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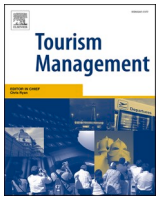

Progress in Tourism Management

Dementia as a global challenge: Progress and prospects for creating more dementia-inclusive tourism industries

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ABSTRACT

Global Grand Challenges (GCs) have received only a limited attention within the tourism literature and this Progress paper examines one such GC – dementia and the contribution that tourism research can make to helping people live well with dementia. The paper critically debates the concept of GCs, the challenges of addressing them and how dementia presents both a challenge and opportunity for the academy. Using the concept of the visitor journey and the social model of disability as a paradigm, the paper reviews progress towards creating a more dementia-inclusive society through the auspices of tourism research, reviewing the contributions to date and where the interconnections with dementia and tourism exist. The review draws from a wide interdisciplinary framework including health, medicine, travel medicine and leisure and argues for a greater use of trans-disciplinary approaches to address GCs.

1. Introduction

Dementia is a term that refers to an extensive range of symptoms that affect an individual's cognitive ability to process and undertake everyday tasks (Ames et al., 2014). While it is usually associated with older people[1], dementia is not a normal part of the ageing process and results from brain diseases, injuries, and disorders, such as Alzheimer's disease[2]. According to the World Health Organisation (World Health Organisation 2021a), over 55 million people globally are living with dementia, a figure estimated to increase to 78 million by 2030 and 139 million by 2050, and it is commonly termed a silent epidemic (World Health Organisation, 2023). Yet, because dementia encompasses many symptoms and stages, the term hides a complexity of individual contexts, characteristics, motivations, abilities and disabilities. The increasing prevalence, awareness and experience of dementia have prompted different approaches to framing it as a condition that people live with over time, such as the widely adopted notion of living well with dementia. Tourism has a widely accepted role to play in improving wellbeing, and the connections between tourism and living well with dementia is an area of research and practice that arises from the wider policy work advancing the case for greater attention to this issue (e.g. UK Department of Health, 2015; OECD, 2015; Ferri et al., 2017; OECD, 2017; Parra et al., 2019; Cahill, 2020; Price et al., 2022). The aim of this progress paper is to contextualise and chart the emergence of dementia as an issue of relevance in tourism research, and as a potential global challenge (GC). The paper examines how the growing prominence of dementia may shape future changes to service delivery in the visitor economy.

1.1. The case for a narrated review on dementia and tourism: framing the approach

Dementia research has a long pedigree within the social and medical sciences, emanating from the evolution of gerontology[3] in the period since the 1920s (e.g. Hall, 1922; Kaplan, 1946; Shock, 1952), with the first household-based survey of the scale and scope of dementia in a community attributed to Sheldon (1948). Tourism, in contrast, has a more recent history of development and it is constantly expanding its horizons into other areas of scholarly endeavour that connect with emergent themes and new research agendas. It is not surprising to find critical connections emerging between gerontology and tourism as two interdisciplinary fields of endeavour that focus on human activity. There are many scholarly reasons to justify a narrated review that explores the interconnections between dementia and tourism. First, dementia is emerging as a GC in its own right, comprising an interconnected global issue associated with ageing populations where dementia is a

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characteristic of ageing societies. Second, a review is timely because it is an area of research and practice that will grow in scope, scale and prominence for tourism managers over the next decade as people live longer and the prevalence of dementia increases globally. The GC posed by dementia will generate numerous operational and strategic management issues for businesses. Third, there is evidence that the dementia-tourism nexus is creating a wider interest within the tourism and leisure field of study (Page & Connell, 2022). However, knowledge remains somewhat fragmented and lacks a comprehensive roadmap of how the field has developed, the shape of current activity and prospects for future research. Lastly, it represents a further opportunity to contribute to tourist well-being research whilst deepening our understanding of existing research on accessibility and more diverse populations and their needs.

In crossing disciplinary boundaries, and those of linked professional practice, the research community faces numerous epistemological and ontological challenges rooted within disciplinary backgrounds and training. We recognise that the analysis of dementia spans many disciplines, such as medicine, health and social care, social science and the humanities. For this reason, we highlight how the GC concept as a potential transdisciplinary approach offers a more powerful lens to view dementia, particularly given that disciplinary perspectives tend to spawn dialectical approaches affecting the framing of a research problem. The more holistic, interconnected and boundary-spanning approach adopted in this paper examines dementia as a GC in a synthesising and dynamic manner to understand its complexity, multifarious elements and dimensions, and the challenges for the global tourism industries[4]. As this review will demonstrate, much of the conventional knowledge and thinking around dementia has been framed from a health perspective, while interconnections with tourism have only recently emerged. These interconnections, embedded within the broader notion of leisure of which tourism is a key element, broaden the scope of dementia as a GC by posing one key question: *as the prevalence of dementia grows, how will leisure time be adapted, accommodated and nurtured in a tourism context?* Understanding how dementia connects with tourism requires the application of different research frames and concepts outside the usual domain of tourism research to integrate multiple perspectives. This has traditionally been based on an interdisciplinary perspective of drawing upon expertise and knowledge from across disciplinary boundaries. But as we will demonstrate in the discussion of the GC concept, further research and changes to practice can be enriched by an *enabling* approach. For this reason, the focus of this paper is on how that GC approach and its implicit transdisciplinarity may help create a focus across boundaries that engenders that enablement in forming practical solutions to living well with dementia. This means that conventional models such as the social disability model[5], the visitor journey[6] and the dementia lifecycle[7], as well as research from travel medicine and other germane areas will need to be synthesised in future research and practice at the dementia-tourism nexus. In addition, the paper examines the underlying policy agendas starting to emerge around inclusivity and dementia that recognise barriers to access and facilitate greater accessibility for visitors with visible and hidden conditions that are being promoted in transdisciplinary contexts. For example, the UK government is seeking to create the most accessible tourism sector in Europe by 2025, where different disciplines and practices have been brought together to address inclusion (Minister for Disability, 2024). This contributes to the wider debate on access to tourism for all sections of society.

1.2. Structure of the review

The paper commences with a short outline of the contextual issues associated with the GC concept prior to an outline of the approach taken to constructing the review and the narrative literature review approach (see Vada et al., 2022), and the philosophical stance adopted in relation to the stated objectives of *Progress in Tourism* papers. A description of how the literature was assembled for the review and the framework developed to construct a narrative based on the universally accepted concept of the visitor journey follows. A critique of the GC paradigm as a critical turn in research is presented, highlighting the research opportunities which, in the context of this paper, help address issues of social exclusion and marginalisation for people living with dementia (Biggs et al., 2019). Attention then shifts to dementia as a GC followed by a review of the concept of time-space compression in the leisure behaviour of people living with dementia (PLWD) and their carers. The paper then moves on to a substantive discussion that locates the literature within different facets of the visitor journey. Finally, the paper outlines the implications for practice and sets out a potential research agenda.

1.3. The grand challenge concept as a research focus to holistically examine dementia

The notion of a grand challenge (GC) is a term used extensively to identify international scale problems where cross-sector knowledge, skills and research partnerships are recognised as progressive ways to address issues that transcend boundaries. Adopting a GC approach promotes the spanning of conventional disciplinary boundaries to explore and develop evidence-based solutions. Such an approach strives to overcome a problem so often highlighted in research policy – that academic studies do not connect with organisations that possess the power, authority and political support to enact transformational change (Nilsson, 2017). As a collaborative approach between private and public sector stakeholders, the GC approach helps focus on the etiology of large-scale research problems, often pooling expertise and knowledge to create pragmatic, novel, intervention-based and innovative solutions.

Ageing and health are widely recognised as a GC (see e.g., World Health Organisation, 2022) and a major public health issue (Suzman et al., 2015) Taking 2019 as a base year, 1:11 people were aged over 65, equivalent to 9% of the total population. By 2050, this is expected to rise to 1:6 (16% of the total population), with greater concentrations in many developed countries (United Nations Department of Social and Economic Affairs (2019). Because ageing is associated with an increase in health conditions, such as dementia (World Health Organisation, 2023), the nature and scale of the challenges posed by dementia are clear. Schwarzinger and Dufoil (2022) indicate that between 2019 and 2050, the number of people with dementia will be 2.7 times greater than the proportion today. Yet statistical accounts alone do not bring the lived nature of dementia to life (for both the person affected and the carer/supporter/family) as much as the vivid comments that can be found in personal accounts of living with dementia. These diaries, sometimes kept by PLWD and their carers as a reflective account, typically chart the progress of the disease through its life cycle from diagnosis to death (a theme we will return to later in the review). Where such diaries are created in research studies they are viewed as participatory research tools (Hogger et al., 2023). These person-centred diaries can be powerful and emotional records of the lived experience of dementia (see van Wijngaarden et al., 2019 on their idiographic value in dementia research), which often demonstrate how people with dementia strive to achieve continuity in their lives post-diagnosis (Górska et al., 2017). The following extracts from Elkin's (2022: NP) *The Alzheimer's Diaries* provide a stark statement on why dementia is a germane area for a review article: 'Alzheimer's [*a form of dementia*] is set to become the biggest killer in the next twenty years or so, outstripping cancer. There is no cure' (Elkin, 2022: NP) (see also Etkind et al., 2017 on dementia outstripping cancer in terms of mortality). The level of under-diagnosis, individual awareness in society and potential impact upon individuals before its diagnosis is often overlooked. In a tourist context, Elkin (2022: NP) brings this into sharp focus with a vivid depiction of a holiday trip with a PLWD, summarising the disruptive effects as 'disorientation during a holiday in Chicago [asking] (where's our hotel? repeatedly)' where the condition progressively affects spatial awareness and cognition. Elkin (2022: NP) further reflected on a subsequent holiday in

Amsterdam and the effect on the person with dementia: 'Ninety minutes in the Rijksmuseum … was all he could manage. And soon after that we had to go back to the hotel to rest. A walk around the lanes and canals in the Jordaan area was really too much and the crowds are always difficult … '.

1.3.1. GCs as an organising framework to examine the intersection of dementia and tourism

In this review, dementia is broadly framed as a facet of an ageing global population, which as the World Health Organisation (World Health Organisation) (2023: NP) indicates, ' … is currently the seventh leading cause of death among all diseases and one of the major causes of disability and dependency among older people globally'. Further, World Health Organisation (2022: 3) reaffirms that 'dementia is a global challenge'. Within tourism research, the notion of GCs is limited and much of the aligned theoretical development has emerged from management science (e.g. George et al., 2016) which has sought to explore the value of research collaboration across disciplines on addressing GCs. We position this paper on the notion that simply focusing on tourism and dementia fails to understand the complexity of a number of globally, externally and internally driven factors that impact individuals with dementia and their families and carers, social care organisations, interest groups, tourism businesses, health practitioners, researchers and governments and others involved across the broad grouping of interests in this field. Thus, a review of the subject is most effectively contextualised within the broader concept of a GC that reflects the complexity of transdisciplinary real-world issues, GCs have been classified into four types of challenge varying by scale, complexity and the types of issues addressed (Figure 1) (See Appendix 1 for a more detailed discussion of the concept and the social science literature on Grand Challenges).

The tourism industries have started to recognise the role of neurodiverse audiences and cognitive differences within society (Cena et al., 2023; Jepson et al., 2022). Ageing and dementia provide an opportunity for the global visitor economy because of the palliative value of tourism as a contributor to well-being (Adams et al., 2010; Patterson, 2017), achieved through holidays and visits to therapeutic landscapes, such as the coast (Day et al., 2000), as reiterated in Elkin's (2022) reflective diary. A further contribution of the paper is in using the GC framework and the social model of disability paradigm to identify the different challenges in creating a more dementia-inclusive visitor economy so that individuals with this progressive disease may access tourism opportunities. This model embraces an enabling philosophy by identifying barriers to participation and seeking ways to overcome them. However, other approaches aside from the GC exist, which might equally help to address this issue such as an age-friendly paradigm, where public sector investment is broadly targeted at the perceived community needs, although this has failed to recognise the tourism needs in destinations to date (Buffel et al., 2018; Caro & Fitzgerald, 2018; Page & Connell, 2023; Torku et al., 2021). Other approaches that have been introduced include formulating legislation and short-term initiatives to make the environment accessible, which have largely been focused on physical access but have not identified the broader scope of facilitating an ecosystem of access as advocated by the social disability model. In contrast, the GC has as its starting point a wide understanding of how applied research working with a wide range of stakeholders can help co-create solutions with PLWD for PLWD using a more empowering approach to hear their voices and to use the GC framework as an advocacy tool where the research evidence is used to enact change in a more transformational manner. The GC focuses on achieving change, as other approaches in social science have done, with varying degrees of success such as participatory research, although the GC recognises the complexity and scale of the challenge and its cumulative significance year on year.

The notion of a GC is a relatively new narrative in tourism research (see Scott, 2021), offering opportunities for more impactful research that may directly benefit society. The paper acknowledges that within the business literature, some scholars have argued that GCs represent a new 'turn' in research with the potential to create impactful research opportunities (Brammer et al., 2019). This is a welcome focus as research that impacts policy and practice has been a major weakness in business and management research, and tourism is no exception to this (Thomas, 2018). It reflects the tension between the theoretical pursuit of tourism as a social science and an action-oriented and problem-solving approach with a management focus. Tribe (1997) discussed the indiscipline of tourism and these tensions with the sometimes polarised nature of tourism scholarship, which in part, can be traced to the disciplinary bases from which the subject emerged (also see Tribe, 2009). As a subject area, it has been influenced and impacted by wider developments in social science and science while the different sections of the academy seek to claim the centre ground of the subject with internal debates.

