TRAVEL INFORMATION NEEDS OF INFORMAL CARERS OF PEOPLE LIVING WITH DEMENTIA

Abstract. Understandings of tourist' contemporary information needs that emphasize spontaneous travel decision-making do not account for the contexts of people with dementia and their carers, for whom travelling requires unique adaptations. Through netnography in four online fora, this paper investigates the hitherto under-researched travel information needs of informal carers of people living with dementia. The qualitative data highlights the breadth of pre-travel information needs and their strong emotional dimension both when carers plan to travel with and without the person for whom they care. The analysis also uncovers the complex nature of travel-related information queries which refer not only to narrow tourism themes but also to health, healthcare and social policy. This exploratory paper concludes with general recommendations for addressing the travel information needs of this globally growing category of people, wherein collaboration across destinations, tourism and hospitality industries, the healthcare sector and other stakeholders may be required.

Keywords: carer, caregiver, dementia, tourism, information needs, information search, netnography.

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1 INTRODUCTION

The way people seek and find travel information has changed profoundly within the past three decades, as technological advancements have transformed the field of tourism and tourist behaviours (Gretzel et al., 2019; Lyu & Hwang, 2015; Pop et al., 2022). The information and decision-making process has become faster, smarter, more dynamic, more integrated in the tourist experience and often perceived as a positive and enjoyable part of modern tourist activities (Xiang & Fesenmaier, 2020). However, these changes are inaccessible to those groups of travellers with different needs from those of the majority. For people with dementia and their unpaid, informal carers – often family members - travelling comes with many unique challenges, as dementia gradually worsens (Dooley et al., 2021; Innes et al., 2016; Karner & Bobbitt-Zeher, 2005; Scott, 2021). Although tourism may benefit wellbeing, their specific needs, including those in travel information, have been generally overlooked both in tourism industry and tourism scholarship (Bauer, 2019; Connell & Page, 2019; Wen et al., 2022).

Dementia is a neurodegenerative disorder, caused by various diseases, progressively impacting people's cognitive abilities, perceptions, behaviour, and their ability to perform everyday tasks, meaning they gradually become more dependent on their carers, who in turn experience their own limitations in life (Jalbert et al., 2008; James & Bennett, 2019; Schulz & Martire, 2004; WHO, 2022). . Research indicates that whilst leisure activities, such as tourism, remain inaccessible to carers, it can also improve quality of life and wellbeing of carers, providing much needed respite (Connell & Page, 2019; Hansen, 2022; Wen et al., 2022). Some carers travel with the person with dementia, others without or even both. For many, tourism offers an escape; a response to the deteriorating mental and physical health conditions as well as increasing social isolation and exclusion that comes with provision of care (Motta-Ochoa et al., 2021; Ory et al., 1999; Prevo et al., 2018).

Carers seek information which would address their changed needs and situations. Due to the individual and dynamic nature of dementia, information needs are complex – people may require information not only about available facilities, services and environments but also about the condition itself as it develops (Soong et al., 2020). Personal and cultural context also shape information needs, which are not only of cognitive but also affective nature (Harland & Bath, 2008; Motta-Ochoa et al., 2021). While general information needs and information-seeking behaviours of people with dementia and their carers have been studied before (Harland et al., 2017; Harland & Bath, 2008; Soong et al., 2020; Steiner et al., 2016), research on the specific information needs in the context of tourism remains limited.

By 2030 the amount of hours of informal care for people with dementia globally will correspond to approximately 65 million full-time workers (Wimo et al., 2018). As the number of people affected by dementia is expected to "explode", a better understanding of their needs is urgently required (Bauer, 2019; Connell & Page, 2019; Wen et al., 2022). In this article, we address this gap by employing netnography in four different online fora, where informal carers for people with dementia communicate about their tourism-related information needs. We explore and discuss the travel information needs of carers both when travelling with and without the person for whom they care. Before providing more details on the methodology of our research as well as presenting and discussing our findings, we summarize and synthesize scholarly literature on the two focal theoretical aspects of our research – the context of caring for someone living with dementia and information search behaviours of tourists.

