Developing Dementia-Friendly Tourism Destinations: An Exploratory Analysis

Stephen J Page, Anthea Innes and Clare Cutler

Manuscript submitted to Journal of Travel Research

Pre-print version November 2013

doi:10.1177/0047287514522881
Developing Dementia Friendly-Tourism Destinations: An Exploratory Analysis

1. Introduction

There is a growing recognition in tourism research that expanding boundaries mean that the subject is constantly evolving and being redefined as a multidisciplinary subject area, and it is well placed to contribute in a positive and meaningful way to emerging societal debates, particularly through the application of research-based policy-making. The expansion of the current destination paradigm (e.g. Pike and Page 2014) has established a clearly articulated and overarching approach to holistically view tourism issues in a specific spatial context (i.e. the destination) (e.g. Ritchie and Crouch 2003; Morrison 2013). The destination paradigm also lends itself to integrating new perspectives on tourism destination development with the emerging concern in many developed countries of the consequences of an aging population and the implications for developing tourism and accessible destinations (UNWTO 2010), much of which has focused on disability.

One facet of destination development-accessibility debate has been framed around issues of equity and inclusivity, associated with elements of the destination experience (e.g. accommodation, transport, attractions and destination mobility). Organisations such as the European Network for Accessible Tourism epitomise the lobbying to provide more accessible destinations although such accessibility is largely concerned about the needs of people with a defined disability. However the accessibility agenda is not necessarily inclusive or all-encompassing if specific groups are overlooked (e.g. those with dementia) who are allocated to the notion of the ‘disabled’. In other words, certain groups voices and their visibility are neglected in the accessibility debate where it is narrowly confined to notions of disability. The consequence is that the physical needs of certain groups (e.g. those confined to wheelchairs or other afflictions such as blindness or deafness have been subsumed in research on disability and travel (e.g. see Burnett and Baker 2001; Daniels et al 2005; Freeman and Selmi 2005; Israeli 2002; Poria et al 2010 and Yau et al 2004). These groups have very specific access issues which some destinations have developed measures to accommodate. Yet with a growing aging population in many countries, some of whom are living with the effects of dementia which is not a defined as a physical disability and so it not simply an ‘accessibility’ issue for most destinations. Indeed the UNWTO (2010) report on
aging and tourism makes no mention of this emergent issue although it has a significant effect on the tourists’ ability to freely participate and in a holiday within a destination. This is because dementia is a set of symptoms characterised by loss of memory, leading to behaviour changes and a decline in the ability to independently conduct every day activities (WHO 2012).

Consequently, dementia begins to create potential barriers to leisure activities (which includes tourism) thereby impacting upon the freedom of individuals to participate, excluding this group from many activities they previously engaged in. The leisure literature is instructive in this context in demonstrating the research problem this poses on inclusivity and participation. As Roberts (2011) argues, the contribution of leisure to well-being is beyond dispute, but life events such as dementia affects the leisure-well-being relationship in two ways: First, it challenges the unitary state of leisure and well-being relationships, disrupting the participation through being able to access and participate. Secondly, if the barriers associated with dementia can be addressed, then activities such as tourism can make a positive contribution to enhancing the well-being and strengthen bonds in groups where a family member has dementia. The academic literature conceptualises these relationships in terms of the contribution leisure can make to human development in this life cycle stage. As Kleiber (1999) argues leisure can provide a basis for self-expression and potentially improve the human condition, particularly where the needs and barriers are addressed, especially where a medical condition transforms the individual’s leisure life.

Even so, these debates have been limited within the wider tourism literature, where issues of well-being have occurred in isolation in the extant leisure literature despite the growing range of studies on aging. This highlights a potential area for development by harnessing the interconnections between leisure-tourism and aging to understand emergent research themes. However, there is also a more long standing research focus within leisure studies that influences the thinking on tourism, leisure and aging as the leisure constraints literature has been instrumental in identifying barriers to leisure (Crawford and Godbey 1987). These barriers were examined further by Crawford et al (1991) to identify three principal barriers to leisure: intrapersonal (i.e. those associated with one’s psychological state which were felt to inhibit leisure); interpersonal (i.e. those associated with one’s social setting such as family) and structural constraints (i.e. those barriers which were outside of the control of
the individual) as outlined by Scott (2003). In the context of aging, the recent study by Kazeminia et al (in press) outlines the way in which senior travellers cope with the constraints they face, informed by the leisure and gerontology literature. In fact as Scott (2003) argued, much of the research activity on leisure constraints has focused on the notion of structural constraints and this paper is no exception to that popular theme within the wider domain of tourism and leisure research.

Consequently, aging is not a new theme within tourism research (e.g. Paterson 2006; Moller et al 2007; Glover and Prideaux 2009; Darcy and Dickson 2009; UNWTO 2010; Sedgely, Pritchard and Morgan 2011), but what has emerged in recent years is the challenge of increasing longevity in the family life cycle associated with an aging population (Gibson 2006; Pike 2013). Such longevity poses challenges on how to maintain participation and maintain quality experiences for a population more likely to live longer and potentially experience a greater range of health conditions (of which dementia is one example). In the UK there has been an 80% increase in the number of people over 65 in the last six decades (Rutherford 2012). This is a pattern reflected worldwide; the number of people aged 60 and over globally will nearly triple in size, increasing from 894 million in 2010 to 2.43 billion in 2050 (UN.2012). Alongside an aging population is an increased probability of developing dementia. For example, there are 820,000 people with dementia living in the UK (Luengo-Fernandez et al.2010) and over 3 million in the USA (Plassman et al 2007) with 35.6 million people with dementia worldwide. This number is predicted to nearly double every 20 years, to an estimated 65.7 million in 2030, and 115.4 million in 2050 (Alzheimer Disease International 2009). As Plassman et al (2007: 125) argue ‘Dementia is a disease of particular concern because the decline in memory and other cognitive functions that characterizes this condition also leads to a loss of independent function that has a wide-ranging impact on individuals, families and healthcare systems’, illustrating the incapacitating and dependency relationships that this ailment engenders. This is a more complex phenomenon than many other forms of disability that have physical manifestations and where barriers to participation can be broken down by innovative solutions involving access. Dementia in contrast is far more complex.

