

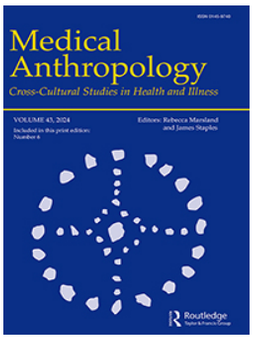
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Sitting in Wait: Everyday Caregiving Practices for People with Dementia in Rural South Africa

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ABSTRACT

Practice theories offer potential to reveal, understand, and attribute value to the everyday thoughts and actions of dementia caregivers. Drawing on ethnographic data from research in rural South Africa, on everyday dementia care practices, we highlight the profound importance of mundane practices – especially "sitting in wait" – for optimizing wellbeing of people with dementia who are cared for at home. We draw attention to the structural drivers of homebased (informal) care, which is underpinned by state inaction. This situates the act of sitting in wait as both an act of care and an embodied form of structural powerlessness.

KEYWORDS

South Africa; care work; dementia; gender; passive caregiving; power; time

Alzheimer's disease and other dementias are characterized by cognitive and behavioral changes. With the progression of dementia, people typically require increased physical and emotional care, and accordingly caregiving consumes increasing amounts of time. The work of such caregiving conventionally falls to close female family members, supported by discourses of gender and the value of aging-in-place. But often there is little option but to age-in-place, and to do so with limited resources and access to formal (state-sanctioned) care. In such contexts, members of the immediate family, other relatives, friends, and community members constitute an informal caregiving network and provide a safety net of sorts. They give care as best they can, often in the face of significant adversity. Yet little is known about the everyday practices involved in informal caregiving for a person with dementia.

Studying caregiving through a practice lens enables the elucidation of the full range of caregiving practices (Cruise and Lashewicz 2022; Wu et al. 2020), including those which have received limited attention because they are mundane and taken-for-granted. Utilizing a practice lens involves collecting data about what caregivers do and using practice theories to understand the foundational role of historically, culturally, temporally, and physically situated "complexes of social practices" (Reckwitz 2002:257) in influencing and being influenced by social structures. Practice theories conceptualize the "bodily and mental routines" (257) that constitute practices as social, not because they necessarily involve social interaction but rather because they are socially reproduced beyond space and time, and simultaneously reproduce the social structures in which they are embedded (Reckwitz 2002). For example, women reproduce domestic and caregiving work routines, and in doing so reproduce a socially structured, gendered division of labor.

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Media teaser: We show that passive caregiving, especially "sitting in wait" for a person with dementia to need care, is challenging but extremely valuable homebased care work.

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Practices are embedded within specific material and social conditions, including social power hierarchies. A person's agency to choose certain practices is always structured (enabled or constrained) by social power inequalities, and by their embodied knowledge of their place within the (gendered) social power hierarchy (Bourdieu and Wacquant 1992). The practices people choose to perform utilize their tacit knowledge of the material and social order, including different types of practical or "background" knowledge – understandings, feelings, desires, and "know-how" – which become interconnected within and shape practices (Reckwitz 2002).

The concepts of bodywork and emotional labor have been prominent, in practice-focused studies of caregiving. Bodywork refers to paid labor that involves one body acting directly on another (Twigg et al. 2011). This situates care work as embodied labor when it involves touch (Buse and Twigg 2018): bathing, grooming, dressing, toileting, feeding, comforting through touch, moving, and restraining, disciplining, or otherwise managing uncooperative bodies (Aulino 2016; Brijnath 2011; Kontos and Naglie 2009; Sadruddin 2020; Twigg et al. 2011). Bodywork involved in caregiving depends considerably on the care recipient's functional ability, for example, whether or not they are capable of self-care (Degiuli 2007). Other caregiving tasks, such as cooking, cleaning the living environment, and vigilance, are physical and rely on the caregiver's bodily labor, but have not been conceptualized as bodywork because they involve neither touching nor acting directly on another's body.

The classic definition of caregiving bodywork has also been confined to paid labor (Twigg et al. 2011). In this context, but also in informal and unpaid care, emotional labor involves managing emotional expressions in order to affect a desired psychological response (e.g. feeling cared for and safe) in another, as well as being attentive to and attuning one's work and emotional expressions to that person's needs (Hochschild 2012). Originating from studies of service workers (e.g. bartenders, airline hostesses) (Hochschild 1983) the concept of emotional labor has been influential in highlighting the gendered division of caregiving within families (Müller 2018). Women perform an unequal share of caring for others' emotions, work which is undervalued and is assumed to require little effort and deserve no reward (Hochschild 2013; Müller 2018). This is true in diverse settings, including in east and southern Africa (Bhan et al. 2020; Mojola et al. 2022; Schatz and Seeley 2015). Although emotional labor produces nothing tangible or commodifiable, it is embodied to the extent that it requires use of the caregiver's body (e.g. facial expressions or gestures) and has corporeal effects (Lanoix 2013).

