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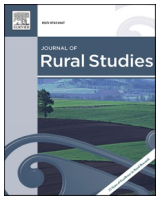

Landscapes of care for dementia in rural South Africa

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ABSTRACT

How does place shape informal caregiving for and by ageing people with cognitive impairment in rural South Africa? Drawing on the care ecology framework, relational conceptualisations of "landscapes," and ethnographic research, we illustrate the complexity of informal caregiving for people living with dementia through a case study of 59-year-old Nonisa, who often became confused and forgetful and would sometimes become lost. In Nonisa's rural village, community members drew on historically produced and embodied knowledge and emotions to intervene in beneficial ways, preventing Nonisa wandering far afield, helping to search for her, and/or finding her and returning her home if she became disoriented or lost. When Nonisa disappeared in a major city, she was found by the police, but identifying her via social media and getting her home relied on an informal network of rural community members who knew Nonisa. Faced with an increasing need for someone to consistently watch over Nonisa and ensure her safety, her family unsuccessfully sought access to a government grant to pay a caregiver. We discuss Nonisa's rural village as a diffusely-bounded, networked landscape of care. We highlight how, in addition to physical paths and emotional bonds, cognitive ties and embodied knowledge between people in the caringscape (informal care system) connected locations at different scales and facilitated caregiving, in beneficial ways. Conversely, passive neglect in the formal care system had detrimental effects. We discuss the implications of this for ageing in place in resource-constrained rural communities.

1. Introduction

Social policies and plans have widely advocated "ageing in place" for older people, with the ideal of people residing for as long as possible in their own homes (Clark et al., 2020; Wiley et al., 2012). Worldwide, in any case, a minority receives care in formal (i.e. government, for-profit and other institutional) settings. The majority of older people have no alternative but to live and age in place, primarily receiving care informally from family, friends and other non-institutional actors. Yet little attention has been given to how care for older people is negotiated and what this involves. Many older people age in rural places with rudimentary housing and facilities, with limited formal state-provided health, transport and other services; this is often assumed to be balanced by being more socially supportive than urban settings (Roberts et al., 2023; Róin, 2015; Winterton and Warburton, 2012). This is arguably a sentimental characterisation of 'rural' compared with urban. Even so, we are interested in how smaller communities, as exist in rural areas, work to support older people requiring care.

Bowlby and McKie (2019) conceptualise informal and formal care "systems" (respectively termed "caringscapes" and "carescapes") spatially, as dynamically interacting parts of a "care ecology." Their care ecology framework builds on the concept of relational "landscapes of care," whereby "landscapes" are networks of relations between people, places and objects (Conradson, 2005; Cummins et al., 2007). Places, as diffusely-bounded networked locations, are connected physically and affectively to each other at multiple scales (domestic, community, local, etc.), through "lines of coordination and control" (Massey, 2004) and flows of information and other resources (Cummins et al., 2007). Places are translocal, that is, interconnected parts of a single system, and mutually constituted; local happenings exert influence at different scales, as global happenings exert effects on local events and circumstances (Massey, 2004).

Landscapes of care are more than physical locations. They are "complex social, embodied and organisational spatialities that emerge from and through relationships of care" (Milligan and Wiles, 2010, p. 736), which are shaped by and shape unequal relations of power

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(Bowlby and McKie, 2019). Human interactions invoke emotional responses. For example, a person may come to feel responsible to care for an elderly neighbour who they see and greet every day; the older person may feel safer knowing their neighbour is watching out for them. Relational approaches account for these affective dimensions of human interaction (Thien, 2005). The concept of landscape accounts for effects exerted by non-human actors, including natural and constructed spaces and the relationships between them. From a landscape perspective, effects are not inherent features of a physical landscape but relational outcomes which arise from embodied experiences interacting in particular socio-natural-material locations. How a landscape affects an individual, such as by influencing the types of care they are able to give and receive, is person-specific; what is beneficial for one person may be detrimental for another (Conradson, 2005). For older people, the nature of effects (and affects) arising from relationships of care within a given landscape may be influenced by health experiences, such as living with dementia or other conditions.

Dementia is associated with ageing and characterised by progressive cognitive decline. It is characterised by forgetfulness, confusion, disorientation and agitation. People with dementia are prone to get lost, even in once familiar environments, and getting lost carries significant distress, injury and mortality risks (Robinson et al., 2007). Because disorientation and confusion are highly unpredictable, people with dementia have particular needs for constant albeit passive supervisory care to prevent them getting lost. They may also need caregivers to mobilise rapidly to provide care if they get lost (Rowe et al., 2011; Thoma-Lürken et al., 2018).