This paper is innovative and makes a clear contribution to the tourism and wider social science literature by being the first to identify the interconnections between tourism and
dementia and more specifically, identifies the concept and implications of developing the concept of Dementia Friendly Tourism (DFT) within a destination context as a concept to address the accessibility-inclusivity agenda, enhancing and extending the provision and inclusive nature of the destination. The paper contributes to knowledge by drawing together these disparate facets of social science research on aging, dementia, illustrated through an exploratory study of the role of the tourism sector in a destination and examines how barriers to DFT may be addressed. The genesis of DFT is a refinement of the current ideology and policy agendas currently being articulated by the UK Prime Ministerial Group on dementia as a national priority area for research and policy action through the vehicle of Dementia Friendly Communities (DFCs) (Department of Health 2012) to help ‘people live well with dementia’ (Alzheimers Society 2013a) by:

- 2015, up to 20 cities, towns and villages will have signed up to become dementia friendly.
- Support from leading businesses for the Prime Minister’s challenge on dementia.
- An awareness-raising campaign.
- The Dementia-Friendly Communities Programme working in partnership with the Dementia Action Alliance will develop evidence on what a Dementia-Friendly Community is (Alzheimers Society 2013a).

Therefore, this paper is a scoping study to look at the issues of tourism destinations becoming dementia friendly as a current social policy that translates across into tourism settings globally. It adopts a largely inductive approach, where the conceptual framework is established from the interconnections of dementia, tourism, a destination context and the role of key actors (businesses) within the policy context of the Prime Minister’s Dementia Challenge. The paper arises from a much wider project designed to examine both the supply aspects and the wider demand issues associated with DFT to scope out the issues relevant to creating a framework for DFT that may be applied in a variety of destination contexts to achieve a greater generalizability from the research.

Dementia costs the UK economy £23 billion each year through the need to provide support and services to people with dementia and their families (Luengo-Fernandez et al 2010). Finding creative solutions to support and enhance the well-being and lives of those with dementia and their families that move beyond traditional health and social care services could not only enhance the lives of those with dementia, reduce the financial burden of care
for families and the state, but create a niche market within the tourism and leisure sector. The baby boomer generation in particular has led to an increase in expectations about living well into older age (Pruchno, 2012) alongside an ethos of the importance of active aging (Page and Connell 2010; Roth et al 2012). This has contributed towards more people seeking tourism opportunities in later life but also for those with specific conditions such as dementia expecting to retain an active lifestyle which includes travel, leisure and cultural pursuits. Therefore, it is certainly timely to consider one facet of the aging agenda and its implications for destinations, namely how an increase in the number of people with dementia poses both a strategic challenge and opportunity for destinations.

Creating DFCs within a destination context includes developing an environment where people can access local services such as shops and banks as well as local facilities such as parks, transport and libraries, which if extended to tourism will extend to the wider destination resource base (e.g. transport, accommodation, attractions and the wider destination infrastructure such as the built environment, shopping and leisure settings. The rationale here is to break down the barriers that cause people with dementia to often feel isolated (Alzheimer Society 2013b) who fail to access the range of services and facilities within their communities, further marginalising and excluding them for many normal day to day (i.e. leisure activities) and more planned activities such as tourism. This approach has a salience for tourism as many coastal resorts in the UK and in other countries service a large aging population and so embracing a DFT approach is potentially valuable in developing a socially inclusive notion of destination development. These precepts have largely been implicit in social inclusion legislation that has previously focused on overcoming barriers to disability in leisure and tourism (Aitchison 2010). The salience with dementia is that it is increasingly viewed as a social disability (Innes 2009) requiring a similar approach to that of the widening access agenda of the disability movement. For those with dementia to move from a marginalised and stigmatised position (Innes, Archibald and Murphy 2004) requires an active promotion of an inclusive approach that challenges the negative perceptions and stigma that many people with dementia experience from the initial diagnosis (Vernooij-Dassen et al 2005) through to their experience of accessing support and services (Morgan et al 2009). The preliminary research findings reported in this paper are from one destination and based on a small-scale qualitative research methodology to understand how to the DFT
concept might be achieved by understanding the perspectives of the stakeholders in the wider visitor economy who are potential gatekeepers to the visitor with dementia and their guests.

More specifically, this paper set out to achieve the following research objectives:

- To identify the feasibility of tourism sector stakeholders developing dementia friendly products and experiences by understanding their knowledge, perceptions and understanding of dementia
- To highlight the barriers and obstacles that potential policy measures may need to address to achieve the conditions conducive to DFT
- To examine the extent to which DFT can be an innovative concept for destinations within the context of establishing DFCs

Whilst the study is exploratory in nature, the findings have importance for the tourism community and policy-makers globally: the findings and implications illustrate how to embrace and develop tourism in a manner capable of meeting the dual needs of people with dementia and their family carers. This follows the arguments by Sedgeley et al (2011: 422) supporting ‘humanist, participatory approaches to the study of older people that adopt the principles of critical gerontology and hopeful tourism’ whereby the notion of duality in the ability of carers and patients to enjoy a holiday experience (Houston 2010) can be reconciled, which is implicit in the conceptualisation of DFT as an inclusive approach for destinations alongside their other work on improving accessibility for people with disabilities. This is far more meaningful than the previous ideology focused on respite care separating families and carers for ease of caring. Such an approach is rooted in the leisure literature arguing that leisure can contribute to human development and enhance well-being. It has evolved within a tourism context from the paradigm of social inclusion (Coles and Morgan 2010) that emanated from a series of policy perspectives globally that sought to ensure that marginalised people (e.g. the disabled) were not excluded from access to activities and opportunities to live fulfilling lives which has salience with their leisure activities such as tourism and holiday-taking. Social inclusion in tourism has culminated in a growing interest in social tourism (e.g. McCabe et al 2012) and the ability to develop tourism so it is not divisive and embodies the seminal notion of equality of access and
participation. This is inherent in Visit England’s (2012) Accessibility Action Plan that recognises the market opportunities in accessible tourism:

The market for accessible tourism is significant. In 2009, over 11 million overnight trips were made in England by UK residents who have a health condition or impairment and their travelling companions... Almost half a million people with a health condition or impairment visit England from abroad each year. Tourists’ who have a health condition or impairment, and their travelling companions, spend well over £2 billion each year in England (Visit England 2012: 2).