These types of tensions spill over into the collaborative challenge of GCs given the epistemological and ontological differences within, and between, disciplines. As Frickel et al. (2016) indicated, frictions exist between and within disciplines (Cetina, 1999), let alone between disciplines and other stakeholders. In epistemological terms, disciplines cultivate their own worldview, methodologies and approaches to valid knowledge creation and scholars often have greater affinity with their disciplines than more fluid and less stable interdisciplinary collaborations that may be seen as working on the edge of their disciplines. At a

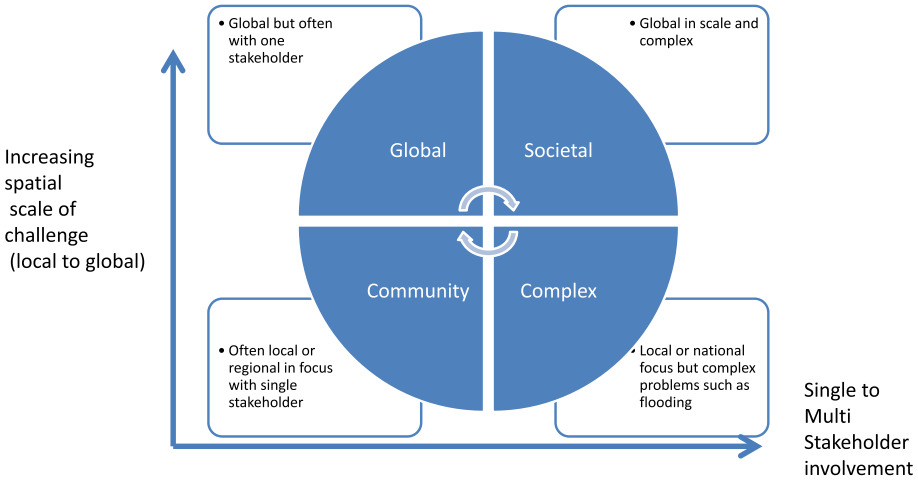

Fig. 1. Typology of grand challenges.

simple level, the disciplines speak different languages of research and methodology, which requires a new phase of learning and accommodation of diverse views to enable collaboration. This often creates a duality of loyalties when navigating the landscape of interdisciplinarity. There are, as Frickel et al. (2016) reviewed, three untested assumptions associated with the epistemological including: first, that interdisciplinary knowledge is better although there are few studies that exist to validate this. Second, disciplines may be favoured over interdisciplinarity, reflected in the disruptive effects of disciplines on interdisciplinarity activity. Again, Frickel et al. (2016) found little evidence to support or reject this assumption. Lastly, interdisciplinary collaborations are based on a level playing field where power and hierarchical relationships have little influence, for which there was little evidence in Frickel et al.'s (2016) study. It is clear that disciplines and stakeholders addressing GCs will have different epistemological and ontological standpoints, which Stephenson et al. (2010) recognised could be overcome by developing a common intellectual (or research) framework. By bridging some of these barriers, and recognising the diversity of positions, perspectives, theoretical lenses and approaches that researchers adopt, this review focuses on enabling PLWD to live life to the full and the implications for tourism management.

2. Reviewing the literature

2.1. Approach to review design

The main objectives of *Progress in Tourism* papers are '(a) to act as a fundamental starting point for researchers seeking to better understand a subject or niche area and (b) to assess the current state of conceptual maturity of the topic in question' (Ryan et al., 2007, p. 1167), and such reviews are premised on the traditional [narrated] review method. This model is adopted in this review primarily because the topic is in a nascent phase so a bibliometric or software-based text analytics approach would be wholly inappropriate. As Byrne (2016) argues in the context of medical research, the narrative review offers flexibility in areas where knowledge is evolving. Even so, it is worth recognising that different disciplines have their own traditions and methods, for example, scoping and systematic reviews are widely used in health and dementia research where the narrated literature review is less common than in business and tourism fields. Nonetheless, Mura and Sharif (2017) criticise the lack of methodological sophistication in many narrated literature reviews in tourism which fail to establish a clear methodology or state the paradigm in which they are rooted.

Given the interdisciplinary nature of the topic, the literature examined in this review emanates from a broad range of studies and disciplines that span systematic, scoping and traditional (narrated) reviews, and empirical studies that cross-cut social science and science. Thus, a narrative approach is justifiable in establishing the scope and nature of such a broad field of emerging interest (see Snyder, 2019). Further, the role of a narrative review in deriving a synthesised roadmap that offers a degree of intellectual debate maintains support as an approach (e.g. Baumeister & Leary, 1997; Ferrari, 2015). Leading journals such as *Progress in Human Geography* and *Progress in Physical Geography* remain esteemed publications within the academy, with many of their narrated reviews advancing thinking in their respective fields and in cross-cutting boundaries. This is not to decry other methods of literature review that are gathering momentum in tourism research but to uphold the place of different approaches.

To structure the review, we examine PLWD as tourists to understand how to accommodate their activities and needs at critical touch points throughout the visitor journey, especially in a destination, with a further dynamic element being the progress of the disease through time that impacts choice and selection of holiday type, activity and destination. We further explore the barriers and obstacles PLWD face in negotiating travel infrastructure to and within destinations, which is implicit in the social model of disability (Moussouri, 2007; Oliver, 2013). This underpins the approach applied to this review, which is informed by the argument that marginalisation and inequality is an endemic problem (see Biggs et al., 2019).

2.2. Exploring the literature

The process commenced with an initial interrogation of the commonly used research databases (primarily Scopus and Google Scholar) along with contents of specific journals aligned to dementia, health, ageing and tourism as well as the broader business and management journals. These yielded over 10,000 social science items on the generic term 'dementia' that needed narrowing down further. The search terms were broad in scope and associated with combining the term 'dementia' with other terms such as 'dementia-friendly', 'leisure, tourism, recreation', 'travel', 'travel medicine', 'mild cognitive decline and well-being' alongside more specific sector-based issues (e.g. 'driving', 'hospitality', 'accommodation', 'air travel' and so forth). The results were then narrowed down to articles, book chapters and books where the material had a specific connection to tourism and the wider visitor economy. The material was read, and the bibliographies of relevant material were checked to highlight references to follow up. As is apparent in the references, a significant number of systematic and scoping reviews of different facets of dementia were examined, predominantly from the health and social care field. This was supplemented with material from the grey literature produced by organisations such as WHO, the Alzheimer's Society, Alzheimer's Society International and ad hoc reports on specific issues such as government reports, commissions or hearings taking evidence. As this was not a primary research-led review, various other domains such as social media were not included in the review although it is evident that organisations such as the Alzheimer's Society have chat groups on holiday-taking which enables them to evidence advice they offer.

Academic papers were assessed in terms of how each would map to the framework of the stages of the visitor journey developed for the review, together with other categories including policy contributions and debates, general observations about PLWD and their carers, and observations about the current and future development of dementia globally. The key findings of empirical studies were also examined in terms of the contribution to deepening our understanding of the dementia-tourism interface, typically based on a reflective approach to the study, combining both conceptual and more applied practitioner implications (see Fook, 1999).

2.3. A framework for the review: the visitor journey for PLWD

The review is structured around the visitor journey model, set out earlier, to examine the process of taking a holiday or journey and the touch points, critical issues or potential barriers on which the social model of disability model focuses (Lane, 2007; Yachin, 2018). This structure must be set against an individual's transition through stages of dementia. From this framework, a number of themes emerged that relate to the visitor journey touch points which were then examined in relation to the social model of disability. The existing research literature suggests that the major market for international/domestic holidays for those with a dementia diagnosis is in the early stages of the disease before time-space compression begins to narrow down the resources and experiences accessed through time (see section 3.4 later). Recent studies (e.g. Wen et al., 2022) propose viewing travel as a treatment for dementia based on the tenets of positive psychology[8] (see Filep & Laing, 2018), suggesting that different types of interventions may assist or are perceived to assist in addressing dementia (see Wen et al., 2022, p. 4 on proposed interventions). This conceptual model proposes medical and non-medical treatment of dementia (see Berg-Weger & Stewart, 2017; Meyer & O'Keefe, 2020) through the auspices of the visitor economy. There is a degree of congruence with the extensive literature on medical tourism (Connell, 2013) in terms of medical treatment as a form of

tourism that can be traced back through history from a passive taking of the waters recommended by quack doctors and then the rise of hydropathy (Durie, 2006) to the more recent focus on surgical procedures undertaken in more cost-effective locations globally. Yet this model raises a more fundamental debate over the nature of medicine-tourism interconnections. On the one hand, medical tourism implicitly assumes a medical intervention. In contrast, the wider debates on social prescribing point to possible options for tourism to be used as a non-pharmacological intervention. The medicine-tourism relationship as a non-pharmacological intervention has seen a much wider use in many countries as a post-treatment option, away from cities in rural or coastal areas (see Tubby, 1905), and was widely used in the treatment of tuberculosis from the Victorian period up to the 1960s. These convalescent hospitals or homes also offered a wider role in rest and recuperation that in the dementia-tourism context has a salience with respite care for people with dementia and their carers.

Other studies illustrate the broader advancements needed in social prescribing (Costa et al., 2020) to implement such a model[9]. As Costa et al. (2020) indicate, social prescribing has potential tourism applications that connect with dementia in a practical and applied context. But the current application of this idea is still in its infancy, especially in the UK, where delivery is challenged due to already stretched workloads of health care professionals and social workers. Wen et al.'s (2022) study also needs to be prefaced by the reality of poor dementia diagnosis rates in many countries (Seeher et al., 2022) which means that the interventions outlined by Wen et al., (2022: 4) may focus on a narrow subset of PLWD currently identified and an even smaller subset targeted through social prescribing or funded interventions. Bridging the conceptual-practice nexus means that whilst the idea that life enhancements may occur through interventions for PLWD modelled on positive psychology, scaling these up to achieve meaningful impact means building an evidence base that demonstrates the positive benefits of tourism within a well-being context. The latter part of the paper will identify how some of these well-being benefits can better be evidenced as part of a wider interdisciplinary focus on helping people to live well with dementia, particularly the role of specific non-pharmacological interventions. Whilst travel may be a potential enhancer of quality of life for PLWD, as Wen et al. (2022) and Hu, Wen, Zheng, & Wang, 2023 advocate, our review demonstrates that research can contribute to the policy debate that tourism has a key role in living well with dementia. If policymakers and health professionals can be convinced of the positive well-being benefits of holidays and tourism[10], the evidence will accelerate thinking and practice beyond a narrow focus on respite care to one that harnesses tourism more fully as a non-medical intervention as dementia is recognised as a global challenge. As the concept of GCs raise numerous theoretical and epistemological issues in research, Appendix 1 summarises these issues as a reference point for the theorisation and debates of how ageing and dementia interconnect to create a GC. With those issues in mind, attention now turns to the nature of dementia as a GC.

3. Dementia as a GC

3.1. Defining dementia to achieve conceptual clarity

The existence of dementia can be traced throughout history (Berchtold & Cotman, 1998; Boller & Forbes, 1998), often in the form of the much-maligned term senile dementia (which was often treated as a mental illness) in the nineteenth century, often being associated with other conditions such as mania. Since the Edwardian period, dementia has seen a shift in its recognition as a pathological aspect of ageing to being deemed a distinct disease (Ballenger, 2017). World Health Organisation (2021a: NP) concisely summarised dementia as a condition thus:

Dementia is caused by a variety of diseases and injuries that affect the brain, such as Alzheimer's disease or stroke. It affects memory and other cognitive functions, as well as the ability to perform everyday tasks. The disability associated with dementia is a key driver of costs related to the condition. In 2019, the global cost of dementia was estimated to be US$ 1.3 trillion. The cost is projected to increase to US$ 1.7 trillion by 2030, or US$ 2.8 trillion if corrected for increases in care costs.

There is also a growing trend in the research literature to move away from using dementia as a catch-all term. Instead, it is becoming more acceptable to consider its relationship with mild cognitive impairment (MCI). MCI impacts cognitive function but does not cause major disruption to daily life, whereas the onset of dementia impacts daily life significantly. In simple terms, MCI is the stage where an individual recognises their mental function or memory has slipped and it may affect their judgement, memory or their ability to articulate things in conversation. Whilst MCI is connected to dementia, it is not a surrogate for it. As Di Lorito et al. (2020: 1) indicate 'Dementia is a syndrome causing deterioration in memory, thinking, behaviour and the ability to perform everyday activities … MCI is characterized by deteriorated cognition without a significant impact on daily activities … MCI and dementia are interlinked, with a rate of transition from mild impairment to dementia of 10–15% annually and of 50% in 5 years'. In fact, dementia is a broad term that covers over 200 sub-types of dementia although the most common types are Alzheimer's Disease, vascular dementia, Lewy body dementia, frontotemporal dementia and mixed dementia, each progressing at different stages and with varying effects. Every person's experience of the disease is unique. In the UK, dementia replaced heart disease (prior to the COVID pandemic) as the leading cause of death (BBC, 2016), reinforcing the case for state intervention and the importance of the Prime Ministerial Challenge on Dementia (UK Department of Health, 2015). Dementia has a considerable degree of stigma attached to it by society (Milne, 2010) and this has been viewed as one of the biggest obstacles to acknowledging its prominence as a GC.

3.2. The scale and scope of dementia as a GC

Schwarzinger and Dufoil (2022) indicate that dementia is disproportionately concentrated in high-income countries which correlates with increases in life expectancy (although it is also prevalent in developing and low to middle-income countries – see Prince, 1997; Ferri & Jacob, 2017). The current ageing population in high-income countries has been the main driver of global growth in leisure and tourism expenditure in the post-war period, particularly among the baby boomer generation (Patterson & Pegg, 2013). Since the 1980s, newly industrialised and emergent regions with a growing middle class have become major contributors to global tourism arrivals (Tolkach et al., 2016), and now these travellers are ageing. World Health Organisation (2023) demonstrates the scale and nature of the problem of dementia.

- Globally, around 1:7 people might be affected by dementia in older age as a worst-case scenario.
- The economic costs of formal and informal care for people with dementia in 2015 were estimated to be US$818 billion, which equates to 1.1% of global GDP.

As an example at a country level, Alzheimer's Society-funded research (Wittenberg et al., 2019) suggests that.

- The number of people currently living with dementia in the UK is over 900,000, affecting 1 in 6 of the over 80-year-old population.
- The cost of treatment and care for PLWD is estimated to be £34.7 billion a year in the UK and these are expected to rise to £94.1 billion in 2040. Disaggregating these figures, the social care component for PLWD is around £15.7 billion, expected to rise to £45.4 billion a year by 2040.