2 LITERATURE REVIEW

2.1 What does it mean to be an informal carer for a person living with dementia

The clinical symptoms of dementia gradually make it difficult for people living with this condition to engage in various daily activities, meaning care and assistance is required, often provided by informal carers, such as family members (Schulz & Martire, 2004; Skinner et al., 2021). .

Informal care comprises various activities, including domestic and personal care tasks such as assistance with dressing, feeding, housework, taking medications and other treatments, as well as social tasks such as facilitation of contacts between the person living with dementia and healthcare workers and other social groups, e.g. friends and other family members (Garcia-Ptacek et al., 2019; Skinner et al., 2021). Although these tasks in themselves are often unpleasant, stressful and physically demanding, observing and coping with the decline of a person with dementia have been recognized as the most emotionally demanding and exhausting part of care (Adams, 2006; Cheng, 2017; Karner & Bobbitt-Zeher, 2005; Skinner et al., 2021).

Providing care for a person with dementia can result in so-called caregiver burden or caregiver distress, associated with lower levels of perceived quality of life, poorer mental health, depression, mental as well as physiological and functional disorders (Bremer et al., 2015; Cheng, 2017; Fonareva & Oken, 2014; Joling et al., 2015; Karg et al., 2018; Pinquart & Sörensen, 2003; Stall et al., 2019).

Restrictions in leisure commonly brought up in the context of coping with caring, as care is typically performed by one carer (REFERENCE NEEDED). It is estimated that a person with dementia on average receives 6 hours of care per day, implying a substantial deduction in the available free time for other activities, such as leisure (Wimo et al., 2018).. Apart from the amount of time, it is the satisfaction with leisure that has been shown to be crucial in shaping the outcomes of caring, as not all leisure is considered beneficial (Lee et al., 2007; Romero-Moreno et al., 2016; Schüz et al., 2015).

Where carers have been used to travel as a meaningful leisure activity, restrictions in travel due to provision of care may significantly harm their wellbeing. Gladwell and Bedini (2004) discovered carers expressed “a particular sense of loss for leisure travel,” and saw their travel possibilities impeded by physical, social and emotional barriers –when travelling with/without the person with dementia. Travelling as a carer comes with additional considerations, many of which are new or previously unknown to the carers themselves, resulting in additional stress and anxiety (Bauer, 2019; Peterson et al., 2022). Yet, Bauer (2019) highlighted the lack of research on carers for people with dementia as a travel population. As such, the next section of the literature review summarises the latest research on travel information search behaviours of the general population.

2.2 Travel information search in the general population

Information-related activities are considered a key element of decision-making, thus a crucial component of travel behaviour (Jacobsen & Munar, 2012; Xiang & Fesenmaier, 2020; Zins, 2007). Travel information search or information-seeking refers to people actively collecting, processing and integrating information for making a choice or reducing uncertainty related to travel (Fodness & Murray, 1997; Xiang & Fesenmaier, 2020; Zarezadeh et al., 2019). Apart from influencing the decisions themselves, information search is also seen as affecting the creation of expectations of the travellers, thereby shaping travel behaviour in multiple ways (Xiang et al., 2015). Research indicates that tourists’ engagement with information is rather complex, and its common patterns develop dynamically alongside changes in the tourism industry and the field of information and communication technologies (Gretzel et al., 2019; Xiang & Fesenmaier, 2020).

Research on travel information-seeking takes a variation of a cost/benefit perspective. Costs are typically associated with information seeking itself and can include monetary costs, the time spent on looking for and processing information as well as other forms of effort; benefits mostly refer to the travel experiences and can take form of monetary benefits (i.e. lower expenses) or experiential benefits (Gursoy & McCleary, 2004; Vogt & Fesenmaier, 1998; Xiang & Fesenmaier, 2020; Zins, 2007). The reduction of trip-related uncertainty is another sought benefit (Fodness & Murray, 1997). As information search is becoming more integrated into the travel experience (Xiang & Fesenmaier, 2020), the cost/benefit perspective is losing in its prominence. However, the continued focus on making information search increasingly convenient reiterates the general assumption of information-seeking being an effortful instrument for enabling pleasurable and frustration-free travel.