The challenge from a research perspective is that accessibility is largely framed in terms of disability and ill-health, broadly constituted, and does not recognise the specific challenges and opportunities which aging and the issue of dementia faces at a destination level. As a consequence, this research is framed with reference to a growing international agenda on accessibility for the population, though not necessarily focused on the narrow conceptualisation of physical disability. To advance knowledge in this area, the paper commences with a review of the literature informing this study as there are no previous studies of tourism and dementia in the research literature to base this study and so a wider set of interdisciplinary studies are used to construct the context and framework for the research study to understand the interconnections between tourism and dementia. This is followed by a discussion of the views of tourism providers in our research about the obstacles and potential opportunity to provide DFT and the implications for destination development.

2. Literature review

Within the wider tourism literature, there are no existing conceptual frameworks which exist to underpin the analysis of the interconnections between tourism and dementia. In this respect, the subject is new to tourism research, with the most obvious linkages formed through research that has emerged since the 1990s on the interconnection between tourism and health (e.g. Clift and Page 1996; Wilkes and Page 2003) which has been primarily concerned with addressing visitor behaviour associated with risk, consequences of traveller health and development of travel medicine as an area of study. An underpinning conceptualisation can be traced through the evolution of sociological and social psychological research in leisure (e.g. Argyle 1996) which has focused on the notion of leisure and well-being). A number of studies within tourism have extended this
conceptualisation to highlight the positive benefits of tourism to well-being and the quality of life of participants (Hartwell et al 2012; Gilbert and Abdullah 2004). This has its roots in the work of human geography and health studies in the 1970s with the focus on human welfare (e.g. Smith 1974) and its more recent transformation into wider notions of well-being, and how to enhance human health through engagement with leisure (of which tourism still remains a neglected theme beyond simplistic notions of the standard benefits of holidays). Historical studies of health and tourism have demonstrated how health can be enhanced by specialist forms of tourism (e.g. trips to spas and hydrotherapy,) as well as the growth of medical tourism (overseas travel for operations and health treatment) but understanding how tourism enhances the lives and experiences of specific groups such as families with a family member with dementia remains neglected. There are a number of potential benefits from examining the wider leisure studies literature in this context (e.g. Wearing 1995) as dementia has received greater attention in recent times in relation to experiences of living with dementia (Innes et al 2005, Innes, Abela and Scerri 2011) although not in relation to holidays.

There is a developing literature within leisure studies that has examined the meaning of leisure for people living with dementia (Genoe & Dupuis 2011) which is congruent with much of the social psychology literature on the benefits of leisure and holidays (Tedrick 1999). As Genoe and Dupuis (2011) and other studies show, there are a number of key benefits of leisure for people with dementia such as enabling people to ‘be me, to be with others, the pursuit of freedom, finding balance, making a difference, growing and developing and having fun’ (Dupuis et al 2012) which identifies the positive benefits of daily activity and stimulation of different environments to help with the management of dementia as a medical condition. These findings also indicate the congruence with many of the benefits cited from taking holidays, albeit with a deeper and richer set of extended experiences emanating from an extended holiday away from the normal home environment. The wider leisure literature relevant to aspects of dementia can broadly be classified into:

- Leisure and participation amongst dementia patients (e.g. Schreiner et al 2005; Phinney et al 2011; Mapes 2010, 2012; Menne 2012; Woods 2010; Jennings 2006; Johnson and Walker 2008)
• Home-based leisure and dementia (e.g. Kuzamanov 2005; Paillard – Borg et al 2009) and other forms of leisure activity with families such as eating out (e.g. Cassolato et al 2010) and the impact on carer’ leisure (e.g. Carbonneau et al 2011; Chattillion et al 2012)

• Experimental research on how to improve one’s cognitive function through leisure (e.g. Hall et al 2009; Wang et al 2012).

In theoretical terms, the findings from Dupuis et al (2012) illustrate that there is a clear rationale for leisure and tourism to feature in the lives of people living with dementia as ‘perceptions of dementia and its associated symptoms tend to be negative. Indeed, the label of dementia is associated with fear since discourse surrounding dementia has focused on the debilitating, demeaning and despairing features’ (Genoe 2010: 309). Therefore, leisure pursuits provide the person with dementia with the power to resist these stereotypes (i.e. leisure and tourism as a form of resistance) as an outlet to battle against such stigma, to break away from the tendency to consumer private spaces (i.e. the home) in one’s leisure time. The intentional resistance which tourism offers can assist in building a greater confidence to live with dementia and to make more informed life choices and be confident in gaining greater independence and identity loss (Genoe 2010). This may also provide unintentional resistance to aging. However prior to examining the research study, it is important to challenge negative perceptions and stereotypes of what dementia might mean for the provision of tourism services. It is often believed that those with dementia may present a risk or challenge to service providers generally, yet recent policy work demonstrates the need to frame those with dementia and their family carers in a positive and inclusive manner (Prime Minister Dementia Challenge 2012), in much the same way that tourism has promoted a widening access agenda to enable barriers to participation to be overcome. In particular, VisitEngland’s (2012) Action Plan on Accessibility provides a useful framework for understanding the domain of destination’s being able to be truly accessible. This focuses on the facilities, customer service and information for visitors and a shift away from purely operationally focused concerns which the implementation of the disability discrimination legislation has created with a predominant focus on mobility issues rather than the wider gamut of those people with other needs, such as dementia.

Consequently, research from a supply perspective is an important starting point for scoping
out the nature and challenges and opportunities which dementia poses for destinations wishing to develop a competitive edge through the becoming a truly accessible place to visit. Therefore, this paper argues that tourism can actively provide the opportunity for people with dementia to participate more actively in society and also offers a hitherto untapped market for tourism providers.

