

## **DEMENTIA TOURISM AS AN OPPORTUNITY FOR DESTINATION REJUVENATION: SIMPLY A SUPPLY SIDE OFFER OR A NEED FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS?**

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**Abstract.** *Many tourism destinations worldwide have lost their attractiveness and reached stagnation. In order to enable them to find a way to rejuvenate they need to find new innovative offers and explore new target markets. Recent changes in the population, in particular the aging factor, enable to identify new promising markets, such seniors. Seniors are considered as an important new target market to invest in since they have spending power to travel and they travel for longer time and off-season. Although seniors are an interesting market, they bring with them the effects of ageing, i.e., disability. Among different disability, dementia plays an important role. This made policy makers and businesses starting to be interested in dementia tourism. Some supply led initiatives have already been created, but further insights are needed to understand whether people with dementia and their caregivers are interested in such offers. This paper aims to explore this further. The qualitative findings of this research shows that people with dementia and their caregivers will benefit of such tourism offers, and they are willing to participate in them if extra-care is offered. This shades positive lights on the fact that such an offer could be successful. However, it is important to notice that not every caregiver is positive in making their beloved one participating in such activities, and they won't be willing to participate as well. As a matter of fact, factors such as the level of cognitive impairments, and the level of behavioral impairments influence the possibility to join such activities. The willingness of joining such activities is also influence by the family bond: husbands and wives are more prone to participate than children. This depends as well on the perception of tourism as a beneficial activity by caregivers, and the need of diversion, respite, and enjoyment of time together. If caregivers do not see tourism as something positive for their wellbeing and the one of the beloved one they will not be interested. Last but not least the lifestyle before dementia and past experience of tourism in early stage of dementia influence strongly the willingness to participate. With this in mind the markers should spend time in making sure*

*that this offer will be appealing to their target market before starting an initiative, which although being extremely good in theory, might not be actually needed in the reality.*

**Keywords:** *destination rejuvenation; seniors; dementia friendly tourism; people with dementia; caregivers; enablers for dementia friendly tourism.*

## **Introduction**

For many destinations living the challenge to find ways for rejuvenation, there is an urgent need to innovate their products and identify new targets for tourism development. For them an alternative positioning strategy is needed to deliver superior value to existing and alternative clients (Kotler, Bowen & Makens, 2014). One of the new markets on which to invest is seniors with dementia and their caregivers. The encounter between tourism and dementia creates a niche market that represents an opportunity for rejuvenation (Page, Innis & Cutler, 2014). As it is well known the World population is ageing (UN, 2014), and as a consequence, ageing diseases are as well increasing. Among different ageing disease, the most common one is dementia (60-70% of dementia is due to Alzheimer (WHO, 2012)). Due to dementia people see their cognitive ability deteriorate and their behavioral problems increase, compromising their emotional control, and social behavior (Mace & Robins, 2006). This causes as well caregivers' burnout (Alzheimer Research UK, 2015). In such a scenario it will be important to provide people with dementia and their caregivers, opportunities, among which tourism opportunities, that will allow them to remain active (Page et al., 2014).

Under this circumstance a tourism offer for people with dementia could benefit them and also stakeholders at tourism destination that see in it an important business opportunity (Page et al., 2014). Some governments have already recognized this opportunity and already invested in it (e.g., UK). One of researches on dementia tourism was the one of Page et al., (2014). They looked into the topic of dementia friendly tourism destinations by researching the supply side. Although this effort was extremely important, little has been done into looking at the demand side. The aim of this paper is to enable further understanding into this aspect. It explores the willingness of people with dementia and their caregivers to take part to tourism activities with the aim of giving to policy makers and entrepreneurs a clearer understanding of whether investing in dementia tourism could be convenient.

## **Literature review**

The current tourism scenario is characterized by the existence of some tourism destination that lost their attractiveness as tourism destination due to different reasons. Under these circumstances these destinations are entrapped in the stagnation: they lost their attractiveness and are at a crossroad between finding ways for rejuvenation or abandoning the tourism industry (Baum, 1998). If these destinations are willing to find opportunities for rejuvenation it is needed, according to Faulkner (2002), to identify innovative products and new targets. This will then allow them to redefine its positioning strategy (Kotler et al., 2014) by identifying more appealing value propositions to new markets. Given the recent increase of them, one of the potential new markets explored are the seniors. This paper emphasizes on the likelihood of investing on seniors' tourism by looking on a particular sub-niche of the seniors: seniors with dementia.

