et al. 2016). These factors compound the challenges of MND caregiving.

Limited knowledge about MND added to emotional and practical strain. Participants reported confusion about the disease, echoing international literature (Tang et al. 2021). The lack of accessible information in South Africa worsened this, highlighting the need for educational interventions (Alankaya & Karadakovan 2015). This knowledge gap led to self-doubt among caregivers, while poor community awareness created additional administrative challenges.

A unique challenge was loadshedding, previously unexplored in caregiving research. Power outages heightened anxiety, especially for those using power-dependent medical devices. This finding aligns with Bentley (2023) and Marchetti-Mercer (2023), who noted loadshedding's psychological distress. This study extends those findings by showing caregivers' fear of life-threatening risks during outages. Alternatives such as inverters were often unaffordable, underscoring the need for reliable power.

Experiences of objective burden

The objective burden of care includes tangible demands such as time, physical effort and financial costs (Jones 1996), which are central to the caregiving experience and linked to perceived burden (Gallant 2017). Schene, Tessler and Gamache (1994) identify four areas this burden manifests: (1) direct caregiving tasks, (2) indirect responsibilities, (3) managing emotional needs, and (4) daily life disruptions. This study's findings reflect all four.

Physical strain was common, with caregivers reporting exhaustion, musculoskeletal pain and injuries, especially older women caring for larger male patients, consistent with MND's higher male prevalence (Daude & Chowdhury 2017; Henning et al. 2021). Sleep deprivation and stress worsened these issues, with women more vulnerable than men (Revenson et al. 2016).

Social disruptions and indirect responsibilities were significant. Caregivers experienced isolation because of a lack of time and energy for social life, avoiding events because of guilt, a lack of enjoyment and mental preoccupation (Thrush & Hyder 2014), all of which indicate the impact of caregiving on physical and social well-being.

Financial strain was another major burden. Most caregivers lost income, with many leaving jobs for full-time care. Medical and equipment costs were high, compounded by limited welfare support and exclusion of MND from medical aid 'dreaded disease' lists, leaving caregivers unsupported (Malakoane et al. 2020; Statistics South Africa 2019).

Healthcare difficulties further compounded the objective burden. Caregivers described poor support from professionals at diagnosis and post-diagnosis (Aoun et al. 2016; O'Brien et al. 2011). Limited resources and high patient load in South Africa's health system likely contribute to care gaps (Kipp et al. 2007). Untrained staff and occasional unprofessional conduct increased strain, with caregivers sometimes providing basic care themselves (Kisorio & Langley 2019). These findings highlight the urgent need for improved MND training, communication and empathy among healthcare providers to support patients and caregivers.

Experiences of subjective burden

Subjective burden refers to caregivers' personal evaluations of their circumstances and the perceived demands of caregiving (Liu, Heffernan & Tan 2020). Schene et al. (1994) describe subjective burden as distress, guilt, worry, shame and stigma, often triggered by caregiving's physical and logistical demands. In this study, caregivers reported subjective burdens across daily life, encapsulated in three themes: loss of self and love, guilt, and emotional strain.

The first theme was a perceived loss of self and love, especially among spousal caregivers. Participants described sacrificing careers, social lives and interests, resulting in diminished identity. Nearly half of those in relationships noted reduced affection as roles shifted from partner to caregiver. This loss of intimacy led to emotional fatigue and loneliness (Oh, Kim & Chu 2021; Thrush & Hyder 2014). Though not a traditional sub-theme, this loss regularly triggered distress and relational strain, thereby justifying its inclusion.

Guilt also emerged as a prevalent emotional response. Caregivers stated that they felt guilty for prioritising their needs or comparing themselves to others. Guilt, as defined by Losada et al. (2010), arises from perceived failure to meet expectations. A lack of support intensified these feelings, increasing self-blame and exhaustion (Muro Pérez-Aradros et al. 2023). Evidence suggests that psycho-educational interventions that build confidence and knowledge may help reduce guilt and improve caregiver coping (Gallego-Alberto et al. 2021; Theißen et al. 2024).

The broader emotional impact included persistent worry, sadness and frustration, especially during diagnosis.