Dementia is not a physical disability and yet all the accessibility research has focused on disability (although there is also a literature that argues that dementia is a social disability so it may potentially be categorised in this way). However, dementia presents a market opportunity and response to a major problem in respect of aging and tourism and so framing a research study to examine the supply side of dementia from a business perspective is critical to understand what the key drivers and factors are that will assist and inhibit the development of a DFT destination. This involves understanding businesses perceptions and a deeper interrogation of their views as an exploratory study in view of the absence of existing studies and a more qualitative approach as advocated by Sedgely et al (2011) in relation to aging research per se. However, prior to examining these issues and the methodology, it is pertinent to examine the context of the study.

3. Bournemouth as a coastal tourism destination: The context of the study

There is a well-defined literature relating to coastal tourism (e.g. Hall and Page 2014; Page and Connell 2010) that outlines the evolution of coastal resorts as destinations in the UK and the changes they have encountered in the post-war period in terms of their markets changing as overseas travel became a cheaper and more attractive proposition (Soane 1993). Coastal resorts in the UK currently attract around £4.8 billion in visitor spending from domestic tourism with 8 of the top 20 characterised as beach destinations such as Bournemouth located in southern England. In addition, coastal resorts have traditionally attracted a retirement market that has added an additional aging dimension to their local population. This has also compounded the geographical concentration of dementia in these localities as acknowledged in Dorset. In the Bournemouth region, in 2001 21% of the population were aged over 65 compared to 16% of the national population while in 2012, Christchurch was singled out as the place in the UK with the greatest concentration of population over 65 years of age due to its attractiveness as a retirement location. As a
consequence, this destination had a dual dimension to dementia: in the resident population likely to engage in coastal recreation or wider urban-based leisure and the visitor population. Despite the paucity of studies of coastal tourism in the UK and in the south coast region, changes in the fortunes of UK coastal resorts have led to several influential publicly-funded research studies of UK coastal resorts which have highlighted the internal social and economic contradictions of the image of the fun seaside destination. For example, the House of Commons Commission and Local Government and Communities (2007) inquiry observed the characteristics of coastal resorts where:

- Many resorts were socially and physically isolated and characterised by seasonal trade and employment including a dependence upon tourism
- High levels of social problems (e.g. deprivation and poverty) combined with an aging population induced by outmigration, with large numbers of the population living in rented accommodation and Houses of Multiple Occupancy. In some instances there was also a transient population A low wage economy existed with areas of deprivation concentrated in specific areas of resorts compounded by a declining economy.

A further study by Beatty and Fothergill (2004) observed that a wide range of resort types existed and in the case of Bournemouth, it was composed on an urban core with a Greater urban area incorporating nearby resorts at Christchurch and Poole with a total population of 335,000. Bournemouth does not exhibit all of the characteristics of a declining resort, given that it has been highlighted as a destination that has managed to diversify its economic base to include a growing financial service sector and retailing associated with its urban service centre status. In the House of Commons report (2007), Bournemouth was identified as a success story that had addressed some of the prevailing issues of decline and over-dependence upon a seasonal tourism market, although many young people were priced out of the local housing market compounded by the retirement market and 6000 of the total 80000 housing stock comprising second homes. Even so, Bournemouth’s post-war market for tourism has changed with a greater predominance of leisure day trips in the peak summer despite its large accommodation base dominated by small and medium sized enterprises (McLeod et al 2010).
Bournemouth, like many other UK coastal resorts has seen its markets change dramatically since the 1970s with a refocusing away from large domestic tourism holiday volumes associated with a 100 year history of coastal visiting and the family holiday. Whilst the over 50 year old market has persisted in reduced volumes, typified initially by organised tours by coach, but increasingly comprises self-planned trips by coach, car and other means of transport. Complementing these markets have been examples of innovation and diversification in major resorts in the UK such as Blackpool and Bournemouth by attracting the business tourism through conferences and conventions, by investing in purpose built convention centres. Unintended developments such as the rise of the resort as a focus for weekend Stag and Hen Party market associated with the night-time economy have proved a controversial development for large resorts such as Bournemouth and they co-exist in juxtaposition to the aging market which can sometimes be problematic. However, underpinning the market for coastal tourism has been an increasing dependence upon the senior markets, especially outside of the main tourist season as the mainstay of the local tourism sector. In this respect, focusing on the relationship between a major coastal tourism resort area and dementia as a growing phenomenon associated with a coastal tourism destination visitor profile means that there is a logic and coherence in selecting this locality a focus for this study. This is given a greater value as a major destination such as Bournemouth and surrounding environments has attracted comparatively little attention aside from generic studies of UK resorts and their relative decline since the 1970s in relation to the life cycle concept. In this respect, the aging market has remained a lifeline for many resorts prior to the recent domestic campaign by Visit Britain extolling ‘staycation’ (domestic holidays) as a way to boost a declining visitor economy combined with a declining value of Sterling. In the last three years, ‘staycation’ has led to one of the greatest resurgences in domestic tourism for many decades (Social Trends 2011). Whilst the UK visitor economy is estimated to comprise around 8.2% of UK GDP, in the case of coastal resorts such as Bournemouth tourism comprises 12.8% of GDP. This reflects a dependence upon tourism and the wider visitor economy which supports 9700 jobs and is valued at around £413 million. To offset resort decline and in an attempt to reimage and reposition parts of the resort area, urban regeneration such as the creation of an artificial surf reef was created with £13 million of public sector investment and £48 million of private sector
investment at Boscombe. With these issues in mind, we will now focus on the research methodology to illustrate how this study was undertaken.