Even so, there are numerous uncertainties associated with these forecasts. For example, they do not necessarily allow for progress in

public health interventions and behavioural changes to slow the progression of the disease (or the discovery of a drug to reduce the incidence). What is certain from the forecasts is that the demand for health services, carers (paid and unpaid, including family and friends) will be substantial. It is at this juncture that the broader visitor economy and the leisure lives of PLWD become important. Although this paper uses the term *leisure lives* which encompasses travel and tourism, we do not review leisure and dementia *per se* in this paper. This is because a well-developed literature already exists that outlines the positive benefits of regular exercise/leisure activity outdoors to reduce the isolation experienced through dementia (for example, see Dupuis & Smale, 1995; Genoe & Singleton, 2006; Genoe & Dupuis, 2012, Genoe & Dupuis, 2013; Innes et al., 2016; Verghese et al., 2003; Stern & Munn, 2010; Genoe, 2010; Dupuis et al., 2012; Genoe & Dupuis, 2011; Stern & Konno, 2009; Su et al., 2022). The focus here is explicitly on tourism and how research is evolving to meet the hidden challenges that dementia will pose for PLWD as consumers of tourism services.

One would expect a significant research effort on the analysis of dementia as a GC spanning the interdisciplinary literature but only a limited number of articles have explicitly developed that theme to date (e.g. Collins et al., 2011; Kuljiš, 2010) or as part of a wider review of ageing (Mahmood & Dhakal, 2022). One explanation may be the implicit acceptance in the health and social care literature of dementia as a GC associated with ageing. Yet for cognate areas, where the effects of dementia will also impact lives (e.g. the visitor economy), these perspectives are relatively new and novel. It may also reflect the lack of knowledge crossover between disciplines, with their very different world views and agendas on research as well as the lack of portability of research approaches across boundaries (Mukuni & Price, 2013). This is one reason why this review adopts an interdisciplinary focus, emphasising where research interconnections exist for the tourism academy.

3.3. The leisure lives of people living with dementia and challenges for carers

According to Shannon et al. (2019: 2035) dementia leads to 'impairments related to neurological changes, [that] together with environmental challenges, result in disability for people who have dementia'. This poses significant barriers and challenges for PLWD. The consequences are that dementia can lead to marginalisation within society, which occurs due to the barriers that emerge with the continued deterioration of cognitive functions, including visuospatial difficulties (i.e. the inability of the brain to process 3D objects). This impacts the wayfinding ability of the individual (see Bosch & Gharaveis, 2017), compromising the PLWD's ability to perform daily activities that require navigation skills outside of the home (e.g. driving, walking and negotiating steps and 3D objects and certain patterns and colours on objects). Although occupational therapy is advocated in the early stages of dementia to help develop spatial orientation skills, physical exercise is shown to be beneficial (see Kumar et al., 2014). Leisure and tourism have a role to play in helping to overcome social isolation, promoting friendship, social engagement and interaction through meaningful experiences (Fortune et al., 2021), as studies that promote happiness among PLWD indicate (see a review by Capaldi et al., 2014).

As the diagnosis of dementia at an early stage is not seen as a high public health priority in some countries, many early cases go undiagnosed or are diagnosed late by GPs (see Petrazzuoli et al., 2017). In addition, among family members and friends, early symptoms can often be related to very subtle changes in behaviour and are often simply attributed to the ageing process (e.g. forgetfulness and diminished verbal communication). Globally, the WHO estimates that at least 75% of cases are undiagnosed globally, rising to 90% in low to middle-income countries. There may also be an increased risk of falls associated with the onset of dementia, with physical activity the most important strategy to reduce the risk of falls (see Allan et al., 2009) along with identifying and reducing intrinsic and extrinsic risk factors (Fernando et al., 2017).

To provide a more theoretical explanation of the changes that occur in the leisure lives of PLWD, of which tourism is a potential component, we now introduce the concept of time-space compression and its relevance to tourism.

3.4. Time-space compression and dementia: towards hyperlocalism

Within human geography, the conceptualisation of capitalism (Harvey, 1990) has seen the formulation of a macro concept of time-space compression (Warf, 2014). At the heart of the concept is the shrinking of time and space, which Massey (1994) argued also needed to pay attention to local social contexts. This represents how capital shapes the lives of people, with the speeding up and spreading out of society that Harvey (1990) attributed to capitalism. If one extends these arguments to the issue of dementia several facets of time-space compression become pertinent to PLWD and their carer and support network.

1. First, the progressive deterioration of an individual's cognitive functioning and abilities, as the disease develops, creates a temporal decline in the individual time-space paths[11] (Hägerstrand, 1970). A series of constraints begin to restrict the ability to participate in leisure and other activities commonly pursued prior to the onset of dementia (see Duggan et al., 2008). This creates a paradox given that leisure time increases in older age especially after retirement (Atchley, 1971; Nimrod & Shrira, 2014), opening up more time for holidays for people with disposable income. As Wang et al. (2012) indicate, active participation in leisure in older age is a potentially protective factor in retaining mental agility and health (Roland & Chappell, 2015). However, how that time is perceived and understood, as Liu et al. (2021) examined, directly impacts the ability to navigate subjective time in the working and episodic memory. Lapses in timekeeping, problems in recalling recent and distant memories as well as judging time intervals combine with a declining ability to carry out future intentions (i.e. using the prospective memory). This alteration to understanding time is a significant contributor to the resulting time-space compression compared to other older people not impacted by dementia (Ekerdt & Koss, 2015). Some other emerging theoretical debates around hyperlocalism describe these changes as 'practices that are in isolation even within the same spatial and temporal scale' (Lambert & Beilin, 2021, p. 66). Hyperlocalism, which may be of relevance in this context, denotes how a resident is increasingly localised in time and space, often with compressed timescales and where their activity patterns are measured in blocks/streets and neighbourhoods, and where the conception of time may be understood in minutes and hours. Lambert and Beilin (2021:66) also introduce the concept of temporal passivity which is 'temporal disconnection between future or past events', examined by Liu et al. (2021) from a neurodegenerative perspective. There may also be a greater fear of falling outdoors with the onset of dementia (Curl et al., 2020) which curbs confidence to negotiate environments outside the home.
2. Second, Hägerstrand (1970) identified constraints to human behaviour and movement in a time-geographic framework as three interconnected domains that are relevant to an analysis of leisure and tourism behaviour and dementia:
   - *capability constraints* — the biological and health limitations that impact the activities engaged in.
   - *coupling constraints* — the spatial and temporal limitations that shape participation such as the time available, opportunities available (i.e. where) and social opportunity (e.g. what other individuals are available) as well as the means to interact (e.g. transportation/mobility outside of the home) that shape the consumption patterns (see Banister & Bowling, 2004).
   - *authority constraints* — the structural constraints that shape the time-space dimension in terms of how the events and specific activity is governed (which have subsequently been examined in a

leisure context – see Godbey et al., 2010 for a review).

This conceptualisation is not simply a descriptive model of how time and space is organised but plays a much greater explanatory role in understanding structural constraints.

3. Third, in the case of dementia, the time-space interactions that occur begin to shrink where compression does not work in the way Harvey or others posited. The scale of shrinking and compression for PLWD means that potential opportunities for travel, tourism and leisure begin to become restricted through the progression of the disease, compounded where participation in society diminishes to the point of feeling confined to the home (see Frantal et al., 2020)[12].
4. Fourth, the time-space compression can marginalise PLWD and their caring network as it creates a growing sense of dependency, social isolation and feelings of loneliness and loss of independence. From these changes, we arrive at the simplified schema to depict time-space compression in Fig. 2, informed by the theoretical thinking on time-space compression and time geography (Dijst, 2020; Hägerstrand, 1970) and subsequent conceptualisation as *topoecology,* (Hägerstrand & Carlstein, 2004). In the most advanced stage of dementia, where permanent professional care is required, PLWD may transfer from home to a nursing or care home and their leisure lives then become structured around that environment.

Studies of lifespace are also worthy of note at this juncture. Liddle et al. (2021) capture the spatial dimensions of living and well-being based on out-of-home activity by analysing weekly travel episodes from home using geolocational data. This research illustrated the need for longitudinal studies to add more precision and to understand the nuances and intricacies of the time-space compression concept to further refine or validate it. Much larger sample sizes of people living with MCI and dementia are needed, including studies that use time-budget methods (Little, 2008), to assess activity type in time and space (Lokon et al., 2016). The major impact on the leisure time of carers (see Gladwell & Bedini, 2004) may also be recognised. We also need to recognise that leisure and tourism occur within places and communities in which different policy agendas for dementia have sought to create more enabling spaces for PLWD and their carers.

3.5. *Current debates about PLWD shaping our understanding of dementia as a GC: From dementia-friendly to dementia-inclusivity*

A number of other current debates within the research literature shape how we understand dementia as a GC and these debates have a bearing on the intersection with tourism. A key concern is the design (see Ancient & Good, 2014) and development of communities that are more dementia-friendly (DF) (i.e. dementia-friendly communities (DFCs) – see Shannon et al., 2019; Buckner et al., 2019; Lin, 2017) and how the touch points in a local community need to be designed for DF purposes to address the marginalisation issues associated with the progression of the condition. This topic has been extensively researched (e.g. the journal *Dementia* has over 1000 articles published containing the terms dementia-friendly – see Hebert & Scales, 2019 for an overview of the area) and we do not need to review those studies here. What is important is how this strand has impacted place and space and the ideology promoting change. For places and spaces for tourism, this means adjusting how communities, businesses and organisations think about and take actions on dementia to create a more dementia-friendly environment.

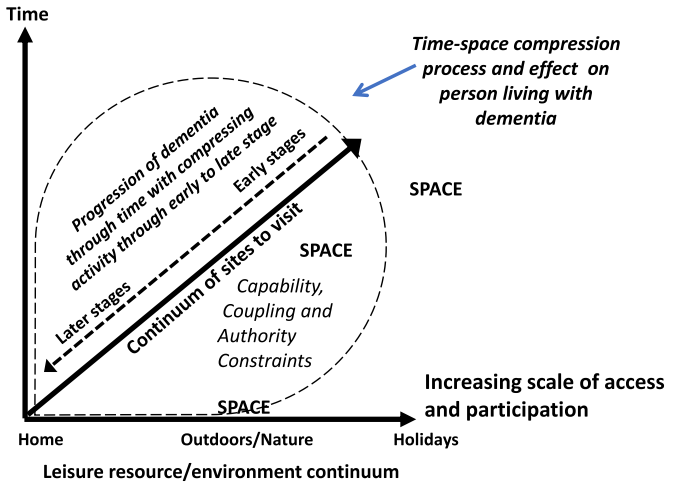

Fig. 2. Time-space compression and dementia.

Much of the research since the 1990s on dementia emanating from health (World Health Organisation, 2012) and social care has promoted the notion of dementia-friendliness which is transformative in intent. The real stimulus was provided by World Health Organisation's (2016) Dementia in Public Health report as outlined by Lin (2017). The promotion of DFCs by the UK's Alzheimer's Society saw this concept embraced in the UK and other countries. Numerous studies have reviewed the basis of being DF (e.g. Buckner et al., 2019; Hebert & Scales, 2019; Shannon et al., 2019) and Fig. 3 summarises many of the underlying principles for becoming a DF community. While tensions between the community framework for becoming DF and competing agendas, such as the age-friendly community ideology (Torku et al., 2021; Turner & Cannon, 2018) have emerged, there is consensus that some degree of intervention (described as salutogenesis, which denotes a positive action to promote health) is required (see Bengt & Monica, 2005).

The concept of becoming a DFC has been achieved by lodging an application in the UK with the Alzheimer's Society, receiving recognition and then a labelling process occurs where DF conformity is assessed against a series of standards (Alzheimer's Society/British Standards Institute, 2015). Although there have been many critiques of this process (e.g. Wright, 2014), it has been analysed in terms of four domains 'relying on the four discourse types of knowledge, responsibility, dignity, and illusion' (Hansen et al., 2021, p. 8) among applicants for DF status. Contradictions and tensions in people's views were observed by Connell et al. (2017). For example, some champions of DF issues were motivated by personal experiences of people they knew who had the condition, arguing for very specific interventions for their organisation. Other organisations either ignored the issue or were motivated by other concerns around legal compliance with accessibility issues. Yet if other visitor economy organisations do not share these values, while a number of beacons of best practice will exist, practice and provision will most likely remain problematic for PLWD. Other studies such as Crampton et al. (2012) and Crampton and Eley (2013) have conceptualised how a DF city might be envisaged with the various interconnections and touch points that need addressing in a community. When these arguments are extrapolated to businesses seeking to join DFCs to make their offer DF, similar tensions are evident (Connell & Page, 2019a) and a degree of self-interest surfaces for inclusion in a DFC. However, World Health Organisation (2022) seeks to change the rhetoric and narrative from DF to dementia-inclusive, which they define as.

'A society in which people with dementia and their carers fully participate in society and have a place in it. It is a society where they enjoy respect, freedom, dignity, equality, accessibility, and quality of life. It is one where they are empowered to live independently, free from stigma, discrimination, exploitation and violence or abuse' (World Health Organisation 2022: X).