Notably, 88% experienced delayed diagnoses, higher than global averages, exacerbating distress and reducing trust in healthcare (Donaghy et al. 2008). Emotional strain remained high throughout the disease trajectory, with many caregivers describing symptoms of depression and psychological overwhelm (Soundy & Condon 2015; Trail et al. 2003). These needs were often overlooked, reinforcing what Adelman et al. (2014) call the 'invisible patient'. Worry was linked to MND's unpredictable progression (Flemming et al. 2020). Many caregivers also reported frustration with loss of autonomy, but often suppressed these feelings, intensifying distress.

A thorough understanding of subjective burden is key to effective intervention. Braithwaite (1992) argues that recognising internal experiences reveals stressors often overlooked by focusing on objective burden alone. Themes such as loss of self, guilt and emotional fatigue should inform support strategies addressing both visible and hidden aspects of caregiving.

Strengths and limitations

This study addresses a gap in South African research by exploring adult informal caregivers of individuals with MND, a group often overlooked in favour of younger caregivers or high-income country populations. It provides local insights into caregivers' emotional and practical challenges in a resource-limited context and lays a foundation for future intervention research. Using interviews enabled rich, nuanced data, enhancing the authenticity of participants' accounts. However, the small, mostly female and racially homogenous sample limits generalisability. The demographic composition of the participants, predominantly white, female caregivers, likely reflects a more resource-advantaged subgroup within the broader South African context, which may have influenced the perspectives and challenges reported. Participants were self-selected, and most were from urban areas, which may not fully reflect the experiences of caregivers in rural regions.

As the study focused solely on the perspectives of informal caregivers, data from other relevant stakeholders, such as healthcare professionals, policymakers and individuals living with MND, were not collected. This limits the ability to capture a more holistic understanding of the caregiving experience.

The lack of local MND caregiving literature made contextualising findings challenging, and conducting interviews exclusively in English may have excluded some participants. Additionally, most interviews were conducted virtually, which, while necessary for accessibility, may have influenced participant comfort and the depth of responses.

Recommendations

Further studies, including quantitative research and formal needs assessments, are urgently needed to better support informal MND caregivers in South Africa. Given that this study was based on a small, relatively homogeneous sample of predominantly white, female caregivers, the recommendations below should be interpreted within this demographic context. The insights primarily reflect the experiences of caregivers with similar socio-economic and cultural backgrounds and therefore require validation across more diverse populations.

This study revealed significant emotional, financial and systemic burdens, including inadequate post-diagnostic support, lack of empathetic healthcare and high isolation. Findings highlight the need for psycho-educational interventions and accessible support groups to address caregivers' distress and lack of guidance. To enhance the practical implementation of such initiatives, collaboration among key stakeholders, including the Department of Health, NGOs, professional training institutions and community-based organisations, is recommended.

Improved healthcare professional training is recommended to raise awareness and responsiveness, as poor communication and MND knowledge were common concerns. Community awareness initiatives are needed to reduce stigma and exclusion. However, these proposed interventions should be viewed as preliminary and most applicable to caregivers similar to those represented in this study. Broader research involving caregivers from varied racial, linguistic and socio-economic groups, as well as perspectives from other stakeholders, is essential to further refine and generalise these recommendations.

Furthermore, financial support, such as equipment subsidies and medical aid reforms, is essential to ease costs and employment sacrifices reported by many caregivers. Future policy work should consider the feasibility and equity implications of these recommendations across the diverse South African caregiving population.

Conclusion

Informal caregiving for individuals with MND has a profound emotional, social and financial impact. This study underscores the urgent need for improved support systems, policies and societal understanding to improve the well-being of caregivers. By addressing these gaps, we can work towards building a more inclusive and compassionate society for both caregivers and care recipients in South Africa.

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

CRediT authorship contribution

Bailey Allan: Conceptualisation, Methodology, Writing – original draft. Ashraf Kagee: Methodology, Writing – original draft, Writing – review & editing.

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Data availability

The data that support the findings of this study are not openly available because of the sensitivity, and are available from the corresponding author, Ashraf Kagee, upon reasonable request.

Disclaimer

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