4. Methodology

The selection of the Greater Bournemouth area and environs as a focus for the study sought to look at the resort and its immediate hinterland as a basis to understand the wide range of tourism businesses and organisations that would affect the visitor experience of people with dementia visiting the resort as opposed to a narrow focus on Bournemouth Borough Council area and the central resort area. The study built upon the recent analysis of business networks and activities in the region (McLeod et al 2010) which identified around 300 actual businesses operating in the visitor economy. From that initial 300, it was decided to seek a 10% sample of these businesses and organisations with a spread of business interests in the wider visitor economy as opposed to the problem that many tourism surveys report of a dominant focus on the accommodation sector. The 10% sample was identified as a starting point to draw around 30 businesses as a possible sample with a target population of 20 businesses due to the selection of a qualitative research method. The initial 30 businesses were selected after a discussion with key a Board Director from Bournemouth Tourism who had a very good overview of the business landscape. A degree of market intelligence to inform this selection process arose from separate focus group interviews in the region with people with dementia and their family carers. These discussions shaped the selection of businesses that had or had not received visits from people with dementia and carers. Twenty semi-structured interviews with well-known tourism organisations and independent companies within the Dorset region, concentrating predominately on the Bournemouth and Poole areas were conducted between May and July 2012. Semi-structured interviews were conducted for two reasons, first as this study is a pilot project and as such involved an initial scoping exercise to assess the type of issues and debates associated with the dementia theme in one resort that can be used to inform future research on dementia and tourism. Second to enable an initial exploration of the experiences of dementia of those providing tourism services.

Thirty one organisations and companies in the Dorset region were identified as representative of the tourism industry within this area. Each was sent a personalised letter
(explaining the research) and an information sheet (describing what would be involved) as an invitation to take part in an interview (via telephone or in person). Ethics approval was obtained from the University Ethics Committee. Participation in the project was voluntary. Information sheets were given to potential participants prior to the conduct of interviews taking place. Consent forms, which confirmed that participation was voluntary, that the participant could leave at any time and that all data collected would be kept confidential and de-identified where necessary were completed. Follow up telephone calls were conducted two to four days after the initial letter was sent. Three contacts agreed to an interview after the first follow-up call. Further telephone calls were required before more interviews were agreed. A total of 20 semi-structured interviews were conducted and recorded, lasting from 15 minutes to one hour. After identifying specific aspects of their business, participants were asked to; describe dementia; state what specific needs they thought people with dementia may have when visiting their tourism service; if they felt their business was suitable for people with dementia; if they felt there was anything the tourism sector could do to promote Dementia Friendly Tourism, and their thoughts on the impact, if any, on their business if the region was labelled as dementia friendly.

The locations of the organisations and companies spanned the Dorset region and included areas of Bournemouth (9), Poole (5), Christchurch and border of Hampshire (4), rural Dorset (2) as shown in Table 1.

5. Results and analysis

The interviews undertaken with tourism providers were subjected to a qualitative thematic analysis (Bryman 2008) using Nvivo9 for data management purposes. An inductive process was followed where a coding frame was developed by one researcher and then independently checked by a second. A final set of 28 codes were agreed enabling a robust coding process to underpin the subsequent analysis (see Appendix 1). The resulting analysis identified 4 overarching themes (awareness and understanding, cost, extra effort and on-going development) as being significant when considering tourism for people with dementia.

5.1 Awareness and understanding
Awareness and understanding will be discussed under the sub headings; general awareness and understanding, experience and attitude, and stigma reflecting the issues arising from the coding and analysis of the interview data.

5.1.1. General Awareness and understanding

It is evident that general awareness and understanding surrounding dementia was limited amongst tourism providers. Comparisons were commonly made between physical disabilities and dementia, particularly the visibility of symptoms. The absence of visible signs of dementia was challenging for some tourism providers who felt that dementia was more challenging to identify when compared to recognising a person with physical disabilities. There was also no connection made between people with dementia also having a physical disability, it was either one or the other as the following textual comments infer.

Tourism provider: ‘So yes, dementia’s hard to. You can’t see that. You can see someone in a wheelchair, someone with a walking stick but you can’t necessarily see dementia’ (01)

Tourism provider: ‘With dementia are less likely to stand out. Or less visible to stand out. It’s the ones with the physical disabilities that are more noticeable. But ones with dementia obviously don’t’ (02)

The terminology used to describe a person with dementia was confused and it appears that some tourism providers do not understand the relationship between Alzheimer’s disease and dementia, both of which were commonly perceived as separate illnesses rather than dementia as an umbrella term for a range of conditions. A lack of understanding has resulted with some tourism providers displaying a contradictory attitude towards dementia and Alzheimer’s. There appears to be a negative association with the term dementia yet a sympathetic association with the term Alzheimer’s. This reflects the general lack of understanding about dementia that is found within the limited literature examining the views of the general public about dementia (McParland et al 2012).

A negative view of people with dementia using the facilities of one tourism provider led them to comment that:
Tourism provider: *Normally they appreciate they’re causing trouble ...*
Interviewer: *Would it be something that maybe you... you would actually openly encourage that customer base to come?*
Tourism provider: *What, for just one afternoon?*
Interviewer: *Yeah, or on a regular basis maybe or do something different?*
Tourism provider: *No, I don’t think so, I don’t think we want to go down that path.*
Interviewer: *No?*
Tourism provider: *No, thank you.* (06)

A sympathetic view to an Alzheimer’s group using the same facilities:

Tourism provider: *We do have the Alzheimer’s, the [xxx] Alzheimer’s Group, they come in and do a tea.*
Tourism provider: *And we have a lot of people who are on the borderline of being Alzheimer’s.*
Tourism provider: *Yeah, I would say once a summer as an annual outing that they come and they have tea and sit by the pool, buy some things in the shop.*
Interviewer: *And that has always gone smoothly, there hasn’t been any particular challenges?*
Tourism provider: *That’s never a problem.*
Tourism provider: *No, never a problem.* (06)

Tourism providers held contrasting views about the type of activities people with dementia may like to take part. Six of the twenty tourism providers offered specific ideas which mainly centred around familiarity, peaceful and friendly environments and doing the same as everyone else. In contrast, other providers believed that people with dementia require to be assisted in their enjoyment of the attractions on offer.

