

BARRIERS TO PARTICIPATION IN TOURISM LINKED RESPITE CARE
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ABSTRACT

Successive interventions designed to curb the spread of COVID-19 have all served to exacerbate the demands placed upon informal carers, a population indispensable to health care systems. The need for breaks from caring has never been so pronounced. This paper adopts, and extends, the theory of hierarchical leisure constraints to better understand barriers to tourism respite participation. Lived experiences are collected via story-telling techniques (n=157) from carers taking trips of one night or more away during times of palliative and end-of-life care. Three cross-cutting constraints are emergent in the data: *awareness (knowing)*; *access (doing)*; and *anxiety (feeling)*. Negotiation strategies are suggested, hierarchical implications questioned and the opportunity to explore a temporal dimension to tourism constraints in future research signalled.

Keywords: informal carers; hospices; ageing population; Trajectory Touchpoint Technique; theory of hierarchical leisure constraints; temporality

1.0 INTRODUCTION

Public health is defined by the World Health Organisation as ‘the art and science of preventing disease, prolonging life and promoting health through the organised efforts of society’ (Acheson, 1988, p. 432). It refers to interventions designed to prevent disease, promote health and prolong life expectancy. Three strategies form the core of associated interventions: *prevention* aimed at encouraging healthier lifestyles often targeted at health inequalities; *protection* linked to surveillance and monitoring, currently exemplified by the work linked to COVID-19 and the associated vaccination programme; and *promotion*, associated with health education and specifically commissioned services (Royal College of Nursing, 2021). Successive policy documents have consistently identified a number of agencies, operating at both state and local levels, that contribute to the public health agenda. These most often include: healthcare providers; public safety agencies; human service and charity organisations; education and youth development organisations; recreation and arts-related organisations; economic and philanthropic organisations; environmental agencies and organisations (World Health Organisation, 2021). Nowhere in this list, or others associated with it, does the tourism sector gain any explicit recognition. This paper challenges this oversight. It draws upon empirical data linked to respite care to expose multiple barriers to participation which exist concluding that by negotiating through these barriers, there is an important opportunity for tourism to make a pivotal contribution to the public health agenda.

Respite care, a term commonly associated with the temporary relief of continuous care responsibilities, is most often positioned as a service where the care recipient receives periods of alternative care to allow caregivers to receive planned breaks from the responsibilities of caring (Scharlach & Frenzel, 1986). Whilst the notion of enjoying planned breaks sits well within the tourism landscape, the recognition and examination of any relationship between respite care and tourism has received only scant coverage thus far.

Consequentially it represents an area of considerable uncertainty, unmet need, and missed opportunities. Examples of extant research include lost leisure (Gladwell & Bedini, 2004), senior carers and cancer carers (Hunter-Jones, 2010), caring for a child with Autistic Spectrum Disorder, or Attention Deficit, Hyperactivity Disorder (Thompson & Emira, 2011), or a terminally ill child (Hunter-Jones et al., 2020) and medical tourism (Holda, 2019). At a time of particular uncertainty in the tourism sector, alongside increasing demands upon the caring population (Willner et al., 2020), better understanding the needs of a growing population (Family Caregiver Alliance, 2016) offers both societal and economic opportunities.

This paper is interested particularly in informal carers, a population estimated to be in the region of 6.5 million in the United Kingdom pre-pandemic (Carers UK, 2019). Even before COVID-19, informal carers were the bedrock of society providing unpaid care to older, dependent and/or terminally ill persons where a pre-existing social relationship exists. Informal carers consequently often include a spouse, parent, child, relative, friend, neighbour, or other non-kin relation (Carers UK, 2019). From the earliest writings on family and informal care, carers have expressed a need to be temporarily relieved from the demands that providing continuous care can impose (Zarit et al., 1998). Respite care is the vehicle most commonly deployed. There is an array of literature highlighting the benefits of respite to patient and carer welfare, especially in the fields of functional and developmental disabilities (Abelson, 1999), frail ageing (Shaw et al., 2009) and chronic illnesses such as dementia and Alzheimer's disease (Neville et al., 2015).

Despite this, the needs of informal carers remain unmet and a contributor to the worsening of inequalities emerging as a consequence of COVID-19 (Bourquin et al., 2020). Successive interventions designed to curb the spread of COVID-19, be it lockdowns, enhanced regulatory systems, limiting social contact, have all served to exacerbate the demands placed upon informal carers. Familial support has been compromised. Support from external agencies, care homes for instance, at times, removed entirely. The consequences of this are potentially profound. As Willner et al., (2020, p. 1523) argue 'the measures implemented to manage the COVID-19 pandemic have been shown to impair mental health. This problem is likely to be exacerbated for carers'. The need for respite care has never been so pronounced. Consequently, the underlying research question at the heart of this paper is, in an evolving COVID-19 landscape, how might the tourism industry, an industry capable of accommodating short breaks, reach out to a hitherto under-appreciated market and better support unmet respite care needs?

To answer this question there is a pressing need to better understand the term respite care along with the barriers which exist to carer participation. Drawing upon the theory of hierarchical leisure constraints (Crawford & Godbey, 1987; Crawford et al., 1991; Jackson et al., 1993), this paper utilises a specific healthcare context, palliative and end-of-life care, with a longstanding history of respite care offerings, to gain a more detailed understanding of which constraints exist in respite participation and which negotiation strategies are deployed, or could be deployed, to negotiate these constraints. It focuses upon a particular carer population, adult carers informally supporting their family and friends transitioning through the final months of their lives. It adopts an innovative, purposefully designed story-

telling methodology, the Trajectory Touchpoint Technique (Sudbury-Riley et al., 2020), grounded in service design literature, to empirically capture caregiver experiences of respite care (n=157). The multiple barriers to participation exposed lead the researchers to identify and conclude on the lessons and practical opportunities these findings present to tourism destinations and tourism businesses located within them. Whilst the findings are important in aiding our understanding of respite care per se, the contribution of the work goes beyond this. It seeks to bridge the gap between tourism and public health research, positioning tourism as a sector capable of delivering important health enhancing interventions at a time of critical need. It also provides two important theoretical extensions to our understanding of the theory of hierarchical leisure constraints. It both questions hierarchical arguments reached in earlier research and also adds a temporal question to our understanding of tourism constraints.

2.0 LITERATURE REVIEW

2.1 Respite Care

Even with the emergence of COVID-19, advances in healthcare, coupled with an ageing population, have prompted the significant rise in people living longer and with more complex and co-morbid needs (van Excel et al., 2008). Socio-cultural trends emerging in response to these patterns include 'ageing in place' where the preferred setting to age, and be cared for, is in the home (Sixsmith & Sixsmith, 2008, p. 219). This is supported in the United Kingdom for instance through government policies and investment which aim to support five extra healthy independent years of life at home. The associated responsibility for enabling this preference falls into the hands of the informal sector and the care that is provided by informal carers (Carers UK, 2019). This responsibility is not a new phenomenon (Zarit et al., 1998).