Within this definition, there is a direct recognition that normalisation is the end point of any dementia-inclusive society, thus the services and elements within it should adhere to the common features of fairness and equality so PLWD can exercise the human right of quality of life. The

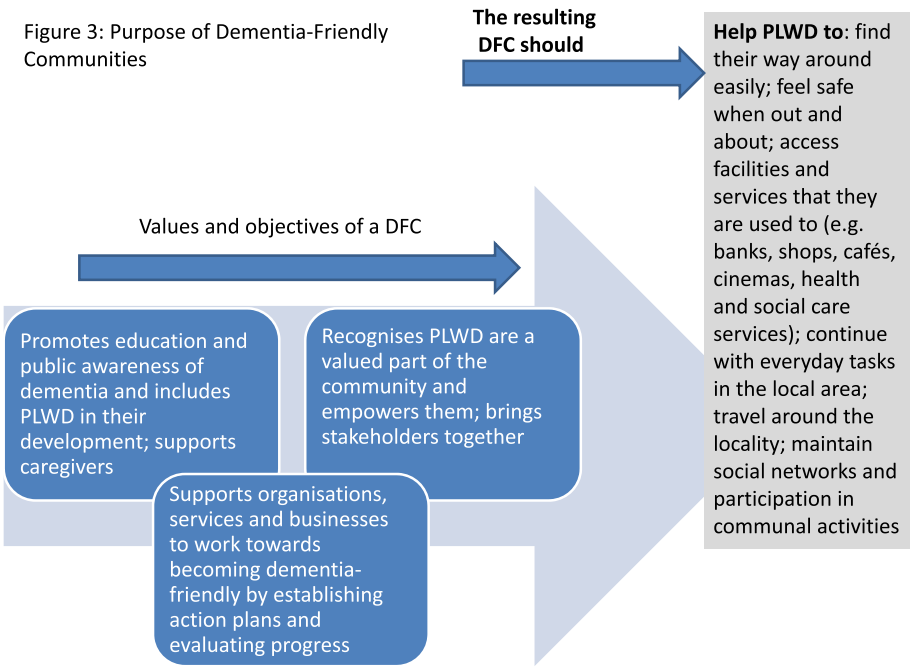

Fig. 3. Purpose of dementia-friendly communities.

narrative of dementia inclusivity has emerged from a UN Convention on the Rights of People with Disabilities (United Nations, 2006), recognising that full participation in society is achieved by identifying and then removing barriers using a social disability lens. The focus of dementia-inclusivity follows a similar model to the age-friendly cities where the change process is directed at social, economic and physical environmental changes (Torku et al., 2021). In the age-friendly and DF model, Universal Design is implicit (Centre for Excellence in Universal Design, 2023) in seeking to modify physical environments that benefit ageing people and PLWD (Lauria, 2016). Although some changes may need to be nuanced in the case of specific design features for PLWD (e.g. using certain colours to avoid confusion and avoiding heavily patterned carpets), the two models have similar objectives to overcome barriers. World Health Organisation (2021b) outlined a pathway for making society more dementia-inclusive: it argues that it will be piecemeal, and driven initiative by initiative, so that change is evolutionary rather than revolutionary, which we explore later in more detail in terms of the pursuit of normalisation in the tourism and visitor economy. Recognising that capitalist societies are based upon exploitation and processes that perpetuate inequality, the more pragmatic perspective advocated by World Health Organisation (2021b) argues that normalisation ensures equal treatment without stigma. But this alone will not remove the obvious barriers that exist without equality legislation that intervenes to rectify obvious market imperfections in a capitalist society or where perceived barriers exist (i.e. the attitudes and views of the general population) and investment in DF adaptations and infrastructure is required.

A popular term that has emerged alongside DF is helping people to live-well with dementia (see Bradshaw et al., 2012; Clare et al., 2014) which is reviewed in terms of the burgeoning literature in health and social sciences more broadly on enhancing the quality of life of PLWD and their carers (Martyr et al., 2018). The narrative behind this terminology, as Watson (2016, p. 5) emphasised is premised upon the argument that 'part of living well with dementia is having fun, in whatever form that takes'. Translating this proposition into action requires the engagement of PLWD to try to help them maintain participation in activities that add meaning to their lives such as holiday-taking. This will depend upon the stage of dementia a person is experiencing, their past behaviour (including holiday-taking habits) and leisure behaviour more generally (Genoe & Dupuis, 2014). In the leisure field, this has often been based upon arts and cultural activities (Hanser et al., 2011), although as this review later examines, there is a much more extensive visitor economy to draw upon for this engagement process since studies of leisure may or may not translate across to tourism. This is because tourism involves travel and, unlike leisure, a stay away from the home environment, often to unfamiliar and unknown environments.

There has also been a counter-narrative challenging the live-well proposition by Bartlett et al. (2017). Their arguments hinge upon the notion (and, note, much-contested use of terminology (see DEEP, 2014)) of a more grounded realisation that living with dementia involves suffering in two ways: as dementia sufferers and those suffering with dementia. The second category may involve the quality of service and the treatment a person receives as opposed to the physical effects embodied in the first category. Yet for change to occur policy action at a government level within individual countries is required and World Health Organisation (2021a) acknowledged that only a quarter of countries worldwide had a strategy or policy for dementia which illustrates vast variations in practice. These ranged from countries with major investment in this field (e.g. the UK and Canada) through to the experiences of developing countries (Alzheimer's Disease International, 2015).

4. Tourism, holidays and dementia

4.1. Planning for holidays and travel for PLWD and their carers: perspectives from travel medicine

Since the first article setting out dementia as a new area for tourism research (Page et al., 2015), the subject has seen a limited development of intellectual inquiry from an explicitly tourism focus until comparatively recently. The paucity of research has seen much of the impetus for travel-related research emanate from travel medicine (Page, 2009), given the extensive debates in travel medicine on ageing and travel (Flaherty et al., 2018; Gautret et al., 2012; Low & Chan, 2002; McIntosh, 1998; Wang & Feng, 2014). In this context, dementia is viewed as a travel health issue. There is also a larger literature on ageing and tourism (see Page & Connell, 2022 for a review of this body of knowledge) that is broadly set within a consumer behaviour paradigm (see Otoo & Kim,

2020) but this has not broached the dementia-tourism nexus, as the ageing focus of the review was on seniors/older adults as consumer markets. Building on the review by Wen et al. (2022), we pursue travel medicine as another potentially useful avenue of research. Travel medicine is broadly concerned with the promotion of health, especially pre-travel (Sanford, 2002), en-route and destination-based health care (Mårdh, 2002) and traveller health when returning home, making the visitor journey concept applicable in this review as travel medicine implicitly adopts those stages in its analysis of traveller health. On that basis, it is a logical starting point for the discussion of the tourism-dementia nexus if one accepts the propositions in Wen et al. (2022) on travel as a tool to positively enhance well-being. Yet to get to that point, there are a large number of issues to be negotiated and navigated. As dementia is a progressive disease, and with traveller well-being and medical perspectives (both pharmacological and non-pharmacological) having a major bearing on both the tourism and travel experience, changes may occur for PLWD when leaving the home environment because of 'cognitive, mood-related, and other psychological and behavioural symptoms' (Wen et al., 2022, p. 1) connected with dementia.

The absence of research on travel medicine and dementia led Bauer (2019:1) to focus on carers where 'anecdotal evidence suggests neglect when it comes to the inclusion of the special needs of the caregiver who travels with the burden of caring for the travel companion and may return home exhausted, depressed, distressed, and disappointed'. Popular studies like Dougherty (2019) explore the issue further highlighting many of the travel tips for PLWD and their carers but it underlines a need to examine the existing knowledge about travel planning to understand how issues of outdoor mobility and cognitive changes are brought about by travel. One solution advocated is the use of Assistive Technologies (Asghar et al., 2020) to obviate disorientation in unfamiliar places by PLWD and to support independence in MCI (Teipel et al., 2016). Such Assistive Technology is controversial because of the issue of consent (see Hughes, 2023), but it helps to monitor the location of PLWD via global positioning systems (GPS), tracking intended activities, correcting deviations from planned activity due to cognitive issues. There is further work to be done before autonomous mobility can be assured by such technology, but it does illustrate how some of the pre-travel stress might be obviated. A wide range of pre-planning advice and guidance exists on non-governmental organisation websites such as the Alzheimer's Society (2023a) which has a section on Holidays and Dementia with specific advice on each aspect of the visitor journey.

From a travel medicine perspective, Rosenstein (2022: 1) advised that 'Careful planning, such as seating arrangement, noise reduction, activities, and adjusting sleep schedules before a flight may be necessary. Dementia should not prevent adults from enjoying travel and visiting family and friends'. The latter part of the statement is a positive endorsement of encouraging PLWD to travel. It is a liberating call for a greater understanding of travel planning, since we need to recognise from a travel medicine perspective, the physiological and physical issues which travel poses for PLWD. As Lee et al. (2017) argued, at the travel planning stage, older travellers planning international travel, irrespective of health conditions, should consult a travel medicine clinic (see Darrat & Flaherty, 2019) or professionals to assess fitness to fly (Sadlon et al., 2020), which often comprises a risk assessment (Hill et al., 2006). This is because the propensity for health conditions to be more prevalent in older age groups is recognised epidemiologically. There is also a recognition that cultural differences between Western and Asian perspectives of travel medicine (see Piyaphanee et al., 2012) exist. Yet interestingly, a narrative literature review of international travellers acquiring a travel-related illness while travelling found this to be considerably lower among the older population (Angelo et al., 2017). The notable exception is the Hajj (Ahmed et al., 2006) where the population profile has a greater concentration of people aged 50 or over (Parker, 2010).

One neglected area in terms of travel planning is information to help with planning trips. Connell and Page (2019b) examined this facet through an analysis of destination management organisation (DMO) websites in the UK to assess their preparedness for attracting PLWD. The actual DMO website and supplementary information (e.g. accessibility statements and guides) were examined and a limited amount of web-based material existed to assist with destination pre-planning for trips. Most of the information was focused on accessible accommodation, reflecting a long-standing agenda promoted by Visit England's accessibility team. DF issues were largely absent from the websites with only a small percentage (7%) containing relevant accessibility information.

4.2. The trip: in-transit to the port or point of departure or travel to the destination

4.2.1. The car

Car ownership in many developed and developing countries is a personalised form of mobility that creates flexibility, allows for spontaneous leisure trips and is used to facilitate tourism. Given the paradox of dementia and leisure, with increased time available but diminishing cognitive ability, driving has become a contentious issue for PLWD alongside travel. A generic literature exists on ageing and car usage that has scoped the broader issues of driving, the mobility needs of an ageing population as well as the potential for adopting innovations such as autonomous vehicles (Schwanen & Páez, 2010; Shergold et al., 2015; Zandieh & Acheampong, 2021). Literature exists on ageing and driving for recreational and tourism purposes (see Guinn, 1980; Prideaux et al., 2001). As Toups et al. (2022: 225) found in the USA, around '60% of older adult drivers with mild cognitive impairment, and up to 30% with dementia, continue to drive'. As dementia progresses, driving safely diminishes due to cognitive decline (Breen et al., 2007; Lundberg & Religa, 2022, p. 251) as several reviews suggest (e.g. Adler et al., 2005; Brown & Ott, 2004; Lloyd et al., 2001). Within the existing literature on tourism and road traffic accidents (Wilks et al., 1999), unfamiliarity with road conditions can pose serious risks that are compounded by long-haul travel and tiredness (Castillo-Manzano et al., 2020; Wilks et al., 2000), let alone cognitive decline. This intersects with the debates in dementia research on competency/fitness to drive (see Bennett et al., 2016) and navigability and getting lost (e.g. Hunt et al., 2010). But deriving generalisations on safety is difficult, as some drivers remain safe in their navigation and driving whilst others do not. Even so, Rapoport et al. (2018) argued that clearer guidelines are needed for assessing PLWD and their driving capability internationally. Travel by car is often a worry for carers after a diagnosis as Taylor and Tripodes (2001) highlighted with reference to cessation of driving and the increased risk of driving accidents. Toups et al. (2022: 225) conclude that 'research indicates that there is a complex and inverse correlation between multiple cognitive measures, driving performance, and risky driving behaviors. The fragmented nature of available peer-reviewed literature, and a reliance on correlative data, do not currently allow for the identification of the temporal and reciprocal nature of the interplay between cognition and driving endpoints'. Consequently, this is an area for further development by transportation researchers to connect with tourism behaviour and driving.

4.2.2. Transport terminals, interchanges and services for PLWD: the toilet conundrum

Transport interchanges are often viewed as one of the major barriers and stressors for PLWD when they travel for holidays or recreation by air, road or rail (Innes et al., 2016). O'Reilly and Shepherd (2016) found that PLWD flew on average twice a year, predominantly long-haul in Australia but no equivalent studies exist elsewhere. The unpredictability of accessibility issues (e.g. stairs/lifts to change platforms or to access departure – see Graham et al., 2019) alongside crowded modes of transport has been widely understood in both the scientific and popular literature on dementia (Turner, 2022). Much of this has focused on

generic accessibility and disability debates (e.g. Darcy, 2012) but subsequent discourse has shown that PLWD do not necessarily want to identify with being termed disabled (Hare, 2016). This evokes a much wider travel law debate as Rochford-Brennan and Jenkins (2018) illustrate with reference to EU legislation on special assistance that is a mandatory right if booked 48 h in advance. Turner (2022) identifies that some airports have made major strides in this area but support is still framed around special needs, especially disability (see Abeyratne, 1995). Yet there are some PLWD who do not request assistance due to stigma. Peterson et al. (2022) summarised the main issues for airport terminals for PLWD as generating underlying anxiety, with inaudible announcements, noise and a lack of quiet spaces, invasive security protocols and a lack of dignity in toilet facilities. Indeed, the availability of toilets in transit proves to be among one of the greatest deterrents to most forms of recreational and tourist travel for PLWD (O'Reilly & Shepherd, 2016).

4.2.2.1. Toilet provision, tourism and dementia. A substantial literature exists on the issue of urinary incontinence and dementia, particularly the greater frequency of urinating (Hägglund, 2010; Tales et al., 2017). There is an ongoing debate on greater inclusivity in toilet provision for people travelling (Yap & Tan, 2006; Bichard & Knight, 2011; Matthews et al., 2022), with some destinations seeking to gain awards for quality toilets (see Cook & Martirosyan, 2018). The peer-reviewed tourism literature has largely ignored this fundamental issue of service provision, with the exception of a passing mention in disability-related papers. In some countries, access to public toilets while travelling, in outdoor recreational environments (Cocoran, 2019) and town centres remain a constraint to tourism for PLWD (Handler, 2014; Innes et al., 2016). Around 25% of older people suffer from urinary incontinence. Saner (2021) found a staggering loss of 50% of public toilets 2011–2021 in the UK making some destinations potentially inaccessible for PLWD. Building on the time-space compression concept, for leisure travel, this makes PLWD seek out familiar routes where known toilet provision exists. The geographical effect is one of 'bladder leash' and whilst not a popular facet of tourism research or tourism organisation lobbying activity, it can be a major constraint on PLWD's choice of how and where to travel (i.e. toilet mapping – see Cole & Drennan, 2019), when to travel and the location of accessible toilets (e.g. motorway service stations for road travel) or from airports with suitable provision.