Tourism provider: ‘*The fact that they have dementia is one thing, but they’re actually here as a person just wanting to enjoy, you know, the sea, and the fish and chips, and go to a beach, and watching the boats in the harbour go to Brown Sea Island and, you know, just as anybody else might’* (05)

Tourism provider: ‘*...Alzheimer’s, or whatever, so, they tend to be happier if they can be placed in a tractor trailer, and moved through an experience rather than finding the experience themselves.*’ (08)

5.1.2 Experience and attitude

The findings seem to suggest that attitudes towards dementia are a consequence of direct experience. Tourism providers who disclosed that they had experiences of dementia in their
personal lives or had witnessed someone else affected by dementia tended to have a sympathetic and understanding attitude and approach.

Tourism provider: ‘We have a member of staff whose mother has dementia so we do know how difficult it can be sometimes’ (06)

In direct contrast, tourism providers who had no experience of dementia in their personal life, but had experiences of disability in general as part of their business lives, often displayed negative attitudes towards dementia, people with dementia, carers and disability in general. These negative attitudes were often a consequence of a previous negative experience as the following statement infers:

Tourism provider: ‘I mean a lady come in once with her son who had obviously learning difficulties, but I would say, like he couldn’t read. But he’d got learning difficulties and that’s what she took out of it. Well he’s got learning difficulties he’s disabled. So I had to give him a discount and he’s only four quid anyway and she came in free of charge. And then he proceeded to charge around the centre like a loon toon, and you think... that doesn't tape does it!’ (01)

Despite personal experience and attitude towards people with dementia and disability in general, tourism providers recognise that they have a responsibility as business owners or employees to provide all customers with a good service regardless of personal thoughts and feelings as the following comment illustrates:

Tourism provider: ‘We ensure that we treat that guest no differently than any other guest.’ (09)

It appears that having direct or indirect personal experience of dementia provides the tourism provider or employee with a greater awareness of dementia and an understanding about its implications for the person with dementia and their families. Whilst most experiences tend to be indirect, having personal exposure to dementia often results in having a greater general understanding and awareness of dementia as a whole, enabling a more considered service to be provided when in the work environment. Negative attitudes towards people with dementia and disability appeared to reflect a general lack of understanding. Whilst most tourism providers strive to provide a good service to all customers, negative attitudes towards dementia create barriers to the possible services and opportunities which could be provided.
5.1.3 Stigma

Some tourism providers believed that having people with dementia as customers would have a negative impact on other customers and place limitations upon their business:

Tourism provider: ‘...it’s created an incident and, as I said, we do have people with young children who find it difficult to cope with.’ (06)

Tourism provider: ‘So there’s always a danger when you’ve got a group of a certain type that other people feel intimidated or uncomfortable or surrounded by them because it’s a presence of a group of folks.’ (07)

By contrast, some tourism providers confirmed that they would be happy to have people with dementia as a customer base and would want them to feel comfortable. However, it was suggested that this would be subject to a family carer taking full responsibility for the person with dementia’s actions. This highlights the expectation of some tourism providers that if a problem occurred that the family carer should manage this appropriately and quickly and remove themselves away from other customers. Whilst this suggests that some tourism providers are happy for people with dementia as a customer base, there is also a parallel stigma and preconceptions of potential ‘problems’ that having dementia may bring:

Tourism provider: ‘Provided the carer is doing as much as possible to alleviate the problem and is not just letting them run riot and everything else, well that’s the other public member’s problem, not the problem with the disabilities’ (01)

Tourism provider: ‘The carer is aware that it sounds much louder so takes themselves out of the situation’ (06)

There is also the belief that promoting businesses as being dementia friendly would be detrimental for the business and would deter other potential customers:

Tourism provider: ‘My only concern with any real proactive marketing, and Bournemouth as being a dementia-friendly location, would be that I think we suffer a stereotype sometimes that Bournemouth is a place for elderly people, and that we just need to be careful that we don’t alienate everybody else...’ (09)

Tourism provider: ‘One of the things that would have to be considered with that is, again, like I said earlier, you have to be careful that you’re not becoming known as a destination that just does this, otherwise it can deter other group... because you don’t want to be reinforcing the view that, you know, the destination is all about...’
older people, as it would be, probably, conveniently tagged, you know, that you’re just after people who have lost their marbles, if you want to be unkind about it, and it’s not like that, but that’s really the, sort of, perception that would then deter other business...’ (03)

5.2 Cost

The issue of cost was important and will be discussed in relation to two specific examples: adaptations and discounts.

5.2.1 Adaptations

While most tourism providers strive to meet the minimum requirements of government legislation, building improvements and inclusivity specifically for people with disabilities, there is also a sense from some tourism providers that they will do what is required, but no more. The implications of costs incurred through building adaptations and installation of appropriate facilities was of concern and restricted what the tourism provider could adapt. This was a direct result of compliance required from recent disability legislation:

Tourism provider: ‘The problem is that it does cost us a great deal of money, the construction of the ramp costs us about a thousand pounds each time we do it’ (08)

Tourism provider: ‘The paths all really need re-doing they need re-surfacing but I can’t afford that’ (01)

Tourism provider: ‘We have got to do something about the toilet, though. We’ve got to do something. It’s one of those things on the agenda to do. You’re talking about, probably £5,000/£6,000 to do it, and that’s always a constraint, always a problem, because what do you do next?’ (13)

In some cases some tourism providers are unable to meet government legislation and Disability Discrimination Act standards due to restrictions in particular buildings:

Tourism provider: ‘You can’t just plonk a lift in the middle of a listed building.’ (15)

Tourism provider: ‘We haven’t got a disabled toilet, yet, and the problem is, it’s where do you put it? We haven’t got anywhere.’ (13)

5.2.2 Discounts
While there were examples of tourism providers having difficulty meeting the minimum requirements, there were also examples of some tourism providers adapting buildings and facilities to reach their target market requirements. However a paradox becomes evident; enhancing buildings and facilities to promote inclusivity for people with dementia and other physical disabilities, results in an increase to entry prices to cover the providers additional costs, which then do not meet the expectations of concessionary discounts which some customers are accustomed to, often deterring the target customer base entirely. This is reflected in the following experiences:

Tourism provider: ‘What annoys me about disability, and no particular disability is they expect a reduction on the door but they still expect to have all the facilities in here especially for them. So the ramps and the disabled toilets which cost money to put in. Because I've just altered something around there which I had to put a ramp in, which that was - there was already steps there so I didn't need a ramp. But I had to put a ramp in, and then they still want a discount on the door. How am I going to pay for this? If they want the discount, how am I going to pay for all the extra bits that I need to put in?’ (01)

Tourism provider: ‘There’s a perceptions that it’s bad value for ten minutes, as opposed to great value for an hour. Some people...our group rate would be £3.75 and people resent paying it...This is done with people like you in mind, not exclusively for you, but with people like you in mind. Why don’t you want to use it?’ (14)

5.3 Extra effort

Although there is evidence in general terms that tourism providers need to consider the services they provide for people with dementia more specifically, there were examples where extra (non-cohesive) efforts have been made by some tourism providers to provide a service above and beyond what is required for both people with dementia and people with disabilities. Such considerations were in the areas of; customer care, security, staff training, advertising and promotion and on-going development.