The use of a practice lens or concepts such as bodywork and emotional labor, are particularly rare in studies of dementia caregiving in low and middle-income settings (Cruise and Lashewicz 2022). In high-income settings, the focus has largely been on caregiving practices in residential aged care homes (Wu et al. 2020). For example, a qualitative review of studies of caregiver experiences and practices in Africa, included six articles (Adedeji et al. 2022). The only one from South Africa, the setting for our study, reported on male caregivers' experiences not their practices (Hendricks-Lalla and Pretorius 2020). A systematic review focused on sub-Saharan Africa, included 12 studies from South Africa (Mwendwa et al. 2022). They covered a broad range of topics, yet references to caregiving were scarce and were either general references to caregivers performing numerous tasks (Gurayah 2015), and/or passing mentions of practices such as heating water (Mahomed and Pretorius 2022), providing constant supervision or cleaning up after incontinence (Gurayah 2015), that were not specific to dementia care. This gap in knowledge on dementia care practices in South Africa may also be due to a research focus on action and movement, and the more extraordinary aspects of dementia caregiving such as dealing with wandering episodes or witchcraft accusations, while neglecting the passive, silent, and still ways of doing and being (Scott 2019), which caregiving may involve.

Yet everyday caregiving is burdensome, consuming time and energy (Yakubu and Wet Schutte 2023). It is also taken-for-granted, with little recognition or reward, despite the considerable physical and emotional work required to maintain a daily routine and appearance of normality, amidst unusual happenings (Das 2010; Mattingly 2014), such as dementia-related behavioral changes. Drawing on practice theory, we illustrate and analyze this through an account of the everyday dementia caregiving practices of one woman in rural South Africa.

Methods

The data which we present derive from a study conducted in rural Bushbuckridge, north-eastern Mpumalanga, South Africa, part of the Agincourt Demographic and Health Surveillance site (Kahn et al. 2012). The area was formerly part of Gazankulu, a bantustan or self-governing area created during apartheid to segregate Black people of Shangaan/Xitsonga ethnicity from other ethnic groups and areas of White settlement. Some 30 years after the end of apartheid, there has been limited investment in developing former bantustans. The primary health care system has been strengthened post-apartheid, through the construction of numerous community-level primary health clinics, and expansion of essential health and specialist medical services, which are provided free of charge to people 60 years and older. Yet accessing clinics and hospitals is still challenging for many and basic services such as water, waste management, sanitation, transport, and housing are inadequate and have in some cases declined (Hoffman and Roos 2020). Unemployment is extensive. As in other areas of southern Africa, domestic labor routines were influenced by colonization and are sharply gendered, and women are expected to undertake most care work (Mojola et al. 2022; Schatz and Seeley 2015; Yakubu and Wet Schutte 2023).

We draw on ethnographic data collected as part of "Kaya," a mixed-method study of informal caregiving for people with dementia (Manderson et al. 2022). Kaya included a survey of over 1000 people who were identified as caregivers, through names generated by the primary caregivers of older people. Kaya was nested in a larger study on aging (HAALSA – Health and Aging in Africa – A longitudinal study in South Africa) (Gómez-Olivé et al. 2018). Older people in the HAALSA study, who were identified as having dementia, were framed as "care recipients" within Kaya. The study received approval from the Human Research Ethics Committee (Medical), University of the Witwatersrand (M200373), as well as relevant South African government committees.

We purposively sampled primary caregivers for maximum diversity in terms of age, relationship to care recipient and care recipient's dementia severity. Participants were recruited and data collected by Michelle, a tertiary-educated, cis-gender White female who had moved to the study community to conduct fieldwork. Themby, a cis-gender Black female, who was a life-long resident of the study district and had years of experience conducting research fieldwork within it, worked alongside and translated for Michelle during fieldwork. They invited caregivers to participate by visiting them at home, which was usually where they lived with the care recipient, and using a standard written voluntary informed consent procedure to elicit permission to visit the caregiver and their care recipient and to record what they saw and heard. Care recipients were often involved in the consent discussion to respect cultural norms. Our research involved regular (approximately monthly) interactions with 21 participants for 9–12 months. This included three people, two considered care recipients and one a caregiver within Kaya, who had psychological and behavioral symptoms that were consistent with those expected of a person with moderate-to-severe dementia, although none had been medically diagnosed with dementia. Their symptoms included forgetting the names, faces, and/or deaths of close family members, confusion, difficulties with everyday tasks, repetitive behavior and/or wandering and getting lost.

Below, we focus on one care recipient whose symptoms indicated moderate-to-severe dementia, although she had not been diagnosed and her symptoms were not recognized by her caregivers as dementia symptoms. Rhandzu was cared for by her sister Xisthembiso (pseudonyms). Michelle made specific enquiries about and purposively documented observations of dementia-related caregiving tasks when she and Themby visited Xisthembiso and Rhandzu from October 2022 to August 2023. Her data amounted to ~ 61,000 words of transcribed field notes detailing 34 hours of interactions and a 45-minute audio recorded interview with Xisthembiso. During several readings of these data, Michelle tagged data on dementia-specific caregiving and the practices it entailed, as she wrote and re-wrote a summary narrative. We present the summary below, then discuss this in relation to practice theory.