The benefits of ageing in place for people with dementia stem partly from them being in a landscape which offers a "relational sense of place" (Clark et al., 2020, p. 112927), that is, physical and emotional proximity to familiar, recognisable and meaningful people and places. Familiar physical features of natural and constructed landscapes such as a sign or tree may facilitate wayfinding, and enable people with dementia to continue to walk around alone (Brittain et al., 2010; Clark et al., 2020). Familiar places, including family homes, also contain material items such as furnishings and mementos through which people remember and maintain their identities and wellbeing (Róin, 2015; Winterton and Warburton, 2012).

Living amidst familiar people is also beneficial for people with dementia because shared social history and practical knowledge assist those who provide care. Acts of care occur between people who know each other well enough to feel a responsibility to care, have enough knowledge of each other to be able to care, and have empathy which enables anticipatory and responsive acts of care (Brittain et al., 2010; Clark et al., 2020; Massey, 2004). Being familiar with and knowledgeable about a person with dementia enables acts of care (Brownlie and Spandler, 2018), such as greeting or keeping an eye on a neighbour, or guiding them home if they become disoriented. Geographic proximity often produces affective ties — social and emotional proximity between people — and a sense of responsibility to care for them (Clark et al., 2020; Massey, 2004; Milligan and Wiles, 2010). For people with dementia, being physically close to familiar others may enhance agency and enable relatively safe risk-taking, for example, walking or living at home independently. Small acts of care, such as keeping an eye out to ensure a person with dementia does not walk away and get lost, or that a stranger does not enter their home, enable this agency (Clark et al., 2020; Marsh et al., 2018; Thoma-Lürken et al., 2018). Feeling a relational sense of place may also be beneficial for people with dementia because it enables them to reciprocate care in identity enhancing ways, for example, by greeting neighbours, watching out for neighbours' pets or property, or talking to children (Clark et al., 2020).

Landscapes may also have detrimental elements (Brittain et al., 2010; Dyck et al., 2005; Milligan and Wiles, 2010). Change can be disorienting for people with dementia and others, who often rely on familiar people and structures to guide and give them a sense of belonging and safety. Recurring seasonal dynamics such as changes in how people dress in winter or summer, as well as one-off changes such as the construction or demolition of a road or sign, or death or emigration of a familiar person, can be frightening (Brittain et al., 2010; Clark et al., 2020). Caregivers may invoke a sense of anxiety that inhibits independence, such that a person might become too afraid to take a walk (Brittain et al., 2010). Rural landscapes of care may be characterised by material scarcity, which makes accessing health and other essential services challenging and expensive (Róin, 2015). Family homes and other community settings may be landscapes of physical, emotion, structural and other types of violence, underpinned by power inequities based on race, age, gender and other personal characteristics (Thelen, 2021). Conditions such as dementia are misunderstood and stigmatised in some places, and in certain African settings people with dementia may be subject to violence (Adebiyi et al., 2016; Jacobs et al., 2022).

Whether in a home or institution, or a rural or urban area, the landscapes approach highlights the significance of social and material aspects of the "place" where care is provided (Milligan and Wiles, 2010). Yet little is known about how socio-material landscapes shape the experience of ageing in place (Brittain et al., 2010; Clark et al., 2020; Marsh et al., 2018; Thoma-Lürken et al., 2018; Wiley et al., 2012). We present an ethnographic case study about caregiving for a woman with dementia in a rural South African setting. Nonisa (pseudonym), 59-years-old, experienced confusion, forgetfulness and disorientation. She relied primarily on informal care from relatives and others in the rural community where she lived. She walked, got lost, and was found several times in a year. We analyse her experiences to draw out how Nonisa's small community organised to care for her, and how processes embedded in networks of relations between people, places, materials and care, within formal (carescape) and informal (caringscape) care systems, exerted effects on her wellbeing and her agency to successfully age in place.

2. Methods

Our data were collected within "Kaya" (Manderson et al., 2022), a mixed-method study of informal caregiving for people with dementia conducted within the Agincourt Demographic and Health Surveillance site (HDSS), which constitutes 30 rural villages in Bushbuckridge Municipality in north-eastern Mpumalanga, South Africa (Kahn et al., 2012). The HDSS is an umbrella for several large studies including HAALSI (Health and Ageing in Africa – A longitudinal study in South Africa) (Gómez-Olivé et al., 2018). HAALSI includes a population-representative, longitudinal sub-study of the prevalence and incidence of dementia (HAALSI-Dementia) (Bassil et al., 2022), within which Kaya was nested. Kaya received ethical approval from the University of the Witwatersrand Human Research Eithics Committee (Medical- approval number M200373) and Mpumalanga Province Health Department- Health Research Committee (MP_202201_004)).

During apartheid, laws such as the Group Areas Act designated Agincourt a bantustan, that is, a segregated, self-governing territory for Black people, in this case people of Shangaan/Vatsonga ethnicity. Black people who migrated to work in South African cities, mines and farms maintained links with family who remained in their designated bantustan, and they were required to return annually. This pattern of "circular" migration and maintenance of ties with a rural homestead persists despite the abolition of the Group Areas Act. Thirty years after the end of apartheid, the former bantustans, including the villages in which the study took place, remain especially poor, with limited public infrastructure and services and high levels of unemployment.