Yeoman and Butterfield (2011) underline how nowadays the demographic changes, in particular ageing population, strongly influence the population characteristics, their behavior and preferences. They also create new and attractive trends for tourism development (e.g., senior tourists, and disable tourists). Senior tourism is a growing market (Paxson, 2009, Nimrod, 2008) that, as per WTO (2001) will characterize tourism development for the future. Seniors are seen as the future most important target for tourism destinations and organizations (Huang & Tsai, 2003, Fleischer & Pizam, 2002): if destination are able to grasp this opportunity, as long as the one of disable tourists, they will be able to develop a strong competitive advantage that creates value for a growing target (Alén, Losada & Domínguez, 2012) and themselves. Since seniors have high willingness to travel and holiday for long periods, also off-season (Fernandez-Morales & Mayorga-Toledano, 2008) this ensures a good level of tourism expenses in the destination that might enable destinations to prosper. According to Buhalis, Eichhorn, Michopoulou & Miller (2005) the value for accessible tourism, that includes seniors and disabled people (in 127.5 million of tourists in Europe), is high. It is estimated on average on 124.5 billion€ (Alén et al., 2012). According to Frye (2015) 2 out of 3 of disabled people are over pension age, and 1 out of 3 has some form of cognitive disability such as dementia. More and more seniors and disabled people would like to travel – travel is a fundamental right (Darcy & Buhalis, 2011) – it is important to set conditions to allow people with disabilities, among other dementia, to travel. The creation of universally designed tourism products is the key for this (Darcy & Dickson, 2009). This would also create a stronger connection between social welfare, community (Williams, Rattray & Grimes, 2006, Wu & Cheng, 2008), disabled people, and business outcomes (Sheldon & Tucker, 2005).

Since 2012 dementia has been recognized as a priority of public health (WHO). Every year 7.7 million new cases of dementia are diagnosed, and no cure exists (WHO, 2015). Dementia is defined as a disease of the central nervous system that bring to cognitive impairments due to progressive deterioration of the brain (Calvarese & Lovati, 2014; WHO, 2015). The first symptom associated with dementia is a memory loss, however there are other symptoms that cause the inability of people with dementia to continue living their lives normally. Dementia affects orientation, comprehension, language, and judgment, etc. (WHO, 2015). It is as well accompanied by behavioral symptoms (e.g., depression, anxiety, aggression, apathy, wandering, etc.) that affect people emotional control, and social behavior. Being dementia an increasing issue for many seniors (46.8 million people affected by dementia in 2015 world wide, with 74.7 million forecasted within 2030, and 131.5 million within 2050, and a cost of US\$ 818 billion (WHO, 2015)), affecting negatively their caregivers as well due to burnout, it will be critical to provide opportunities that allow people with dementia to remain active and independent as much as possible, to be engaged in the community. Leisure and tourism is one of these options, that also help to slow down the progress of dementia, and in particular ss able to reduce behavioral problems. These people, in the early stage of the disease, that lasts 7-10 years (WHO, 2012), maintain a sufficient level of physical, cognitive and behavioral abilities to enable them, if assistance is given, to travel and to be involved in tourism activities. Tourism activities, activities in the open air, and physical activities are in fact beneficial for people with dementia, limiting their behavioral and cognitive problems (Dupuis et al., 2012; Genoe, 2010; Zeisel, 2009; Mapes, 2013; McNair, 2013), providing support for caregivers as well. Actually the entire health system will also benefit, since this provides significant saving to the entire health system (Graff et al., 2008). Live well with dementia is possible if adequate support is given to people with dementia and their

caregivers (WHO, 2012). According to the literature it is then possible to conclude that if policy makers and entrepreneurs invest into this niche market, creating tourism opportunities, they might be able to obtain important business outcomes as well, as also underlined by Page et al. (2014).

However, although such a good opportunity is visible, a little has been done in researching the willingness of this target market to participate in tourism activities. This paper provides further insights into it, to provide evidence of the fact that also people with dementia and their caregivers would like to be involved in such practices.