For destinations, Greed (2004) illustrates the type of spatial strategy needed for locating toilets at key nodes and major termini as well as in city centres, major car parks receiving visitor traffic, and ensuring flat accessible access (Mitchell & Burton, 2006). Yet in the UK, for example, there is no mandatory requirement to provide public toilets, and typically, more male than female toilets are often provided (Greed, 2019; Ramster et al., 2018). Where toilets are provided in any tourism setting for PLWD, design features become important (Chaudhury & Cooke, 2014; Day et al., 2000). For PLWD, navigational arrows and direction finding, the internal design features of toilets and individual perception of safety for PLWD (e.g. Ellisa & Luana, 2022) are critical. Some age-friendly programmes have sought to try and overcome these barriers in destinations, with free access to businesses toilets to address a shortfall in provision (Page & Connell, 2023) but it remains a much broader issue for PLWD around dignity, and a major element of stress for a carer. Studies such as Mathews et al. (2022: 1146) conclude that the issues for people with cognitive impairments and those who are disabled include 'toilet accessibility, usability and design, emphasising the distressing sensory experience of the user when confronted with an inadequate or inaccessible toilet'. This is evident with tourists turning up at visitor attractions after a long journey to find no accessible toilets being available at the arrival point or requiring a RADAR key to open the toilet door[13]. The contribution of key innovations such as the Great British Public Toilet Map (2023) are critical to help in pre-trip planning and for in-destination activities and it fills an important gap in local knowledge given the public concerns with toilet provision. This is reflected in the decision in 2021 by the Levelling Up Minister to provide a £30 million fund to create much larger and better equipped Changing Places toilets for people who have difficulty in using existing accessible toilets adding to the 1200 already in existence (UK Department for Levelling Up, Housing and Communities, 2024). In 2023, a £1 million investment in public toilets in Edinburgh, one of the UK's major urban tourism destinations, was announced (City of Edinburgh Council (2023). This is in contrast with the poor level of toilet provision for London's daily commuters and visitors, outlined in a report by Russell (2023) highlighting the access to provision in and around stations. The report identified the need for at least £20 million to remove the well-known toilet deserts and problem of 'loo leash' within London that do not befit a world city. For example, the report highlights that in a £700 million upgrade of Bank Station, a major interchange on the London Underground and one of the busiest tube stations, there is no public toilet provision as this has not been seen as a political priority by successive London Mayors' and the main managers of London's public transport network – Transport for London. If the provision for the general public is so poor, then one can only surmise the barriers this poses for people with dementia in seeking to navigate a transport system with no readily accessible toilet provision. Visit London has issued the following information on downloading an app which is an indication of the nature of the issues visitors face (Visit London, 2023). It seems to be a sad state of affairs for a major world city that you are advised to download an app to locate where the toilets are because of the poor state of provision away from mainline stations (who have recently made access free) given the volume of people passing through those locales each year. But that means toilet provision is spatially concentrated and you need to be able to navigate to their exact locations. It is perhaps exemplified by the visitors to the UKs largest paid visitor attraction – the Tower of London who are greeted with a paper sign at Tower Hill underground station – 'there are no public toilets at this station' (and realistically a visitor needs to locate accessible toilets by accessing the City of London interactive toilet map (City of London, 2024). This has to be set against the fact it is a locale where the Tower of London attracts over two million visits a year and the nearby Tower Bridge attracts around 600,000 visits a year.

4.2.3. Air travel and dementia

There is a nascent body of scientific knowledge, initially from travel medicine, that is focused on the physical and physiological changes which may occur during flight among an ageing population (e.g. Low & Chan, 2002) that have considerable relevance for PLWD, some of which emerges from the disability literature on air travel (e.g. Chang & Chen, 2012). What is rarely discussed for PLWD is where MCI or dementia has not been recognised or diagnosed; when these people engage in air travel and then experience different problems they did not anticipate (see Lawson et al., 2012; MacPherson et al., 2007). Rosenstein (2022) reviewed the scope of the issues that may impact PLWD that range from deliriogenic changes associated with cabin pressure and additional changes such as humidity and ozone (see Bekö et al., 2015). These affect the metabolism and brain functions; although there is some evidence that medication may help address some of these effects. As Sadlon et al. (2020) indicated, additional risk factors may be time zone changes and in-flight medication issues requiring in-flight interventions. This may mean that PLWD require specific assistance from cabin crew to assist the carer with frequent toilet trips in-flight and pre-boarding assistance to reduce the stress of flight. Cases of in-flight emergencies arising from the adverse effects of flying have been reported along with confusion and as Elkin (2022: NP) observed when travelling with a PLWD: 'when we were flying home from Kuala Lumpur recently, he thought the aircraft was 'messing about' and that the pilot had turned off the engine. I had to explain that we were cruising at 35,000 feet somewhere over Russia'. There is also considerable potential for post-flight confusion associated with jet lag (McCabe, 2017; Rands, 2017). McCabe's (2017) practical advice on keeping a PLWD active and occupied in-flight reflects many

popular exposés of travelling with dementia. The problems of activity tend to exacerbate on long-haul flights (see Kelly & Caplan, 2009), and jet lag (Petrie & Dawson, 2006) and disorientation compound confusion issues, leading to calls for greater training for the air transport sector (Turner, 2022). Research has focused on the voices of PLWD and their carers in various air transport settings (e.g. Acton et al., 1999; Edwards et al., 2016; Turner, 2022) to understand some of these issues.

4.2.4. Cruising as a mode of travel and holiday experience for PLWD

The existing literature on cruising within tourism and transportation research has a stereotype of cruise holidays traditionally appealing to retired and older travellers. Although this imagery has been modified with the expansion of cruising to family groups and much younger age groups, knowledge of the business aspects of the cruise ship industry is largely *terra incognita* as the competitive nature of the industry means the data around their operations is limited. Much of the research on cruising and cruise tourism tends to be based on smaller sample sizes often using snapshot surveys with the on-board behaviours and activities relatively poorly understood. As Holland et al.'s (2022) review illustrated, there is considerable scope for development of the research agenda. Yet there has been an enduring interest from travel medicine dating back to the 1970s as cruising reached a mass audience (Carter, 1972), around ageing and fitness to travel. Travel medicine remains the route into the limited data on dementia and cruising, as many of the recent studies in cruising have been interested in post-COVID recovery. From a dementia perspective, cruising is promoted as a positive means by which to maintain a daily routine while on holiday and numerous advocates of this form of leisure travel have been endorsed by organisations such as the Alzheimer's Society (2021, 2023) and TripAdvisor (2023). However, cruise ships are not without their risks as modes of transport and floating destinations in their own right (Weaver, 2005). The literature on cruising and dementia is non-existent and so the only surrogate for the likely travel medicine issues associated with cruising are through interrogating the travel medicine literature to examine the extent of dementia in their studies. Of the available studies, Isom et al. (2018) highlighted the older profile of a cruising population, with 47% aged over age 65 and the most common problems they encountered were slips, trips and falls (STF) that is consistent with the majority of accidents and injuries in the tourist population (e.g. Bentley & Page, 2008). However, among older women, STFs meant they sometimes needed hospitalisation for falls and hip fractures, but there was no link to dementia in the study. Aoki et al. (2021) found low numbers with dementia on-board a cruise ship presenting with illness, and none were present in Visser's (2021) study. Thus, there is no credible scientific data currently on dementia and cruising despite its promotion and the availability of DF cruises. One issue to consider is the size of cruise ship for PLWD as on-board large mega-cruise ships (Vukonic et al., 2016) crowding issues may arise that may not be conducive to reducing anxiety among PLWD. Interestingly, an emergent literature on on-board crime is also developing as cruise ships become larger and more anonymous places (Wilson & Hanley, 2022), with PLWD potentially more vulnerable targets.

4.2.5. The hospitality sector and dementia

The hospitality sector has a broad remit covering food, beverages, eating out, accommodation and associated services in hotels, cafes, restaurants and other premises such as visitor attractions and events. The sector is people-intensive, in common with most sectors of the tourism industry, and because it relies on people for service delivery is subject to multiple touch points for PLWD during a holiday or trip. Conversely, the prevalence of dementia amongst the workforce in hospitality remains under-developed as a theme (Ritchie et al., 2015). The first key study to explore the scope and extent of the hospitality-dementia connection through a systematic review was Hayden et al. (2022), which identified 16 articles on the subject. Among the key issues identified in the review were negative attitudes towards PLWD due to ignorance alongside more generic barriers reported by PLWD. This research is confirmatory in terms of what various visitor economy businesses were taking action on in coastal locations in the UK in DF communities in terms of their action plans (Connell & Page, 2019a). A subsequent study by Hu, Wen, Zheng, & Wang, 2023 followed the approach embedded in travel medicine developed by Page (2009), highlighting the points made in Wen et al. (2022) on dementia and positive psychology. Hu, Wen, Zheng, & Wang, 2023, reframed the positive psychology approach developed in Wen et al. (2022) in terms of the travel medicine-hospitality-dementia nexus.

4.2.6. Accommodation

The accommodation sector assumes a significant place in the tourism experience as it is the temporary location of the guest(s) and the base in which about a third of their time every day will be spent, evident from Elkin's (2022) reflective account of caring for someone with dementia. Comparatively few studies have examined the accommodation needs of PLWD. Blanas, Kilindri, and Chrysikou (2016) examined what it takes to create a DF hotel space, based on many of the principles of Universal Design to cater for a wider range of accessible needs. Their study also examined the visitor journey through a hotel, highlighting the skills needed to engage PLWD at check-in (tact, patience and understanding), as well as the room needs and eating facility requirements. Much of this is achievable through good staff training and would have unintended consequences for better care for all customers with accessible needs, as Visit England (2019) indicate. In most cases, hotels offering accessible rooms are now being designed with a broad universal accessibility. However, the availability of health facilities/respite care for the carer and other innovations are clearly a wider package that hotels seeking to promote DF visits will need to consider. Interestingly, Blanas (2016b) found the majority of the 20 webpages of DF hotels in Europe were located in the UK, with several hotel chains in the USA advertising DF stays. The self-catering sector has also seen some development as a niche activity, as Grice (2017) outlined, where the regimentation of the hotel experience is removed by more flexible and relaxed and tailored holiday environments for PLWD.

4.2.7. Visitor attractions

Visitor attractions are the lifeblood of many destinations (Connell et al., 2015) and a major focus of activities of holiday visitors in the built and natural environment: in short, they animate the place, or the environment, and are often a central element of the tourist experience of place, with many sensory elements that have a major implication for PLWD in view of cognitive and sensory decline. Not surprisingly, the area of visitor attractions has been the main focus in the tourism-dementia research nexus, not least as this market has potential for all-year visitation. The existing research has several strands to it. First, there is the generic well-being research that is indirectly related to attractions extolling the value of visiting therapeutic landscapes and locales for leisure and holidays (Innes et al., 2016) in the positive psychology domain to enhance happiness (Filep & Deery, 2010) through well-being (Coghlan, 2015). This research is based on the literature from several areas (e.g. health and social care and leisure/sport) that argues that seeking out-of-home activities and longer periods of time such as holidays, can contribute to reducing the loneliness and isolation often felt by PLWD by keeping occupied and taking exercise (Dowling, 1995). Second, the environment in which these tourist trips may occur is important as green and blue spaces are seen to have enriching qualities that help the PLWD to relax, sometimes reminisce (where the cognitive function allows) and to achieve a degree of normality in their daily life (Van Vliet et al., 2017). Third, different types of attractions have been shown to appeal to PLWD (e.g. Innes et al., 2016) such as historic houses with a large and secure greenspace setting with a combined café and range of accessible activities and events to create engagement at a level the PLWD can pace themselves with, helping them cope with dementia (Bjørkløf et al., 2019). Fourth, the existing research offers many leisure

examples but the crossover into tourism is less well understood for PLWD as epitomised by the findings of Genoe and Dupuis (2012: 33) which: revealed that participants 'experienced daily life with dementia, including leisure, within a paradox of challenge and hope. They struggled with the changes they experienced as a result of dementia, such as muddled thinking, fluctuating abilities, draining energy, frightening awareness, and disquieting emotions. However, they found ways to tackle life with dementia, by reconciling life as it is, battling through by being proactive, living through relationships, being optimistic, and prolonging engagement in meaningful activity to live their lives with hope'.

This quotation illustrates the experiential issues of living with dementia and the health and training issues required for working with PLWD and cognitive decline in the tourism industries. This quotation also illustrates that the needs of PLWD are very different to the type of consumer behaviour-led research that characterises many tourism studies. Some notable exceptions of examining marginalised people in the tourism literature using participative research methods, published in *Annals of Tourism Research* (e.g. Hunter-Jones, 2005; McIntosh, 2020; Sedgley et al., 2011, 2017) illustrate a trajectory of studies focused on the voices of marginalised people including several in the journal *Tourism Management* (e.g. Hunter-Jones et al., 2022; Sedgley et al., 2012) alongside a generic interest in disability and accessibility issues.

The most detailed examination of the visitor attraction sector and tourism to date remains the study by Connell et al. (2017), based on primary data from one country, complemented by other studies such as Pozo Menéndez and Higueras García (2022) that highlighted the slow museum movement and other public space developments in cities[14]. Yet to date, no primary-data-informed studies of the attraction sector have developed since Connell et al. (2017) which, in summary, highlighted.

- 71% of visitor attraction managers were aware of someone who had dementia
- Business responses towards DF initiatives were characterised as not on the radar; some awareness, building infrastructure to move towards greater DF accessibility; advocacy and the pursuit of mainstreaming (especially in public sector-funded attractions) in pursuit of normalisation
- The values of individuals promoting DF initiatives were important alongside the perception of DF as a relevant issue for their organisations that was often formulated through the accessibility agenda.

As a people-facing and diverse series of environments, the attraction sector faces a wide range of challenges on the journey to become DF. However, some categories of attractions are making substantial progress. A growing body of literature is now emerging on the natural environment as an area for development to enrich the visitor experience through attractions.

4.2.8. The natural environment as a visitor attraction

The natural environment when framed as a visitor attraction has a significant role to play when approached from a health and well-being perspective as a potential intervention to help PLWD live-well (Taylor et al., 2022; Bennet et al., 2022) and to improve mental health (Buckley, 2023; Coghlan, 2015; Whear et al., 2014). This is because the psychological benefits of visiting nature and getting outdoors in a tourism setting are only slowly being translated across from the leisure and sport literature, where improvements in mental health are evident. The benefits of visiting nature in tourism settings may be summarised in terms of therapeutic benefits rather than in the tourism language of hedonism (see Collins et al., 2023 for a review). The benefits for PLWD emphasises the transformative value of tourism to individual health and well-being (Hartwell et al., 2018) that errs more towards eudemonia than hedonism. Probably the most important study that surveyed this dementia-nature connection was Mapes et al. (2016) where key relationships were examined from interviews including the contribution to social connectedness issues (e.g. enhancing inclusion, reducing isolation, improving self-esteem and as a shared experience) (also see Bennett et al., 2022; Page et al., 2023; Stapley et al., 2024).