Similarly, the need for breaks from caring, respite, has been well documented in established writings on family-based caregiving. Here, whilst there are a number of cases evident whereby carers have expressed feelings of satisfaction and reward from their caring role (Kramer, 1997), it is more common for caregiver experiences of stress and demand to be longer-lived (McNally et al., 1999). Stress patterns also differ, accentuated in times of terminal illness. In a study by Morasso, et al., (2008), 25% of family caregivers experienced emotional suffering as a direct result of impending patient death and fears regarding the quality of care they were providing. Moreover, De Korte-Verhoef et al., (2014), found that experiences of heavy to severe caregiver burden increased from 32% (2-3 months before patients' death) to 66% in the patients' final week of life prompting calls for UK government legislation to deem the wellbeing of carers a national health concern (Carers UK, 2019; Department of Health and Social Care, 2018).

2.2 Respite Care in Palliative Care Settings

Much of the literature regarding respite care and service outcomes derive from studies of caregivers of older adults with chronic impairments or long-term illnesses, but not necessarily from carers of patients with advanced disease (Ingleton et al., 2003). Palliative care is described as a specialist approach to care that improves the quality of life of terminally ill patients and their families (World Health Organisation, 2018). Key elements of palliative care are rooted in the treatment of the patient rather than the disease, focussing

on the relief of disease-related symptoms and suffering to allow patients to live as fully and comfortably as possible (Pastrana et al., 2008). The term has undergone a series of definitional transformations over the years, consequentially impacting the tasks and goals of those providing palliative services (Pastrana et al., 2008).

Respite has become a key service in supporting the family of a terminally ill person and is often delivered by organised health care providers such as hospice organisations (Payne et al., 2004). Respite care not only allows carers to have a break from caring, but also provides a means to tackle unplanned patient admissions during end-of-life stages (Skilbeck et al., 2005). Within the United Kingdom, specialist palliative care providers offer a variety of formal respite options for both patients and carers that primarily involve planned and unplanned (e.g. emergency) inpatient admissions, short intermediate care/day services, and in-home support such as hospice-at-home schemes and 'night sitters' (Ingleton et al., 2003, p. 571). Despite these reported opportunities, in general, user adoption of palliative respite services has been found to be significantly low (Skilbeck et al., 2005), with uptake thought to be based on ritual and habit as opposed to a needs-based approach (Payne et al., 2008).

2.3 Respite care and tourism

Literature related to respite care and tourism can be synthesised into three core areas. The first area, respite care providers, is dominated by reference to the not-for-profit sector (Hunter-Jones, 2011; Shaw et al., 2020). There is also an underlying subject association with literature examining different aspects of social tourism. Exploring the relationship between charities and social tourism for instance, Hunter-Jones (2011) argues that a number of charities play a surrogate role in providing tourism opportunities for those disadvantaged. Charities associate their provision with respite care offerings, although make limited distinctions as to who the beneficiary is i.e. caregiver or care receiver. A more granular analysis by Shaw et al., (2020) into the supply side of social tourism included reference to respite services within a similar not-for-profit footprint concluding:

'not all respite care can be classified as tourism as short breaks can mean a cared-for person being looked after in a residential care home so that the family can enjoy 'normal' family life for a short time' (Shaw et al., 2020, p. 125).

The authors go on to acknowledge:

'the provision of short breaks that does include leisure travel is not insignificant and some leisure breaks can involve leisure activities for the cared-for person' (Shaw et al., 2020, p. 125).

Through two surveys and follow-up interviews, the authors were able to establish that 8.3% of survey respondents focused the allocation of their resources on respite services, with just over a quarter (28%) of the charities identifying carers as one of the groups they support. Concluding that the scope for support remains considerable, suggestions as to reaching out to other providers, the tourism industry in particular, are mooted as worthy of further enquiry.

The second area, research examining the different groups engaging with respite care services, is focused most often upon people who experience a disabling impairment (person-first language) (Darcy 2002; Shaw & Coles 2004; Thompson & Emira 2011) and associated family caregiving (Gladwell & Bedini, 2004; Thompson & Emira, 2011; Holda 2019; Hunter-Jones et al., 2020); ageing (Hunter-Jones, 2010); and terminal illness (Hunter-Jones et al., 2020). Research contributions are seldom discrete with overlap often the case. Darcy (2002) disputes the separate identity attached to respite care asking why people who experience physical impairments are marginalised and have to apply for specialist respite care whilst the general population have access to the wider tourism industry. Shaw and Coles (2004) conclude that the needs of people who experience a disabling impairment are complex and underappreciated, with mention of respite care incidental in this paper. Thompson and Emira (2011) add a further dimension examining the perceptions of carers of children with Autistic Spectrum Disorder, or Attention Deficit, Hyperactivity Disorder in accessing a variety of leisure activities, as well as short breaks and respite care.

Other studies have also considered the relationship between family care-giving and respite care. Gladwell and Bedini (2004) noted that travel opportunities were pursued for functional rather than leisure reasons with a lack of accessibility, mobility, and finances influencing the travel experiences of family caregivers. In adding to the social tourism literature, Hazel (2005) uses reference to respite care to illustrate the absence of holiday support for children and families in need. Attempting to link the concept of medical tourism as an avenue for relaxation and respite to enhance the wellness of carers, Holda (2019) positions the family caregiver as one of the most misunderstood segments of society. Hunter-Jones et al., (2020) outlined the multiple roles paediatric focused hospices play in providing respite opportunities akin to short breaks for both caregivers and care receivers.

The third area, and the focus of this study, is linked to barriers to respite participation. This has been previously considered by Thompson and Emira (2011) who highlight the barriers to participation carers of Autistic children faced. Emergent themes included concerns about staff training, public attitudes, isolation, mainstream or specialist provision, transport and accessibility. Impediments to travel faced by carers of cancer patients and aged relatives are also a feature of the work of Hunter-Jones (2010) who concluded that a range of physical, structural, and financial barriers, including lack of suitable holiday options; lack of private sector awareness; poorly trained staff; and shortfalls in information available contributed to carer psychological distress. Both sets of findings have much in common with the widely recognised theory of hierarchical leisure constraints founded in the family leisure constraints literature (Crawford & Godbey, 1987; Crawford et al., 1991; Jackson et al., 1993). These constraints, suggested to be hierarchical and renamed 'influences' more recently (Godbey et al., 2010), are thought to coalesce around the existence of three types: structural constraints, time or financial for instance; intrapersonal constraints, health and travel preferences for instance; and interpersonal constraints, the lack of a travel companion for instance (Crawford & Godbey 1987; Crawford et al., 1991).

Positioned originally as a process beginning with intrapersonal constraints and progressing through the sequential negotiation of interpersonal constraints and structural constraints, subsequent arguments suggest that 1) constraints are nested in a single model composed of a hierarchy among these three categories (Crawford et al., 1991), influencing participation

in different ways at different times, and 2) they do not start with intrapersonal constraints, but rather should be viewed in a circular capacity, the starting point is where the individual or group is/are in their daily lives (Godbey et al., 2010). Their importance and strength are relative to the social, cultural, and historical contexts they operate within.

