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ARTICLE

Singing with my mum: an autoethnography of care aesthetics and everyday moments in the context of dementia

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Abstract

There is increasing attention to 'being present' and 'being in the moment' in the context of living with dementia, challenging narratives of decline. Keady and colleagues have situated this within a 'continuum of moments' including 'creating the moment', 'being in the moment', 'ending the moment' and 'reliving the moment'. They call for further conceptual work on moments and dementia, examining how moments fit together as part of everyday life. At the same time, literature on care aesthetics draws attention to moments of beauty, creativity and multi-sensory engagement as part of care practice. Building on this literature, this article explores daily life as a 'series of moments' in an autoethnographic account of caring for my mum who is living with dementia, exploring shifts between moments that are difficult, sad, challenging, beautiful, joyful and/or caring. It offers new insights into challenging moments as well as positive ones and the relation of moments to reciprocal emotion work. The article considers tensions between supporting my mum's continuity of self and constant adaptation, and challenges involved in creating, being in, ending and reliving moments. The discussion explores implications for care practice, highlighting how a focus on moments can help make sense of experiences of caring, and the need for further support with the emotion work associated with care aesthetics.

Keywords: autoethnography; care aesthetics; dementia; emotion work; family carer; moments; temporality

Introduction

This article presents an autoethnographic account of caring for my mum who is living with dementia, explored through the lens of 'everyday moments' (Keady et al. 2022) and the 'aesthetics of care' (Thompson 2015, 2023). I am writing this primarily as a daughter and family carer, but also as a researcher in dementia studies. When my mum – who is also my best friend – was diagnosed with dementia, I wanted to make the most of every moment together. However, as her dementia progressed, we had to creatively adapt to find new ways of being together. Keady et al.'s (2022) framework for understanding experiences of dementia as a continuum of moments inspired me to attend to, (re-)create and record enjoyable moments together. They call for further conceptual work on everyday moments and dementia, exploring how different moments fit together within everyday life (Keady et al. 2022). Drawing on this framework, I explore how moments were created, experienced, relived and ended in my experiences of caring for my mum.

Previous research has generally focused on positive experiences of 'being in the moment', although, as Keady et al. (2022) acknowledge, '"being in the moment" can be layered with positive or negative attributes' (291). I extend this framework to examining daily life as a 'series of moments', exploring shifts between moments that are difficult, sad, challenging, beautiful, joyful and/or caring. An autoethnographic approach is limited to reflections on one case, and in this autoethnography it reflects on my perspective as a carer, rather than that of the person living with dementia. Autoethnography can extend understandings of 'moments' as biographically situated, and provide an in-depth account of moments throughout the day, at times when an ethnographer would not normally be present.

My autoethnographic reflections are organized around different aesthetic practices and contexts of being in the moment; 'being alongside in the garden', 'walking and being together in nature', 'rhythm, poetry and visual storytelling' and 'music, singing and improvisation'. Through analysis of these aesthetic practices, I explore challenges and dilemmas around creating, being in, reliving and ending moments and tensions between supporting continuity of self and ongoing adjustment (Haeusermann 2019). Moments are connected to shifting emotions (Gabb and Fink 2015, 972) and the discussion considers implications for understanding the emotion work of unpaid care (Özen 2020). The term 'emotion work' is used rather than 'emotional labour' to refer to the management of emotions in family caring relationships (Hochschild 2012). The article also explores emotion work as reciprocal and relational (Palmer and Scott 2018) and how people living with dementia can provide – as well as receive – emotional support.

Background

In theoretical and practice literature on dementia care, there is an increasing emphasis on 'being in the moment' and 'being present' with the person living with dementia (*e.g.* Killick and Allan 2001; Lillekroken et al. 2017; Damsgaard et al. 2024), and trying to 'fill as many of these moments with as much meaningfulness as possible' (Killick 2016, 181). Narratives of people living with dementia similarly emphasize being 'present in the moment', and how selfhood, meaning and connections are enacted within moments, even if moments are not recalled (Bryden 2020, 78).

This focus on being in the moment is situated within a recognition of the ongoing personhood or selfhood of people living with dementia (Sabat and Harré 1992; Kitwood 1997), challenging stereotypes of a loss of self and agency and the narrative of decline (McColgan 2004). Kitwood (1997) defined personhood relationally, emphasizing how feeling, emotion and the ability to live in relationships continue despite cognitive impairment. His discussion of person-centred care draws attention to moments of recognition, empathy and validation. Building on this, Kontos (2004) emphasized the embodied dimensions of selfhood – how selfhood and agency are enacted by people living with dementia through the body and pre-reflexive embodied knowledge. More recently, Kontos et al.'s (2017) work on 'relational citizenship' explores mutual care, highlighting the 'reciprocal nature of engagement and the centrality of capacities, senses, and experiences of bodies to the exercise of human agency and interconnectedness' (182).

Building on this, Keady et al. (2022) describe being in the moment as 'a relational, embodied and multi-sensory human experience' which is 'both situational and autobiographical'. They situate moments within a continuum involving (a) 'creating the moment' – the process and practices that enable the moment to take place, (b) 'being in the moment' – the multi=sensory experience of being in the moment, (c) 'ending the moment' and (d) 'reliving the moment'. They argue that '"being in the moment" did not appear in isolation but in connection with other moments' (686). Keady et al. (2022) describe how moments may emerge spontaneously or may be deliberately curated by the person living with dementia, their friends, family or care-workers. They argue for recognition of the significance of moments, without the requirement for them to be remembered and retold.

