

‘Being’ and ‘doing’ well in the moment: Theoretical and relational contributions of health geography to living well with dementia

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Abstract

Over the past two decades, advancements have been made towards de-medicalising the term ‘dementia’, attending to in-the-moment lived experiences of people with the condition, and exploring the connections between dementia and place, relations, activities, and well-being. In the same timeframe, a range of prominent researchers within health geography have proposed new renegotiations of well-being that consider it as something relational, process-oriented, and emergent. Although these progressions in both dementia studies and health geography are ontologically aligned, the two lines of enquiry have only recently started to see crossover, pioneered by geographers seeking to better understand what it means to ‘live well with dementia in the moment’. In this theoretically driven paper, I celebrate these contributions to dementia and well-being studies through a timely review of the literature that informed the theoretical underpinnings of my own doctoral studies. Through the literature, I consider how a relational well-being lens can make supportive and empowering in-the-moment contributions to people living with dementia, who seek ways of ‘being well’ and ‘doing well’. As part of a special edition of *Area*, this paper takes us from the early inputs of health geographers to dementia and relational well-being knowledge, through to present-day literature and the future of dementia research framed around the in-the-moment movement. The contents of this paper ultimately support the importance of pushing the theoretical and conceptual boundaries of dementia research and well-being studies, to subsequently broaden our understandings of dementia and provide a new well-being lens that better captures the perspectives of those living with it.

KEYWORDS

dementia, embodiment, emergence, in-the-moment, participatory, relational well-being

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1 | INTRODUCTION: DEMENTIA AS DIAGNOSED, LIVED, FELT, AND EMPLACED

The global population is ageing, accompanied by a worldwide rise in dementia cases (Todd et al., 2013). The term ‘dementia’ refers not to a specific disease, but to a set of symptoms caused by forms of neurodegeneration, wherein progressive damage impacts the nerve cells and neural networks of the brain (Livingston et al., 2020). The most common diagnosis received internationally – accounting for approximately 60%–70% of all cases – is Alzheimer’s disease, followed by vascular dementia, Lewy bodies dementia, frontotemporal dementia, and mixed dementias, respectively (World Health Organization, 2022). The condition is broadly characterised by memory loss, disorientation and confusion, concentration difficulties, communication changes, and variable mood shifts, though symptoms can vary depending on the person, diagnosis, and stage of progression (Alzheimer’s Society, 2023). Given the physical basis and behavioural presentations of dementia, it has often been studied – and continues to be explored – by biomedical, psychiatric, and psychological fields, with attention on neuropathology, brain atrophy, individual behavioural observations, and interventions. While biomedical and psychological models aid our growing knowledge of dementia and its related conditions, social researchers have long recognised the implications of medicalising dementia, including the neglect of social, economic, and environmental factors (Bond, 1992; Lyman, 1989). Furthermore, there are no cures for dementia-related conditions and only limited treatments to slow progress, indicating the need to prioritise and improve the everyday lived experiences of those impacted (Alzheimer’s Society, 2022).

Some of the earliest involvements of medical and health geography in the study of dementia have been through global epidemiology – including incidence and prevalence rates of dementia sub-types (e.g., Ineichen, 1998; Rizzi et al., 2014) – and the analysis of mortality data to better understand geographical factors of dementia deaths within populations (e.g., Martyn & Pippard, 1988). Although these research contributions lend themselves to the over-medicalised ‘dying with’ dementia narrative as opposed to the ‘living well with’ line of enquiry more associated with social and human geographies, they have played a vital role in addressing global disparities in diagnosis, treatment, care, and social support. From such studies, we have learned that while some countries are shown to have lower numbers of diagnoses, this may not necessarily equate to lower dementia prevalence; rather, it may be more suggestive of lower dementia *detection* (e.g., Chen et al., 2013). Low detection and diagnosis rates can be the result of various factors – such as lack of dementia awareness in healthcare systems, socio-economic factors, rural/urban neighbourhood classifications, cultural influences, and dementia-related stigma – which can impede the health care plan and living support arrangements for those with dementia. A recent international report commissioned by Alzheimer’s Disease International (2021) confirmed that low diagnosis rates are a continuing concern, with an estimated 41 million people currently living with undiagnosed dementia, a high percentage of whom live in low to middle income countries. According to the report, failure to diagnose is partly due to clinician attitudes, alongside cultural, familial, and environmental biases. Although these factors remain hard to measure or determine, they nevertheless reveal that a person’s experience of dementia does not purely consist of individualistic, biomedical, and psychological phenomena; rather, it varies depending on the surrounding people, places, and services available. Subsequently, there are crucial social and environmental implications of dementia that can be, and are being, addressed by health geography.