5.4 Customer care

Delivering a level of customer care which aimed to treat customers with dignity and respect regardless of any illness or disability appeared to be a priority for some tourism providers for example:
Tourism provider: *We have to ensure that people are comfortable, feel that they’re in a friendly, accessible area, that we are not judgemental, that we are open and concerned. That we will treat everybody even-handedly.* (08)

5.5 Monitoring and security

Extra security procedures had been implemented by some tourism providers for the safety of customers who may be considered vulnerable. Whilst these measures were not primarily put in place for people with dementia, it demonstrates an understanding of the need for security and monitoring:

Tourism provider: *If they see a guest in a corridor – you know, we have this thing called 15/5; at 15 feet they have to make eye contact and at 5 feet they have to speak to the guest. So if you’ve got a guest who has perhaps lost their way around the hotel, they would never walk past one of my staff without some form of engagement.* (09)

Tourism provider: *‘We radio the gardeners, we radio the rangers, we take the telephone mobile phone number of the person who is the carer, we monitor the loos [toilets], the restaurant, and the shop, and we stay in touch by radio.’* (08)

5.6 Training

The interviews suggest that most tourism providers require employees to attend customer service and Welcome All training, although these sessions do not include dementia specific modules. Of the 20 tourism providers interviewed, two described a course that all employees were required to take (whilst not dementia specific) which recreated situations people with disabilities may encounter, so as to provide an experiential opportunity to promote greater understanding of challenges which may be faced for that particular customer base:

Tourism provider: *Most of the training that the staff are given are with the physical disability side, so they get training on how to guide blind people, people with wheelchairs and disabilities, and getting them on and off trains.* (11)

5.7 Advertising and promotion

In some instances, tourism providers appear to be activity advertising and promoting their companies as suitable for people with disabilities although this is still somewhat in its infancy:
Tourism provider: *Visit Britain, and Visit England. So, they would be the main ones, we also try and promote as well the national accessible scheme.* (05)

5.8 On-going development

Some tourism providers confirmed that they would consider ideas of supporting DFT and developing the necessary skills, understanding, services and facilities required in order to facilitate this, as there was an acknowledgment that they could perhaps do more to promote access to those with dementia:

Tourism provider: ‘Yeah. It’s the sort of thing where I’d be delighted to do it and be very accommodating to a group organiser who’s got a group of folks and spend time with them to create something that was suitable for them and would give them the best kind of day. Absolutely love it.’ (10)

Tourism provider: ‘I’m open to anybody coming up with any suggestions. Can we do anything, I will tailor it. If groups come in I tailor my shows around those groups.’ (01)

A number of tourism providers suggested that establishing partnerships with specialist companies would be appropriate before taking the concept of DFT forward:

Tourism provider: ‘I mean it depends A on the space and B the partnership, because I think one of the things we’re quite keen is to have an on-going partnership.’ (15)

It was evident that the majority of tourism providers interviewed did not aim to meet the needs of people with dementia and their family carers. Rather efforts have been made to address disability in general rather than dementia specifically. It is also evident that a lack of understanding and awareness of dementia by tourism providers creates barriers for people with dementia in accessing tourism.

Whilst most tourism providers aim to meet statutory requirements relating to government legislation and building adaptations, this can have a detrimental effect upon business operational costs as adaptations and facilities are often higher than small businesses can afford. This leads to the question, do governmental pressures to meet targets contribute to nurturing negative associations of people with disabilities?
Experiences of people with dementia and disabilities provide some tourism providers with negative attitudes which are taken into the workplace, creating implicit barriers for people with dementia to access tourism. However, some tourism providers’ experience of dementia have contributed to providing facilities above and beyond government standards but have not met with the popularity they envisaged as customer expectations of discounts and entry fees were not met due to the increase in admission to match operational costs. Nevertheless, there are examples of personal experiences leading to a sympathetic attitude by some tourism providers towards people with dementia. This level of understanding promotes an environment that could be more appealing to people with dementia. There are also examples of some tourism providers making extra efforts surrounding staff training, security, customer care and advertising to activity engage and facilitate access to their services for people with dementia and disabilities. Such actions promote accessible tourism. The idea of taking DFT forward was welcomed by some tourism providers who suggested that more could be done for this particular group. However, most tourism providers had concerns that this concept may be detrimental to the business or would need to be considered carefully so as not to deter other customers. It was suggested that creating partnerships between companies and specialist organisations may be appropriate in taking the idea of dementia friendly tourism forward in the future.

6. Implications: Developing Dementia Friendly Destinations – A Policy Agenda

The findings of this study illustrate that bringing new issues such as dementia into a wider policy debate on the accessible destination, where well-being is a central tenet of the destination ethos is certainly challenging for the one resort examined here. The research indicates that whilst national strategies set out very enviable objectives and outcomes, integrating new perspectives such as dementia into a destination development strategy will be challenging. This is not because operators or policy developers are not supportive of the broad notion. The timing in a UK context has been particularly problematic as the implementation of the disability legislation and the introduction of physical adjustments to buildings and premises has created additional costs for many businesses who are unlikely to wish to suddenly assume a new series of capital costs when the issue of accessibility is raised even if this is not the reality. Interestingly, many initiatives related to dementia for specific sectors of the visitor economy do not necessarily involve major capital cost or major
adaptations; it is the changed perception and training that is critical to understanding both the nature of the issues surrounding people with dementia and their carers taking a holiday. Yet the benefits to those with dementia of promoting access to different tourism venues, perhaps by having specific times/days when carers and those with dementia know that the venue is specifically open to them with staff who will be available to support their use of the venue and enhance their experience of tourism.