Being in the moment is also associated with creativity and 'flow', being absorbed in a creative activity 'only aware of what is relevant here and now' (Csikszentmihalyi 1997, 112). Discussions of creativity have often focused on 'creativity with a capital C', involving a novel end product (Csikszentmihalyi 1997, 27). However, research on 'little c' or 'everyday creativity' highlights everyday acts of improvisation (Kaufman and Beghetto 2009). A focus on everyday creativity makes room for understanding how people living with dementia are creative in their daily lives, without requiring a novel end product (Bellass et al. 2019). There is a growing body of research highlighting the benefits of participatory arts interventions for people living with dementia, including music, dance, theatre, poetry, storytelling, visual arts and object handling (Zeilig et al. 2014; Ward et al. 2021). Previous research has generally focused on organized group activities (Bellass et al. 2019), although these activities sometimes flow into everyday life (Ward et al. 2021; Dowlen et al. 2022). Bellass et al. (2019) call for further research on how people living with dementia and carers creatively adapt in their everyday lives, and how creativity is 'negotiated relationally' in different contexts (2801).

Discussions of 'everyday creativity' also relate to literature on 'care aesthetics' (*e.g.* Thompson 2015, 2023; Cribb and Pullin 2022). Care aesthetics includes the interweaving of art with everyday care practice but is also 'far wider' than art (Thompson 2023, 15), encompassing the 'creation of sensory and embodied experiences' that are part of everyday care practice (Thompson 2023, 2). This can include multi-sensory engagement with the aesthetic features of objects or environments (Thompson 2015) and the embodied and sensory aspects of bodywork such as bathing (Thompson 2023). There is a temporal dimension to care aesthetics, as aesthetic experiences are biographically situated and subject to change over time (Cribb and Pullin 2022).

The concept of 'care aesthetics' has been brought to dementia studies, in dialogue with the 'moments' framework (Campbell et al. 2024). For instance, research on an inpatient dementia assessment ward highlights how multiple people, the environment and embodied practices create the 'care moment' (Jones et al. 2024, 17). Dowlen et al. (2024) apply the care aesthetics framework to analysing experiences of music-making for people living with dementia, exploring how embodied and sensory connections are created through 'improvising together' (8). Fox et al. (2025) examine how people living with dementia and carers self-identify 'meaningful moments of connection' (3) in their everyday lives, including connections with other people, enjoyable activities, material things and the 'lived environment'. They call for further research in this area, including research on negative – as well as positive – emotional experiences of moments.

Method

Context

An autoethnographic approach is used to reflect on my experiences of caring for my mum. Autoethnography involves a 'form of self-narrative that places the self in social context' (Reed-Danahey 1997/2020, 9), connecting personal experiences to their wider social location (Méndez 2013). These reflections focus on a period of 18 months from spring 2021 to autumn 2022 when my mum's care requirements were increasing and I was supporting my dad with caring for her at home, before she later moved into a nursing home. For six months this was alongside full-time work, for six months it was full-time during an unpaid career break and for five months it was alongside part-time work. At this time the Covid-19 pandemic was still ongoing, but travel restrictions in the United Kingdom had been eased. When I was able to visit my parents again in spring 2021, my mum's dementia had progressed significantly. My dad was finding caring extremely challenging and exhausting, and also experienced physical health difficulties himself, reflecting wider statistics on older carers (Age 2024).

Taking a career break to care for my mum and spend time with my parents was something I wanted to do following time apart during the pandemic. However, it is situated within wider social constraints, including the challenges of juggling paid work and care (Carers UK 2024) and caring at a distance (White et al. 2020). There is currently no paid carers leave in the UK, although there is now a statutory right to five days' unpaid leave (Carers UK 2024). I was fortunate that my employer supported my application for a six-month unpaid career break, which is something that Carers UK (2024) is campaigning to have more widely available at the time of writing. Being able to take unpaid carers leave is dependent on financial resources (Carers UK 2024), reflecting my privilege as a middle-class woman. In spring 2021 my parents had not accessed any support in terms of social care, partly owing to the pandemic and their concerns about risk (Muldrew et al. 2022) and efforts to 'manage' independently. Following a referral from their memory clinic, we accessed support via Social Services, which involved a care-worker visiting for a couple of hours on one afternoon a week to provide a break. Although the care was excellent, the amount of available care was limited, reflecting wider constraints on care services in the UK, exacerbated during the pandemic (Muldrew et al. 2022). There were also barriers around introducing paid care-workers into the home, as my mum was very uncomfortable about 'strangers' visiting (see MacLeod et al. 2017). This was partly owing to the progression of dementia and decreasing awareness of her condition, but also longer-term concerns about Social Services 'taking people away', perhaps situated within her biography as a working-class woman with Disabled parents. It took a long time to find the right care-worker and slowly introduce her to my mum, starting with short ten-minute visits. After I returned to work part-time in summer 2022, this was increased by a couple of additional visits, but my dad was providing 24-hour care and I was travelling back and forth (a five-hour journey), so it eventually became unsustainable and my mum moved into a nursing home.