Xisthembiso's caregiving practice

> Things will not change. I moved here to care for my sister and will not go back [to my own home] while ever she needs me. (Xisthembiso Nkuna, 6 October 2022)

Xisthembiso (aged 69) had been living with and caring for her sister Rhandzu (aged 72) for about 6 months when we (Michelle and Themby) met her in October 2022. Xisthembiso had left her home, which she had shared with her husband until his death in 2013, after receiving a call from Rhandzu's neighbor Tintswalo, who asked her to come urgently because something was wrong with Rhandzu. Xisthembiso left immediately for Rhandzu's house, which Rhandzu had built herself with money she earnt working in domestic and farmhand roles under apartheid. Xisthembiso returned home only to collect her clothes. While she maintained the pay-television connection in her home and returned periodically to clean the yard, Xisthembiso tacitly recognized that Rhandzu was not going to get better, and would continue to need care as her health, mobility, and cognition declined. She vowed to care for Rhandzu indefinitely.

Xisthembiso initially represented her role as providing physical care only – cooking for Rhandzu and administering her antihypertensive medications. Perhaps because Rhandzu was sitting with us, participating in the conversation as she loved to do, Xisthembiso initially downplayed Rhandzu's memory problems and unusual behaviors, and the emotional labor involved in her caregiving. Later, Xisthembiso opened up, especially when Rhandzu was out of earshot. She described her sister forgetting who she was and forgetting that their mother was dead, wandering off, hallucinating, becoming emotionally and physically violent and experiencing mood swings and incontinence. Over time, in bits and pieces, we experienced and Xisthembiso related to us, the types of care Rhandzu needed and her own mundane "everyday" life as primary caregiver.

The physical work that Xisthembiso initially presented as central to her caregiver role included many forms of labor that are undervalued. Xisthembiso woke early every morning to cook thin maize porridge for Rhandzu, lighting a fire outside when the electricity was cut, as it often was for up to 10 hours per day. She would heat water and pour this into a large metal basin for her sister to bathe. Although Rhandzu could physically perform activities of daily living such as bathing unassisted, she often needed encouragement to bathe, apply moisturizing lotion, or select clean clothes to wear.

The sisters often spent the morning working outside together, raking up leaves and fruit fallen from the 20-odd mango and avocado trees in the yard, or planting and weeding food crops including cassava, peanuts, and maize in the rainy season. When water was running from the outdoor standpipe, as it usually did for several hours each Wednesday, Xisthembiso filled the water containers and washed the clothes. Without a washing machine or hosepipe, these were physically demanding and time-consuming tasks. For example, Xisthembiso filled a 200-l water drum in the kitchen by carting ten 20-l buckets of water, one at a time, approximately 10 m from the standpipe to the kitchen. In between trips, Xisthembiso would wait by the tap for the bucket to fill. This could take ages if the water pressure was low, but water needed to be stored for use until the tap was turned on again the following Wednesday. On the days when there was tap water Xisthembiso also washed all the clothes and blankets by hand in large metal basins.

Everyday caregiving also took Xisthembiso away from home into public spaces, but going out was rarely easy, as Rhandzu was prone to wander. The first-time Rhandzu disappeared it was just before dusk. When Xisthembiso noticed Rhandzu was missing she called out. When there was no response, she went to ask neighbors if they had seen Rhandzu. One had, and pointed Xisthembiso in the direction of the local supermarket, some 350 m away. Xisthembiso walked there in the fading light, and was told that Rhandzu had been there looking for some missing children and had left in the direction of home. Xisthembiso walked back in the dark, worrying her sister would get hit by a car or otherwise harmed. She found Rhandzu safe at home, walking around the yard with a candle, still searching for the (imagined) missing children.

Xisthembiso started locking the gate. This was usually enough to stop Rhandzu from wandering off. But one morning Xisthembiso woke to find the keys that she kept hidden in her drawer, missing. Rhandzu had "stolen" them, opened the gate and walked off in the dark. She was found 4 hours later at their eldest brother Sergi's house, which was built on land where the siblings had grown up, approximately 2 km from Rhandzu's home. Rhandzu had fallen over and grazed her face, leg, and arm while she was wandering.

Xisthembiso eventually stopped Rhandzu wandering by convincing her that there were lions and hippopotamuses lurking outside the fence. Rhandzu stopped wanting to wander and instead started telling passersby to hurry home or they might be eaten by a lion. This relieved Xisthembiso of much everyday worrying and the particular anxiety of trying to find Rhandzu when she managed to escape and wander off.