Conceptualized as a process unfolding over time (Fodness & Murray, 1997; Xiang & Fesenmaier, 2020), travel information search is typically mapped out along all phases of tourist behaviour, including increasingly in-situ information search (Bieger & Laesser, 2004; Gretzel et al., 2019; Xiang & Fesenmaier, 2020). These developments are enabled by the spread of smartphones, mobile internet coverage, and the increasing availability of dynamic information, allowing for spontaneous information needs. Differentiating between the phases of travel behaviour is practical for identifying and grouping the most salient decisions, for which tourists are searching for information. In tourism, these decisions are rather diverse and may include the choice of destination, route and schedule, carrier, budget, accommodation, attractions, restaurants etc. (Xiang & Fesenmaier, 2020).

There is also a variety of information sources that tourists use. Developments around social media and online communities made information search particularly fluid, flexible and fragmented (Choe et al., 2017; Xiang et al., 2015; Xiang & Fesenmaier, 2020), as these tools cut through the dichotomy of personal (e.g. friends, other fellow travellers) and external and commercial travel information sources.

While certain elements, such as time, types of decisions and information sources are common elements of travel information search, the process itself is very diverse across different tourists, influenced by gender, income, age and culture etc. (Gretzel et al., 2019; Zarezadeh et al., 2019; Zins, 2007). The context of being a carer for a person with dementia inevitably affects one's travel information search and one's travel information needs specifically. We thus continue by explicating the methodology we have employed in this paper to explore this issue.

3 METHODOLOGY

This interpretive piece of research explores the information needs of carers of people with dementia in regards to tourism. We employed netnography – a method for studying online communities through investigating "online traces" of their thoughts, feelings and actions (Kozinets, 2020). Similar to ethnography, netnography enables the investigation of contemporary social issues and behaviours, but in an online context (Lund et al., 2018). This method was chosen due to the tourism literature's suggestion most of today's travel information search takes place online (Gretzel et al., 2019; Xiang & Fesenmaier, 2020; Xiang & Gretzel, 2010).. Netnography provides an unobtrusive way of reaching the relatively large but spatially scattered population of carers of people with dementia with the possibility of retaining their anonymity. This was particularly important, given that dementia and caring for someone with dementia are commonly associated with shortage of time and social stigma (Cohen et al., 2014; Herrmann et al., 2018; Nguyen & Li, 2020). Second, netnography enabled us to "meet" carers in places "where they already are" (Langer & Beckman, 2005), which had the advantage of observing the carers' travel information search in one of its natural settings.

We conducted our research in online spaces where the carers are likely to communicate their travel information needs. Based on an exploratory search of relevant online fora, we selected four of them – the travel forum on *Tripadvisor* (https://www.tripadvisor.com/ForumHome) – the world's largest online travel platform (Tripadvisor, 2022), *Reddit* (https://www.reddit.com) – the self-proclaimed "front page of the Internet" and one of the world's most popular websites (Amaya et al., 2021), *Dementia Talking Point* (https://forum.alzheimers.org.uk) – the online message board of the UK Alzheimer Society and finally *ALZ Connected* (https://www.alzconnected.org/default.aspx) – the online message board of the US Alzheimer's Association. The intention was to explore diversity within different online communities. Users of Tripadvisor are primarily united by the theme of travel, the *Dementia Talking Point and ALZ Connected* are both online communities of people with dementia and carers for people living with dementia, while the millions of Reddit users communicate in thousands of diversely themed "subreddits" – pages dedicated to a given topic. In our research, we only considered posts on these platforms written in English, and we do acknowledge the cultural biases this linguistic restriction causes.

We resorted to passive netnography, meaning we did not engage in interactions with the users, observing the communications covertly. All posts and responses to them on the four chosen platforms were posted publicly and under pseudonyms (i.e. usernames). Practically, the netnography was performed by the first two authors of this article, where one of the authors conducted it on Tripadvisor and Reddit, while the other collected and ordered data from *Dementia*

Talking Point and ALZ Connected. Data was analysed through thematic analysis collaboratively by all authors. To narrow down content in the otherwise extensive amounts of material on each of the platforms, certain keywords were searched: in Tripadvisor Forum – “dementia” and “Alzheimers”, in Reddit – “dementia” and “Alzheimers” in the “r/travel” subreddit and “travel”, “trip”, “vacation”, “holiday” in the “r/dementia” and “r/Alzheimers” subreddits, whilst “travelling with dementia”, “holiday” and “vacation” were used in *Dementia Talking Point and ALZ* Connected. Considering the amounts of found materials, only Tripadvisor, *Dementia Talking Point and ALZ Connected* threads posted from 2019 onwards were visited, while all found threads on Reddit were observed, some of which were more than 10 years old. Where mentions of dementia were out of context, these threads were not included in the analysis.