Autoethnographic approach

Autoethnography can be based on notes recorded at the time or written from memory (Ellis 1999). My autoethnographic account draws on a journal kept at the time to record my experiences and emotions, typed up on my laptop in the evenings after my mum and dad had gone to bed. I started recording enjoyable moments with my mum to remember them, as well as noting more challenging moments to help process them. I also kept a sketch diary 'in the moment' with my mum outdoors (see later). Other events that were not recorded in the diaries are written retrospectively from memory.

After my mum had moved into the nursing home I began to consider writing up my experiences, as a way of making sense of them and hoping that my reflections may be useful to others (Ellis 1999). As a family carer and a researcher in dementia studies, I found it hard to reconcile a focus on 'living well' with dementia and challenging the narrative of decline, with the sadness experienced when someone you love is diagnosed and aspects of your relationship change. I found that reflecting on everyday moments helped me to negotiate the complexity of how such experiences are 'lived', and it gave me hope that difficult moments will pass, while joyful moments will return – it is hoped that this might be useful to others. Caring for my mum deepened my understanding of living with dementia, but also highlighted tensions between what I would view as 'best practice' and the day-to-day challenges of care-giving, as discussed later. Revisiting my written and sketch diaries was an emotional experience, reminding me of difficult and special moments, while evoking sadness that my mum is no longer at home with us. Autoethnography involves 'systematic sociological introspection and emotional recall to try and understand an experience' (Ellis 1999, 671) and involves the researcher accessing their 'vulnerable self'. It has taken a long time to write this because at times the emotions became overwhelming, and I had to take a step back from it.

In analysing my recollections, I am taking an interpretive stance, acknowledging that recalling subjective experiences is always an interpretation shaped by social location (Ellis 1999). The analysis of themes draws together thematic and narrative approaches (Riessman 2008). As I was reading and re-reading my journal, I noted themes alongside daily entries, and these were then organized into larger thematic categories. In analysing and writing about these themes, extracts from my journal are intertwined with personal recollections and biographical narratives.

In autoethnography, your own story is connected with those of other people, which raises complex ethical issues (Méndez 2013). In keeping with previous autoethnographies of caring (*e.g.* Malthouse 2011; Wilkinson and Wilkinson 2020), as this is based on my diary and personal recollections analysed retrospectively and did not involve gathering data for the purpose of research, ethical approval was not required by my university ethics committee. However, I invited my dad, my older brother and one of my younger brothers to read this article and checked that they were happy for me to submit it. My mum no longer has capacity to review the article; however, I have tried to consider how she is represented and avoided including anything which – to the best of my knowledge – she might be uncomfortable with. In line with the discussion of Wilkinson and Wilkinson (2020), I have drawn on my embodied knowledge of my mum who was always supportive of my work and took part in other people's research because she knew how important research is to me. I have left the names of my family members anonymous, although it is possible that someone who knows us as a family could recognize them from the article, and also altered any potentially identifiable details (*e.g.* place names, descriptions of neighbours).

Autoethnographic reflections on aesthetic practices

Being alongside in the garden

As my mum's condition of fronto-temporal dementia progressed, speech became increasingly difficult. We therefore had to find ways of being together that relied less on verbal conversation. Sitting outside in the garden took the pressure away from conversation and provided a way of 'being alongside' (Latimer 2013) while engaging with the multi-sensory environment. In the past my mum had rarely sat in the garden; however, this was something she increasingly enjoyed. In the warmer weather of summer 2021 we spent a lot of time in the garden, often rushing out first thing in the morning. Creating the moment required material adjustments to dress and the arrangements of the garden. At that time my mum was often reluctant to change out of her nightie and dressing gown in the morning. In an effort to normalize this, I sat outside in my onesie; if it was cold, my dad and I helped her put on a coat on top of her nightie. This reflects how dementia can disrupt norms of 'appropriate dress', but also that being in the semi-private space of the garden meant that 'appropriate dress' seemed less important (Buse and Twigg 2014). My dad fetched the deckchairs and we searched for a sunny spot as the sun crept over the hills behind the garden. As argued by Taylor (2008), dementia can provide opportunities for slowing down and being in the moment and often the person with dementia notices things that others might not. One morning when we sat outside my mum pointed out the dew sparkling on the grass. A robin was singing nearby and she remarked, 'Someone's singing'. This highlights the ongoing ability of people living with dementia to be attentive and to 'co-create' moments (Campbell et al. 2024), challenging narratives of decline and loss (Kitwood 1997; McColgan 2004).

When I was sitting outside in the garden with my mum, I sometimes sketched in watercolours, which provided another way of 'being alongside' that was not reliant on verbal conversation (see also Cleeve et al. 2021). My mum expressed enjoyment at watching me sketch and looking at the colours, and it enabled her to continue her role as a supportive mum. As I was sketching she would often make encouraging remarks, saying, 'That is gorgeous' or 'I love the colours'. This reflected her ongoing practice in showing care through support and encouragement, which was part of our relationship and how she interacted with people more generally. Continuing family roles can be part of how people living with dementia enact selfhood and competency (Harris and Keady 2009; Hellström et al. 2015) and this example illustrates my mum's ongoing ability to demonstrate mutual care (Kontos et al. 2017).