Kaya included ethnographic research with 21 purposively sampled participants who had self-identified as the primary caregivers of people predicted, based on the results of the HAALSI dementia surveys, to have mild cognitive impairment or dementia. These caregivers largely lived with the care recipients, and they were recruited individually following home visits and discussions, formal invitation and their provision of written informed consent. The ethnographic fieldwork, conducted by

Author 1 (Michelle) and Author 2 (Themby) a Shangaan-speaking research assistant, primarily used participant observation to document informal conversations and observations of daily life events during interactions with the caregiver participants, the people for whom they cared, and others in their social network, for 9–12 months. Although we initially intended to conduct and audio-record numerous formal interviews with caregivers, we consciously limited audio recording after noticing that participants often spoke formally and provided superficial descriptions when being audio recorded.

Among participants and care recipients, very few — two designated care recipients and one designated caregiver — showed signs of cognitive impairment; other care recipients appeared not to have memory problems. Nonisa's caregiving network was selected as the focus of the ethnographic case study we present herein because it was a "critical case", that is, one involving extreme experiences of dementia that might be considered "outliers" in large statistical studies that homogenise the experiences of heterogenous groups (e.g. people with dementia) (Flyvbjerg, 2013). Ethnographic case studies involve examining a single case intensively, in context and often for an extended period of time. The results are not intended to be generalised to a broader population, nor to produce predictive or explanatory theories (Flyvbjerg, 2013). Rather, they are intended to provide intimate and detailed information to support claims and propositions made in relation to the case, and their potential relevance to contexts beyond the case (Longhofer, Floersch and Hartmann, 2017). This approach may highlight limitations in conventional thinking, reveal unexpected processes or outcomes, and/or advance understanding of complex social phenomena (Flyvbjerg, 2013).

Nonisa was designated a caregiver within Kaya, but, while never diagnosed with cognitive impairment, her behaviours were consistent with dementia and she relied on care given by family and friends. Michelle and Themby visited and interacted with them regularly. Michelle made notes about what she saw and heard during each visit, and later expanded and transcribed the field notes which detailed 14 h of face-to-face interactions and several telephone conversations. She also conducted a 90-min audio recorded interview with Rhulani, Nonisa's father-in-law, who was one of her caregivers. Michelle drew on this data to generate a summary narrative detailing Nonisa's "landscape of care". We describe and analyse this data to characterise the relationships of people, places, caregiving practices and their effects, with reference to the informal (carescape) and formal (caringscape) components of Nonisa's landscape of care.

3. Findings – Nonisa and Rhulani

Nonisa and her 92-year-old father-in-law Rhulani lived about 400 m or 5 min' walk away from each other, in a village named Musha (pseudonym). Musha was created during the 1950s, when the Group Areas Act was being implemented. Rhulani told us that Nonisa had moved to live there in the 1980s, with a friend from her parental home village, located about 50 km away. Nonisa's friend married the owner of the local supermarket and Nonisa married Rhulani's first born son, who for much of his time worked as a driver in Johannesburg, a city some 450 km away. Nonisa's husband died in 2006, around the same time Nonisa's memory problems started. Rhulani told us he and his wife had been "buying food for her ever since," and visited to check on her regularly. From October 2022, after Rhulani's wife died too, Rhulani and Nonisa kept each other company, visiting daily and helping each other with domestic and agricultural work.

We (Michelle and Themby) had known Nonisa and Rhulani for about six months when Rhulani first expressed concern about Nonisa because:

> We know that her husband has passed away but she was talking as if her husband is still alive … She will go to the forest to get some firewood but she will come back here carrying only one branch. When we ask her 'Why are you going to the forest? … you will get lost.' She says … 'because I want to … warm water for my husband so that he can bath.' … and she also talks about her mother – and her mother has also passed away … Sometimes she can … go with her grandchild, but along the way she will chase the grandchild, saying 'I don't know you, who are you? I did not come with you.' And when she goes to the shop to buy, she will buy and end up leaving the stuff there. And when we ask her, she will say 'I did not go to the shops'.

We had initially missed Nonisa's memory problem partly because she was good at hiding it. The first day, when we visited hoping to recruit her into our study, we found Nonisa in the yard and she welcomed us with a smile. When we asked if she was the woman we were looking for, she said, no, Nonisa didn't live there, we must be in the wrong place. A moment later she laughed out loud, told us she was joking, and identified herself as Nonisa. She agreed to participate and we stayed for a chat, which she seemed to enjoy and prolonged each time we indicated that we had to leave. During this chat we asked about her late husband. She replied: "He's not dead, he lives and works in Gauteng." Embarrassed, we forgot that Rhulani had told us about caring for Nonisa since her husband's death. We listened as Nonisa told us about driving to Johannesburg to visit her husband just weeks before, in the car he had given her.