The investigative part of the netnography took place in two forms. The authors kept an extensive journal capturing their general thoughts and impressions from observations. At the same time, we used the *Hypothes.is* tool for the initial round of open, inductive coding, informed by the literature review. *Hypothes.is* is a free annotation tool, which we used to highlight and annotate elements of webpages and sharing them with each other, to capture the internet address (URL) of the thread, the text passages of interest, add notes and tags (as codes). Overall, 21 threads were coded in Tripadvisor, 49 in Reddit, 20 in *Dementia Talking Point* and 11 in *ALZ Connected.* Consequently, the captured data were systematized in a spreadsheet, upon which a second round of individual coding was performed. Following this, we discussed our codes and initial ideas of themes collaboratively to arrive at the final list of themes, which we dwell into in the next section of the paper.

4 FINDINGS

We present our findings by discussing the carers’ thoughts and considerations separately in two situations. In the first one, carers consider travelling together with the person for whom they care. In the second situation, plan to travel without the person for whom they care joining them..

4.1. Carers travelling with the person for whom they care

4.1.1 To travel or not to travel. For many carers the notion of traveling with someone with dementia goes beyond the usual idea of a vacation, with some questioning whether travelling is a good idea at all. Concerns exist over whether the potential detrimental effects outweigh the potential benefits, thus presenting a dilemma. Seemingly, the uncertainty leads to fear over possible outcomes regarding the negative impact of travelling on the person with dementia and the difficulties of travelling together. Thus, carers seek the experiences of others, illustrating a lack of knowledge. Yet, the data suggests an expectation that unpleasant things are unavoidable, especially if consequences of dementia are prominent in everyday life (e.g. *“I’m terrified […] that he is going to get confused and aggressive”,* a user on Reddit). Fear and nervousness over the uncertainties can turn to helplessness and restlessness, as one ALZ Connected user puts it, *“One day dementia is likely to spoil your trips just as it spoils everything else.”* Seemingly, carers fear not *if* dementia will spoil travelling, but *when* it will.

Despite the challenges, carers also consider the advantages of travel, including respite, “checking off bucket list items” and fear-of-missing-out . Yet, as dementia progresses very quickly the situation can change between deciding to travel and actual travel. This places additional pressures on carers to make quick decisions, and potentially even moving travel plans. The data indicates carers prioritise the condition of the person with dementia, as opposed to the facilities and services available for travel at the point of purchase.

4.1.2 Destination and activities. One of the most common queries refers to destinations and activities, presenting rather complex decisions. A key consideration is the personal preferences. Travelling with someone with dementia is often seen as a last vacation, meaning pressure exists on making the trip special, with one user expressing a desire to *"bring some light back to his [father-in-law's] eyes"*. Destination choice often revolve around reliving past moments and "taking a trip down memory lane" to induce positive memories.

Importantly, the itinerary should be interesting for everyone travelling. Accordingly, some levels of flexibility and diversity are required in the plan. Cities provide more options for activities catering to diverse interests and audiences, yet carers seek to avoid these destinations, searching instead for "calm", "stress-free", "relaxing" and "regenerative" activities. Paradoxically, the activities should be "active", "stimulating" and "engaging,", resulting in a conundrum. Additionally, people with dementia tend to be of older age, and often co-morbid.

Practical considerations include proximity to home and short duration of travel, with a desire for destinations near by.. Avoiding air transport seemed preferred, considered too stressful and limiting for persons with dementia. However, due to ageing, driving a car may not be an option either. As such, some carers are willing to use the services of specialized tour organizers, although these appear limited..