Initially thought to be unsurmountable, a keener focus upon the behavioural (actions) disposition of the participant by Jackson et al., (1993), along with the cognitive (mental) disposition by Crawford and Godbey, (1987) prompted the introduction of a series of negotiation propositions, the first proposition suggesting that participation might be dependent not upon the absence of constraints, but rather upon an ability to negotiate through them (Jackson et al., 1993). For a fuller review and analysis of the remaining propositions see Jackson et al., (1993) and Loucks-Atkinson and Mannell (2007). Associated research has uncovered multiple examples of negotiation strategies arising including time management - the reduction or alternative use of time, skill acquisition – learning and encouraging others to try new activities and learn skills (Hubbard & Mannell, 2001). Travel schedule alterations and securing travel companions and/or assistive devices. Altered flight schedules and length of stay to secure the best available service (Poria et al., 2010). Successive attempts to examine this thinking have generated a patchwork travel constraint negotiation literature (see for instance, Kong & Loi, 2017; Karl et al., 2021). This paper seeks to add to this patchwork by questioning the triad of constraints in relation to respite care. It examines which constraints exist in respite participation and which negotiation strategies are deployed, or could be deployed, to negotiate through these constraints.

3.0 METHODS

This study is part of a larger research project comprising patients and their caregivers. For the purposes of this paper, we limit our data to that collected from caregivers of adults. We collected qualitative data from caregivers designed to explore their experiences of caring. It is the barriers to respite participation which are the primary focus of this study.

3.1 Research Design

Taking a social constructivist approach (Cresswell, 2003), we used a qualitative method in the form of storytelling, pathographies, to collect data from caregivers in order to understand their experiences of caregiving. Interpretive methodologies are appropriate for experience evaluations (Helkkula et al., 2012), with storytelling a most effective way of collecting rich data that enables a holistic understanding of experiences in both health (Bate & Robert, 2007) and tourism (Arnould & Price, 1993; Hsu et al., 2009). Storytelling is particularly useful in such contexts because people think narratively; detail comes from retrieved memories that are episodic and focus on incidents, experiences, and the self-evaluation of these (Woodside et al., 2008).

3.2 Sample

We collected data from 157 people who were currently primary caregivers (n=73) or who had recently (within 6 months) been bereaved and had been a primary caregiver (n=84) to a palliative care patient. In the United Kingdom, a person can access palliative care from a hospice at any stage in their life-limiting illness, which differs from the United States of America where a person is eligible for hospice care only in the last 6 months of life (Meier,

2011; National Quality Forum, 2014; Paget & Wood, 2013). We wanted to achieve as varied a sample as possible, hence we used purposive sampling (Hesse-Biber & Leavy, 2005) from a diversity of palliative care providers situated in parts of England with different socioeconomic profiles. Table 1 details the sample.

Table 1: Caregiver Sample

	Caregivers			Age				Gender		Socio-economic Status		
	Current	Bereaved	Total	13 - 34	35 - 54	55 - 74	75+	M	F	AB	C	DE
Hospice A	12	8	20		6	12	2	6	14	9	11	
Hospice B	4	9	13		2	6	5	3	10	5	6	2
Hospice C	9	5	14	1	2	6	5	5	9	6	6	2
Hospice D	6	4	10		1	4	5	1	9	6	2	2
Hospice E	12	7	19	6	11	2		4	15	9	3	7
Hospital Inpatient Unit	16	4	20	2	7	7	4	6	14	12	8	
Hospital based – patient at home	10	3	13	3	4	6		4	9	3	3	7
Hospice based – patient at home	4	44	48	2	6	27	13	8	40	30	13	5
Total (n)	73	84	157	14	39	70	34	37	120	80	52	25

Caregivers of current patients were approached by a palliative care nurse in the first instance, and given details of the research. Bereaved caregivers were recruited via bereavement groups attached to the hospices and palliative care services detailed in Table 1 or via letters explaining the research and how to volunteer.

3.3 Ethics

A full and detailed ethical application, with researcher attendance for scrutiny of the protocol and application, was made to the Central Ethics Committee at the University. Prospective participants understood that involvement in the research was totally voluntary, and all gave written, informed consent. Anonymity and confidentiality were assured. No personal details were collected, narratives were audio recorded and then uploaded to secure, password-protected files until they were transcribed verbatim and deleted. Participants were free to stop narratives at any time, either for a break, or to withdraw from the study, if they so wished. Given the sensitive nature of the narratives, a distress protocol was in place along with the opportunity to be referred to a counsellor, if participants so wished.

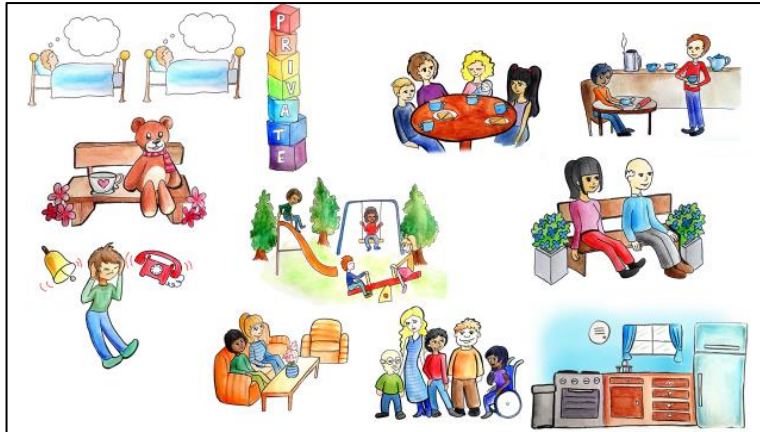
Self-care was an integral part of the ethics and research process. The team adopted multiple techniques consistent with the work of Shamar and Rickly (2017), most notably journaling, peer debriefing, time-out and member checking. Self-care was further supported through the immersive, ethnographic nature of the research which granted open access to wards, staff rooms, lounge facilities, training days and so on, and ample opportunities to seek advice and support from hospice nurses, doctors, volunteers, trustees, Chief Executive Officers, General Practitioners and community nurses if needed.

3.4 Data Collection

One of the advantages of storytelling as a research tool is that the storyteller can actually try to make sense of events while telling their story (Woodside et al., 2008). The potential disadvantage of this, however, is that such narratives can wander off topic or omit parts that may have been important. For this reason, we developed the Trajectory Touchpoint Technique to aide participants with their storytelling. The development of this technique began with our first collaborator, red hospice, our pilot study, and an exploration of which service touchpoints can be identified in the customer journey through palliative care. The eight-stage design process is detailed in full, with illustrations, in a separate, methodological paper (Sudbury-Riley et al., 2020).

Once customer journey touchpoints through palliative care were identified, the selection of rich pictures followed. Initially multiple pictures were selected from open access visual databanks to illustrate each touchpoint, and tested with pilot study participants to determine their suitability. This testing stage resulted in the reduction in the number of images included along with a move away from the use of real photographs, to a user preference for cartoons (see Figure 1 for examples). Rich pictures are also recognised as enabling people to explore their memories and deeply held feelings (Bell et al., 2016; Cristancho et al., 2015) and as such are useful to guide storytelling by helping to keep narratives on track (Conte & Davidson, 2020). Each set of rich pictures pertains to a stage in the palliative care journey, from the pre-diagnosis and pre-arrival at palliative care stage, through to bereavement support. For caregivers of current patients, this final stage was not applicable. What is important about this technique is that participants are free to use all, none, or some of the images. The addition of touchpoints as the need arose is also possible personalising the tool to the service in question. For instance, hospital touchpoints were slightly different to hospice touchpoints with adaptations made accordingly.