We continued visiting Nonisa and asking about her caregiving for Rhulani. She would welcome us warmly, as if we were old friends. Although she never used our names or gave any specific indication she remembered who we were, her manner and the comments she made implied familiarity and friendliness. She would tell us how nice it was to see us and what a long time it had been since we last visited, shaking our hands or giving us a hug. Yet other things suggested a serious forgetfulness that Nonisa seemed to be trying to cover up. She would repeat stories, often with inconsistencies. She would refer to the same people by different names and relationships; a co-resident adolescent girl, who Nonisa introduced as her sister, told us she was Nonisa's granddaughter.

We visited Rhulani, hoping to find out more about Nonisa's memory. Nonisa accompanied us and interacted affectionately with different people in Rhulani's homestead. She laughed when Rhulani's co-resident grandson Life greeted her "Sis' Nonisa" and teased her about going around with a "white friend" (Michelle); she greeted people who came from working in Rhulani's fields in a friendly manner, with the same warmth she used when she shouted greetings to neighbours and passers-by at her own house. But her demeanour changed rapidly, as we discussed with Rhulani, her forgetfulness.

Nonisa sat quietly in the corner, looking sheepish, when Rhulani announced, unprompted, that he was worried about Nonisa forgetting, especially when that resulted in her getting lost in the forest when she went to cut firewood. It had happened several times and Rhulani would search and find her sitting lost in the forest and take her home. He ordered Nonisa not to go to the forest, and started cutting firewood for her. When that did not keep her at home, Rhulani tried to scare Nonisa, telling her that thugs were hiding in the forest and might harm her.

Rhulani wanted to hire a caregiver for Nonisa. As he could not afford this from his meagre income — he relied solely on the South African Government Older Person's Grant of ZAR2100 (~US110) per month — he asked his children (Nonisa's siblings-in-law) to contribute money. They refused, telling Rhulani that Nonisa was his daughter-in-law and his responsibility. As we will describe, Rhulani decided to apply for the grant-in-aid to help pay a caregiver, as he felt it was unsafe for Nonisa to stay alone with only "children" who he considered irresponsible and unable to care for her properly.

Nonisa lived with her first-born daughter Praises (35-years-old), Praises' adolescent daughter and her infant (respectively Nonisa's grandchild and greatgrandchild), and three grandsons aged approximately 9, 12 and 14. We initially misunderstood these living arrangements, because Praises was always at work when we visited and Nonisa told us her offspring all lived in Johannesburg. When we eventually met Praises, she told us her mother frequently forgot her name and who she was.

Praises, Nonisa's co-resident and primary caregiver, juggled Nonisa's daily care with paid work cooking lunches at the local creche, and caring for her own children. She had attempted to get Nonisa's memory problems assessed and treated locally. After several trips to clinics and hospitals in the area – each visit taking a full day because of distance, transport irregularities, and waiting times – the attending clinician simply told Praises that she must keep loving her mother and caring for her, because her memory problems would not go away. There was no mention of dementia or an alternative diagnosis, and Praises was not given advice about how to care for Nonisa (or herself). Some blood tests were undertaken, but Nonisa lost her clinic card; without the missing card Praises could not retrieve Nonisa's clinic "file" (medical record), which would have included a summary of the consultations and the test results.

In early 2023, Nonisa's other daughter, Rachel, moved Nonisa to stay with and be cared for by her in Johannesburg. "I told her daughter that they must not take her to [the city]. How can she look after her while she is at work? … here at home it is safe … we know each other," Rhulani said. "When they took [Nonisa], they were planning to take her to live there permanently until this incident of her going missing."

Rachel was hoping to get Nonisa's memory problems assessed and managed in the urban public health system. The first step was visiting a clinic, where Nonisa would be assessed by a nurse and provided a medical referral. While waiting at the clinic, Nonisa went to the toilet alone and failed to return. Rachel started to worry. She searched for her mother in the clinic, and when she didn't find her, raised the alarm. Relatives in Johannesburg came to help to search for Nonisa in the clinic and surrounding streets. They called other relatives to see if Nonisa had turned up at their places. There was no sign of her.

Nonisa was found by a security guard the night she disappeared, many kilometres from the clinic, wandering around an upmarket hotel and casino, looking lost. The security guard called the police because he could not communicate in Xitsonga, a minority language spoken by <5 % of South Africans and the only language Nonisa spoke fluently. The police officers could do little more than take Nonisa into their watchful care, because they too could not speak Xitsonga. They had difficulty establishing who Nonisa was and where she was from. When they eventually established she was from Bushbuckridge, the police distributed her photo on social media, and sent it to all police stations in the municipality. By chance a distant relative saw the photo and alerted Nonisa's relatives in Musha.