4.1.3 Mobility and transport. Transport to the destination is commonly seen as the most stressful and problematic element of travel, with the conditions relating to transport often defining destination choice or indeed the decision to travel or not. Where air transport may be unavoidable, carers seek information to make the journey simpler, more comfortable and alleviating stresses. This would imply having fewer connections and using available support services at airports and airlines. The type and level of available services appears unclear to carers, as most airports and airlines address all disabilities under one umbrella, with dementia disregarded. Indeed, the data revealed that users were often concerned over the sheer size, unfamiliar environments and structured nature of airports and cruise ships, whilst the restrictive nature and smaller size of airplane cabins were noted as stress inducing to the person with dementia due to the inability to leave and thus difficult to manage by the carer. As such, carers are uncertain as to what they can expect (or demand) from transport providers. The issue of communicating dementia to staff and other passengers is thus critical.

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4.1.4 Communication. As dementia is considered a hidden disability and therefore does not have the same widely recognized visible markers like other disabilities (e.g. wheelchair, white cane), a challenge arises over communicating the disability – both to relevant staff members and the surrounding public. On the one hand, carers would like to communicate this fact to explain or excuse the behaviour of the person with dementia that people may find inappropriate in certain situations. On the other hand, communicating this information is necessary for receiving the necessary assistance. One important consideration however is to maintain the dignity of the person with dementia and thus to keep such communication discreet and possibly unnoticeable for the person with dementia. The idea of "sunflower lanyards" – a UK-based global initiative - discreetly signifying one has a hidden disability was discussed and praised by the forum users, uncertainty remained on how broadly these lanyards are accepted and recognized.

4.1.5 The (not so) mundane. Carers are concerned about situations occurring in unfamiliar contexts, where their skills or experiences of caring might be insufficient. Carers thus inquire about tips on keeping a person with dementia safe during a vacation, fearing that the person gets lost in an unknown environment. Accordingly users enquired about how to keep track of the person with dementia, with various tracking devices recommended in response. For example, a *Dementia Talking Point* user recommended *"getting an AirTag for keys or on a lanyard. It helps to locate things/ him"*.

Another critical consideration, and potential barrier, is appropriate travel insurance. As many insurance providers do not cover for dementia as a pre-existing condition, carers seek viable alternatives, with costs proving a considerable barrier, according to users on *Dementia Talking Point*. Some carers also search for temporary care or support services for persons with dementia at the destination enabling the carers to have a rest from caregiving during the vacation without jeopardizing the safety of the person with dementia.

4.1.6 Connecting with everyday life. While travelling usually provides a break from everyday life, the symptoms of dementia make it difficult to adjust to new environments, new conditions, new timings, etc. Therefore, many carers are concerned about how they can soothe such adjustment during travel and upon return home. These concerns are not without merit, as illustrated by an ALZ Connected user: *"The safe and familiar routines we have at home faded away and the new environment provided new challenges for both of us"*. Another *Dementia Talking Point* user commented: *"The trouble with holidays is that the person with dementia is often much worse in an unfamiliar environment that they would be at home or on more familiar territory"*. The carers' questions relate to ways of maintaining the usual routines, picking flight options aligning with usual daily rhythms, and tips for coping with returning home.

4.2. Carers travelling without the person for whom they care

4.2.1 To travel or not to travel. The dilemma of whether to travel or not is also present in situations where the carer considers travelling without the person with dementia. Vacations are seen as opportunities of respite, to rest and relax, thereby improving quality of life of the carer. Yet, the decision is often wrought with feelings of guilt, resentment and worry. The netnographies pointed to two aspects of this issue, around practicalities and emotions.

"I've been wrecked with guilt [...] while I took my family on vacation, guilt over not spending more time with him" wrote one Reddit user, illustrating the guilt and unease that many carers feel when going off on a holiday. Simultaneously, users were often in need of confirmation from others that travelling without the person with dementia was indeed acceptable : *"I guess I hope someone will just tell me it's ok to go on vacation"* (an ALZ Connected user).

4.2.2 How to make space and time to travel. Even when convinced to travel, the practicallities of doing so were unclear. Due to the increasing prevalence of cases of dementia, more diverse population groups are affected by caregiving, with a common theme aroundsome carers in the early stages of adulthood feeling "trapped" and thus resentful as a result. One user commented: "*When do I get to live my life? By the time my parents were my age, both had travelled around the world and were well into their careers?"*. People may have a strong desire to travel, but may not have the means – time-wise or financially – to cover for both caregiving and leisure. Therefore, there is an increasing need for information on social insurance schemes or other frames that allow carers to travel. Another, less obvious side of this issue is the availability of information on last minute travel possibilities, when an unexpected break from caregiving occurs, such as it happened for a

Tripadvisor user, whose granddaughter volunteered to take care of her great-grandmother for a short period of time.