With no effective cure yet discovered, an increase in sociologically and geographically informed research is exploring dementia-related lived experiences and non-pharmacological ways of living well with dementia. This is also supported outside of research contexts by national policies, such as the United Kingdom’s ‘Living Well with Dementia’ national strategy (Department of Health and Social Care, 2009). Social and geographical research promotes greater emphasis on the individual behind a dementia diagnosis, their sense of belonging and relationship with place, and their changing role within society, be it a *perceived* change by others or a real *experienced* change (e.g., Thomas & Milligan, 2015). A pivotal moment in understanding lived experiences of dementia was established when the focus shifted from disease-centric and symptom-centric approaches, towards person-centred and inclusive approaches, which broadly aim to support individual identity and well-being *despite* the presence of dementia (Kitwood, 1997). The growth of person-centredness in dementia research began with early observations in professional care settings, but has since progressed beyond conventional care to everyday geographies, home environments, and local neighbourhood landscapes, all of which can be viewed as extended care settings necessitating a conscious dementia-friendly approach (Clark, Campbell, et al., 2021). Across different social and physical spaces, person-centredness can help overcome a bias for ‘what people with dementia cannot do’ and instead enable ‘their interests, pleasure, and use of their capacities’ to create a life of meaning and wellness (Vernooij-Dassen & Moniz-Cook, 2016, p. 668). Person-centredness is therefore synonymous with asset or strength-based approaches in

dementia, which encourage a 'can do' attitude by attending to the enduring capabilities and desires of individuals that are paramount to everyday life (e.g., Grove, 2021; Sen, 1999; Sturge et al., 2021).

Given the unpredictability of dementia on a day-to-day basis, a person-centred and asset/strength-based approach inherently leads to an in-the-moment perspective, where attention is re-positioned away from the past and future towards the present. By expanding beyond dementia as simply 'diagnosed' or 'lived' and also considering its moment-by-moment affective or 'felt' aspects, an individual's capabilities, ideas, and selfhood can be better attended to. Furthermore, the opportunities afforded by the present moment can help to overcome challenges most associated with dementia-related diagnoses, including memory loss, verbal challenges, and altered time awareness, by taking pressure away from reflections of what *used* to be and what *could* be, and instead finding a way of attending to what simply *is* (Andrews, 2021).

A new wave of in-the-moment (or moments-based) research has been pioneered by academics interested in supporting people with dementia in alternative ways. As explained by Keady et al. (2022), a moment is something 'transitory' and can be used as a 'metaphor for the present' (p. 683). A move away from past and future perspectives, towards those that are more emergent and present, can be empowering for people living with dementia not only in terms of research participation or care, but also more generally in day-to-day living. Being in the moment can offer communicative support to those who are living with dementia, in addition to providing them with a sense of inclusivity in the events that are unfolding before them. Opportunities to present their identities and selfhoods in more unconventional ways may include movement, non-verbal activity, and performative modes (e.g., Campbell et al., 2023). While an in-the-moment lens is beneficial for the individual living with dementia, it not only attends to *the person* with dementia, but also offers further context by considering what the moment itself entails; what factors or features assemble to enable that moment to emerge, and how the moment can assist the development of well-being opportunities. It is through this consideration of dementia that attention is extended to its 'felt' qualities. This idea is familiar with health geographers, who in recent years have explored 'the ways in which health presents or *feels* within everyday contexts or environments' (Kaley et al., 2019, p. 1). When applied to the 'living well' with dementia concept, an in-the-moment approach with a geographically informed lens can aid a holistic exploration of what it means to live with dementia *in relation* to other people, places, things, and circumstances. Although the promotion of 'landscapes of ageing' has been growing for two decades (Kearns & Andrews, 2004), it remains underdeveloped in dementia research more specifically. Hence, health geographers have recently proposed a shift in understanding dementia as something that is emerging, 'emplaced', and situated (Clark, Ward, & Phillipson, 2021, p. 2). This is where the acknowledgement of relationality and relational well-being becomes paramount in progressing dementia research and in understanding how being in the moment can connect with 'being-well'.