Nonisa was taken back to Rhulani's homestead by her sister-in-law Katekani, who was married to another of Rhulani's sons and who worked in Johannesburg as a security guard. Katekani and her husband had built a large house in Rhulani's yard, where they stayed during visits home for Christmas, Easter and events such as weddings and funerals; they had plans of eventually returning when they were old enough to retire. Katekani took one week's leave from work to accompany Nonisa home on public transport. She stayed with Nonisa for a week in the house they had built, keeping Nonisa busy during the day, sitting with her and preparing food, while joining other relatives to pray for Nonisa and to discuss what to do. They kept the gate to Rhulani's yard secured with a padlock when no one was available to directly observe Nonisa.

This relatively safe arrangement was always temporary; it could only last while Katekani was on leave from her job in the city. Rhulani would not allow Nonisa to stay at his homestead permanently, despite being worried about sending her home. A week after her return from the city, Nonisa was back living with Praises, her grandchildren and great grandchild. Rhulani reprimanded them for not locking the gate to prevent Nonisa from going to the forest or other places where she might get lost, but they kept leaving it open.

Several months later, twice in the same week, Nonisa walked away from her rural home in a state of confusion and disorientation. The first time she had been left at home with her infant great grandchild, while other householders went to the forest to cut firewood. Rhulani explained:

> The other day when she got lost … she took her grandchild and went to the [local] shop. People saw her and asked her, 'Where are you going?' She said she was going somewhere … then she started chasing the child, saying 'Go away, I did not come with you, I don't know you.' … and one of the neighbours took her to her house [and] sat with her. The other went to school to call her son … and then others came and told me …
>
> [Earlier that week] they found her at the [neighbouring village], .. saying she is going home … to see her mother. But because people know her, somebody … brought her here and she called Nonisa's daughter.
>
> [Some months before, Nonisa was seen in Musha] carrying her bag … [A community member] asked her where she was going. She said she was going to visit her mum. Then [the woman] invited her inside the house. They started to sing church songs and preach until she became calm. And then [the woman] called me.
>
> A lot of people know about her situation and some of them are helping her.

When asked if Nonisa experienced any mistreatment from community members, Rhulani replied, emphatically, "No." He added: "A lot of people like her so much. Most of them invite her to church [they accompany her there] and come back home with her."

Faced with the increasing need to constantly watch over Nonisa, Praises, Rhulani and Life tried to register Nonisa for a grant-in-aid allowance from SASSA [South African Social Security Agency]. This payment of ZAR500 (~USD25) per month is given to those deemed by a medical doctor to require care, to contribute to paying for a caregiver (South African Government, 2023). Rhulani also wanted to apply for the grant himself. We drove and accompanied them to the different places they needed to go to register Nonisa, in order to better understand the process. Rhulani was happy to have our assistance with transport, as public transport in Musha was scarce and using it would have made the process more expensive and cumbersome. We first took them to the local SASSA office — an 18 km round trip — to get a form, which they needed to get signed by the doctor who visited the local public health clinic on Thursdays. We had already stopped and requested the form one day when driving past the office, thinking we could take it to Rhulani and save a special trip. Our request was denied: Nonisa and Rhulani needed to go to the SASSA office themselves, with their identity documents, to collect the form. Our first planned trip to SASSA was postponed; Rhulani's brother had a fatal stroke.

After Rhulani and Nonisa eventually got their forms, we drove them and their nominated caregivers, Life and Praises, the latter with a newborn baby, 4 km to the local clinic on three consecutive Thursdays. Life and Praises went to the clinic because the civil servant at SASSA, a member of Rhulani's extended family, told Rhulani that both he and Nonisa had to go to the clinic with their caregivers, or they would not get their forms signed.

On the first Thursday, we arrived at the clinic gate with Rhulani and Life. Rhulani had just hauled himself out of the backseat when the security guard told us that the doctor was not coming that day. We took them home and went to inform Nonisa and Praises, who were dressed up and waiting to be collected. The next week we stopped at the clinic to check before collecting everyone. It was buzzing with elderly people, who we assumed were at the clinic because they needed to see the doctor. We were told that the doctor had phoned to say that she could not make it again. We went to Rhulani and Nonisa's respective homes to tell them. Praises agreed to try the following week, although she would need to take a day off work: the school holidays were now over. On the third occasion, we dropped Rhulani and Life, then Nonisa, Praises and the baby, at the clinic at about 11am, despite a rumour circulating that again the doctor would not show up. We were unable to wait at the clinic with them because of other commitments.

We suggested that Rhulani, Life and Praises ask the staff to try to find

Nonisa's missing file, using her national identity number, as we had observed clinic staff do this before. Life phoned us quickly to report that the staff could not find Nonisa's file, which included the medical record which detailed her previous visits to the psychologist. Nonisa could only see the doctor if she opened a new file. Although this effectively meant deleting the official record of Nonisa's memory problem and Praises' efforts to get her help, they decided to open a new file so that Nonisa could see the doctor.