4.2.3 Temporary care. Possibilities for temporary care whilst away on vacation is the most sought-after piece of information, according to our data. Depending on the condition of the person with dementia, there might be a need for only occasional visits by someone to check-upon the person with dementia or a placement in a specialized facility might be required. Either way, difficulties are expected And some carers thus seek advice on which information should be provided to those providing temporary care,.

Crucially, ease of mind, enabled by a trust in temporary care, is important for the wellbeing of carers on vacation. A Reddit user, for example, emphasized how, *"it is so relaxing [...] knowing that everyone around is trained enough [...] and can act appropriately".* Nevertheless, carers fear the quality of care delivered whilst away can result in detrimental impacts on the carer during and after the vacation and may aggravate the condition of the person with dementia. One user uncovered the horrific state of care delivered and reflected: *"All the respite and the relaxation of the few days away feels for naught"*

5 DISCUSSION AND RECOMMENDATIONS

Netnography allowed us to observe the specific travel information needs of carers for people with dementia thereby developing a wider understanding of their information search, an essential part of travel behaviour (Jacobsen & Munar, 2012). Throughout, the travel-related queries overlapped with medical and health-related matters, legal matters, practical everyday matters, moral and social matters, thus indicating the breadth of needs that the tourism industry needs to be aware of when catering to this group of travellers. The mere amount of posts and questions and the carers' reliance on peer-to-peer communication suggest that this information is currently inaccessible; echoeing the common recognition of information access as a barrier for people with disabilities (Fennell & Garrod, 2022). Healthcare professionals and health-related resources are often seen as possible sources of such information, but our research confirms that their capacities in providing relevant, nuanced information are insufficient; carers' needs are generally overlooked beyond the clinical needs of persons with dementia (Bauer, 2019; Soong et al., 2020).

Our research also suggests carers are uncomfortable inquiring about travel-related information from people with little knowledge of caring. This became obvious from comparing the conversations between the four different platforms, as users fitted their messages and queries within the thematic positionings of each of the online communities. Notably, responses on TripAdvisor were less supportive and sensitive to the complexities of dementia, whereas users of Reddit, ALZ Connected and Dementia Talking Point fora, users posted supportive, detailed and personal stories.

Importantly, users on all platforms were seeking personal experiences of other users rather than simple directions to available resources as these were considered more authentic and trustworthy. The fora on the UK's and US's Alzheimer Society websites stood out with numerous rich and thick descriptions of users' past travel experiences, which makes these platforms useful sources of information for other carers. Unfortunately, this latent information is likely hidden to those who do not engage with the fora as it is not prominent in search engines and likely hidden by the abundant Internet-usage of terms "dementia" and "Alzheimer" that do not refer to these conditions directly.

Key to our research is the emotional valence that comes with information search, most notably the worry and guilt carers experience when travelling with or without the person with dementia. The data suggests that information needs are in fact rather complex. One plausible explanation is that the everyday contexts of carers clash with the way tourism is presented and organized. Travelling is typically considered a joyful experience. Yet, our data reveals travelling also includes various obstacles and uncertainties beginning long before the vacation starts, including worry, guilt, resentment etc..

As such, carers are forced to engage in extensive and elaborate planning, which seemingly leaves little room for spontaneous and *in-situ* decisions, which is in contrast to developments in mainstream travel information search behaviour, where tourists are seen as thriving on spontaneity (Gretzel et al., 2019; Xiang & Fesenmaier, 2020). Carers address their anxieties by making sure all details and options for both the journey to/from and within the destination are established before departure. Travelling without the person with dementia might offer a break from caring duties and be a way of dealing with caregiver burden (Bauer, 2019). However, extensive planning is still required and the journey is still wrought with feelings of guilt and worry. Thus, whether travelling with or without a person with dementia, the traveller still has special needs..