Sketching can be a way to record and 'relive' moments (Keady et al. 2022) – my mum enjoyed looking back through my sketchbooks and commenting on the colours. However, sketching with my mum became increasingly challenging as her dementia progressed, and she was less able to sit still or concentrate for a period of time. As her walking became more unsteady it became difficult for her to use the garden independently, in part owing to the garden being on a hill with a steep slope and retaining wall, with steps going into it. We adapted creatively by walking around the garden holding hands (Bellass et al. 2019), which provided a way of accessing the garden safely while connecting at an embodied level.

As sitting still in the garden became more difficult, an alternative way of being in the garden was doing 'garden tours' – this is something that I have used as a researcher (Buse et al. 2024), but here it was initiated spontaneously by my mum. My dad had always been the gardener, but my mum enjoyed looking at the flowers, plants and changing colours. One of her favourite flowers were the bright red roses and she would regularly remark, 'They're gorgeous'. By instigating these garden tours and drawing attention to the beauty of the flowers, my mum demonstrated engagement and agency at an embodied and sensory level (Kontos 2004). In the autumn and winter, getting out became more challenging – we had to make sure that my mum was dressed in warm clothes, and it became too cold to sit outside. However, the 'garden tours' were able to continue, and still evoked moments of wonder:

> After lunch we went around the garden. Mum said, 'I haven't been out here for ages' – she spent ages noticing little details like the ivy, noticing how the colour of the hydrangeas had changed to a faded brown, and she said how lovely it was. The stream is quite full after all the rain and was quite visible; Mum enjoyed looking at it. (14.12.2021)

Here my mum found wonder in seasonal changes including the faded hydrangeas, which would not normally be considered beautiful (Thompson 2023). This again illustrates the ability of people living with dementia to co-create special moments (Campbell et al. 2024) through noticing small details (Taylor 2008). However, my mum's temporality was sometimes out of sync with changing rhythms of light and dark (Ward et al. 2022) – earlier that day she was annoyed because she did not understand that it was too dark to go outside first thing, and on other occasions she wanted to go into the garden in the middle of the night.

The following year when summer returned it became more challenging to encourage my mum to go out, as we tried to show her where the garden was and explain what we had in mind, and assisted with putting on her coat and shoes, which could be difficult and took considerable time. We no longer rushed out into the garden first thing in the morning. Dress is part of 'creating the moment' – changing clothes marks transitions between spaces and aspects of identity, and can help create a sense of occasion (Buse and Twigg 2014). However, getting dressed and changing clothes was often something my mum found stressful and it could become a source of tension (Buse and Twigg 2018). Yet tours around the garden or briefly sitting outside still offered potential for creating enjoyable moments together.

Walking and being together in nature

Walking had always been one of my mum's main hobbies and an important way of spending time together as a family. It was during a walk that my mum first disclosed to me about the initial stages of her diagnosis, telling me that she was forgetting things and getting some tests done. As my mum's dementia progressed, walking remained important to creating 'meaningful moments of connection' (Fox et al. 2025, 3):

> Went for a walk, which Mum really enjoyed. We saw the nice neighbours with [their dog]; Mum stroked it and said hello. Lots of birds singing nearby; Mum stopped to listen. We saw a robin singing in the tree. Mum noticed the nice smell of log fires that you always get on the corner of the road, and pointed out some remaining autumn leaves. (15.10.2021)

Here my mum spontaneously created the moment through attending to the multi-sensory experiences of the walk (Keady et al. 2012) – the smell of the log fire, the sound of birds singing, stroking a dog and seeing the brightly coloured autumn leaves. This example highlights the ongoing abilities of people living with dementia to connect at a multi-sensory level, challenging narratives of decline (Kontos et al. 2017). My parents repeatedly walked along this local road during the Covid-19 pandemic owing to travel restrictions, and we continued this walk regularly while caring for my mum at home. This created familiarity and connection with neighbours on this road who would stop and say hello. As my mum's dementia progressed, most neighbours continued to greet her, and some told me about their personal experiences of dementia. However, sometimes passers-by were more hesitant and unsure of how to interact with her, perhaps reflecting the stigma and lack of understanding associated with the condition (McColgan 2004; Bryden 2020). On this walk, my Mum sometimes said, 'There's a lovely atmosphere', illustrating the sensitivity of people living with dementia to the intangible qualities of place (Richardson and Campbell 2024). Atmospheres reflect the multi-sensory aspects of a material environment, but can also be generated by connections between people (Bellass et al. 2019).

As well as local walks, day trips in the camper van facilitated 'moments that jump out from the routine' and 'new, less familiar, sensory pleasures' (Thompson 2023, 32):

> We had a nice trip to [seaside town in North Wales, UK] – Mum cheered me up singing walking down the prom, and then doing a little dance [and a] jog! She pointed to the low winter sun shining through the trees and said, 'Lovely gold', but then pointed out the black clouds over the sea and said, 'Some sad bits there'. I think maybe Mum can sense when someone is sad and needs cheering up – I was feeling a bit anxious and she gave me a hug and said, 'I love you'. (07.01.2022)

Here my mum sensitively engaged with the multi-sensory environment, as she noticed the colours in the sky and connected them with emotions, referring to the black clouds as 'sad bits'. Prompted by this environment, she noticed that I was feeling sad and anxious and gave me a hug to cheer me up, demonstrating the ongoing ability of people living with dementia to connect emotionally (Kitwood 1997) and engage in acts of mutual care (Kontos et al. 2017). This example highlights the capability of people living with dementia to provide emotional support, illustrating emotion work as reciprocal and relational (Palmer and Scott 2018).