Three hours later Life phoned again to ask us to collect them. They had just been informed that the doctor was not coming. We dropped the four of them home, and made a second trip to drop four other elderly women from the clinic back to Musha. The women spoke about how the doctor would have shouted at them if they had not shown up on their scheduled appointment date, but that they could not complain about having wasted their time, money and energy to come to consult a doctor who had not even reported that they were not coming.

Life contacted us a week later to tell us they had managed to get back to the clinic and get the forms signed on the fourth Thursday. From there they went back to SASSA to collect another form, which they needed to have signed by a second doctor at a regional hospital some 30 km away. Life's father provided his utility vehicle, and Life drove Rhulani, Nonisa and several other people from Musha, all trying to apply for the grant-in-aid, to the hospital. Rhulani got his form signed. Nonisa did not: the second doctor said he could not see anything wrong with her. Nonisa had never been to the hospital before, and there was no medical record to confirm her memory problems. The doctor refused to provide the signature that Nonisa needed to be eligible for the grant-in-aid, which would have assisted her family to ensure that someone could stay at home, keep her company, and watch over her.

4. Discussion

Our findings paint an ambivalent picture of the experience of ageing in a rural landscape of care in South Africa. We base our insight on a single ethnographic case, selected purposively because Nonisa's experiences of getting lost with dementia were extreme. This does not represent what all people with dementia in rural South Africa experience, nor the entirety of Nonisa's experience. Despite its extremities, Nonisa's case was typical in the way her dementia presented (albeit with early onset) — symptoms such as forgetting who loved ones were and getting lost in familiar places, are classic dementia symptoms and well-recognised sources of stress for caregivers. The challenges Nonisa and her caregivers faced attempting to get to, and get help from, the public health and social welfare systems were also common in the caregiving networks in our study, albeit more typically for physical health conditions. Her living arrangements in a relatively stable, close-knit rural community, and her experience of being cared for by family members, were also quite ordinary. Our detailed presentation of Nonisa's case highlights limitations in current understandings regarding: the role of cognitive ties based on practical knowledge in networked locations; the spontaneity of care arrangements in response to acute need; and the support for and understanding of people with dementia in rural South Africa.

Nonisa's experiences of giving and receiving care in a particular rural "landscape," and the outcomes of caregiving practices, were profoundly influenced by happenings in other networked locations. This illustrates for South Africa what Clark et al. (2020), following Massey (2004), describe as "translocal" and networked landscapes. Nonisa's case provides insights into the nature and extent of physical and affective ties between networked locations within and between rural and urban areas that Nonisa and her relatives inhabited at different times, and how these influenced caregiving needs, practices and outcomes. Nonisa was emotionally attached to the forest which was linked to her home via physical paths. She walked there because she reminisced about and planned to care for her husband, who she forgot had died. People who cared about Nonisa moved her to places near and far, via roads, in the hope of accessing formal health services. They also moved themselves between networked locations to provide care, epitomised by people searching for Nonisa and taking her back to the safe space of Rhulani's homestead.

In addition to physical and emotional links, we highlight the impact of cognitive ties and proximity between (rural and urban) people in translocal places, in the form of practical knowledge. Local residents knew Nonisa, and knew that she had memory problems; they knew who her family were and where to find them, and knew how to speak her language, Xitsonga. Knowledge of Nonisa's everyday life and cognitive condition, which she was adept at masking by performing familiarity, enabled community members to assist Nonisa, in ways that a doctor, security guard, police officers, and even relatives from Johannesburg, could not. The doctor denied that she had memory problems because he could not see it. Police officers and security guards were unable to communicate effectively with her because they did not know her minority language. Our data suggest that physical, emotional and cognitive proximity are all important, and that when they co-occur, caregiving is optimal. Those able to help Nonisa the most were physically, emotionally and cognitively close. However, when their capability to provide good care relied on distant others in powerful positions, such as the SASSA civil servant or the doctors, closeness was insufficient.

Our findings also provide important insights into "time-space discontinuities" (Bowlby and McKie, 2019, p. 534) — limits to caregivers' capacities to constantly be in the right place to provide care, at the right time — that create potentially dangerous gaps in care for people with dementia such as Nonisa, who rely primarily on the caringscape (informal care system). Time-space discontinuities resulted in gaps in caregiving for Nonisa due to the entirely unpredictable nature of her symptoms. As disorientation and confusion can arise in a person with dementia quickly at any time, there is a need for constant watchful care (Marsh et al., 2018). Nonisa got lost in both the city and her rural village because of short breaks in watchful care. The minutes which it took her to move from the clinic waiting room to the toilet — a time during which her daughter believed she was safe and so could be unattended — was enough for Nonisa to get lost. Getting lost in her rural village followed a slightly longer — but still relatively brief — period when Nonisa was left unattended. Without watchful care, Nonisa moved into spaces where she was at risk; on two occasions her movement also put her infant great grandchild at risk. Risk was averted only because of the spontaneous involvement of members of a peripheral informal caregiving network — people to whom she was physically proximate and with whom she was familiar and had emotional and cognitive ties, produced over decades of interaction.