Figure 1 Trajectory Touchpoint Technique Set of Images



The Trajectory Touchpoint Technique was purposely designed as a phenomenological approach to delving deeply into people’s subjective experiences. Frequently, the nature of the stories narrated by caregivers inevitably, and naturally, led to a conversation between caregiver and researcher, and thus moved to a reflexive approach, which is important to acknowledge (Bradbury-Jones, 2007). Rather than disadvantaging the research, however, we support previous claims that reflexivity is imperative to good qualitative research (Ahmed Dunya et al., 2011), concurring with Sharma and Rickly (2017, p. 42) that it is ‘necessary to the maintenance of integrity, credibility, and reliability in the process of interpreting participants’ experiences’. We found this reflexivity to be highly beneficial in ensuring we as researchers came across as unthreatening and empathetic, even in light of the story content which was often distressing.

3.5 Data Analysis

We subjected transcribed stories to a manual reflective thematic analysis, closely following the method advocated by Braun and Clarke (2006, 2019). In step one the authors each analysed the data pertaining to each set of touchpoints then shared the major themes with each other. Carer and bereaved data were analysed separately. Three sub-themes emerged from this review which were cross-referenced with the hierarchical leisure constraints framework. This reflexive team approach (Russel & Kelly, 2002) can alleviate the inevitable bias that qualitative data analysis can suffer due to the individual stances of researchers (Josselson, 2007).

4.0 FINDINGS

Not all respite care can be classified as tourism (Shaw et al., 2020). Consequently, this section focuses specifically upon the carer narratives which did associate respite with a breakaway of one night or more from their caring responsibilities. The aim of this section is to specifically unpick which constraints exist in respite participation utilising exemplar quotes from both carers and bereaved families by way of illustration (Table 2).

Table 2: Mapping Carer and Bereaved Feedback

INFLUENCE	CROSS-CUTTING THEME	K Aware	D Access	F Anxiety	CARER EXEMPLAR QUOTES	BEREAVED EXEMPLAR QUOTES
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Intra-personal	Digital literacy	✓			1: I couldn't find any information online about it at all (...) If I hadn't known, I wouldn't have known at all would I? (Wife)	2: People [healthcare professionals] kept wanting to send text appointments or messages. I have a house phone and found it all very confusing (Wife)
	Guilt, worry, isolation			✓	3: I know how he likes his food, and when he likes a drink (...) Are they going to be that bothered at all? (Wife)	4: The chappy opposite was a drug addict (...). I kept thinking how could I have left him here? I just needed a break (...) I felt like I couldn't go on (Wife)
Inter-personal	Mis-information	✓			5: ...if I've got to pay for respite care for Dave, how can I afford a respite break for me too? (Friend, male)	6: Problem was that he always did the money things so I didn't know where to start (Wife)
	Public attitudes			✓	7: ...my perception always was that you came in and didn't come out (Friend, female).	8: You get really frowned on if you don't look after your own you know (...) (Husband).
	Resources		✓		9: How do you get away overnight with just 5 extra hours? (Dad).	10: There was definitely not a phone so maybe that was lacking (Wife, bereaved).
	Staff training			✓	11: I just don't think they [staff] realised how upsetting it is when things like your teeth go missing (...). I just never felt I could leave her	12: I remember thinking I feel so tired and know a break would be good, but is it the right time to? (Wife)

					<i>after that (Daughter)</i>	
Structural	Information shortfall	✓			13: <i>Well we knew basically that [hospice name] was for those that are terminally ill. (Daughter)</i>	14: <i>The thing that makes me sad is that a chance to have a break would have been amazing (...) A break would have made a big difference. (Wife)</i>
	Mis-information	✓			15: <i>I didn't realise they had any capacity to stay for short breaks (...) (Wife)</i>	16: <i>When we left the hospice for the last time no-one said you can come back to use the facilities (Daughter)</i>
	Accessibility		✓		17: <i>There's no schedule you can book onto. You just have to keep ringing up and asking if they have any availability. (Daughter)</i>	18: <i>I knew you could come in for respite support (...). I knew that from carers who came into care for my mum last year. (Daughter).</i>
	Staff training			✓	19: <i>Nobody seems to have come across a cochlea implant before, (...) we've had to show them how to do that (Daughter)</i>	20: <i>I just think they should have known how to fix equipment (Son)</i>

4.1. Cross-Cutting Themes

4.1.1 Awareness

Travel motivation literature commonly details the beneficial impacts of travelling upon health, wellbeing and relaxation (Chen & Petrick, 2013), themes regularly embedded in destination marketing campaigns (Bandyopadhyay & Balakrishnan Nair, 2019). When it comes to the needs of carers however, our data illustrates a dearth of material which speaks either to the needs of this population in general, or celebrates the salutogenic properties tourism participation might realise. Our carers lacked self-awareness of the need for a break. Exhibited profound guilt at even the thought of such an activity. Had no sense of where to turn to plan a break, and were often reliant upon health care workers who assumed the role of pseudo travel communication channels even though they were themselves ill-equipped to offer practical advice. Inevitably choice was compromised with

conversations extending as far as the hospice environment to support patients. Yet, here, rather than generating tourism opportunities and experiences (Jordan et al., 2019), narratives were dominated by an over-riding fear of the word hospice and anything associated with such an environment. Associations with death, and death alone generated powerful negative perceptions which acted as a barrier to carers seeking any further information on which services might be available. Inevitably, links to opportunities for respite care became a casualty of this fear (Table 2, quote 7).

Gaps in respite services knowledge were commonly associated with a simple information shortfall (Table 2, quote 13), generating regret for the bereaved lamenting missed opportunities (Table 2, quote 14). Information deficits were particularly dominant where financial matters were mentioned, many dissuaded from looking into respite opportunities for themselves unaware that support options might be available (Table 2, quote 5). Whilst financial considerations have long been recognised within a travel constraints literature which acknowledges that the discretionary nature of holidays renders them susceptible to cancellation during periods of financial uncertainty (Huber et al., 2018), in this study it is *financial (il)literacy* which is a powerful travel constraint. The words of a bereaved wife explaining the need to learn a whole new monetary language are illustrative of the financial complexity many alluded to (Table 2, quote 6).

Literacy shortfalls extended to *digital (il)literacy* which is particularly problematic in a tourism context where digital media has, and continues to greatly impact tourism consumption practices, radically altering the way in which information is generated and communicated (Buhalis & Law, 2008). Directed towards online materials when raising questions as to services available, carers struggled to disentangle information (Table 2, quote 1), whilst the bereaved reflected upon the additional burden felt with trying to uncover information (Table 2, quote, 2). Even where carers embraced digital information sources, they still observed a perceived reluctance for providers to share specific information about respite care opportunities (Table 2, quote 1).

Comparing the comments of those actively caring alongside the bereaved offers a deeper appreciation of barriers than ordinarily the case. For instance, whilst a fear of hospices dominated conversations, bereaved relatives were able to unpick this fear further speaking candidly of the additional burden of a fear of public attitudes inhibiting their use of a hospice environment (Table 2, quote 8). Their financial fears were associated in part with limited monetary acumen (Table 2, quote 6). Their grief impacted by the lack of direction offered by others at such an intense time (Table 2, quotes 14, 15 and 16).

4.1.2 Access

Whilst the use of global internet-based reservation systems continues to dominate the tourism industry, offering price comparisons, rates and customer reviews amongst other intelligence (Gössling & Lane, 2015), their application did not extend to the carers in our study who instead spoke of the role serendipity played in helping them to access tourism opportunities, by chance, through unplanned conversations with others (Table 2, quote, 18). Inaccurate and incomplete information also proved to be a further constraint, failing to meet the standards of being 'accessible at an architectural, urban, transport, information,

communication, technology and leisure and tourism level', as previously recommended by Vila et al., (2018, p. 2896) in their study of website accessibility in the tourism industry.