Despite serious challenges, carers remain motivated to engage in tourism activities. Travel is important, offering“last chance tourism” with their loved ones, trips down memory lane, checking off bucket lists, and creating shared memories, and bringing respite from caring and improving quality of life (Connell & Page, 2019; Hansen, 2022). In Table 1, we provide a schematic overview of the key issues, we identified in our research and suggestions for managerial policies and actions that can turn the informational barriers into opportunities in tourism.

Table 1. Key issues identified in the research and suggestions for managerial policies and actions

Key issues	**Managerial implications in tourism**
Carers lacking information on travel possibilities when performing full-time care.	It is in the interest of travel-related entities to provide information on social tourism possibilities, social support programmes.
Carers being uncertain regarding the benefits and dangers of their travel for the person with dementia for whom they care	Service providers and dementia organizations (e.g. Alzheimer Societies) should collaborate with healthcare professionals on developing general guidelines on travelling for carers, adapted to the national and cultural context of the carers.
Carers being uncertain regarding available facilities and services for themselves as well as the person with dementia for whom they care.	Destinations and service providers should explicitly communicate the existence of dementia-friendly services, facilities and resources. Where dementia-friendly services or facilities are not available, such absence should be explicitly communicated.
Carers lacking knowledge on travel itineraries and activities for travel parties that include people with dementia	Destinations and service providers should develop itineraries containing diverse activities , where distances between destinations are short and do not require public transport, .
Carers desiring to hear stories and experiences of other carers.	Destinations, service providers and dementia organizations should communicate testimonials from past travellers who are carers or persons with dementia, making them accessible for wider audiences.

Carers desiring to receive custom recommendations for their own context.	Service providers and dementia organizations may direct carers to resources where carers can feel comfortable to share details of their personal context and ask for peer recommendations (such as online fora)
Carers feeling a wide range emotions throughout information search.	Destinations, service providers and dementia organizations can use rhetorical tools in the communications to acknowledge the emotional challenges of carers planning for travel and help them gain confidence through the information-search process.

6 CONCLUSIONS

In this research, we conducted netnography in four online fora to explore the travel information needs of carers for people living with dementia. To our best knowledge, this is the first published attempt to address the special information needs of carers in a travel context in a systematic way. This paper not only deepens understandings of the interrelations between dementia and tourism, but also expand the perceptions of what it means to be a tourist by enumerating the often unpleasant aspects of being a carer-tourist. Most notably, a carer-tourist requires much more planning prior to a trip, has little room for spontaneous and *in situ* decisions or information search *en route,* and their travel information search is accompanied by strong emotional journey that in itself can negatively affect the wellbeing of the carer. Based on our analysis, we provide a list of general recommendations for improving information provision relevant for carers, who would like to engage in tourism.

The challenges faced by carers of people with dementia are complex. Travel-related information needs are not bounded by offerings of destinations, the tourism and hospitality industries, but also touch upon issues of health, healthcare and social policy. This means that for improving information provision, tourism businesses and destinations have to collaborate with other stakeholders, such as healthcare professionals, public health bodies, social workers, government agencies as well as organizations that represent the interests of carers and persons living with dementia. Such collaboration is even more crucial, considering that some of carers' information search is directed to finding facilities and services that may not even exist. Crucially, the growing number of people with dementia and other demographic changes in our societies leads to an increasing number of younger informal carers lacking the financial means or social capital required for traveling, effectively making tourism inaccessible to this demographic, with implications on their mental and physical health. This is a societal problem and our research highlights the need for social tourism options for informal carers to be developed.

This paper's empirical findings should be considered through the prism of limitations of our research approach, pointing toward future opportunities. While netnography provided us with a comprehensive and unobtrusive way of exploring the information needs of carers of people with dementia, it restricted our ability in assessing the information needs of those carers that do not use the online resources we explored or do not actively post in them. Evidently, the key points identified in our research may not only need further evaluation but possible expansion through a more active involvement of carers in future research. Another limitation is that our exploration of information needs took place from the standpoint of identifying gaps in information provision. As a result, we do not capture the carers' existing behaviour beyond the four online communities. It is notworthy that despite the challenges and difficulties in finding some information, many carers are resourceful and effective in searching, finding and co-creating information with others.

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