For PLWD, the outdoors and nature as a tourism attraction can be framed in multiple ways from walking (e.g. Silverman, 2019), to passively observing and landscape appreciation to visiting sites of which nature is a component (e.g. a historic house and gardens). This also includes landscapes with visual and sensory prompts (coasts, mountains and settings as a backdrop to a destination – see Kah et al., 2022) or a unique environment that contrasts with the everyday (e.g. forests – see Cook, 2020). The sensory stimulation remains an important motivation as part of a wider pursuit of meaning in the interaction with the outdoors (e.g. Mmako et al., 2020) alongside day trips (Evans et al., 2022). However, there is a growing research focus on PLWD, animals and interaction as a therapeutic visitor activity that builds on the emergent field of anthrozoology and the relationship of humans to nature (Markwell, 2015). Rather than focusing on the narrative of tourist exploitation of animals, the focus is on therapeutic benefits of such interaction termed Animal Assisted Therapy (Yakimicki et al., 2019). This is shown to reduce agitation and aggression in PLWD whilst enhancing social engagement. It illustrates a potential role for attractions with animals, although zoos as tourist attractions remains a widely contested issue (Winter, 2020), despite the high levels of visitation. The role of zoos and their suitability for dementia visitation is unclear. However, Evans et al. (2022: 64) argue that the outdoors and nature is a right for PLWD as they 'are denied such opportunities, often because of practitioner perceptions of risk and poor design of outdoor spaces' raising issues of access and environmental design.

5. Dementia initiatives to make the tourism economy more dementia-inclusive: policy to practice

From a research perspective, seeking to engage the tourism and wider visitor economy with DF initiatives in pursuit of a dementia-inclusive society raises a number of theoretical and practical issues. From a theoretical perspective, a number of possible research paradigms exist around marginalisation, the social value of tourism and other emergent approaches such as transformative tourism as a way to approach dementia as a GC (see Page et al., 2023). The transformative paradigm, for example (Farmaki & Pappas, 2022; Nandasena, Morrison, & Coca-Stefaniak, 2022; Pritchard & Morgan, 2013; Reisinger, 2013), has advocated this approach to create a more inclusive tourism offer. Other approaches towards tourism and inclusivity such as Butler and Rogerson (2016) and Biddulph and Scheyvens (2018) approach the issue from a different perspective, but the outcome is similar: the integration of all sections of society as visitor groups. The difference with the transformative paradigm is that it has an implicit action agenda to seek measurable and visible change among those groups, such as PLWD, currently excluded from accessing the tourism offer. Bueddefeld and Duerden (2022) highlight specific business objectives that are needed to effect change, particularly in service delivery (Anderson & Ostrom, 2015). World Health Organisation's (2021b) DF initiative-led approach has a change in business practices as a central feature, meaning that the visitor journey touch points need to become DF. Several studies have examined the practicalities of making these touch points DF (Connell & Page, 2019b) although the inherent weaknesses in these approaches are commonly cited problems around awareness and knowledge of dementia, business commitment to more than simply familiarity training (e.g. Dementia Friends training as provided by the Alzheimer's Society) and industry leadership. Although a model of how to develop DF destinations exists (Connell & Page, 2019b), DF initiatives are led by WHO and there is little evidence of this being on the radar of the United Nations World Tourism Organisation (UNWTO).

Not surprisingly, no destinations globally have sought DF status as there is no international organisation like the UNWTO or World Travel and Tourism Council (WTTC) that promotes this journey for the tourism

industries. Furthermore, the WHO is simultaneously promoting two similar schemes to become DF and age-friendly cities (e.g. Goldman et al., 2016; Handler, 2014) from different parts of the organisation. There is some evidence that World Health Organisation (2021b) is now looking at the common objectives (see the commonalities outlined in Buckner et al., 2018; Turner & Cannon, 2018), but tourism is not on their radar. However, it is evident from Davies (2015) that city council and voluntary actions by businesses have enabled Bruges to become the first DF city. This is a major turning point for the tourism sector, given its tourism status as a historic city and world heritage site. Bruges receives over 8 million visits a year, of which 2.5 million convert to tourist stays with a resident population of around 120,000. Around 60% of all visits are domestic in origin with a strong visitor market from coterminous countries in the EU. This DF city was an initiative-led project to raise awareness and engender change (psychological and physical) among stakeholders. Currently, this is a beacon of what can be achieved with a concerted and coordinated effort with public sector support to drive the agenda forward. The example of Bruges appears to conform to the models put forward on developing a DF city by Crampton et al. (2012) which pivoted around four key constructs: people, networks, place and resources with other notable facilitating factors such as leadership and advocacy. Adapting this for the DF destination saw Connell and Page (2019b) evidence this with a country-based study of Destination Management Organisations (DMOs) to understand the barriers and factors that would need to be overcome to implement such a model within the four constructs devised by Crampton et al. (2012). Even so in the case of Bruges, the focus is not on destination development but the city and generic accessibility for dementia. Consequently, destination promotion and branding around DF projects is not a path any destinations have selected yet, given the general unease among some destination managers that anecdotally show some alarm at associating destination image with DF, a theme that certainly needs exploring further.

6. Practice interventions in the visitor economy to promote dementia inclusivity: the experience of the UK

The example of Bruges demonstrates what a coordinated place-based approach may achieve, but most countries are not at that point of advanced development to become DF. A number of policy interventions and practice guides have been developed to promote greater awareness and action on dementia. The UK appears to be a leader in this field, based on the Alzheimer's Europe (2020) ranking for dementia-inclusivity, so it offers a number of examples of best practice. The UK's approach has used an industry-led model of collaboration that seems to fit the social GC model of broad multi-interest/stakeholder involvement (see Fig. 1). The model of intervention is predicated on developing and cascading best practice (Codling, 1995) to encourage visitor economy businesses to address barriers and obstacles to dementia. The origin of this approach stems from developing sector- or subject-specific guidance with stakeholders to advise how to make services more DF (see Seetharaman et al., 2020). To facilitate this, the Alzheimer's Society created a series of limited-life working groups framed as Communities of Practice (Wenger & Snyder, 2000) around different themes. These used an economic argument for intervention, based on the Centre for Business Research (2019) report, which highlighted the potential contribution of PLWD and their spending potential. The most pertinent report to emanate from that process was a Historic Royal Palaces (2017) best practice guide, highlighting many of the themes later examined by Sharma and Lee (2020). Subsequent evaluation of the guide after its dissemination indicated that it raised awareness of DF practices, with organisations using it as an advocacy tool. It also helped create a number of DF initiatives such as health walks, organisational learning and specific events for PLWD around crafts and reminiscing although this was largely directed towards the leisure visitor in the locality. For tourists, adaptations at some sites created sensory and stimulating experiences in gardens and exhibitions. A more focused development for the tourism sector was the Visit England (2019) dementia guide emanating from Visit England's Inclusive Tourism Action Group. A short and simple guide was produced, targeted at tourism businesses focused on the steps to become DF, based on other accessibility guides produced by Visit England. One further development was England's National Trust (NT) decision in 2019 to launch a three-year plan (prior to the impact of covid) for its 500 heritage properties (many attracting a major tourism audience, to make its sites DF (National Trust, 2019). The scale of changes proposed is significant as the NT (prior to the COVID-19 pandemic) received 26 million visits a year, and around 3% of its 5 million members were estimated to be PLWD.

Lastly, a partnership between the UK's Alzheimer's Society and the Mayor of London in 2021, led by the ambition to become the world's first DF city, resulted in the Dementia Friendly Venues Charter (Greater London Authority, 2021) for cultural public spaces. This initiative builds on the Alzheimer's Society Dementia-Friendly Arts Guide (Alzheimer's Society, 2019), seeking to build better knowledge of the needs of PLWD, promoting greater inclusivity in programming of events, accessibility to venues and clear communication in the materials produced for events for PLWD. A significant proportion of the charter is focused on training and people, so the delivery of events is more DF with ongoing support for organisations providing events. Other ad hoc approaches to the arts and events, promoting DF activities for leisure were evident in other parts of the UK, being public-sector or charity-led in the museum or cultural sector where organisations had a wider accessibility mission for their local communities. This is the most developed area of the visitor economy for direct interventions predominantly directed at local population leisure time, with tourism deemed a lower priority. Several global icons such as New York's Museum of Modern Art and other city museums have devised programmes for PLWD that are directed at local residents (Parsa et al., 2010; Lamar & Luke, 2016; Phillips & Evans, 2018). Sharma and Lee (2020: 279) highlighted the problems which built heritage posed for PLWD. As these can impact the visitor experience, the built heritage may require adaptations to accommodate 'cognitive impairments that may arise that can alter psychosocial processes, such as lighting, temperature, acoustics and materiality, so that they can be understood and suitably adapted to support the well-being of those living with dementia'.

From these studies, a key element was engaging with PLWD and groups such as the UK's DEEP Network of Dementia Voices (DEEP, 2023) so that the lived experience of being a tourist with dementia is incorporated into inclusive design for destinations (Gillovic et al., 2018). PLWD can perform an important role in helping to act as auditors of service provision to identify barriers and improvements required (see McLean, 2016), known as service blueprinting (Bitner et al., 2008). This can assist in service design and innovation in service provision in tourism. As a tool, service blueprinting may help in looking at break points in service delivery such as the physical setting, customer actions in their customer journey and where various actions occur (e.g. negotiating a journey across a site), where staff interactions occur (see Alzheimer's Society, 2014) and what is happening behind the scenes. This approach has been used in terms of inclusive service design in events (Dickson et al., 2016) where a transformative service research lens was used that also has a focus on how to improve the 'quality of life of present and future generations of consumers and citizens through services' (Ostrom et al., 2010, p. 9).

7. A future research agenda for dementia and tourism research: engaging with the GC paradigm and new direction for the tourism-dementia nexus

It is evident from this *Progress* review that tourism as a subject has a significant contribution to make towards addressing dementia as a GC at a variety of spatial scales. One of the principal challenges in developing dementia as a GC is how it is configured, developed and then actioned. Once the nature of the GC has been agreed, then more detailed inputs

can be supported from people with different disciplinary and practitioner backgrounds to focus on the opportunities such collaboration offers. A fundamental starting point for implementing a GC work programme is ensuring it is people-centric so PLWD are at the heart of it so it is grounded and relevant. A useful acronym often used to describe setting project goals applies equally to a GC in terms of its management and delivery, namely ensuring the goals are SMART (i.e. Specific, Measurable, Achievable, Relevant, and Time-Bound – see Conzenius and O'Neill, 2005). The SMART goals help to provide a degree of structure and a focus for stakeholders in seeking to create dementia-inclusive solutions.

7.1. Management challenges in addressing dementia as a GC: pragmatic implications for tourism research

Numerous studies in management have embraced the GC paradigm (e.g. Gümüsay et al., 2022), and Seelos et al. (2021) note the explosion of research interest in this territory. Yet, as Brammer et al. (2019: 520) argue 'the origins of GC definitions are complex—they emerge from myriad sources (e.g. policymakers, practitioners, and academics), from a "diverse set of literatures" … and often "focus on specific domains" …. GCs can be understood as calls to action, as they articulate "large unresolved" … and "yet potentially solvable problems"'. It is evident that the fluidity of terms and definitions adopted in GC-based research reflects different disciplines, perspectives and research agendas. A first step in forming dementia as a GC for researchers is to recognise the types of GC that exist (see Fig. 1) which may blur through time as some GCs evolve and develop into larger or lesser issues. GCs by nature are multidimensional and require a multidisciplinary, interdisciplinary or transdisciplinary approach to get to the root of the challenge and frame appropriate solutions. For the tourism sector, beyond the most obvious GC (i.e. climate change), a number of other lesser contributions emerge in the prevailing sustainable development agenda around community development and poverty alleviation which have been a long-standing interest in tourism research (Scheyvens & Biddulph, 2018; Wall & Mathieson, 2006). These agendas are identified in Fig. 1 as societal challenges.

A major criticism of the broader academic literature on GCs is that there has been a tendency to over-use the term GC to try to elevate the importance of specific issues and to attract attention within the academy. Simply attaching the term GC to an academic research agenda is not in the spirit of a GC, which arguably needs a wide range of stakeholders to agree on its existence. Thus, for tourism research this means that it is hard to argue a case that places academia as the sole conduit for problem-solving globally, as non-academic agendas and interests have a major role to play in GCs. The implication is that tourism researchers, following the climate change GC, will need to embrace transdisciplinarity to draw together the key focus for a GC to harmonise the different interest groups around an agreed focus. The term GC should be used with some caution and precision so that its use has both a clear rationale with an underpinning claim from national or international organisations such as the United Nations and/or collective views of governments.

7.2. Factors impacting the formulation of dementia as a GC

Brammer et al. (2019) set out two broad categories of factors that impact the etiology of GCs - amplifying and confounding factors - that will shape future research agendas. To participate in a meaningful way, tourism researchers need to recognise these factors. Amplifying factors tend to shape the GC, helping form the issue(s) for development, including its attributes (i.e. whether the scale of the problem requires single, multiple agency and organisational involvement). There is also debate associated with amplifying factors as to whether GCs are realistically formulated (i.e. is the issue actionable or is it intractable, and not capable of resolution through intervention?). This certainly connects with the articulation aspect of a GC and whether it can be formulated with a clear rationale, where the issue can be amplified by ambition and advocacy. Ambition and advocacy, which (along with passion and visionary leadership), can elevate a GC as an attention-grabbing issue. Lastly, from an operational and organisational perspective, the ability to assemble stakeholders, resources and people to be heard is a further amplifying factor. Conversely, a number of confounding features of GCs may limit progress with a GC agenda, described as convolution, which is associated with the degree of complexity and ability to identify causality. For example, by understanding if a GC approach can tackle the root cause, or not, will determine whether the GC has traction and should proceed. Where a GC agenda is formulated, a major risk to action is that the scale and nature of the activity planned may be watered down causing ambiguity. This may generate conflict as opposing groups challenge the ideology of change needed or whether a GC exists. There is also the potential for contortion to occur which is where ambitious goals may be diluted to become less ambitious.