A particularly dominant theme amongst the bereaved was a simple wish that staff had taken a more proactive role in explaining different stages of illness and what to expect, which in turn would have assisted in determining whether seeking access to respite care, or alternatives, was even a sensible option (Table 2, quote 12).

Where carers spoke of a knowledge of respite care it was common for participants to then struggle in gaining access to the service. Poor co-ordination of respite support services proved to be common obstacles for those deep in the caring role (Table 2, quote 17) reinforced in the reflections of the bereaved. Carers and the bereaved were united in their experiences of altered patterns of employment to accommodate illness which, in turn, limited their personal finances, a long-recognised travel constraint (Huber et al., 2018), with little support forthcoming (Table 2, quote 9).

4.1.3 Anxiety

Reviewing tourism impacts, emotions and stress, Jordan et al., (2019, p. 214) argue that 'emotions are an important part of the human experience, and play a critical role in individuals' psychological and physical well-being'. While many tourism experiences generate positive emotions, fun, excitement, happiness for instance, they also have the capacity to elicit negative experiences including worry and anxiety. This later grouping proved to be most dominant in our carer data, with a twist. Contrary to the commonly recognised travel worries and barriers evidenced in literature which include studies of political and safety situations (Karl et al., 2020), climate and weather (Huber et al., 2018) or travel distances (Wu et al., 2011) for instance, in this study, anxiety related to intrinsic factors associated with guilt and worry when leaving their dying relative in an inpatient setting.

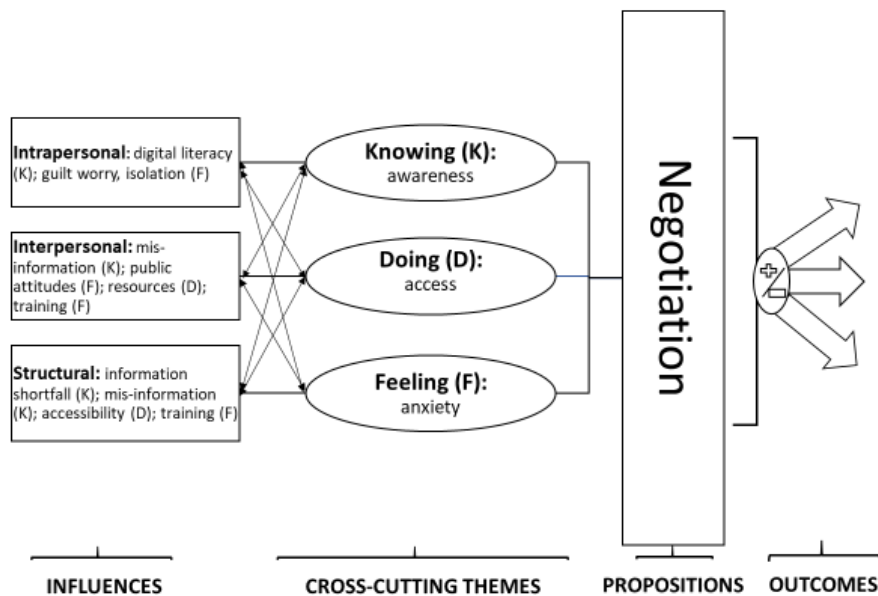
Carers worried about whether their family/friend would be well cared for if they utilised respite care for their charge whilst taking a break themselves (Table 2, quotes 3 and 11). For the bereaved, the guilt of what they had subjected their relative to was a cause for distress, even though with the benefit of time to think in bereavement, they recognised the exhaustion and strain they were living under (Table 2, quote 4). Carers worried about the capacity of those providing respite care to successfully accommodate particular needs (Table 2, quote 19), whilst the bereaved came to terms with the difficulties they had experienced keeping in touch with their relative during the precious final stages (Table 2, quotes 10 and 20).

5.0 DISCUSSION

Research on caregiving has consistently shown that respite care, whilst one of the most important services for caregivers, is experienced by carers as one of their most unmet needs (Hirsch et al., 1993). Using an innovative, experience capturing methodology, this study has applied a theory of hierarchical leisure constraints lens to more fully understand which constraints impact carer tourism participation. Figure 2 visualises the complexity arising, mapping the theoretical triadic constraints (influences) against the three cross-cutting

constraint themes emergent in the carer data: awareness of travel opportunities (*knowing*); access to travel options (*doing*); and anxiety arising as a result of tourism participation (*feeling*).

Figure 2: Barriers to Tourism Participation: A Framework for Respite Care



The absence of information and support (*awareness*), online and offline, at a time of heightened vulnerability and uncertainty, prevented carers from making informed choices during different stages of their relatives' illness trajectory (Payne et al., 2008). Indeed, the notion that carers were able to take planned breaks from the responsibilities of caring (Scharlach & Frenzel, 1986) was almost entirely absent in this study as many spoke of the only respite opportunities arising born out of serendipity rather than any planned activity. Carers were guilt-ridden (*anxiety*) and, akin to the findings of McKercher & Darcy (2018) felt judged for their decision to take a break. Carers were living in a complex, busy personal space, where the opportunity to research breaks at leisure was neither easily possible, or readily welcomed. They suffered financial and digital (il)literacy when confronted with travel decision-making activities which had previously been the domain of their partners (*access*).

Whilst commonalities with extant travel constraint research transpired, financial restrictions along with the holiday type for instance (Huber et al., 2018), when it came to the ability of carers to negotiate their way through travel constraints, complex patterns of influence arose as illustrated in Figure 2. Contrary to Godbey et al., (2010), carers did not negotiate constraints through a hierarchical process beginning with intrapersonal constraints (*influences*). Indeed, progress through any sequential negotiation of intrapersonal, interpersonal or structural constraints (Crawford & Godbey, 1987; Crawford et al., 1991; Jackson et al., 1993) was anything but straightforward as it was entirely dictated by the caring responsibilities in focus. In the case of palliative and end-of-life care, these responsibilities changed by the minute, the hour, the day, introducing a temporality dimension into our theoretical understanding. Tourism constraints were directly impacted by the changing health status of a third party. Inevitably this impacted upon tourism

decision-making practices which did not follow the traditional rational, problem-solving approach so often documented in tourism research, or even the adaptable and opportunistic practices proposed by Decrop and Snelders (2004). The window of opportunity to take a break was seldom clear cut with all the usual planning and anticipation associated with travel activity largely absent. Last minute changes to plans were common.

Consequently, negotiation strategies commonly deployed in tourism research were less effective for this travel community. Time management, arranging to try new activities and learn new skills, orchestrating travel activity with travel companions, selecting travel schedules and options to maximise experiential consumption (Hubbard & Mannell, 2001; Poria et al., 2010) were all casualties of a changing landscape. Nevertheless, even with this backdrop, carers did take breaks demonstrating that an appetite for travel did exist. Patterns of participation indicate the need for an additional negotiation proposition to those previously detailed in the leisure constraints literature (see for instance Jackson et al., 1993):

Respite care participation is inhibited by a deficit in flexible support packages along with a dearth of information accurately depicting opportunities and service offerings available.