However, 'creating the moment' can be challenging, relating to tensions between bodywork and the aesthetics of care (Thompson 2023):

> Slept in a bit and woke up with Mum calling 'Chrissy' in a cheerful voice! She was quite confused in the morning, trying to put gloves on her feet. Went to [seaside resort in North Wales, UK]; she got a bit flustered when we were trying to help her put on her coat and gloves but then when we got out walking she cheered up and said, 'This is beautiful' and turned to my dad and said, 'You're [name of my dad]' and apologized for being grumpy. Then we got back and I was trying to help put her things away and she got really upset because she thought I wasn't putting them in the right place (Dad was on the phone). She got annoyed and then didn't seem to know me and Dad and thought we were other people … She kept giving me a furious look. It was quite upsetting. (30.10.2021)

Here a trip to the seaside is situated within a 'series of moments' throughout the day – after difficulties getting dressed and ready, walking by the sea facilitated a moment of connection (Fox et al. 2025) and recognition. However, assisting with going to the toilet or putting on outdoor clothing – particularly in the small space of the camper van – often prompted stressful moments. After we returned home and the moment was ended, this was followed by upsetting moments when my mum was annoyed with us and did not recognize us, reflecting the emotional challenges of caring (Herron et al. 2019). This highlights how recognition and connection are not only embodied (Taylor 2008) but also shift from moment to moment, affected by people, environments and embodied practices. As my mum's dementia progressed, travel in the car became more stressful – she was sometimes very distressed in the car, and my dad often found driving difficult owing to disrupted sleeping (and I cannot drive), so we kept to local walks near to their home.

Walking required embodied adjustments as my mum's dementia progressed. Several years into her condition, she had lost a significant amount of weight and become more physically frail and prone to losing balance. At first, one of the family held hands with her on difficult bits of the walk such as stepping down from the kerb. As her spatial awareness and balance worsened over time, we held her hand throughout the walk. This was both a change and continuity of practice – she and my dad always held hands on walks, but she had not held my hand or my brothers' hands since we were children. Holding hands provided a way of connecting at an embodied level, as part of the aesthetics of care (Jones et al. 2024). It was also important to being 'safely imaginative' (Rendell and Carroll 2015, 18) as there were no pavements on local country roads. However, sometimes this presented challenges:

> … awful weather, stuck in trying to find things to do, Mum in a 'difficult' mood a lot of the time. Got upset on walks due to rain, then starting talking about things I couldn't understand and wouldn't hold my hand. Difficult to keep her at the side of the road when traffic going by.
>
> Nice moments: Mum holding my hand and comforting me when I was upset. (02.03.2022)

Here rainy weather changed the mood and atmosphere (Mason 2016), disrupting 'being in the moment' and the embodied practice of holding hands. However, later in the day my mum held my hand to comfort me, illustrating the shifting and situated meanings of this embodied gesture in moments throughout the day, and our shifting roles in providing emotional support (Palmer and Scott 2018).

Rhythm, poetry and visual storytelling

Engagement with books, poetry and photographs became interwoven with our everyday practices of caring, illustrating how 'aesthetic concerns need not be "distanced" from routine concerns but are deeply embedded in all aspects of our lives' (Cribb and Pullin 2022, 2). My mum was an avid reader and liked her stories to have a happy ending; she sometimes skipped to the end of a book to check that it did not end badly. She had never expressed an interest in poetry, although her father (who had also been diagnosed with dementia) had been a keen poetry reader and recited poems by heart.

Reflecting her diagnosis of 'aphasia' and 'fronto-temporal dementia', reading became difficult early on. My mum was initially able to read large print, but as this became difficult my dad started reading to her. Reading as a 'moment' between my mum and me came about by chance – she had bought *A First Book of Nature* (Davies 2012) for her grandchildren, featuring beautiful artist illustrations and lively rhythmic text, capturing the wonder of the changing seasons. She sometimes took it out from the bookcase to look at the illustrations, and when I tried reading it to her she seemed to enjoy it, so this became a regular activity. I later bought some nature poetry books designed for people living with dementia with large print and photographs. She appeared to enjoy listening to the rhythm of the poems and looking at the pictures, which created moments of togetherness:

> [Mum] looked so pleased to see me and that I had come back. We just walked round a bit holding hands. Then we read one of the poetry books. The storm was raging outside and it felt nice and cosy inside' (30.09.2022).

This illustrates the creation of an atmosphere of 'cosiness' through reading poetry together, in combination with the atmospherics of the weather and the storm raging outside (Bille 2015).