7.3. The research challenge in formulating dementia as a GC: policy implications

The implication for dementia, as Cataldi et al. (2022:690) argue, is that 'dementia research remains highly fragmented globally, with broad variability in investment and quality of research efforts' which explains why the World Health Organisation (2022) blueprint for research was introduced (also see Wallace & Brayne, 2022). Policy debates guided by WHO as the lead agency internationally have advocated for dementia as a GC, making this a novel topic to examine through multiple lenses, such as the social disability model and travel medicine. The current challenge is to assess where further relationships can be forged by tourism researchers to develop problem-solving, multi-stakeholder, transdisciplinary and translational research. To develop the contribution and role of tourism in the expanding research efforts globally, identifying the role and value of tourism research with greater dementia-inclusivity is critical. Part of that process is to understand the interconnections and boundaries of tourism and dementia to make the transdisciplinary connections. It is disappointing that calls for a global research agenda (World Health Organisation, 2022) state one focus as the lived experience of dementia which would elevate the significance of tourism (and leisure), yet the overall tenet of the document is on public health to connect research together in these areas largely in health and medicine. Therefore, this blueprint for research does not offer any obvious direction for tourism research to create better baseline data or identify ways for better knowledge translation from research to practice.

World Health Organisation (2021b) provides examples of how to create DF initiatives that contribute to a dementia-inclusive society and start to shift the global focus by disrupting ableist thinking. These types of initiatives are salient to previous and current research in tourism around the broader accessibility debate (see Duignan et al., 2023 for a review of that debate). The maxim of the accessibility research agenda is that addressing barriers for one group may help other groups as an unintended consequence. Therefore, the accessibility and dementia focus within tourism research provides a route into connecting with the GC paradigm. The World Health Organisation (2021b) inclusivity agenda presents helpful phrases that assist in formulating a research agenda around 'awareness raising', 'education', 'enhancing participation', 'improving accessibility and safety', 'making business and services accessible' and 'implementing enabling technology' including making the internet accessible (see Arch & Abou-Zhara, 2007). From this generic perspective, attention now turns to examining a more specific range of potential research directions for the tourism-dementia nexus relationship to help build a greater presence of tourism in examining dementia as a GC. The argument here is that increased research activity in transdisciplinary and multi-stakeholder teams that produces research outputs, from journal articles to grey literature and best practice advice, will stimulate the potential for innovative practical and policy impacts

that address elements of life with dementia. This is evidenced in studies such as Historic Royal Palaces (2017) and Visit England (2019) and at a national scale in the UK.

7.4. A future research agenda for the tourism-dementia nexus

A key element of most *Progress* papers is to create a synthesis of the current literature and from that to generate a future research agenda where opportunities exist to expand the knowledge base to inform thinking on the subject. Table 1 develops a research agenda on the dementia-tourism relationship based on themes reviewed in the paper to further expand the intersection of dementia, tourism and other disciplines and growing opportunities for greater interdisciplinary (and potentially transdisciplinary) research. A clear starting point for tourism research is a review of the debates in the existing literature on tourism and dementia, with the most recent studies such as Wen et al. (2022) and Hu, Wen, Zheng, & Wang, 2023. These have a clear theoretical frame from positive psychology to develop the tourism and well-being dimension, as advocated by Pearce (2009), which has the potential to inform a much deeper analysis of the relationship between holidays and dementia. These themes are writ large in Table 1 as this relationship is explored in popular accounts of the experiences of people with dementia and carers (e.g. Elkin, 2022; Jauhar, 2022). These accounts are based on individual life experiences and are a good starting point in the absence of any studies of PLWD and holidaytaking behaviour. Further empirical verification could develop our understanding given the numbers of people and families globally living with dementia and its effects. As Kiper (2023) outlined, there are over 16 million caregivers in the USA looking after PLWD, who at the very least, should be able to take respite care, such as a short holiday to help with their own mental well-being given the pressure posed by being a 24-h-a-day carer. The experience of Alzheimer France, mentioned earlier, illustrates the importance of holidays in helping people to live well with dementia although the well-being impact remains absent from wider academic research. This raises a wide range of issues around the value of social tourism initiatives as an area for future development. Different disciplinary and methodological approaches may certainly yield different results and enrich our understanding. If triangulated, these approaches would start to build a better case for support for people with dementia and their carers with the eudemonic focus. Given the different experiences social tourism offers for carers and PLWD, identified by Alzheimer's Europe (2020), research needs to look at how social tourism opportunities can be devised, developed and funded as a supportive framework for families affected by the dementia journey.

From this starting point on holidays and their well-being value, further knowledge is needed, as the quotations at the outset of the review by Elkin (2022) highlighted, on a detailed understanding of what is manageable for PLWD in a destination setting. Specific timeframes and contexts are needed, meaning a greater focus on segments of the visitor journey throughout an entire holiday, could be a fruitful area for research. Once specific attributes are more fully recognised, greater opportunities for destinations and tourism settings to identify the steps to become dementia-inclusive may develop. The opportunities may well open up the reimaging of destination attributes to enrich the visitor experience for PLWD by developing DF itineraries for different ability levels. Such developments are likely to have research outcomes that need to be understood in terms of value and impact at personal, health and societal levels. These are likely to leverage unintended consequences for other people/age-friendly developments that drive the accessibility agenda for destinations. There is certainly a role for technology to help carers and PLWD to navigate the visitor journey in a more user-friendly manner and this would connect with the major research activity in psychology on wayfinding, social media, apps and digital platforms in tourism research.

There is a recognition that multigenerational holidays and dementia will grow in scale and significance (e.g. Ruspini & Del Greco, 2017),

Table 1
Prospective research themes to examine the dementia-tourism nexus.

Theme	Typical research questions to address	Potential research methodologies
Theoretical developments in tourism and well-being	What is the relationship between tourism, dementia and the well-being economy and how will it develop as a discrete area of positive psychology?	• Participative research methods where PLWD and their carers design techniques to capture their lived experiences drawing upon the dementia literature • Drawing upon multi-sensory research techniques (e.g. Lauria, 2016)
The relationship of holidays and dementia	How do holidays and locations connect tourism, dementia and happiness?	• Focus groups with PLWD and their carers to capture lived experiences, and past histories of travel through oral history to understand change through time
How PLWD navigate the visitor journey throughout an entire holiday	What touch points were easy to navigate and what were difficult and caused stress and anxiety?	• PLWD and service blueprinting using various techniques such as video diaries, photographs, and the involvement of DEEP groups, informed through the social model of disability
Creating destinations/ places that can be badged as DF	How can tourism managers and other stakeholders be coordinated in a destination to create a DF offer and how can it be promoted without impacting other markets segments?	• Focus groups • Scenario planning exercises • Using case studies of best practice to evidence the economic benefits and social return on investment in the public sector
Reimaging destination attributes to enrich the visitor experience for PLWD	How can visitor attractions and destinations harness the power of nature (i.e. greenspace and blue space) to enhance their enjoyment and therapeutic landscape benefits?	• Drawing upon environmental psychological and psychogeographic techniques to promote elements valued by PLWD to encourage visitation (i.e. to understand the sensory elements)
Unintended consequences of other people/age-friendly developments for DF initiatives	At a destination level, auditing and examining how location friendliness can enhance dementia-initiatives	• Developing the site audit techniques from safety science to identify possible risks and how to ameliorate these • Connecting Universal Design auditing with destination adaptations for PLWD using DEEP networks to advise and help road test design principles with demonstration projects • Development of best practice guides to help showcase and scale up innovations that work for the tourism sectors
Technology to help navigate the visitor journey	What types of Assistive Technologies (AT) need to be built for destinations to simplify the overall and individual site navigation?	• The use of GPS software and techniques that simplify navigation based on the needs of PLWD from destination and site audits (which will have wider benefits for many groups

(*continued on next page*)

Table 1 (*continued*)

Theme	Typical research questions to address	Potential research methodologies
		requiring more accessible experiences) • Research on specific ATs that help reduce wandering, as explored by Neubauer et al., 2018)
Multigenerational holidays and dementia	Building on the research on multigenerational households and tourism, developed by Ruspini and Del Greco (2017), to understand how this area of tourism behaviour is changing	• Diary and participant interviews to understand past and current holiday behaviour and potential adaptations (e.g. shifting from family package holidays to self-catering) and impact on PLWD.
Transdisciplinarity and GCs	What types of disciplines and stakeholders can tourism researchers engage with to make dementia connections that directly or indirectly help PLWD live-well?	• Multi-methods, action research and new techniques and tools from other non-tourism areas that add value to the live-well agenda
Time-space compression and holidays for PLWD	How does the lifespace and time-space compression impact holidaytaking behaviour through time?	• Oral history research with PLWD and carers to understand how the conception of time/space changed through time and how holidaytaking behaviour continued/adapted or was substituted by local leisure Use of GIS to map multiple time-space paths for PLWD to identify the type of holiday choices that are evolving
How to help carers of PLWD also enjoy the holiday experience	• What elements of the holiday experience does the person value and are they potentially excluded, as argued by Hunter-Jones (2010)? • How do these experiences link to the research on carers and travel such Whitmore et al. (2015) where the key constructs were responsibility, vulnerability and mutuality.	• Development, of constructs to capture these experiences from interviews, national surveys of carers looking after PLWD and
Respite care and social tourism holidays for carers of PLWD, as Alzheimer Europe (2020) identified from some European countries that funded respite holidays for carers	• How has respite care evolved as a holiday experience for carers as explored by Holda (2019) to address stress and burnout from 24 h a day care. • What is the full remit of these funded holidays and what are the pan-European experiences of funded opportunities to take holidays?	• The current thinking on respite care as a form of medical tourism that is likely to look at lived experience, emotions, feelings, moods and research methods that can capture these elements of carers.
Addressing specific knowledge gaps on cruise tourism, land transport and driving and tourism	• What types of travel experience do PLWD and their carers have in using different	• A multi-method approach to capture both the supply and demand aspects including destination transport

Table 1 (*continued*)

Theme	Typical research questions to address	Potential research methodologies
	modes of transport for tourism?	and where transport as tourism (e.g. cruise ships) exists
Nostalgia, tourism and dementia	• How does visiting a past location featured in a previous holiday help with reminiscence and feelings of happiness and pleasure?	• Re-thinking the notion of visitor satisfaction measures to understand what happiness and pleasure means for PLWD throughout the life course of the condition using psycho-social survey techniques or interviews
A deeper understanding of events and dementia	• How are destinations adapting events for PLWD and carers?	• Interviews with event providers and DEEP groups
Hospitality and dementia	• What does the term hospitality mean for PLWD and their carers?	• Techniques to help theorise and measure the business-hospitality relationship from a simple commercial transactional basis to one that fulfils the notion of 'being hospitable'
Travel medicine, tourism and dementia	• How are PLWD and their carers preparing for domestic and international travel? What types of advice are they seeking and how well informed is that advice?	• Simple short surveys with carers to capture experiences of travel preparations and advice received from GPS, travel clinics and self-management through web-based material
Organisational change in the visitor economy to make services more dementia-inclusive	• What steps are different sectors taking to become DF? How can researchers help them change their practices?	• Collaborative stakeholder research, typically action-oriented, ideally, supported by DMOs.
The importance of toilets and tourism in the holiday experience	• What degree of toilet use do PLWD need and how accessible are these facilities throughout the visitor journey?	• Diary research and estimates of frequency of urination by PLWD and carers to establish how destination planning and development can build on existing work like toilet mapping (see ToiletMap 2023) so that this need is pre-planned into visits
Alzheimer's Europe (2020) identify a number of countries not promoting any DF initiatives	• Why do some countries promote DF initiatives and others do not? What are the implications for their future tourism offer as destinations?	• Policy-oriented research methods using secondary data (reports) and interviews with policymakers to understand how and why implementation varies

particularly in the early stage of the condition, for family holidays and gatherings. For the visitor economy, initial research has shown that extended family tourist groups may require different accommodation types, such as self-catering accommodation with capacity for additional family members with adaptations for PLWD. Different research tools and approaches may well help understand how these new forms of family holidays and events create new opportunities for the self-catering market.

This study has also introduced the observed patterns of time-space compression, which is likely to provide a future area for research when connecting the progress of the dementia care journey with the propensity for holidays for PLWD. The contribution of oral history as a research methodology, as pioneered in the seminal work of Thompson

(1978) to understand family life transitions, would be invaluable in starting to examine how time-space compression has occurred in the travel histories of PLWD through time. An important part of that reconstruction, using oral history with PLWD, family and carers, is in reconstructing their journey with dementia and subtle differences in their spatial behaviour and holidays prior to diagnosis and after diagnosis. This type of research could examine the intersection between history, family life (e.g. sociology), human geography (space, place and destination visiting) and the emergent connections with tourist travel and mobility studies.

As the visitor journey focus of the review has indicated, there are specific knowledge gaps on cruise tourism, land transport and car-based tourism which would benefit from a much deeper series of insights around PLWD and their carers. Critical evaluation of the barriers and opportunities for product, experience and service development is needed to help the visitor economy reorient business development, particularly where the connection with nostalgia, reminiscence, tourism and dementia can be fostered. There is a growing debate in cognate areas such as event studies that a better understanding of events and dementia is needed, a feature highlighted by Elkin (2022) that also has a very close synergy with the emerging research on hospitality and dementia. This also has wider implications for experience design for creating greater inclusivity in events research and tourism. In its purest sense, hospitality and hospitableness for PLWD and their carers will require employees in the visitor economy to develop greater compassion and understanding of inclusivity, where it does not already exist, as opposed to the sometimes mass market approach for dealing with visitors in a standardised manner where personal interactions are often time compressed.

The underlying focus of this review utilising the insights from the visitor journey and different facets of travel medicine, tourism and dementia illustrates how the interconnections and touch points at different stages of the visitor journey may need greater organisational change in the visitor economy to make services and experiences more dementia-inclusive. Arguably, in some settings, this will involve a transformative research agenda to rethink how inclusivity is achieved whilst in other settings only very minor adaptations may be needed (Page et al., 2023). Existing research on ageing and dementia frequently points to the fundamental human need for toilet provision yet this is poorly developed within existing tourism research, despite being of wider benefit for all visitors. In the holiday experience, public toilets must be accessible, well-signposted and better planned within destinations to respect the visitor and assure dignity. Simple audits of how often a PLWD needs access to a toilet and the geographical distribution of toilets in destinations would be a useful starting point. Once these types of fundamental infrastructure requirements have been better understood and actioned for more inclusive tourism, then policy research at a national scale may well help start to answer the question posed by Alzheimer's Europe (2020) on why some countries are not promoting any DF initiatives.