## **Methodology**

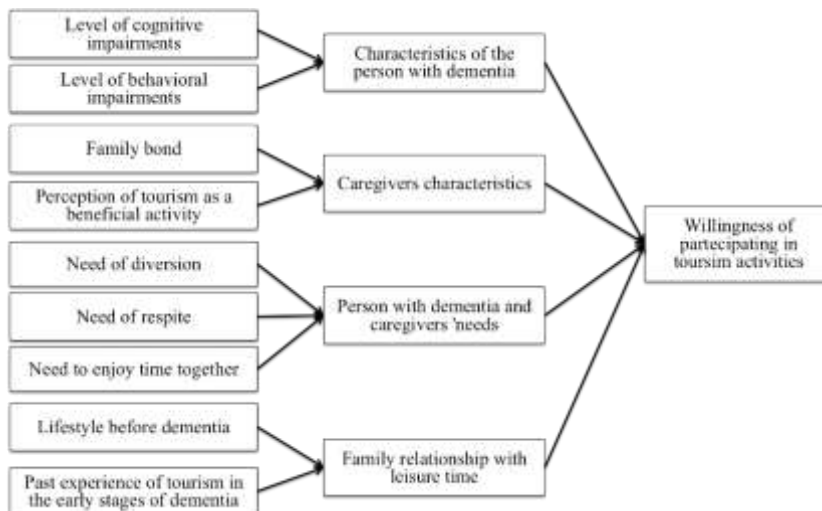
To give further insights into the willingness of the people with dementia and their caregivers to be involved in tourism activities, an exploratory qualitative research was used. This is based on Grounded Theory (Glaser & Strauss, 1967), and Charmaz (2006) approach to Grounded Theory inspired the analysis. Semi-structured interviews were coded and analyzed with the support of NVivo for Mac 11.1.1. Face to face interviews, tape-recorded with the approval of the interviewee, were transcribed verbatim, to avoid recall bias. Non-probability sampling was used to identify the sample of informal caregivers. The total sample size is of 15 caregivers living in in the North of Italy and being either spouses or children of people with dementia. Their age ranges from 40 to 80-year-old; the majority of the people interviewed were females, and the majority of them were assisting people with mild dementia. For this research findings here presented have with significant insights.

## **Results**

The aim of the paper was to understand the willingness of participating in tourism activities of people with dementia and their caregivers, in order to get a clearer understanding of the demand before suggesting policymakers and entrepreneurs to invest in dementia tourism.

Among caregivers there is a positive consensus towards tourism activities. They would like their beloved one to join these activities, and they would like to take part to them as well. In order to be able to make them participate it is important to involve people in activities that they like, trying, whenever possible, to be as much personalized as possible. The essential request is to provide support in dealing with caring for people with dementia in their day-to-day activities when on holiday, and give them care in supporting them during lunch and dinner and when on public transportation.

According to our findings, obtained by analysing interview content through content analysis, there are several factors that influence the willingness of people with dementia and their caregivers of participating in tourism activities (Figure 1). These factors are summarized in the following figure. After the figure further insights are given to explain these factors and their relationship with the willingness of participating in tourism activities.



**Figure 1. Willingness of participating in tourism activities: the model (Authors' Own)**

The degree of willingness to participate in tourism activities depends on the characteristics of the person with dementia, caregivers' characteristics, person with dementia and caregivers' needs and the family relationship with their leisure time.

As it is possible to imagine the cognitive and behavioral characteristics of the person with dementia influence their ability to join tourism activities. Only those people that have maintained sufficient cognitive abilities and do not have severe behavioral problems might be able to join tourism activities. This is a precondition to enable them to enjoy the tourism benefits, showing lower problems related to transportation and to the adaptation to a new environment. People with dementia might join these activities by themselves, but it is very interesting to see that caregivers would like to join as well. As reported by some caregivers interviewed, the tourism offer could offer as well respite opportunities for them without abandoning their beloved one, and it is also an option of respite for people with dementia. This gives an opportunity for both to share happy moments together far from everyday difficulties.

Although it is possible to see enthusiasm behind this opportunity, there are some skeptical caregivers as well. If caregivers see tourism and leisure activities positively there is a higher level of opportunity to see them be willing to participate in tourism activities. If they are not positive, see only barriers, instead it might be difficult to have them be willing to join and have their beloved to join as well. This shows that the perception of the caregiver is essential when it comes to the willingness to participate in tourism activities. The type of behavioral problems that the person with dementia shows influences their perception. The type of family bond that exists between the person with dementia and the caregivers also influences this perception: husbands and wives are more likely to join tourism activities. Another essential aspect to take as well into consideration is the family relationship with leisure (lifestyle, and participation in tourism activities in the beginning of the disease). It is more likely for families to be interested in tourism activities if the family loved tourism and leisure activities before the disease and in the beginning of it.

Representative quotes of the different themes identified in our analysis are summarized in the following table (Table 1). They represent the elements linked to the factors that

influence the willingness of people with dementia and their caregivers to participate in tourism activities.