The poems in these books became interwoven with daily walks, and we sometimes said lines from the books as we walked along, illustrating how aesthetic practices create 'ripples into everyday life' (Dowlen et al. 2022, 17). For instance, when we walked past the field of lambs in spring, my older brother and I recited the line from the nature book 'lambs tails wiggle when they are happy, a wiggle, wiggle squiggle, it shows just how they feel' (Davies 2012, 18) and my mum sometimes laughed or smiled. Reciting lines from these books in different contexts or re-reading them facilitated 'reliving the moment' (Keady et al. 2022), connecting them with ongoing jokes and reflections. For instance, the nature book described how in summer 'everywhere you go just listen: someone's always singing' (Davies 2012, 33) and my dad or I would laugh and say, 'It's normally us' and my mum laughed too. This illustrates reciprocal moments of care and attentiveness between my mum and different family members, involving 'multiple cross-connecting relations between people, and people and objects and between people and the natural world' (Thompson 2023, 35).

However, sometimes my mum had difficulty perceiving the pictures in these books, concentrating or understanding the words, which created frustration and 'disenchanted moments':

> [Feeling] jittery and anxious. … Not a brilliant day. Mum in a funny mood; moods kept swinging from being happy to really upset or annoyed. Possibly related to struggling to understand, perceive or communicate things, e.g. she asked me to read from her book, but then got frustrated because she couldn't take things in. (12.11.2021)

Engagement with aesthetic practices is therefore never fixed but requires ongoing adjustment as dementia progresses, and according to the person's emotions and interests in a particular moment. The effects of aesthetic practices are unpredictable and can evoke positive and negative emotions on different occasions. My mood was 'jittery and anxious' as I struggled to engage with my mum that day and activities that were usually enjoyable affected her mood negatively, illustrating the complex interconnection of care aesthetics with emotion work (Herron et al. 2019).

We also told stories and narratives through engaging with the visual images in my mum's family photo album. As we looked through it, she often retold the same 'small stories' (Phoenix and Sparkes 2009) – short fragments that had emotional significance as 'stories of the self' (Mills 1997, 679). Stories often focused on memories of fun times – images of my little brothers having a food fight, my older brother's school play, or me getting ready for a night out, wearing the clothes that she helped me make – saying things like 'It was fun!' or 'We had fun'. Her stories also recalled moments of upset or outrage; for instance, when she looked at a picture of my younger brother, she retold a story of how he had been 'put in the bin' by school bullies, and she had tried to complain but the teachers 'weren't bothered'. As her verbal communication became more impaired, we increasingly 'curated' these stories (Crichton and Koch 2007):

> Looking at the photos with Mum; she said, "I'm starting to remember", and started to really engage with it and remember people and stories – although she could only tell them as fragments, I could fill in the gaps' (11.03.2022).

As her temporal routines of sleeping and waking became disrupted, if my mum was up in the night and distressed or anxious, my dad, my older brother or I would look at the photo album or read a book with her as a way to calm her. Reading together helped create a transition between moments and affective states, moving from distress to calm and connection, illustrating aesthetic practices as a strategy of managing emotions (Lee-Treweek 1996).

While interest and enjoyment in activities comes and goes, a challenge can be knowing when to stop doing an activity. Over time it became more difficult to engage my mum with the photographs, and sometimes she found it difficult to see or recognize the pictures. On one occasion she recognized pictures of her parents, and remarked, 'They're all dead, aren't they?'. I was not sure what to say and instead tried to distract her – I worried afterwards that I did not make enough room for those difficult emotions and tried to maintain emotional equilibrium (Lee-Treweek 1996), reflecting concerns among carers about 'responding the wrong way' (Herron et al. 2019, 475). That was the last time that we looked at the photograph book. Ending moments therefore not only involves an instance when a moment stops but can be more finite, where particular practices of 'being in the moment' are no longer enjoyable.

Music, singing and improvisation

While walking was embedded in my mum's biography, music and singing were not; she frequently referred to herself as 'tone deaf' and I had rarely heard her sing. Yet music became increasingly important as her condition progressed, reflecting previous research with people living with fronto-temporal dementia (Kindell et al. 2018). The use of music to create meaningful moments began with my older brother playing his guitar when he was visiting from Australia in spring 2021, following an easing of Covid-19 travel restrictions in the UK. When he started playing the guitar, my mum enjoyed listening to him, and my dad or I sang along. These 'performances' created moments of connection (Fox et al. 2025), as we gathered in the front room and played music from my mum's youth such as Johnny Cash or the Beatles. Over time, perhaps related to the progression of her condition, she became less inhibited and increasingly enjoyed singing and moving to the music. Sometimes she improvised creatively (Dowlen et al. 2022), for instance joining in with the 'wooos' in the Beatles songs, waving her hands to the music or saying, 'Oh no', and pulling a sad face in response to sad lyrics.

As my mum's verbal communication declined, singing offered a way of communicating and gave her a fluency that her verbal conversation was now lacking (Kindell et al. 2018). Like other forms of everyday aesthetics (Thompson 2015), singing created 'ripples into everyday life' (Dowlen et al. 2022, 17), and we often sang on our walks. One spring morning we were walking together and singing and a blackbird started singing at the same time, and my mum said, 'Someone's singing too!'. Sometimes my mum improvised with her own words and tune while we walked:

> We then went for a walk and Mum said, "I love singing". She then sang a line and got me to take turns singing a line – she was making hers up as she went along' (14.12.2021).