In small, stable rural settings such as Nonisa's village Musha, the caringscape unconsciously enabled supervised risk taking and provided a safety net when there were gaps in watchful supervision, which inevitably occur when caregiving is informal (Clark et al., 2020; Marsh et al., 2018). Familiar people were able to use their practical knowledge of Nonisa and the village to perform small, beneficial acts of care (Brownlie and Spandler, 2018). Rhulani knew the forest well and could find his daughter-in-law using knowledge developed over years of walking around, herding cattle and cutting firewood. Through decades of interaction with Nonisa and her family members, others too knew her well enough to recognise when she was disoriented and agitated. They knew how to calm her or get her home, or where to find and alert family members to come and get her.

When Nonisa got lost in the city, people lacked the practical knowledge necessary to find her. Relatives conducted a futile search of the clinic and surrounds. Why and how Nonisa ended up at the casino is unknown. But much of Nonisa's movement was purposeful — to the forest to get wood, to visit her mother in a neighbouring village, to visit her husband in Johannesburg. If the casino was meaningful for Nonisa – perhaps she had been there when visiting her husband in the city – her relatives in Johannesburg had no knowledge of this. Others in the carescape — security and police officers — had no emotional or

cognitive ties — they did not even speak a language Nonisa could understand. Their sense of responsibility to care was driven by their employment role rather than emotional ties. They could do little except keep Nonisa safe in the liminal space of the police station while trying to identify her. They were successful only because people from the rural community, who knew of and cared about Nonisa, saw the photograph the police had distributed.

The spontaneity of involvement, and the willingness of rural people to enter Nonisa's caregiving network, is an important and somewhat novel finding. Although spontaneous small acts of dementia care by familiar but loosely tied others have been noted in Euro-American research settings (Brittain et al., 2010; Clark et al., 2020; Marsh et al., 2018), studies of dementia care in African settings – in Nigeria, Uganda, and South Africa – report that people outside or on the periphery of a caregiving network misunderstand and stigmatise dementia by associating it with witchcraft (Adebiyi et al., 2016; Jacobs et al., 2022; Owokuhaisa et al., 2020). In Nonisa's case, there was no indication of stigmatisation from community members, and Rhulani explicitly denied any mistreatment of Nonisa. He emphasised that people liked her, and he gave numerous examples of spontaneous care for her in times of acute need. While witchcraft accusations are common in some African communities, they are not universal responses to behavioural symptoms of dementia. Community responses to Nonisa were, like all interactions, person specific; Nonisa was loved because she was a vibrant, friendly and active community member. Interacting with her likely meant community members gained knowledge of dementia, which led to understanding the condition, as Marsh et al. (2018) found in Australia.

Scholarship which articulates "asking rules" (Bowlby and McKie, 2019) that govern if, when and who to ask to assist with care, imply more structured involvement in caregiving than occurred in Nonisa's times of acute need. Asking rules were apparent in arranging searches for Nonisa in the city and her financial care. When Nonisa went missing, geographically proximate family members were asked to search. However, the people who inadvertently found Nonisa and reconnected her with her family were not asked to care for her, although this might be suggested by their paid positions (e.g. police officers) within the carescape. Meanwhile, despite his concern and desire to help when Nonisa got lost in the city, Rhulani could do little but wait at home for news.

When Nonisa got lost in rural Musha, people involved themselves in caregiving without being asked and did not bother — because there was no need or value — to involve police or other carescape actors. No-one who intervened to stop Nonisa leaving or who went searching for her were asked to provide care and there were no discernible asking rules. Rhulani often led the efforts to find Nonisa when she got lost in the village, or responded when community members alerted him that Nonisa was in trouble. Although community members did not ask Rhulani to care for Nonisa, they expected him to, as Rhulani's children constructed Nonisa's financial care to be his responsibility. Spontaneous acts of care, as observed, may occur to fill gaps created by acute and unexpected care needs, as occurs when a person becomes confused, agitated and/or lost. Unlike everyday routine caregiving, ad hoc contributions to prevent or respond to emergencies appear to work differently, according to less structured "asking rules".

In situations of acute need and in the absence of a robust state-managed care system (Bowlby and McKie, 2019), caregivers were found in fairly unconventional places — a rural tuck shop, a suburban casino, and on social media. While effective in the instances we observed, the informal networks within the caringscape through which Nonisa's care was provided were precarious, as they were serendipitous — they as easily could never have happened. Nonisa and her family had very limited power to determine the trajectory of her care. They relied on others to whom they were loosely tied in a range of networked locations, and who happened to be in the right place at the right time, to prevent Nonisa getting lost or to find her and bring her home. There was little more they could do. Praises and Nonisa's co-resident grandchildren were unable to provide constant supervision because they were balancing caring with education (grandchildren) and work and child-rearing (Praises). They were denied the assistance of a paid caregiver through a grant-in-aid, by a doctor who met Nonisa only once.