Although she worried about leaving Rhandzu alone, Xisthembiso needed to go out to collect their old age social grants from the nearest town and go shopping. She seemed to enjoy the opportunity to get out and dress in nice clothes and makeup. Yet as Xisthembiso described them, her shopping trips did not sound like much fun. She would delay leaving until her sister had eaten, done some outdoor work and fallen back to sleep, so that Rhandzu would not become agitated when Xisthembiso left. After checking that Rhandzu was asleep, Xisthembiso would leave, locking the gate behind her and walking around 250 m to wait by the side of the main road, for up to an hour, for a minibus taxi (South Africa's most common form of public transport). The taxi would slowly drive Xisthembiso and other passengers around 40 km to the nearest major town. Once she arrived, Xisthembiso would stand in line waiting (often for hours) to withdraw her own and Rhandzu's social grant money, using their SASSA (South African Social Services Agency) cards and PINs. She would do more or less shopping, depending on the time and how urgently she felt she needed to get home. Shops were always busy on social grant days and Xisthembiso would usually wait in the supermarket queue for 15–30 minutes to pay for the groceries, before carting the heavy bags to the taxi station and waiting for the 15-seater vehicle to fill up with passengers before driving them home. If she was unlucky and waited too long, Xisthembiso would be dropped at the end of her street after sundown, and have to walk home in the dark, worrying that she would be robbed.

Xisthembiso often needed to do more physical caregiving work immediately upon her arrival home. She would spoon feed Rhandzu the food she had prepared before leaving, but which Rhandzu had forgotten to eat in her absence. Rhandzu would sometimes protest and push away the loaded spoon or cup, which Xisthembiso held to Rhandzu's mouth with one hand, while holding her chin still with the other. Xisthembiso would show Rhandzu the *mahinyahinya* (nice food) – apple flavored soft drink, multi-colored ice cream, packets of potato chips, and other treats which she had bought to make her sister feel special, so Rhandzu knew what she was spending her social grant money on.

Some days Xisthembiso would return home to find Rhandzu waiting by the locked gate with her bags packed ready to wander "home." In such cases, it was the less discernible but more demanding work of tempering emotions and (re)-establishing relations, that awaited Xisthembiso. She would remind her sister who she was if Rhandzu did not recognize her and try to convince Rhandzu to go back inside. This type of emotional labor often also awaited Xisthembiso when she woke in the mornings. Rhandzu would sometimes wake before Xisthembiso and pack her things ready to go, every day for weeks at a time. Xisthembiso usually managed to convince Rhandzu to go back inside fairly quickly, but sometimes she refused. On these occasions Xisthembiso would prepare tea and bread and serve it to Rhandzu in the driveway, before administering her anti-hypertensives as she waited by the gate. When she eventually convinced Rhandzu to stay, Xisthembiso would walk her sister back to the house with her arm around her. They would also walk back to the house arm in arm on the days they walked us to our car to say goodbye at the end of our visits, when Rhandzu wanted to come with us or wander off. At first glance it looked like an affectionate, loving touch. It was. But Michelle realized 1 day when Rhandzu put her arm around her, leaning heavily for support and simultaneously pulling her toward the gate, that this form of touch was about much more than affection. Rhandzu leaned on others' bodies and hugged them to keep her balance, especially when

navigating uneven surfaces. Xisthembiso's affectionate touch was also a means of controlling Rhandzu's movements, directing her restless body away from the gate and back to the house.

It was easy to mistake the sisters walking arm in arm as simple affection, partly because Rhandzu frequently expressed her affection through touch. When Michelle and Themby arrived to visit, Rhandzu might walk to the gate and reach through it to grab Michelle's hand and stroke her skin while she waited for Xisthembiso to come with the key. She often held her hand for extended periods put her arm around Michelle, gave her a kiss or played with her hair. As an ethnographer, these touches symbolized that Xisthembiso and Rhandzu accepted and trusted Michelle and might share intimate aspects of their lives. But being there for Rhandzu to touch, in ways that allowed her to express her affection and feel connected, might have felt like work for Xisthembiso, who had to be there for Rhandzu (to touch) all day, every day. Xisthembiso might need to engage with Rhandzu's affection moments after experiencing hostility from her sister.

Paradoxically, the emotional labor Xisthembiso did to maintain their loving sisterly relations often involved "letting it go" and "going along," when Rhandzu forgot. When Rhandzu asked where their late mother was, Xisthembiso would tell her that she was out drinking alcohol with her friend and would be back later. When Rhandzu called her by their late elder sister's name, Xisthembiso would pretend to be their elder sister. When Rhandzu looked straight at her and asked, "Where is Xisthembiso?," Xisthembiso would smile and remind her gently, "It's me, I'm right here." Accepting her affection, and making nothing of her forgetfulness, Xisthembiso tried to make Rhandzu feel good and hold onto a sense of dignity and identity. But going along with whatever Rhandzu remembered, or letting go when she forgot, was emotionally demanding work for Xisthembiso. She was particularly upset the day Rhandzu promised to talk to their brother Sergi, to organize how much they should pay her. Xisthembiso was distraught that her sister didn't realize she was caregiving for love not money. But she pretended to be who Rhandzu thought she was – a hired caregiver expecting a paycheck.