The question now is which negotiation strategies might be deployed to more effectively enable participation and what role might the tourism sector play in realising this?

Existing literature suggests that the third sector currently has the edge in supporting carers, particularly through initiatives linked to social tourism (Hunter-Jones, 2011; Shaw et al., 2020). These initiatives have been responsive to tourism participation which is characterised by heterogeneity, not homogeneity. They have shown an understanding that barriers and constraints are not absolute, rendering stereotypical assumptions reached regarding tourism participation as meaningless too. And have often concluded that many tourism constraints exist as a consequence of environmental deficits, a social model, rather than individual tourist deficits (McKercher & Darcy, 2018). The third sector is also well placed to enable carers to negotiate the minefield of tourism information with umbrella organisations in the United Kingdom such as Carers UK, capable of signposting vulnerable would-be tourists towards accurate and focused third sector information sources.

Opportunities also exist to energise the commercial tourism sector to support carers in negotiating travel constraints. Whilst ill-equipped to accommodate patients experiencing complex conditions, providers are well-equipped to support carers. It is within their gift to anticipate and respond to *awareness* deficits, embedding information about opportunities available for carers more prominently into marketing campaigns, just as would be the case for other niche tourism market segments. To actively review the *accessibility* of stays, taking initiative and exploring the potential to develop offers and packages during low season or partnering with healthcare organisations to offer packages which may suit both carer and cared for needs, albeit in different locations, hotels for carers, nursing homes for their charges. To offer social support to assist carers in overcoming *anxiety* and aiding carer

satisfaction with respite services. Here the work of Nicoll et al., (2002) is insightful, arguing that whilst carers can enjoy the freedom that comes with periods of respite, often carers can feel marooned and directionless when away from the care recipient and the responsibilities of caring. This may create a dilemma of having to choose between feeling unable to cope with overbearing caring demands and feeling intense loneliness during periods of respite. Tourism services are well-equipped to address a sociability deficit respite care might introduce.

However, to suggest interventions on a sector by sector basis alone is not enough. All this will do is most likely further exacerbate many issues carers shared in this study. What is really needed now is a mixed economy response which champions respite care, just as palliative care, as a means of supporting both individual carers, but also extending to supporting the needs of extended family. Which is driven by connectivity, evidenced for instance through buy-in to the benefits of an integrated marketing communications strategy. Is capable of accommodating a plethora of digital and financial (il)literacy. Can celebrate support opportunities available and the benefits derived from pursuing participation. Is collectively equipped to provide detailed information about financial support, provide case studies of which respite care is suitable for which circumstances and when. Is attentive and responsive to the need for accessible booking processes. Is capable of capturing information on personal needs and wants and offering assurances as to the service levels which might be expected. Whilst the driver of such a response is most likely to be public or third sector-led organisations, supported through policy frameworks, all sectors have a role to play in designing offerings cognisant of these needs. To attempt such would see a seismic shift for the tourism community to one proactive in creating opportunities for carers and equipping them with tools to more readily negotiate the barriers to tourism participation evidenced in this research.

6.0 CONCLUSIONS

This paper set out to contribute to understanding of respite care at a time of profound need. It sought to identify the barriers to tourism participation experienced by the caring community, informal health carers in particular. It has adopted, and extended, the theory of hierarchical leisure constraints to better understand barriers to respite participation and introduced a new negotiation proposition which might be deployed to overcome tourism constraints. Whilst this is not the first attempt at extending our understanding of tourism constraints, indeed recent work by Karl et al., (2021) has similarly sought to achieve this within the context of cognitive and behavioural travel constraints, what the findings here do signal is two inter-related extensions to existing theoretical understanding. First, they question the hierarchical order previously debated in relation to both leisure and tourism constraints, this time illustrating the complexity arising when the needs of a silent third party are pivotal to the decision-making process. Second, they raise the need for further explorations of the temporality of tourism constraints, time taking on new meanings and availability where life limiting illness is involved, as the case in this study.

Inevitably there are also a number of considerations to take account of when interpreting the data. This study is part of a larger empirical research project comprising patients and their caregivers. We have limited our data to that collected from caregivers of adults

focusing specifically upon the barriers to tourism participation shared by carers. We have focused upon the consumer perspective and not sought to listen to service providers. We have considered the palliative care landscape which is important, but not necessarily reflective of all types of care. We have collected qualitative data via pathographies, a form of story-telling, from a United Kingdom perspective. We have positioned our work within a leisure and tourism literature rather than necessarily disability studies. Whilst we have no reason to question the quality and integrity of this multi-site, multi-researcher study, future studies will serve as important tests of the validity of the data included.

A number of avenues for future research can be identified. The current study brings into focus the role of caregivers as service users of respite care in palliative care contexts, with specific focus on respite service models in hospices. Hospices are not the only providers of palliative care however. A beneficial research venture exploring how respite service models are constructed in different tourism settings would complement this study. Moreover, broadening research out to question the tourism needs of other carers, those focused upon chronic or progressive conditions, supporting short or long-term circumstances for instance would help us to both better understand the applicability of the travel constraints identified in this study along with further analysing whether the temporality considerations of caring identified in this study are transferable to other caring contexts. Adapting the story-capturing touchpoint (physical, sensorial, symbolic and social) tool applied in this study, the Trajectory Touchpoint Technique, with its staged analysis, will allow for a fuller temporal appreciation of tourism constraints than is ordinarily the case.

Perhaps the greatest barriers to overcome though is finding ways to generate awareness and access to respite services whilst also navigating through the anxiety participating in respite breaks can generate. The empirical data suggests a narrative which argues that seeking respite care is not an easy decision for the caring community, those attending to palliative and end-of-life-care patients likely more so. The backdrop which underpins demand for respite care is largely under-appreciated in the tourism literature. Decision-making processes attached are similarly neglected. Further studies examining this and questioning where tourism providers might sit in the mixed economy approach to supporting respite participation outlined in this study are needed. Opening these conversations will help to both mitigate the concern by Cox (1997) that often respite services remain vulnerable to under-utilisation or use by only a marginal group, whilst also providing a further opportunity to validate the data and bridge the gap between tourism and public health research, positioning tourism as a sector capable of delivering important health enhancing interventions at a time of critical need.

REFERENCES

- Abelson, A. G. (1999). Respite care needs of parents of children with developmental disabilities. *Focus on Autism and Other Developmental Disabilities*, 14(2), 96-100.
- Acheson, E. D. (1988). On the state of the public health [the fourth Duncan lecture]. *Public Health*, 102(5), 431-437.

Ahmed Dunya, A. A., Lewando, H. G., & Blackburn, C. (2011). Issues of gender, reflexivity and positionality in the field of disability: Researching visual impairment in an Arab society. *Qualitative Social Work, 10*(4), 467–484.

Arnould, E. J., & Price, L. L. (1993). River Magic: Extraordinary Experience and the Extended Service Encounter. *Journal of Consumer Research, 20*(1), 24-45.

Bandyopadhyay, R., & Balakrishnan Nair, B. (2019). Marketing Kerala in India as *God's Own Country!* for tourists' spiritual transformation, rejuvenation and well-being. *Journal of Destination Marketing and Management*. Vol 14, December, DOI: 10.1016/j.jdmm.2019.100369

Bate, P. & Robert, G. (2007). *Bringing User Experience to Healthcare Improvement*. Oxford: Radcliffe.