The care ecology framework conceptualises the interactions between informal ("caringscape") and formal ("carescape") care systems (Bowlby and McKie, 2019). The framework was developed to aid in understanding how changed circumstances shift responsibility for care, from the carescape to the caringscape. It guided us to explicitly examine links and influences within and between formal and informal care systems, and separate the processes that occurred within each. The findings highlight the way that passive state neglect, in the form of overly bureaucratic processes and inefficient systems, manifests as structural violence — the "social machinery of oppression" (Farmer et al., 2004, p. 307), that is, violence enacted systematically and indirectly by socially powerful people — with detrimental effects.

The beneficial effects of caregiving for Nonisa by her rural family and friends within the "caringscape" were undermined by more or less passive forms of state neglect within the "carescape." Nonisa's family had insufficient physical, financial and emotional capacity to care: an elderly father-in-law who provided materially for Nonisa as best he could; daughters already juggling work and childcare responsibilities, one living and working away in the city; grandchildren who were still in school. The government ultimately holds the responsibility to ensure rights for its citizens, but was absolved of responsibility for Nonisa's care, including through state-controlled processes such as the grant-in-aid application that resulted in denial that Nonisa needed care, and by developing policies that advocate and celebrate "ageing in place" (DSD South African Government Department of Social Development, 2005, 2021) without acknowledging the precarious conditions in which care is often provided.

The unequal power relations that shaped and were shaped by processes in Nonisa's landscape of care (Bowlby and McKie, 2019) were evident in the challenges Nonisa and her caregivers faced when interacting with public health services and SASSA, and the limited availability of formal support. Nonisa's file (medical record), which legitimised her family's claim that she had cognitive problems, was lost despite being linked to her national identity number. The processes to access a grant-in-aid were cumbersome relative to their potential benefit. The doctor responsible for providing care out of the public health clinic often failed to show up and did not phone in advance to cancel appointments. Doctors who were far removed from the day-to-day reality of people like Nonisa wielded power to determine eligibility for the grant-in-aid, and denied people like Nonisa, whose conditions were invisible, the right to support. The doctor could not see what was obvious to those with practical knowledge of her: Nonisa could no longer care for herself. Processes involving people and objects — doctors, medical records, application forms and so on — outside of Nonisa's immediate locale, influenced caregiving practices within it.

Bowlby and McKie (2019) present the care ecology framework as a tool to understand how changes in the carescape influence practices in the caringscape. In South Africa and elsewhere where the state's role in care is limited, austerity is more about maintaining highly constrained government service provision, than reducing the constraints. Nonisa's case highlights the profound impacts on people with dementia and their caregivers, that occur when the caringscape changes, despite no change in the carescape. Nonisa's condition was worsening. She needed more care and her family needed more assistance to provide that care. Events such as childbirth and death in the caringscape occurred and restricted, temporarily or in the longer term, family caregivers' capacity to dedicate their time to caring for Nonisa.

5. Conclusion

The socio-material spaces, conceptually representing "landscapes of care," consist of interdependent formal and informal systems of care, which span numerous networked locations at multiple scales. Where the

responsibility to provide care is and has historically been situated in the caringscape (informal system), as in South Africa, austerity measures are directed at maintaining the predominance of informal caregiving, and change in the carescape will likely be limited or marred by bureaucratic processes that make accessing available support (i.e. grant-in-aid) impossible for some. In such contexts, the internal dynamics of the caringscape have profound impacts on who is willing and able to provide care, to what extent. Policies and programs are needed that respond to acute and chronic changes in the caringscape such as an increasing need to give watchful care to a person with dementia. Examining formal and informal components as separate but related aspects of a broader care system, whether labelled a landscape or an ecology, allows us to draw out how and why caregiving practices exert beneficial or detrimental effects.

Care for individual older people, including those such as Nonisa who live with dementia, is provided in various networked locations that are linked by physical, emotional and/or cognitive ties. Physical proximity is salient because it increases opportunities to care for people. Emotional ties between people are important because they represent a sense of responsibility and willingness to care for others. Cognitive ties, which have to date receive more limited attention in scholarship detailing how networked locations are linked, were profoundly important for enabling and optimising Nonisa's care across networked locations.

CRediT authorship contribution statement

Michelle R. Brear: Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Themby Nkovana:** Writing – review & editing, Investigation. **Lenore Manderson:** Writing – review & editing, Supervision, Funding acquisition, Conceptualization.

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Declaration of competing interest

The authors have no competing interests.

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Data availability

The authors do not have permission to share data.

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