Rhandzu also expressed her affection and generated positive feelings through her talk. Going along with her verbal expressions of affection was another important way that Xisthembiso cared for Rhandzu. Rhandzu also expressed her affection for Xisthembiso verbally. For example, 1 day when Xisthembiso jokingly asked if she wanted to leave with us, Rhandzu definitively said no. We took too long to come back and she could not handle being away from her sister for so long.

Although Xisthembiso did not want money, and explicitly stated that she wanted nothing in return for her caregiving, she hinted at a desire for the important and challenging work she did to be recognized and valued. "No one else could care for her like I do. Don't be fooled by appearances, [Rhandzu] is like a child. [Caring for her] needs a lot of patience," she said. She valued her caregiving work and made the physical and emotional labor it entailed apparent, by performing it while we were visiting and telling us about what she did in our absence. She seemed to be convincing herself that she was doing something worthwhile, as much as she was explaining her caregiving life to us.

Some days when we visited, Rhandzu would become anxious and need reassurance, often after falling asleep on the sofa while we were chatting and waking up disoriented. Xisthembiso would rouse her sister, help her up from the sofa and place her arm around Rhandzu's waist, so that she could affectionately guide her disoriented body to the bedroom. Sometimes Rhandzu would fall quickly back to sleep. Other times she would get panicky. One day it was because the pillows were too high and she was convinced they would harm her. Another day Rhandzu had a bad taste in her mouth after taking medicine. One day Rhandzu called out for Miriam, her late elder sister, and Xisthembiso heard and hurried in to sit with her on the bed. She spent a few minutes, talking to Rhandzu softly and soothing her until she fell asleep. Walking back into the sitting room she smiled and told us, "This is our everyday." It was not always the pillows or bad tastes, but everyday something innocuous made Rhandzu anxious.

Another important form of emotional labor Xisthembiso did as Rhandzu's caregiver was broker relationships. She facilitated her sister's relational engagement with family members and friends via her cellphone, taking the calls and handing the phone to Rhandzu, who was no longer able to answer a cellphone herself. Xisthembiso also introduced her sister to new people, enabling her to strike up new

friendships. She took Rhandzu with her to visit family members, especially their brothers, when transport was available. We drove Xisthembiso and Rhandzu to Sergi's house twice. On both occasions Michelle was struck by the way Xisthembiso sat on the sofa and waited her turn, while their brother first welcomed Rhandzu. He looked intensely in her eyes as he held both her hands, then gave Rhandzu a prolonged hug. Later he sat next to her on the sofa holding her hand. Only after affectionately greeting Rhandzu did he acknowledge Xisthembiso, his youngest sister. Xisthembiso also actively brokered a friendship between Rhandzu and usfor example, by telling us Rhandzu had been asking about and waiting for us to visit and offering to (and sometimes actually) rousing Rhandzu if she was sleeping when we arrived or were leaving. Xisthembiso wanted us and other people to love her sister, and actively promulgated our love by speaking of, and making visible, Rhandzu's affection for us.

Because she had to be present, there were many times when Xisthembiso had little to do but sit in wait for and worry about her sister and others. Sitting in wait sometimes literally involved sitting, but more often it involved finding some form of active (albeit invisible) household labor to do – washing, sweeping, or cooking, as described above. Being there (within earshot) was important even though it masqueraded as "doing nothing." Rhandzu could rapidly become anxious, especially upon waking up and in the evenings. She could call out for help at any moment. If help did not come, Rhandzu might start behaving "strangely." She would shout for dead relatives, get out of bed and walk around the house singing and dancing or pack her bags and take them to the locked gate, where she would sit waiting. When she was sitting in wait, Xisthembiso would hear the call and try to calm Rhandzu down or get her back inside.

Sitting in wait for Rhandzu to need her involved Xisthembiso remaining alert and worrying. Xisthembiso worried about what would happen next, never knowing what mood Rhandzu might be in the next minute or if her sister would recognize her. She also worried about which of her loved ones might next experience health problems.

One of Xisthembiso's brothers had already passed away. Her two living brothers were both older and experiencing physical and cognitive decline. The eldest, Sergi, visited daily for about eight months after Xisthembiso moved to care for Rhandzu. He usually came with fruits he had grown and sometimes helped his sisters financially (e.g. he once paid for transport to get Rhandzu to hospital). But after a sudden fall, he stopped being able to walk, and although it sounded like he had had a stroke, it was never referred to as such. Sergi also had an intractable skin rash. Sergi's wife Nkateko, who had also been a regular visitor to and good friend of Xisthembiso and Rhandzu, was now tied to her marital home caring for Sergi, who had become forgetful. Faced with Sergi's rapid health and memory decline, Xisthembiso, who had no children of her own, extended her caregiving to support Sergi's and Nkateko's offspring. She provided comfort and reassurance. She represented the family at the funeral of Sergi's last-born son's wife, because Sergi was too sick to do what was expected of him as the eldest member of the family. Her hopes for the future were often tied to Sergi's children's visits – Xisthembiso's anticipation that her nieces and nephews would come with a car to collect her and Rhandzu and take them to Christmas lunch, a party, a wedding. Xisthembiso even spoke about the funeral with excitement, relating how Sergi's sons had bought her an expensive dress to wear and his daughters had done her hair and makeup.