2 | A SOCIO-RELATIONAL-GEOGRAPHICAL LENS ON DEMENTIA AND WELL-BEING

Broadly speaking, in-the-moment ideas stem from theoretical perspectives of well-being that have been at the forefront of health geography over the past two decades (e.g., Andrews et al., 2014; Fleuret & Atkinson, 2007). While being in the moment, one can recognise the experiences of 'being well' more immediately, with greater awareness of the living-feeling and relational experiences of dementia as they happen in the here and now (Barron, 2019). Regardless of the early engagement with relational and in-the-moment well-being from geographical sub-fields, the term 'well-being' is often poorly articulated, leaving it vulnerable to misinterpretations and reinterpretations. I, too, have found this to be the case when reviewing the broad and multidisciplinary field of dementia research: well-being is richly discussed but inadequately or variably defined (Ward, 2021). In the context of my own doctoral research, I felt it important to clarify my well-being position as a foundation to my enquiries, while also promoting new informed ways of thinking about dementia and well-being, based on an overview of the concept's history within the field of human and health geographies.

Health geographers and social researchers can offer effective alternatives to outdated yet unchanged understandings of health and well-being, and many have critiqued past definitions, such as the World Health Organization's description of 'a state of complete physical, social and mental well-being and not merely the absence of disease or infirmity' (WHO, 1948; as critiqued by Fleuret & Atkinson, 2007; Mossabir, 2019). Although aiming to embrace the heterogeneous population as a whole, this broad portrayal creates further inconsistencies about what a 'complete' version of well-being consists of, and the implications of a well-being that cannot exist in tandem with chronic or lifelong conditions. In the context of dementia, the WHO's health and well-being definition is arguably disabling, given the ongoing physical, mental, social, and emotional implications of a dementia diagnosis. Irrespective of this, many people living with dementia have been observed and recorded maintaining what they subjectively consider to be good health (e.g., Dowlen et al., 2022).

Beyond the inconsistencies of *what* well-being is, other researchers acknowledge the irregularities in understanding *how* well-being comes to exist. Efforts have therefore been made to better understand it in practice from active and experiential viewpoints. From a subjective point of view, well-being can be discussed as the result of personal fulfilment or the outcome of having one's complex personal or individual needs met (Dowlen et al., 2018). Alternatively to desire and self-fulfilment concepts, the well-being contributions of Amartya Sen (1999) focus on the capabilities and functionalities of individuals, where the former refers to the feasibility and freedom of choice held by the individual to achieve particular 'beings' and 'doings', while the latter refers to those which are actually achieved. Moving away from individualistic representations of well-being, others have promoted a spatial well-being that is obtained from being in particular places, thereby implying that well-being is entwined with place itself, such as early therapeutic landscapes work (e.g., Milligan et al., 2004). Researchers engaged in therapeutic landscapes have been evolving these ideas beyond chiefly physical or visual aspects of place, to further consider how landscapes are interacted with and how the body senses them in practice (Doughty, 2013). Well-being can be drawn into this discussion through considering the inter-dependence of space, place, emotions, and senses. Explained by Davidson and Milligan (2004), 'emotions are understandable – 'sensible' – only in the context of particular places ... likewise, place must be *felt* to make sense' (p.524; italics in original). Building on the narrative of therapeutic landscapes in dementia-related work, researchers have discussed well-being as something connected to ordinary everyday places like neighbourhoods, where 'social connection, engagement and interaction' can facilitate wellness for people living with dementia (Clark, Campbell, et al., 2021, p. 23). Other topical publications in health geography have discussed health and well-being as related less to tangible place and time, and more so to atmospheres that engage 'all five human senses as well as ... emotions, hopes, desires and fears' (Andrews, 2021, p. 10). Emerging and assembling as a feeling, well-being can be defined as 'more immediate, momentary ... relational, affective and multi-sensory' (Kaley et al., 2019). Overall, geographically informed well-being research is moving beyond well-being as something that can be constructively or quantifiably measured, and attending to it as an integrally embodied aspect of living; an abstract, heterogeneous, and complex happening, not easily reduced to an all-inclusive single definition.