Bell, S., Berg, T., & Morse, S. (2016). *Rich pictures: Encouraging resilient communities*. New York, NY: Routledge.

Bourquin, P., Delestre, I., Joyce, R., Rasul, I., & Waters, T. (2020). *The effects of coronavirus on household finances and financial distress*. Institute for Fiscal Studies: IFS Briefing Note BN298.

Bradbury-Jones, C. (2007). Enhancing rigor in qualitative health research: Exploring subjectivity through Peshkin's I's. *Journal of Advanced Nursing 59*, 290–298.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Braun, V. & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589–597.

Buhalis, D., & Law, R. (2008). Progress in information technology and tourism management: 20 years on and 10 years after the Internet—The state of eTourism research. *Tourism Management, Vol 29, Issue 4*, 609-623.

Carers UK (2019). Facts about carers. Carers UK, Policy Briefing, August 2019. Available at: https://www.carersuk.org/images/Facts_about_Carers_2019.pdf (Accessed: 24 April 2022).

Chen, C.C., & Petrick, J.F. (2013). Health and wellness benefits of travel experiences: a literature review. *Journal of Travel Research, 52*:709–719

Conte, K. P. & Davidson, S. (2020). Using a 'rich picture' to facilitate systems thinking in research coproduction. *Health Research Policy and Systems, 18*, 14.

Cox, C. (1997). Findings from a statewide program of respite care: A comparison of service users, stoppers, and nonusers. *The Gerontologist, 37*(4), 511-517.

- Crawford, D. W., & Godbey, G. (1987). Reconceptualizing barriers to family leisure. *Leisure Sciences* 9 (2), 119-127. doi: 10.1080/01490408709512151
- Crawford, D. W., Jackson, E. L., & Godbey, G. (1991). A hierarchical model of leisure constraints. *Leisure Sciences*, 13 (4), 309-320.
- Cresswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oakes, CA: Sage.
- Cristancho, S. M., Bidinosti, S., Lingard, L., Novick, R., Ott, M., & Forbes, T. (2015). Seeing in different ways: Introducing “rich pictures” in the study of expert judgment. *Qualitative Health Research*, 25(5), 713-725.
- Darcy, S. (2002). Marginalised participation: physical disability, high support needs and tourism. *Journal of Hospitality and Tourism Management*, 9(1), 61-72.
- Decrop, A., & Snelders, D. (2004). Planning the summer vacation: An adaptable process. *Annals of Tourism Research*, 31(4), 1008-1030.
- De Korte-Verhoef, M. C., Pasman, H. R. W., Schweitzer, B. P., Francke, A. L., Onwuteaka-Philipsen, B. D. & Deliëns, L. (2014). Burden for family carers at the end of life; a mixed-method study of the perspectives of family carers and GPs. *BMC palliative care*, 13(16), 1-9.
- Department of Health and Social Care (2018). *Carers Action Plan 2018 – 2020. Supporting carers today*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf (Accessed: 13 June 2019).
- Family Caregiver Alliance (2016). *Caregiver statistics: Demographics*. Available at: <https://www.caregiver.org/resource/caregiver-statistics-demographics/> (Accessed: 28 November 2021).
- Gladwell, N. J., & Bedini, L. A. (2004). In search of lost leisure: The impact of caregiving on leisure travel. *Tourism Management*, 25(6), 685–693.
- Godbey, G., Crawford, D.W., & S.S. Xiangyou (2010). Assessing Hierarchical Leisure Constraints Theory after Two Decades, *Journal of Leisure Research*, 42(1), 111-134, DOI: [10.1080/00222216.2010.11950197](https://doi.org/10.1080/00222216.2010.11950197)
- Gössling, S. & Lane, B. (2015). Rural tourism and the development of Internet-based accommodation booking platforms: a study in the advantages, dangers and implications of innovation, *Journal of Sustainable Tourism*, 23:8-9, 1386-1403, DOI: 10.1080/09669582.2014.909448
- Hazel, N. (2005). Holidays for Children and Families in Need: An Exploration of the Research and Policy Context for Social Tourism in the UK, *Children and Society*, 19, 225–236.

- Helkkula, A., Kelleher, C., & Pihlström, M. (2012). Characterizing value as an experience. *Journal of Service Research*, 15(1), 59-75.
- Hesse-Biber, S. N. & Leavy, L. P. (2005). *The practice of Qualitative Research*. Thousand Oaks, CA: Sage.
- Hirsch, C. H., Davies, H. D., Boatwright, F. & Ochango, G. (1993). Effects of a nursing-home respite admission on veterans with advanced dementia. *The Gerontologist*, 33(4), 523-528.
- Holda, R. (2019). Respite Tourism for Family Caregivers In. Khosrow-Pour R (Ed) (2019). *Chronic Illness and Long-Term Care: Breakthroughs in Research and Practice*. Chapter 13, *Information Resources Management Association*, USA, 242-254.
- Hsu, S.-Y., Dehuang, N., & Woodside, A. G. (2009). Storytelling research of consumers' self-reports of urban tourism experiences in China. *Journal of Business Research*, 62, 1223-1254.
- Hubbard, J. and Mannell, R.C. (2001) Testing Competing Models of the Leisure Constraint Negotiation Process in a Corporate Employee Recreation Setting. *Leisure Sciences*, 23, 145-163. <http://dx.doi.org/10.1080/014904001316896846>
- Huber, D. Milne, S., & Hyde, K.F. (2018). Constraints and facilitators for senior tourism. *Tourism Management Perspectives*, Vol 27, July, 55-67.
- Hunter-Jones, P. (2010). Consumer vulnerability and exclusion: A study of carers in the tourism marketplace. *Journal of Marketing Management*, 27(1-2), 165-180.
- Hunter-Jones, P. (2011). The role of charities in social tourism. *Current Issues in Tourism*, 14(5), 445-458.
- Hunter-Jones, P., Sudbury-Riley, L., Al-Abdin, A., Menzies, L., & Neary, K. (2020). When a Child is Sick: The Role of Social Tourism in Palliative and End-of-Life care. *Annals of Tourism Research*, 83 <https://doi.org/10.1016/j.annals.2020.102900>
- Ingleton, C., Payne, S., Nolan, M. & Carey, I. (2003). Respite in palliative care: a review and discussion of the literature. *Palliative medicine*, 17(7), 567-575.
- Jackson, E. L., Crawford, D. and Godbey, G. (1993). Negotiation of leisure constraints. *Leisure Sciences*, 15(1), 1-11
- Jordan, E.J., Spencer, D.M., & Prayag, G. (2019). Tourism impacts, emotions and stress. *Annals of Tourism Research*, 75, March, 213-226.
- Josselson, R. (2007). The ethical attitude in narrative research: Principles and practicalities. In: D. J. Clandinin (Ed.). *Handbook of Narrative Inquiry: Mapping a Methodology*. Thousand Oaks, CA: Sage, 537-566.