**Table 1. Representative Quotes Underlying Different Themes – Willingness to join tourism activities (Authors' Own)**

<b>Theme 1: Characteristics of the person with dementia</b>
<p><b>Level of cognitive impairments/ Level of behavioural impairments</b></p> <ul style="list-style-type: none"> <li>- At the beginning my mother was diagnosed with Mild Cognitive Impairment. This allowed us to do more activities. At the moment she has dementia, and her Mini Mental is 15.</li> <li>- Until last year he was able to go outside by his own. In the first years of the disease my father and my mother were tourists. They were travelling in a group, where everybody knew about the disease and understood very well the situation. When the cognitive problems and the behavioural one became too difficult to handle, my parents stopped travelling.</li> <li>- The cognitive impairment is highly visible, but she is still able to walk, she goes for a stroll very often, she might benefit from some further physical exercise: she likes dancing</li> </ul>
<b>Theme 2: Caregivers characteristics</b>
<p><b>Family Bond</b></p> <ul style="list-style-type: none"> <li>- My mother in law used to go on vacation with the husband.</li> <li>- I went on holiday with my mother. We were happy together.</li> <li>- We go walking together, we spend time together</li> </ul> <p><b>Perception of tourism as a beneficial activity</b></p> <ul style="list-style-type: none"> <li>- This is a very interesting idea. It would be lovely to join tourism activities that allow the person with dementia to socialize, and for us to enjoy good time with together, enjoying some respite</li> <li>- Tourism for people with dementia is idyllic. Those that are sick they do not care about tourism. Tourism is for seniors and not for people with dementia.</li> <li>- When she is involved in leisure activities she smiles, although later on she does not remember what just happened</li> <li>- Leisure activities are beneficial, if somebody helps us, especially for lunch and dinner, we could still go for some small trips</li> <li>- If somebody helps us while travelling, this is my main concert, tourism activities could still be beneficial for us</li> </ul>
<b>Theme 3: Person with dementia and caregivers 'needs</b>
<p><b>Need of diversion</b></p> <ul style="list-style-type: none"> <li>- It is important to provide diversion to people with dementia</li> <li>- We hike a lot while we were on holiday. We went as well to the SPA. This helps to break the routine</li> <li>- She likes socializing, this is something she really enjoys: she likes the theatre</li> <li>- He likes to go walking and be in places with people: otherwise he gets bored</li> </ul> <p><b>Need of respite</b></p> <ul style="list-style-type: none"> <li>- Caregivers need some respite.</li> <li>- It is important for both to spend some time by ourselves</li> <li>- I would enjoy see her happy: this will help me as well</li> <li>- I would like to participate in leisure activities as well</li> </ul> <p><b>Need to enjoy time together</b></p> <ul style="list-style-type: none"> <li>- If tourism activities allow me to stay with my wife but also have sometime for myself, it will be great.</li> <li>- We go walking together</li> <li>- We used to travel together</li> </ul>

#### Theme 4: Family relationship with leisure time

##### Lifestyle before dementia

- We were not used to be tourists
- He was not used to spend a lot of time in leisure activities
- She was used to go out, to go to the mountain
- We used to be tourists, nowadays I am not willing to do it anymore, she is too much compromised
- He used to go to work and fishing

##### Past experience of tourism in the early stages of dementia

- My mother and me went to several different destinations as tourists, even after she was diagnosed with dementia.
- My mother in law used to go with the husband on holiday in the beginning of the disease. She went as well last year with her formal caregiver.
- Until last year we used to take the train together and go for short trips to Laveno, Lake Como, etc. Unfortunately, now we cannot go for lunch or dinner in a restaurant, she has eating problems.
- She always liked to be involved in leisure activities, be surrounded by people

#### Discussion and conclusion

This analysis allows us to build further understanding on dementia tourism. It is possible to confirm that there is an interest in this form of tourism and those policy makers and entrepreneurs that will decide to be dementia friendly might be able to succeed. However, it is not possible to assume that people with dementia and their caregivers will be interested in tourism. Integrating dementia into a destination development strategy is an enviable objective, as also stated by Page, et al. (2014), but it is challenging and requires further understanding. Challenges are linked to people with dementia and their caregivers' characteristics, lifestyle and needs. These aspects affect both positively and negatively the willingness of this target market to be involved in tourism activities. Dementia friendly tourism represents an innovative solution for rejuvenation, but it is essential to handle it with care, without assuming that the supply driven initiatives will actually succeed although they are very good in their intentions. Some caregivers in fact won't participate in these activities due to reasons seen before in the result part. This brings us to the conclusion that any business willing to develop such an offer should further research the market needs before investing in such offers. It is as well extremely important to remember that this offer requires adaptation to the existing offer since people with dementia need further support in terms of care. This could be considered as a challenge but at the same time it is an opportunity also in the light of identifying future employment opportunity and new vacancies in the market.

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