Xisthembiso's other brother Menzi had been rapidly losing weight and starting to act like he was "crazy" when we met him in November 2022. At the time he was living with one of his adult sons, who had returned from working in the city to care for his father. Several months later Menzi chased his son away, accusing him of breaking windows and reporting him to the police for this. But Xisthembiso was most concerned because Menzi had dug his own grave, as if preparing to die. He refused to leave the house except to collect his social grant once a month. Xisthembiso was relieved when Menzi's third wife came from the city to care for him. At least she no longer had to worry about what her brother was eating. She could focus on her sister.

Although she may not have recognized and never acknowledged it, Xisthembiso also worried about herself. She avoided directly answering Michelle's questions about who looked after her and alluded to worrying about who would care for her if (when) it was her time to need care. Like Rhandzu she had

no offspring and although she indicated her children from her husband's other wives gave some support, caregiving for Rhandzu had taken her away from her marital home and the comforts and connections it afforded. She usually answered questions about who looked after her indirectly, saying that Rhandzu was lucky to have her, a little sister who was widowed and free to commit her time to caring for Rhandzu in her time of need.

Although Rhandzu needed someone there at all times, she was often socially absent for much of the day, leaving Xisthembiso with nothing to do but sit, wait, and worry. After waking early, Rhandzu was usually ready to go back to bed and sleep for 3–4 hours by about 10am. Xisthembiso might cook, clean, or work in the yard, or sit or lie down to relax, while she waited for her sister to wake up. She rarely went out, although she was still physically fit enough to walk to Sergi's house and eagerly wanted to see him, especially after his fall. Instead she stayed at Rhandzu's home, sitting and waiting, so that she was there to care for Rhandzu if she awoke feeling anxious or hungry, or wanted to wander. Later, she started visiting Sergi occasionally.

On the days Rhandzu didn't fall asleep, Xisthembiso also sat in wait. Rhandzu was often in another social world, unable to recognize her sister and busy enacting another life, seemingly that of a domestic worker. Michelle and Themby experienced this 1 day when they were outside cooking traditional food over a fire with Xisthembiso. Michelle had felt disappointed when Rhandzu greeted her and politely shook her hand as if she were a stranger, without offering a kiss or stroking her or playing with her hair. Rhandzu spent the next hours walking restlessly around the yard, busying herself by attempting different domestic chores – washing dishes and clothes, raking up leaves, bathing. She would sometimes wave at us as she passed, a polite but aloof greeting, with no sign that she recognized us or remembered us being there earlier. After watching the pot and Rhandzu working restlessly for hours, Michelle was ready to announce her departure, when Rhandzu suddenly came to sit and chat. She asked for food, saying that she loved *tihovu*, the traditional dish that had been cooked. She greeted us afresh, saying how nice it was for us to visit and what a long time it had been. She smiled and stared affectionately and told Themby and Michelle how beautiful they were. "My sister is back," Xisthembiso said, then lied when Rhandzu asked, "Who is back?" so as to avoid explaining to her sister her social absence through the day. We had waited for hours for Rhandzu to come back, and to be in need of someone to receive her affection so that she could, herself, occupy a caregiver identity. Michelle and Themby waited another hour before leaving.

Discussion

The account above reflects our observations and interactions with one woman caregiver, and the sister she cared for, over a relatively short period of time (approximately 11 months). It is neither complete, nor representative of any or all relationships of care. Rather it is a partial account of the embodied practice of caregiving, as we saw and heard about it. It is influenced by Xisthembiso's choices about what to tell, as well as her decision not to say anything bad about Rhandzu in front of her. Although partial, we demonstrate the utility of examining dementia caregiving in the home, and in low and middle-income country settings, through a practice lens.

Xisthemibso's caregiving story highlights how passive caregiving practices such as "sitting in wait" and "letting things go," that maintain routines and normality in the face of unusual changes (Das 2010; Mattingly 2014), consume extensive time and involve intensive emotional and cognitive work. Maintaining an appearance of everyday normality, when cognitive decline results in unusual and disruptive behaviors, requires enormous skill, experimentation and emotional investment (Das 2010; Mattingly 2014), which Xisthembiso displayed, for example, by trialing different stories, and eventually knowing what to say to keep Rhandzu from wandering or calm her when she was asking for a dead relative. This kind of caregiving work is typically invisible and masquerades as "doing nothing," despite being a fulltime job with no boundaries (Degiuli 2007).