8. Conclusion

The overwhelming evidence from the literature reviewed in this paper represents dementia as a major global public health challenge. The framing of dementia as a GC is validated by its global reach and scale, the nature and impact of the condition and its growing prevalence. It also offers a framework for analysis that can be applied at a variety of geographical scales. It also offers opportunities for diverse models of collaboration with other academics and disciplines, and opportunities for tourism researchers to contribute to larger teams in non-academic environments. For the tourism sector, dementia is a relevant issue: tourism and leisure activities need not cease with a dementia diagnosis. Indeed, the wellbeing and quality of life elements associated with holidays and day trips contribute to the concept of living well with dementia. That presents challenges and opportunities for businesses. As World Health Organisation (2022: vi) indicates, 'dementia has a profound impact on every aspect of a person's life' but adopting a people-centred and rights-based approach in pursuing the dementia-inclusivity agenda, tourism and leisure businesses, organisations and destinations can provide opportunities to help people live well with dementia. Cahill (2018) examines the narrative of rights-based approaches, developed since 2015, that are designed to ensure PLWD are treated with respect and dignity, protecting their rights and maintaining their social worth. The tourism academy is very well suited to embrace this nascent research agenda on dementia because it has a well-established theoretical interest in social agendas informed by numerous areas of tourism research (e.g. ageing, disability, accessibility social tourism, tourist well-being, transformative tourism and consumer behaviour research). Some of the most notable examples of research outcomes in these areas have occurred through productive interdisciplinary explorations of research boundaries or interdisciplinary collaboration, particularly on disability (e.g. Darcy, 2012).

There are new interconnections to be forged between dementia and tourism, especially from the fields of medicine and psychology. For example, research in event studies has examined the emotional aspects of attending events using electrodermal measurements to study emotional responses. It is certainly a useful starting point to begin to understand how tourism impacts the well-being of PLWD (Stadler et al., 2018) based on empirical study. Other germane areas for research are the relationship between tourism, genetic factors and risk factors (see Hsiung & Sadovnick, 2007) and whether maintaining one's tourism behaviour post-diagnosis either helps to slow down the progression of dementia or has no immediate impact. Studies associated with physiological changes brought about by tourism and their impact on people with dementia and the different types of dementia might be of interest. More detailed cohort studies could also be undertaken to examine the role of new trends in medical research, such as glycomedicine (Wang & Yang, 2023). It is inevitable that entering into the domain of medicine and health research from a tourism management perspective will create some learning curves, with significant epistemological and ontological differences, as well as different approaches to methodology and evaluation, for example, working with logic models of evaluation is almost an implicit part of health research work (e.g. Buckner et al., 2018).

These diverse interdisciplinary perspectives need to be acknowledged, appreciated, and understood if mutually beneficial GC-focused research is to yield results. Working with PLWD and their carers is very different to the motivation research that has dominated the tourist behaviour paradigm seeking to understand why people take holidays (see Hunter-Jones, 2010). One of the most obvious differences here is the impact agenda and translational research pathway (e.g. Honig, 2012) that is implicit in health and medical research compared to tourism. But if we are to seek to help the visitor economy adapt and develop a more inclusive approach for PLWD (and all visitors), then embracing more impactful research collaborations will be essential. Clearly, there is a role for pure or theoretical research to reconceptualise dementia as set out in Wen et al.'s. (2022) and Hu, Wen, Zheng, & Wang, 2023 studies. Tourism research can make a positive contribution as part of the wider portfolio of dementia research. Knowledge and understanding of the condition is still at a rudimentary level outside of medical and health sciences, so engaging tourism businesses and organisations with research is needed as evidence that can help them to change their practices. One obvious issue is in recognising that people who have not had a diagnosis but who may display symptoms will need help in a visitor setting. Models of communities of practice used to develop best practice to target action are important as they have been underpinned by academic research, albeit in an applied sense. This is a very different mode of working for academics where the research output is not the endpoint. Studies such as Phillips et al. (2020) show that the implications from academic papers are not frequently adopted by practitioners. One very good reason for this is that academic research is not tailored to the needs of non-academic user groups, so it remains

locked away in journals and books and unavailable to practitioners. Attempts to break these communication barriers with interventions such as the Australian Cooperative Research Centre model in tourism and the former Tourism Knowledge Scotland initiative as outlined by Franchetti and Page (2009), generated a considerable quantity of 'grey literature' (consultancy reports, customer surveys and how-to guides), which whilst outside the scope of a progress review, were publicly available and tailored to a practitioner audience. In the case of Tourism Knowledge Scotland (and its subsequent incarnation as Tourism Intelligence Scotland), many of the market guides or how-to guides were promoted by a tourism innovation group that was designed to bridge the knowledge gap between research published in academic journals and tourism management practices. This reinforces the need for translational activity to take the academic research and disseminate it to the people who should read it outside of an academic audience.

This knowledge gap was explained by studies such as Kapstein and Yip (2011), who highlight the two audiences for business-related research: other academics and practitioners. External audiences often see academic research as having an inward focus on high-quality scientific research that has little application to the real world. In contrast, many academics are critical of practitioner-oriented or 'applied' research as lacking scientific rigour and too focused on non-academic outcomes. But in the case of dementia and communities of practice, research targeting non-academic audiences is often used to support a planned intervention or outcome, targeted at a specific audience and will often have the voices of PLWD writ large. Yet communities of practice are not without their challenges. As Roberts (2006) acknowledged, these are not stable entities to work with as people enter and leave, and they raise issues of power and trust when working with such groups. However, this does not mean that fundamental tourism research on dementia may not feed into such attempts to address dementia as a GC. Perhaps the key question for researchers who embrace this GC is whether it will develop the same or greater presence in everyday GC narratives in society as climate change has done, or whether the stigma associated with dementia will prevent it from becoming such a narrative unless an individual or organisation is personally touched by the issues. There are certainly lessons to be learned from the experience of climate change (Scott, 2021)in how it has changed society thinking about a GC and how tourism research can contribute to that debate.

The dementia-tourism nexus still represents a *terra incognita* because only a limited number of studies of PLWD exist. Many are based on commentaries that lack empirical validation. There is still considerable scope to expand research on the tourism-dementia nexus with a greater interdisciplinary and potentially transdisciplinary research effort, particularly outside of the largely Westernised models of research that have tended to focus on the current baby boomer generation. The demographic changes occurring globally are not homogenous and so more nuanced research is needed to investigate social, cultural and political differences between ageing and dementia in different settings. Further, adopting participatory models of research that integrate PLWD as co-researchers yields much potential for the development of inclusive research practices. This will help the global tourism industries begin to grapple with the multiple issues that a travelling population seeking to live well with dementia will need to navigate and be accommodated in the visitor journey.

Endnotes

1. But not exclusively as young onset dementia which can set in before age 65, and affect people as young as 30 years of age when symptoms develop – see Dementia UK (2022) who estimate there may be 70, 800 people in the UK living with this condition and many other countries have recognised this trend with organisations focused on young onset dementia such as YODAT in New Zealand (Younger Onset Dementia Aotearoa Trust) (also see Vieira et al., 2013 for more detail).
2. The recognition of dementia as a generic term can be traced to Boisser de Sauvages (1771), and its recognition as a syndrome caused by multiple diseases to Marie (1906). In 1906 the identification of what became known as Alzheimer's Disease as a specific form of dementia by Alzheimer (1906) (see Hippius and Neundörfer (2003) was a landmark development illustrating that medical interest in dementia was well established by the Edwardian period (see Bolton (1905) for one such example).
3. Gerontology was defined by Shock (1952: 1) as ' … the scientific study of the phenomenon of ageing … The problems of gerontology are multidimensional and will require for their solution not only a multidisciplinary approach but also a correlation of diverse finding and viewpoints' in which dementia has been located given its initial correlation with older age.
4. We use the plural as it is consistent with Leiper's (2008) argument on multiple industries that comprise the term tourism sector.
5. The social disability model is widely used by social science researchers and it seeks to view the world from the perspective of the person living with dementia (PLWD) and carer to understand what barriers exist and how these may be overcome and facilitate access to improve lived experience (see Davis, 2016). The social disability model argues that most barriers are caused by society separating out impairments and disabling barriers. The approach moves away from disability as a medical problem where people are empowered to take charge of their own lives and achieve agency in that process, given the assumption that PLWD have little or no agency or involvement in decisions that impact them (Blichfeldt & Nicolaisen, 2011; Boyle, 2014; Jennings, 2009; Zeilig et al., 2019).
6. The visitor journey can be broken down into several components including:
   - A planning and organising stage leading to booking a holiday/trip (or a leisure trip which may be more spontaneous and require less planning and preparation)
   - The departure from home to the mode of transport access to convey them as a domestic or international tourist to the destination or through stages of transportation (e.g., travel by car; public transport; experience of an interchange or point of departure like an airport or port)
   - The transit experience as a tourist on their main mode of transport to the destination (if a cruise is selected that functions as a form of transport that is also the main holiday experience)
   - Arrival in the destination and transit to the accommodation
   - The in-destination experience, including the touch points with the visitor economy (e.g., the accommodation, hospitality services, attractions, retailing and the destination infrastructure such as the built and natural environment)
   - The departure and return home.

From the analysis of these different stages of the visitor journey, policy documents and guidance from different stakeholders on creating dementia-friendly tourism environments and interventions may then be devised to create working dementia-friendly tourism environments.

7. The stages through which a person with dementia progresses from early onset and diagnosis through to end of life largely mirror the stages of ageing that broadly map to changes from being independent to becoming interdependent, to dependence, to crisis, and to end of life. There are no set timeframes for this transition that may be phased over many years, to other cases where the progress of dementia may be rapid, and end of life occurs quickly. This is dependent upon the individual, form of dementia, underlying health, existence of complex medical conditions, how active and fit the individual is and many other factors influencing the progress of the condition.
8. Positive psychology is concerned with the focus on the personal subjective experience of individuals, groups and organisations

and the ways positivity can help overcome negative thinking and draws inspiration from the notion of the humanistic movement with its concern with human happiness, well-being and how positive experiences and attitudes can help enrich human life. Its philosophical basis is drawn from the Greek Philosopher Aristotle and the notion of eudamonia with the emphasis on the good life or how humans can flourish through happiness to achieve enhanced subjective well-being. It has particular salience for tourism research with the focus among tourists on the way holidays and travel experiences may enrich their well-being, by seeking a period of quality rest, relaxation, stimulation and other motivations to achieve greater happiness and fulfilment away from the mundane nature of everyday life and work or routines.

9. Social prescribing is a tool for health professionals to recommend non-medical interventions to improve a person's well-being as a complementary route to health care (Bickerdike et al., 2017).
10. For example, Alzheimer's France runs an innovative scheme where up to 400 people with dementia and caregivers have an opportunity to take a holiday in specially adapted facilities in a mountain or coastal resort for 8–10 days to help with living well with dementia as a themed, relaxation or solo stay with support from local volunteers. In addition, in Paris a local Art, Culture and Alzheimer's Program has been operated by Alzheimer's France with 33 cultural institutions (e.g. the Louvre and other museums and sites) with a programme of events for people with dementia, reflecting the fact that France has over 1.1 million people diagnosed with dementia. These events are largely targeted at the resident population and their leisure time (see France Alzheimer et Maladies Apparentées (no date) Art, Culture et Alzheimer à Paris, https://www.francealzheimer.org/wp-content/uploads/2024/01/ART_CULTURE_ALZHEIMER_Programmation-v62.pdf, accessed [on date] (archived at https://web.archive.org/web/20240106143259/https://www.francealzheimer.org/wp-content/uploads/2024/01/ART_CULTURE_ALZHEIMER_Programmation-v62.pdf, accessed February 16, 2024).
11. Hägerstrand described a time-space path as a way to depict how spatial activity occurs as a mobility pattern, which is controlled by limitations as opposed to the independent decisions of individuals. These paths were pictorially expressed as prisms and the probability of potential mobility was related to time availability. Time geography has a considerable synergy as an approach to understanding dementia as it is a constraints-oriented approach focused on human activity and actions.
12. This issue has also been observed across numerous demonstration projects undertaken as part of a funded research project where participants noted the limited opportunities to access the visitor economy.
13. In the UK this situation is compounded with many accessible toilets being reliant on the RADAR key system that is required to access over 10,000 toilets or the EUROKEY System in Europe as the UK and European keys are not interchangeable. The idea is fine in principle if you have a key but for those people without a key then the issue of dignity needing to find someone to unlock the toilet arises and this can be problematic at busy locations.
14. The slow museum movement emanates from the slow city (Pink & Servon, 2013), slow travel and slow food movement based on the premise of enhancing well-being. The movement suggests that human enjoyment of consumption of travel, mobility, place, food and enjoying the moment can best be encountered through much slower engagement with phenomena. This encourages more reflectivity and has synergies with the mindfulness movement and human emotions. In a museum or visitor economy setting, the slow movement has greater salience for PLWD who may need more time to process visual stimuli or to try and make sense of the objects or experience around them and so a slow approach may help make adaptations to the visitor experience for people with different needs such as PLWD, autism, the visually-impaired and those with other impairments.

Impact statement

This is a review paper that is designed to establish the potential Global Challenge posed by the growth in dementia as an international phenomenon now or will impact most countries with increasingly ageing populations. Dementia is expected to touch 1:2 people in some way during their lifetime in developed countries. Global Challenges as transdisciplinary research agendas have not attracted a great deal of attention explicitly in tourism research beyond the obvious example of climate change and so its discussion is timely in this paper. This is a topic with policy and practice implications for governments and businesses in the wider visitor economy as they recognise the adaptations and developments needed by businesses and public sector organisations to avoid the marginalisation of people living with dementia (PLWD) and their carers. The research adopts the visitor journey concept to outline how the visitor economy, destinations and individual businesses will need to engage with this subject as its visitor markets change. The paper makes a sustained contribution to policy and practice by highlighting the intersection of tourism and dementia and where future research efforts may be directed to enhance the action and changes to practice to accommodate PLWD and their carers.

CRediT authorship contribution statement

Stephen J. Page: Writing – review & editing, Writing – original draft, Methodology, Investigation, Conceptualization. **Joanne Connell:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Conceptualization.

Declaration of competing interest

None.

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Appendix A. Supplementary data

Supplementary discussion relevant to this article can be found online at https://doi.org/10.1016/j.tourman.2024.104916.

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