Karl, M., Bauer, A. Ritchie, B., & Passauer, M. (2020). The impact of travel constraints on travel decision-making: A comparative approach of travel frequencies and intended travel participation. *Journal of Destination Marketing and Management*. Vol 18, December, DOI: 10.1016/j.jdmm.2020.100471

Karl, M., Sie, L., Ritchie, B. W. (2021). Expanding Travel Constraint Negotiation Theory: An Exploration of Cognitive and Behavioral Constraint Negotiation Relationships, *Journal of Travel Research*. doi:10.1177/00472875211011547

Kong, W.H., and K.L. Loi. (2017). The Barriers to Holiday-Taking for Visually Impaired Tourists and Their Families. *Journal of Hospitality and Tourism Management* 32, 99-107. <https://doi.org/10.1016/j.jhtm.2017.06.001>.

Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? What next? *Gerontologist*, 37(2), 218–232.

Loucks-Atkinson, A. and Mannell, R. C. (2007). Role of self-efficacy in the constraints negotiation process: The case of individuals with Fibromyalgia Syndrome. *Leisure Sciences*, 29, 19-36.

McKercher, B. and S. Darcy. (2018). Re-Conceptualizing Barriers to Travel by People with Disabilities. *Tourism Management Perspectives* 26, 59-66. <https://doi.org/10.1016/j.tmp.2018.01.003>.

McNally, S., Ben-Shlomo, Y. & Newman, S. (1999). The effects of respite care on informal carers' well-being: a systematic review. *Disability and Rehabilitation*, 21(1), 1-14.

Meier, D. E. (2011). Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Quarterly*, 89(3), 343–380.

Morasso, G., Costantini, M., Di Leo, S., Roma, S., Miccinesi, G., Merlo, D. F. & Beccaro, M. (2008). End-of-life care in Italy: personal experience of family caregivers. A content analysis of open questions from the Italian Survey of the Dying of Cancer (ISDOC). *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 17(11), 1073-1080.

National Quality Forum. (2014). Measure Applications Partnership. Available online at https://www.qualityforum.org/setting_priorities/partnership/measure_applications_partnership.aspx (Accessed June 4 2019).

Neville, C., Beattie, E., Fielding, E. & MacAndrew, M. (2015). Literature review: use of respite by carers of people with dementia. *Health & social care in the community*, 23(1), 51-63.

Nicoll, M., Ashworth, M., McNally, L. & Newman, S. (2002). Satisfaction with respite care: a pilot study. *Health & social care in the community*, 10(6), 479-484.

Paget, A. & Wood, C. (2013). *Ways and means*. DEMOS. 2013. Available online at https://www.demos.co.uk/files/Ways_and_Means_-_web.pdf?1371658165 (Accessed April 25 2020).

Pastrana, T., Jünger, S., Ostgathe, C., Elsner, F. & Radbruch, L. (2008). A matter of definition—key elements identified in a discourse analysis of definitions of palliative care. *Palliative medicine*, 22(3), 222-232.

Payne, S., Ingleton, C., Scott, G., Steele, K., Nolan, M. & Carey, I. (2004). A survey of the perspectives of specialist palliative care providers in the UK of inpatient respite. *Palliative medicine*, 18(8), 692-697.

Payne, S., Seymour, J. & Ingleton, C. (2008). *Palliative Care Nursing: Principles and Evidence for Practice*. 2nd ed. Maidenhead: McGraw-Hill Education.

Poria, Y., Reichel, A., & Brandt, Y. (2010). The flight experiences of people with disabilities: An exploratory study. *Journal of Travel Research*, 49(2), 216-227.

Royal College of Nursing (2021). Public Health. Available online at: <https://www.rcn.org.uk/clinical-topics/public-health> (accessed 19th June 2021)

Russel, G. M. & Kelly, N. H. (2002). Research as interacting dialogue process: Implications for reflexivity. *Forum: Qualitative Social Research*, 3(3). Available online at: <http://www.qualitative-research.net/index.php/fqs/article/view/831/1806> (accessed 25th April 2020).

Scharlach, A. & Frenzel, C. (1986). An evaluation of institution-based respite care. *The Gerontologist*, 26(1), 77-82.

Sharma, N. & Rickly, J.M. (2018) Self-care for the researcher: dark tourism in Varanasi, India, *Journal of Teaching in Travel & Tourism*, 18:1, 41-57, DOI: [10.1080/15313220.2017.1403801](https://doi.org/10.1080/15313220.2017.1403801)

Shaw, G., & Coles, T., (2004). Disability, holiday-making and the tourism industry in the UK: A preliminary survey. *Tourism Management*, 25(3), 397-403.

Shaw, C., McNamara, R., Abrams, K., Cannings-John, R. L., Hood, K., Longo, M., Myles, S., O'Mahoney, S., Roe, B. & Williams, K. (2009). Systematic review of respite care in the frail elderly. *Health Technology Assessment*, 13(20), 241-246.

Shaw, G., McCabe, S., & Wooler, J. (2020). Social tourism in the UK: the role of the voluntary sector as providers in a period of austerity In Diekmann, A. & McCabe, S. (Eds) (2020). *Handbook of Social Tourism*. Edward Elgar Publishing: UK, 123-138.

Sixsmith, A. & Sixsmith, J., (2008). Ageing in place in the United Kingdom. *Ageing International*, 32(3), 219-235.

Skilbeck, J. K., Payne, S. A., Ingleton, M. C., Nolan, M., Carey, I. & Hanson, A. (2005). An exploration of family carers' experience of respite services in one specialist palliative care unit. *Palliative medicine*, 19(8), 610-618.

Sudbury-Riley, L., Hunter-Jones, P., Al-Abdin, A., Lewin, D. & Naraine, M. (2020). The Trajectory Touchpoint Technique: A Deep Dive Methodology for Service Innovation. *Journal of Service Research* 23(2) 229-251.

Thompson, D. & Emira, M. (2011). 'They say every child matters, but they don't': an investigation into parental and carer perceptions of access to leisure facilities and respite care for children and young people with Autistic Spectrum Disorder (ASD) or Attention Deficit, Hyperactivity Disorder (ADHD), *Disability & Society*, 26(1), 65-78.

Van Excel, J., De Graaf, G., & Brouwer, W. (2008). Give me a break!: Informal caregiver attitudes towards respite care. *Health policy*, 88(1), 73-87.

Vila, T.D., González, E.A., & Darcy, S. (2018). Website accessibility in the tourism industry: an analysis of official national tourism organization websites around the world, *Disability and Rehabilitation*, 40:24, 2895-2906, DOI: 10.1080/09638288.2017.1362709

WHO (2021). Public Health Services. Available at: <https://www.euro.who.int/en/health-topics/Health-systems/public-health-services/public-health-services> (accessed 19th June 2021).

Willner, P., Rose, J., Stenfert Kroese, B., Murphy, G.H., Langdon, P.E., Clifford, C., Hutchings, H., Watkins, A., Hiles, S., & Cooper, V. (2020). Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 33(6), 1523-1533.

Woodside, A. G., Sood, S., & Miller, K. E. (2008). When consumers and brands talk: Storytelling theory and research in psychology and marketing. *Psychology & Marketing*, 25(2), 97-145.

World Health Organisation (2018). WHO Definition of Palliative Care. Available online at <http://www.who.int/cancer/palliative/definition/en/> (Accessed 3 January 2019).

Wu, L., Zhang, J., & Fujiwara, A. (2011). Representing tourists' heterogeneous choices of destination and travel party with an integrated latent class and nested logit model. *Tourism Management*, 32(6), 1407-1403.

Zarit, S. H., Stephens, M. A. P., Townsend, A. & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 53(5), 267-277.