Against a backdrop of biomedical and other discourses that privilege doing anything rather than nothing (Scott 2019), and celebrate searching for or finding magic bullet cures (Seaman

2018), formal and informal caregivers in high-income countries have spoken of their roles in relation to "nothingness" – taking on bodies for which, biomedically, nothing can be done (Borgstrom et al. 2020). Dementia caregivers who aim to provide safety and comfort throughout the experience of, rather than cure cognitive decline, also report feeling as if they are "doing nothing" (Seaman 2018). Our findings show that caregiving for a person with dementia may also be seen as "doing nothing" on an everyday basis, because of the amount of time when the caregiver passively watches over the care recipient, alert to the possibility of an accident, injury, or anxious moment. Yet sitting in wait is more fundamentally mindful of the importance that a person with dementia be free to perform an "occupation," that is, to carry out meaningful and productive activities suited to their abilities (Frank et al. 2010), including enacting everyday routines which give them pleasure, purpose and/or peace (Harding et al. 2024).

In Rhandzu's case attempting domestic tasks was enjoyable and productive in the sense that they kept her busy and feeling like she was doing "something." Showing affection was an enjoyable and relationally productive occupation. By sharing affectionate touches and words, Rhandzu built relationships with people who she could not remember. Enabling or allowing Rhandzu to do so when she was in an affectionate mood, and letting it go when she was disoriented and aloof, was a deliberate, albeit passive, act of caregiving that involved bodies acting on each other. Allowing Rhandzu to express her affection through touch required physically being there when she wanted to touch, to let her emotions act upon others in ways that created mutual affection. This points to an alternative conceptualization of bodywork that may be salient in dementia caregiving.

Bodywork has previously been characterized by the caregiver's active role in working on the body of a care recipient (Twigg et al. 2011). The bodywork involved in caregiving for Rhandzu, conversely, often required passivity from her caregivers, accepting touches when Rhandzu offered them and letting her go when she wasn't feeling affectionate or became aggressive. Rhandzu was the active performer in this bodywork arrangement. She reached out, squeezed, stroked, and kissed the bodies of others, occupying herself and enjoying it, while others sat back and let her do so, and in doing so, they cared for her. Rhandzu produced relationships through acting on others' bodies, and used her body to establish an identity for herself, as someone who cared for others (Kontos and Naglie 2009). Yet passively accepting touch was an emotionally demanding form of bodywork in Xisthembiso's dementia caregiving.

Embodied practices, even if they involve relatively minimal if any touch, might also be considered bodywork. Xisthembiso performed particular types of (unpaid) dementia caregiving work which involved using her body to effect Rhandzu. Sitting in wait was the most time and emotionally demanding of these. The way Xisthembiso walked with her arm around her sister involved affectionate touch but also disciplined Rhandzu's body. Xisthembiso also used her body when she walked the neighborhood searching for Rhandzu. Such embodied practices might be considered body work because they required the presence of one body to achieve the desired effect on the other. In the context of dementia care, practices such as searching for or walking with care recipients need to be recognized as challenging forms of labor, no less than caregiving bodywork for people with functional impairments, such as bathing, feeding, and toileting.

The emotional work of dementia caregivers is relational; it involves negotiating and remaking relationships with people whose cognitive abilities are declining. One of the ways in which caregivers dynamically maintain relationships with care recipients with dementia is by infantalizing them (e.g. referring to them as children) (Seaman 2020). Another is by deceiving them (Seaman and Stone 2017). These practices have historically been considered detrimental because they deny people with dementia agency and identity. More recently infantalizing has been conceptualized positively, because it enables caregivers to extend a relationship of love and care with a person (Gilbert et al. 2021; Seaman 2020). Infantalizing Rhandzu helped Xisthembiso cope emotionally with caring for a sister who often no longer recognized her, was sometimes aggressive, and at other times expressed childlike anxieties. Denying her autonomy also limited any responsibility Rhandzu held for her behavior, in Xisthembiso's eyes. Infantalizing was salient in homebased care, because of Xisthembiso and

Rhandzu's emotional entanglement. Being sisters meant being forgotten was distressing for Xisthembiso in ways that it is less likely to be for formal care workers.

Deception is similarly common in dementia caregiving and enacted with positive intentions (Seaman and Stone 2017). Xisthembiso's deception was partly about protecting Rhandzu – for example, from the grief that she might feel at being told a loved one was dead, or the physical dangers of leaving the yard and forgetting where she was. Yet Xisthembiso indicated that her deception was also about protecting herself from challenging caregiving situations in which Rhandzu was upset, or to ensure she had some freedom to leave. It was also easier for her to pretend to be another person, than it was to recount to Rhandzu their mother's or sister's death. Convincing Rhandzu that dangerous animals were lurking outside the fence reduced Xisthembiso's burden of worrying that her sister would wander off if left alone in the house. Self-protection was an important motivation for Xisthembiso's deception, which has not been highlighted in previous studies of dementia caregiving (Seaman and Stone 2017).