Researchers exploring the perspectives of older adults have found that from participants' standpoints, well-being can entail good physical health; autonomy and independence; a sense of good mental health; emotional stability; social relations; and a continuity of self-identity (Ziegler & Schwanen, 2011). This is a particularly important point to maintain within dementia research, given that a purist approach to being in the moment could deny acknowledgement of those aspects of living and being that were developed in a person's past, and therefore could potentially feed the negative stereotypes within outdated dementia narratives about 'loss of self'. This has recently been raised in regards to other geographically informed approaches that have overlaps with the theoretical underpinnings of this paper, including non-representational theory (Andrews et al., 2014). Disputably, to be entirely in the moment would be pre-cognitive and thereby pre-personal. Well-being cannot rely completely on immediacy, given that 'biography, practice, time, settings and other people, combine to create and sustain the experience of being in the moment ... as part of the complex processes through which moments are created, sustained, ended and ... re-lived once again' (Keady et al., 2022, p. 25). This is further evidenced by Dewitte et al. (2021), who found that present-day experiences of people with dementia were meaningful 'against the background of the entire life lived', to include important memories and activities that are embedded in personal identities (p. 12). When considering these potential facets of being well – and all of the prior discussed well-being perspectives – it can be deduced that 'well-being' is not necessarily a collection of achieved and stable components, but rather a multi-faceted situation that encompasses aspects of the past, interrelated with the present and the potentials of the future.

Drawing on the work of different health geographers, well-being experiences can be considered 'complex assemblages of relations not only between people, but also between people and places, material objects and less material constituents ... including atmosphere, histories and values' (Atkinson, 2013, p. 142). In tandem with this, a brief time spent exploring the 'living well with dementia' strategy offers insight into well-being not as a concept that has potential completeness, but as a proactive state that is integrally linked to action and interaction. The 'living well with dementia' narrative could be deemed as an approach that is centred on the aim of living with a positive attitude, but the term is more associated with activities, programmes, interventions, and actions that people with dementia – along with families, carers, and neighbours – can 'do' in daily life, in pursuit of wellness (Department of Health and Social Care, 2009). This fits with views of well-being that are more experiential, embodied, and *in relation* to aspects of living that are more than something mentally constructed. It is also important to note that dementia can be consecutively described as unpredictable in the short term – characterised by unsettled and changeable moods and behaviours – yet inevitable in the long term – given that the future of dementia is characterised by fatal disease progression, albeit at different speeds for different people (Hall & Sikes, 2020). Considering dementia's fluctuating and unpredictable nature, well-being can be similarly acknowledged as

fluctuating, multi-faceted, and relational, with renegotiation required on a day-to-day or moment-by-moment basis *in relation* to other occurring factors.

In the context of dementia, well-being can be reconstructed beyond subjective and goal-oriented levels, looking towards the relational qualities and the temporally transient nature of moments that contribute to a more inclusive view of health and well-being (e.g., Keady et al., 2022). If well-being is to be better explored within dementia contexts, it needs to be expanded beyond psychological and behavioural tenets, looking at where the person with dementia fits and belongs within society, community, geography, and place.

3 | BEING, DOING, FEELING: THINKING GEOGRAPHICALLY ABOUT DEMENTIA AND WELL-BEING FOR FUTURE RESEARCH

In a bid to gain more informed insights into relational well-being and everyday life with dementia, particular tenets need to be explored to turn this paper's theoretical arguments into something actionable. It is necessary to consider what people living with dementia *do*; where they are situated; who/what they are surrounded by; and how these interactions are recognised through research choices. To uphold embodied, relational, and spatial lines of enquiry, careful consideration must be given to the research designs and data collection methods utilised. It is beneficial to move beyond biomedical discourses that evaluate interventions by prioritising the 'before' and 'after' but not the 'during', such as in pre/post designs (e.g., Dowlen et al., 2022). Equally, it is advantageous to move beyond heavily reflective and discursive qualitative methods, which can be polarising for people who commonly face verbal challenges alongside memory loss (Hubbard et al., 2002). Neither approach is solely suited to exploring dementia as 'lived' or 'felt'.

The challenge is in becoming comfortable with well-being's fluidity and opening it up to less restrictive definitions. This means moving away from measurable scales and re-positioning well-being within social interactions, self-expression, and embodied engagements. Methods that capture these features will be inherently in-the-moment, offering realistic insights into everyday geographies, and withdrawing from a goal-oriented well-being definition towards a process-oriented one that captures the moment by moment 'beings' and 'doings' of life with dementia. With emerging health geographers embracing performative and participatory turns within their field, visual and ethnographic methods are being adopted and adapted to capture more immediate place-based well-being encounters (Kaley et al., 2019). Through relational and participatory activities, attention can be given to the 'living well with dementia' narrative and what people with dementia *can still* do. Whether activities are observed for their well-being potential – such as group-based musicking sessions (Dowlen et al., 2018, 2022) – or are being utilised for data collection – such as arts-based methods and creative research practices (Chauhan, 2020; Zeilig et al., 2019) – these meaningful, embodied, and shared engagements of people living with dementia provide channels of communication, self-expression, and interactive means of research contribution (Ward, 2021). Exemplified through the study of co-creativity and dementia, Zeilig et al. (2019) captured insights into well-being as a relational and ongoing experience, by using arts-based methods as unconventional forms of data collection. Therefore, forthcoming dementia and well-being research may achieve an in-the-moment and relational position by adopting activities that encourage unfolding engagements and can simultaneously be considered research methods in their own right. This is where the duality of 'being well' and 'doing well' is born (e.g., Grove, 2021), in which being well emotionally/affectively is reinforced through bodily engagement and acts of doing that ultimately provide experiential and emergent well-being encounters and help to strip 'communication and connection to what is most important: a smile, eye contact, touch, time' (Lenette, 2022, p. 93).