This illustrates how my mum continued to demonstrate everyday creativity or 'co-creativity' (Zeilig et al. 2018) as we improvised together, inventing words and tunes and creating a 'sing-off' where we took turns to deliver our lines. This highlights how creative and relational skills can continue and even flourish while living with dementia, challenging the focus on a loss of abilities (Petrescu et al. 2014).

While watching films became challenging owing to difficulties concentrating and following spoken language, musicals rely less on verbal communication and were something we enjoyed together. One of her favourite musicals was *The King and I* – as a child she repeatedly watched this film with her mum. While the film is situated within narratives that are problematic in terms of colonialism and sexism, it was part of her early memories, and is also rich at a sensory level, with lavish costumes, musical scores and vivid Techni-colour images. Viewing the film or singing the songs facilitated enjoyable moments together – when we first re-watched it in autumn 2021, my mum said, 'It's beautiful, I'm remembering!'. She was drawn into the emotions of the film, saying, 'I feel sad', during the scene where two star-crossed lovers meet in the garden. I had forgotten the death of the king at the end of the film – my mum remained in shock for the rest of that day, looking sad and saying in disbelief, 'He died!'. This illustrates how 'reliving the moment' (Keady et al. 2022) is not always associated with enjoyment. When we re-watched it, I started editing the ending, and said, 'Let's stop it here for now' or 'It's nearly at the end, the next bit is a bit boring'. This represents a 'compassionate fabrication' – telling 'white lies' to prevent distress to the person living with dementia (Dobson 2023) and 'ending the moment' as a strategy of emotion work (Lee-Treweek 1996). However, compassionate fabrications are also situated within relational biographies (Dobson 2023) and this was in keeping with my mum's practice of checking novels for happy endings or editing out sad endings in films when I was young. One of the best-known songs from the film, 'Shall we dance?', became our 'signature song' that we would regularly sing around the house or on our walks. My mum joined in with the 'dum, dum, dum' that is part of the rhythm of the chorus, illustrating a more positive way of 'reliving the moment'.

Dancing also became important as my mum found it increasingly hard to sit still or concentrate. To create a nice moment together or sometimes to distract my mum if she was upset or distressed, I would put on a CD, and we danced together in the kitchen:

> I put on Tom Jones and we had a dance in the kitchen holding hands; it reminds me of dancing when I was young in [alternative music night club] holding hands with my friend. My mum said, 'Gorgeous voice' [meaning Tom Jones], and when I showed her the CD case and told her it was Tom Jones she was excited and tried to tell my dad, although the words didn't come out quite right. (20.08.2022)

Dancing provided a new way of being together and 'creates an aesthetic experience that flows across bodies in space and time' (Thompson 2023, 29). I had never seen my mum dance; she described herself as 'too shy' to dance in public. The practice of dancing evoked memories of my youth, while the music evoked generational memories for my mum, weaving different moments in our individual biographies together.

Previous research has found that singing can be interwoven with the bodywork of care for people living with dementia (Hammar et al. 2011). As discussed earlier, assisting my mum with changing clothes or using the toilet often constituted challenging moments, and sometimes singing while we helped my mum with these tasks calmed her. However, aesthetics of care (Thompson 2015, 2023) not only had to be adapted as dementia progressed but also day-to-day, depending on my mum's mood. This was not always easy to anticipate – if my mum was upset or agitated, sometimes my singing would cheer her up, but it could also (understandably!) make her feel more annoyed. On one occasion she turned to me and said, 'Your singing and playing around can be annoying!'. When she was less able to indicate this verbally, she would wave her hands or say, 'Shush', indicating for me to be quiet.

Over time, my mum's personal care needs became increasingly challenging and the lack of sleep took its toll, particularly on my dad, reflecting wider literature on caring and stress (*e.g.* Jones et al. 2019). We started looking into possible nursing homes, which evoked 'lots of emotions – a sense of guilt – have I done enough?, anxiety, but also a sense of loss and helplessness' (written diary 06.06.2022). When my mum moved into a nursing home it was one of the hardest days of my life, and I could not stop crying on the way home. Trying to pass on her love of music and singing as part of her 'care aesthetic' was important to easing the transition to care – we tried to pass this knowledge on through her care plan and taking a CD player and her favourite CDs with her. Since my mum moved into the nursing home, music remained important, even as other activities became more challenging. Care-workers at the home sometimes told us that they had been singing with her, or that she had joined in with other residents singing in the lounge. We continued singing her favourite songs like 'Shall we dance?' together as we walked along the corridors of the nursing home, and singing could sometimes help calm her if she was feeling restless. On one occasion when I came to visit her, she did not appear to recognize or respond to me when I arrived, but when I started singing 'Shall we dance?' she turned to me and said, 'Chrissy'. At the time of writing, my mum is now in the advanced stages of dementia but sometimes still responds to music at an embodied level (Kontos 2004). Although she no longer has the words, she will sometimes make noises along with the tune, or smile when I am singing with her. This illustrates how moments of recognition and connection are facilitated by care aesthetics (Thompson 2023) and the continuation of selfhood even as dementia progresses to the advanced stages (Kitwood 1997).