People with dementia are prominently characterized in terms of their "social death," that is, their presumed inability and lack of desire to form or maintain relationships due to cognitive decline (Gilbert et al. 2021). Quite the opposite was true for Rhandzu. She was usually highly affectionate, wanted to have friends and was keen to mingle, meet new people and catch up with old friends. Rhandzu brokered her own relationships by showing her affection toward others. Xisthembiso facilitated Rhandzu maintaining old and establishing new relationships. Unlike some caregivers in our study, Xisthembiso involved her sister in our visits and conversations, and was careful to "say nothing" about Rhandzu's behavioral symptoms of dementia in front of her. Although telling might have lightened Xisthembiso's emotional load, she withheld information at times to avoid upsetting Rhandzu, performing emotional labor by putting her sister's needs ahead of her own (Hochschild 2013). She increased her own emotional burden in order to manage Rhandzu's emotions (Gilbert et al. 2021), not only by keeping quiet, but also by maintaining a positive façade, smiling and laughing at her sister and loving her.

The practice lens that has guided our analysis shifts the focus from what might happen to the care recipient, to what the caregiver actually does and how it influences her present being and future aspirations. It highlights that the appearance of the dementia caregiver "doing nothing" and achieving less is related both to the passivity of everyday embodied practices that involve sitting in wait (Scott 2019), and the neglect of emotional labor. People are used to seeing women undertake time-consuming, physically, and emotionally demanding domestic work, so it is not seen as a deliberate or difficult act. Accounts of caregiving rarely question whether caregivers have made a conscious decision to dedicate their time to caregiving, albeit a decision tacitly structured by embodied knowledge of the social order and its expectations of people – women – like them (Bourdieu 1990; Schatz and Seeley 2015).

Dedicating time to waiting relies on hope (Mattingly 2010). Xisthembiso's hope was not only for her sister's safety and wellbeing, but also that she would receive positive recognition and avoid negative perceptions. In highlighting her burden and situating her sister as lucky to have her, Xisthembiso expressed hope that her sacrifice – giving up much of her own life to enable her sister an everyday normalcy – would be seen as a practice of love, which demonstrated her moral virtue (Mattingly 2014). In a power-laden social system where women are relegated to gaining social status through self-sacrifice to care for others, her choice to become a dementia caregiver, was structured by social expectations of what a woman like her should do (Bourdieu 1990).

The practice lens reveals the oppression inherent in reliance on informal caregivers such as Xisthembiso, mainly women, who lose control of how they use their time in the present and their future aspirations (Bourdieu 2000). Yet importantly this oppression is structural rather than individual (Wacquant and Akçaoğlu 2017). Xisthembiso was oppressed not by Rhandzu who needed her care, but by social structures [including policies such as the South African Government's White Paper on Families (DSD, South African Government Department of Social Development 2021)]. These devalued her time and expected her, and other women, to expend their time caregiving for others, even if that meant

perpetual waiting and losing control. Xisthembiso's active work and her waiting were increased because of the precarious material conditions that characterized Xisthembiso's and Rhandzu's post-apartheid lives. Lack of development meant that Xisthembiso had to wait for buckets to fill, wait for public transport to arrive, and wait in shopping and social grant queues. She had to haul water, cook over fire, and care for her sister in the absence of functional basic services and a formal care system that could provide some respite. If "capital [power] is a set of pre-emptive rights over the future" (Bourdieu 2000:14), the everyday act of sitting in wait implies one's power and right to determine their future is highly constrained.

Conclusion

The caregiving work Xisthembiso expressed most anxiety about was sitting in wait for Rhandzu, needing to be present as much as possible, and worrying when she was away, because she could never predict what would happen next. Yet being there, ostensibly doing nothing and feeling like nothing was being achieved, was the most effective way for Xisthembiso to ensure that Rhandzu received the care she needed, when she needed it. Sitting in wait, watching and worrying are perhaps the most mundane and time-consuming of caregiving practices. Perhaps because sitting masquerades as doing nothing, this has been neglected in studies of caregiving. Similarly passive caregiving practices such as receiving affectionate touches have not received attention compared with active forms of bodywork such as bathing. Future research might valuably investigate how sitting and waiting and other passive practices affect caregivers of people with dementia, how they cope with the demand of being constantly needed to "do nothing," and how they make meaning of and value themselves amidst this nothingness. Such understandings are needed to inform interventions to support caregivers of people with dementia and ensure they attain the power that they need to control the ways they use their time and shape their futures. Caregiving stories such as Xisthembiso's are needed to develop understanding of and increase public recognition for the value of caregiving work for people with dementia. Our ability to identify and describe passive practices such as sitting in wait, illustrates the value of using a practice lens to elucidate and understand the value and demands of the emotional and physical labor of dementia caregiving. We suggest the value of further practice-focused studies of caregiving in different economic, cultural, and health contexts, so to better understand the undervalued and largely invisible work of informal dementia care.

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