Furthermore, who and what people with dementia are surrounded by matters. Adapted forms of participatory, visual, and qualitative research – including ethnographic, phenomenological, visual, sensory, creative-based, and narrative techniques – not only present the experiences of those living with dementia, but also have the potential to endorse holism and a 'socio-relational-geographical' lens by attending to other features beyond the person. The experience of dementia is not entirely individualised, but instead relational, whereby the people, places, objects, and activities involved all have influence, and can therefore offer richness if incorporated into the data collection. The act of doing something meaningful, and doing it with other people, is shown to channel a shared in-the-moment focus that leads to higher levels of engagement, expression, and communication among those with dementia (Ward, 2021). Likewise, the study of well-being in dementia can also be viewed through a similarly relational, in-the-moment, and situated lens, as has been promoted within health geography (Andrews et al., 2014; Atkinson, 2013). This does not, however, imply that experiences centred on the individual are unimportant, but more accurately that an individual can be better understood through their in-the-moment connections, relations, and engagements. Recent

researchers have succeeded in acknowledging these relational aspects through their broad methodological choices, such as the use of sensory ethnography and walking interviews to explore a person's situatedness in dementia experiences (Mossabir, 2019). Other studies promote participatory methodologies, like participatory action research, which provide community-based responsibilities to people with dementia and enable their perspectives to be shared from a place of agency and empowerment (Lenette, 2022; Smith & Phillipson, 2021).

Evidently, our understandings of dementia have grown from early biomedical and epidemiological influences, through to the consideration of behavioural and lived experiences, and finally to the current emerging sub-field of in-the-moment dementia and health geography, where dementia is discussed through relationality, emergence, and place. In light of the past and most current geographically informed research on dementia, an in-the-moment approach can generate new understandings of what well-being may mean when living with progressive neurodegeneration. Understandings of well-being have evolved from the medical, to the subjective and psychological, through to the relational, emergent, social, sensory, spatial, and affective. A geographically informed transition to being in the moment – for dementia, well-being, and research more broadly – can offer accessibility and transparency, and reverse the personal identities expressed by people with dementia, which play an important role in how well-being is understood and felt (Keady et al., 2022). Particular activities – like music and arts – and unconventional research designs – including creative, visual, or sensory methods (e.g., Campbell et al., 2023) – can provide opportunities to people with dementia to live in the moment, despite their dementia symptoms, while also supporting their expression of selfhood through relationships with people, place, and objects, that traditional methods often overlook. The systematic nature of traditional methods and goal-oriented well-being definitions does not fit with dementia's changeability, which requires more regular renegotiation *in relation to* other occurring factors that unfold in a given moment. By rejecting well-being as a goal or scaled outcome, the value of in-the-moment engagements of people with dementia can be understood, and the unpredictable nature of their symptoms accommodated for. This supports better insight into the nuances of being present and can provide empowerment to those with dementia who seek to live well and continue their life narrative (Dewitte et al., 2021). Through unconventional and participatory research methods, not only are people with dementia supported more purposefully, but researchers can develop their 'theoretical knowledge and perspectives', increase 'their competence in working with people with dementia', and allow the strengths of all parties 'to synergize' (Kowe et al., 2022). Conclusively, what people with dementia *do* and how researchers capture this must be complementary, to ensure that future dementia studies remain grounded on inclusive, participatory, place-based, relational, and in-the-moment components.

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The authors report no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are openly available as a doctoral thesis in the Lancaster University Library, ID code 163543, at <https://doi.org/10.17635/lancaster/thesis/1511>.

ETHICAL APPROVAL

This paper is linked to research that was ethically approved by Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHMREC).

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