According to VisitEngland (2012) to motivate individual businesses to improve accessibility, a web portal to access information, booklets to improve the service needs of clients groups such as those with dementia are vital. Research is also recognised as a core element to develop case studies of best practice which will highlight and provide businesses with examples to champion this area of activity. This needs to be accompanied, as VisitEngland show, by training embedded in a wider philosophy of customer care. In the case of dementia, pilot projects may be one way in which to address this major market segment with a destination such as Bournemouth where dementia is examined in terms of the customer journey and their various touch points with the tourism industry to develop a package of DFT offerings as a starting point en route to the dementia-friendly destination status. It is important that sign posting is present to help guide the person with dementia and their carers from the transport point (car park, bus or train station) to their venue; for toilets to be clearly sign posted; for quiet areas to sit and relax while enjoying refreshments are available. This research has indicated that a range of measures that already exist with Bournemouth Town Centre that could be adapted and trialled for wider use in the visitor economy for developing DFT that are used, for example, if language school students get lost and need to be reunited with their party.

At a destination level this requires forward looking leadership and commitment to support the research and pilot projects towards a DFT status supported by market leading research and market intelligence that can then be used to inform other destinations globally on how to create a DFT destination. In other words, there is a need for policy development, and implementation supported by resources for tourism businesses to maximise their engagement and involvement. By creating these destination examples of best practice, the UK has an opportunity to lead thinking in the field of DFT by enabling, facilitating and promoting accessibility for a growing global problem that is potentially a major restraint on
the leisure behaviour of families and their members after the diagnosis of dementia. Yet as this research shows, this is far from an easy process, with the first step being challenging and negotiating businesses engagement with this issue, changing misconceptions about the reality of dementia and its implications for their offer and facilities.

7. Conclusion

Dementia is a worldwide health problem that is set to grow in significance and scale as aging populations, especially in the developed world, generate a large potential pool of people who may be affected by this condition. At the same time, rising affluence and expectations amongst people within developed nations now recognise that their well-being and the immediate family welfare is a major priority to ensure their personal care needs are met, with a growing policy focus on this by governments. Leisure and tourism behaviour has a major, but largely neglected role, in the well-being of people with dementia and their immediate family/carers in the rising agenda associated with the well-being of an aging and more affluent population who have come to expect greater mobility and leisure consumption in later life. For the destinations able to develop DFT status, they potentially have a major competitive edge by developing repeat visitation if their provision is able to meet needs, particularly if it is targeted at non-peak times when resorts need additional visitors. If destinations are able to provide times when those with dementia and their carers can have more time to enjoy an attraction/tourism service supported by staff who understand their needs and who will give them the attention and time to enjoy their experience there is likely an untapped market for tourism providers to benefit from. Furthermore, leisure and tourism have huge potential beneficial effects for people with dementia as more active lifestyles may help to enhance the lifestyle of those with dementia and their carers by potentially promoting mental, physical and social stimulation which can help to moderate the impact of the dementia. Therefore, if dementia is a growing global issue and tourism and leisure are vital ingredients in the lifestyles of people with dementia and their carers, then this provides market opportunities for destinations and businesses willing to engage with the needs of these groups. At a policy level this is part of the widening participation agenda in the UK associated with creating dementia friendly communities. In a tourism context, this issue aligns with the VisitEngland accessible destination notion, which highlights a number of key challenges. As destinations need to
constantly innovate, adapt and engage with new markets, DFT is one major opportunity and challenge within the wider context of social tourism. There is certainly a well developed academic and practitioner literature on accessible tourism that could be used as a basis to build a wider understanding of dementia can be added to the growing understanding of making destinations accessible to all. DFT may form a compensatory form of tourism market, if visitation can be encouraged at non-peak times so that a more relaxed and personalised visitor experience can be devised. It is likely that a number of pilot projects will help blaze a trail and depending upon the experiences and lessons learned, the DFT concept may be rolled out after it has been road tested and aligned to the differing needs of destinations seeking to grow and adapt their visitor offering so as to realise the benefits of a more socially-driven tourism agenda that can add value for both the visitor and destination.

It is clear that this study has only been based on a limited sample of respondents to scope out and identify the nature of the issues associated with DFT and it highlights the need for more substantial research efforts in this field to more fully understand the real potential of DFT and its implementation. For DFT to be a reality requires engagement with the network of businesses that comprise the tourism industry. For example a hotel that provides a DF service may recommend restaurants and cafes that also offer a dementia friendly service and vice versa. In this way the tourism industry can tap into a new market while supporting those with dementia to continue to live active and healthy lifestyles. Nevertheless, the study highlights a number of wider themes that need to be addressed both within the current paradigm of breaking down barriers to disability, but more specifically in relation to building a wider societal understanding of dementia and how it impacts upon developed countries with their aging populations.

References


http://www.alz.co.uk/research/world-report


Prime Ministers Dementia Challenge (2012). *Delivering Major Improvements in Dementia Care and Research by 2015*. Department of Health


WHO (2012) *Dementia Fact sheet N°362*
http://www.who.int/mediacentre/factsheets/fs362/en/

Table 1: Breakdown of tourism interviews

<table>
<thead>
<tr>
<th>Organisation Type</th>
<th>No. Interviews conducted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retail</td>
<td>7</td>
</tr>
<tr>
<td>Local attractions</td>
<td>3</td>
</tr>
<tr>
<td>Tour operators</td>
<td>3</td>
</tr>
<tr>
<td>Accommodation</td>
<td>2</td>
</tr>
<tr>
<td>Local government</td>
<td>2</td>
</tr>
<tr>
<td>Public transport</td>
<td>2</td>
</tr>
<tr>
<td>Business partnerships</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20</strong></td>
</tr>
</tbody>
</table>