Discussion

This article has explored everyday life as a 'series of moments' when caring for someone living with dementia, shifting between difficult, frustrating, joyful, sad, funny and caring moments. Building on Keady et al.'s (2022) moments framework, it extends understanding of how moments 'link together' (698) in everyday life and negative as well as positive experiences of moments (Fox et al. 2025). My experiences illustrate the complexity of how different moments and emotions are woven together, highlighting challenges – as well as enjoyment – in creating, being in and reliving the moment. The article demonstrates how connection, recognition and emotions shift from moment to moment, challenging the narrative of linear decline, but also the polarization of this with solely positive images of 'living well' (Ward et al. 2022). As a family carer I found this approach helpful for acknowledging challenging moments alongside joyful ones and for understanding that you are not 'stuck' in difficult moments.

The article offers novel insights into how 'moments' and care aesthetics relate to emotion work. Sometimes 'creating the moment' can be a strategy for moving beyond difficult emotions, reflecting the 'emotion work' of unpaid care (Özen 2020). The article explores how emotion work can be reciprocal and relational (Palmer and Scott 2018), carried out by the person living with dementia as well as family carers. There is a significant body of work on the emotional impact of caring (Jones et al. 2019) – this article highlights the specific challenges associated with care aesthetics and moments. Aesthetic practices evoked strong emotional responses that were not always predictable; for instance, re-watching a film or looking at photographs could unintentionally evoke sadness or grief, while bad weather could create stressful experiences of 'being in the moment' outdoors. As a family carer I found it difficult to know when to sit with emotions, and worried afterwards that I did not always give enough room for my mum to work through them, reflecting concerns about 'responding the wrong way' (Herron et al. 2019, 475). This article extends the call for further recognition and support for family carers with 'emotion work' (Herron et al. 2019), highlighting the need for specific support and guidance around emotion work relating to 'moments' and care aesthetics.

The article highlights being in the moment as a reciprocal care practice that involves attentiveness and situates aesthetic practices as central to care, rather than an add-on (Thompson 2023). Like paid carework, unpaid care involves physical bodywork and emotion work, but also finding ways of being together throughout the day (Özen 2020). Family carers do not always recognize time spent 'being with' as part of care, especially if it is enjoyable (Bowes et al. 2020). This presents challenges when asked to quantify care. For instance, when my dad and I were going through the Carers Assessment form, although we could find a box for 'keeping an eye' on the person receiving care, we could not find an option that captured spending time with them or doing meaningful activities together. The physical and emotional demands of bodywork can be in tension with care aesthetics (Thompson 2023) and can impact on carer mental health (Jones et al. 2019). My dad and I were caring for my mum together, sometimes with my older brother, which helped to create room for enjoyable moments and 'hold' difficult ones (Kitwood 1997). However, I could see the strain on my dad and I also sometimes struggled emotionally, while finding many aspects of caring rewarding. Not everyone has family support and accessing sufficient social care support is challenging in the UK and globally (Giebel et al. 2024).

Yet, alongside these difficulties, the article highlights my mum's ongoing ability to co-create (Zeilig et al. 2018) 'caring moments' (Campbell et al. 2024), challenging the view of dementia as the loss of self (Kitwood 1997; Kontos 2004). I sometimes came across stereotypes of dementia, with people saying, 'You've already lost her' or 'She's already gone' (see Bryden 2020). However, the article highlights my mum's ability to express care, connection and selfhood at an embodied level (Kontos 2004; Kontos et al. 2017) and situates this within connections to people, everyday aesthetics and environments (Fox et al. 2025). While aesthetic practices were situated biographically, the article highlights how new practices and aspects of the self continued to emerge (Haeusermann 2019). Aesthetic practices require ongoing adjustments as interests and abilities change over time, but also as they fluctuate moment to moment. However, when an activity no longer seems to provide enjoyment or connection, this raises dilemmas about whether and when to end that particular practice.

As an autoethnographic account, this article is limited to one case, and to my experience as a White, middle-class woman. My experiences are situated within a close relationship to my mum and supportive family relationships, whereas different family relationships would produce different experiences of care. Intersecting inequalities related to class, gender and race shape experiences of caring and living with dementia, in terms of structural barriers to accessing services and support (Zubair 2023; Giebel et al. 2024), and financial resources to take up options for flexible working (Carers UK 2024). Further research is needed to explore the interconnection of positive and negative experiences of moments, and their relation to emotion work, from the perspective of the person living with dementia and among a broader and more diverse sample of unpaid carers.

Conclusion

This article presents autoethnographic reflections on my experiences of caring for my mum, analysed through the framework of 'moments' (Keady et al. 2022) and care aesthetics (Thompson 2015, 2023). While previous literature has often focused on positive moments, the present article highlights how joyful, connected, challenging and upsetting moments are woven together into a 'series of moments' throughout the day. It explores the connection of moments and aesthetic practices to emotions, demonstrating how creating moments can provide a strategy of emotion work and moving beyond difficult experiences. This emotion work can be mutual and the examples highlight the ongoing ability of my mum to express care, connection, creativity and selfhood at an embodied level, challenging narratives of dementia as the loss of self. However, the emotions evoked by aesthetic practices are unpredictable and can present challenges to 'being in the moment', highlighting the need for specific support for family carers related to creating moments and care aesthetics.

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Ethical standards. As this is an autoethnographic article based on my personal reflections, ethical approval was not required by my university ethics committee. However, I have tried to adhere to good ethical practice in autoethnography, for instance consulting with family members represented in it where possible (see methodology for discussion).

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