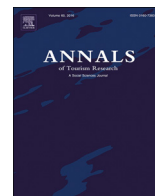




Contents lists available at ScienceDirect

Annals of Tourism Research

journal homepage: www.elsevier.com/locate/annals

The hidden side of travel: Epilepsy and tourism

Alison J. McIntosh*

School of Hospitality and Tourism, Auckland University of Technology, 55 Wellesley Street East, Auckland Central, New Zealand



ARTICLE INFO

Associate editor: Simon Darcy

Keywords:

Accessible tourism

Epilepsy

Seizures

Invisible disability

ABSTRACT

Previous tourism research has examined the barriers and travel experiences of people with physical/mobility and sensory impairments. This paper advances tourism knowledge by revealing the travel experiences of people with the invisible and stigmatising condition of epilepsy. The study employed a phenomenological approach to explore whether, and how, the hidden neurological condition affects the travel experience. Analysis of the data revealed three main themes relating to the experience of travel for individuals with epilepsy: *seizure episodes*; *invisibility of the condition*; and *managing anxiety*. The paper illuminates the hidden side of travel for people with epilepsy and its social stigma, and problematises the socially constructed nature of travel as mostly visible, an escape from normality, independent and authentic.

Introduction

Tourism is a means for social interaction, wellbeing and quality of life for socially marginalised groups (McCabe & Johnson, 2013; Pagán, 2015). Yet the socially excluding and barrier-laden nature of tourism for people with disabilities has been widely reported (Daruwalla & Darcy, 2005; Eichhorn, Miller, & Tribe, 2013; Smith, 1987). Such studies have documented the mobility restraints, physical barriers, lack of access to information, discrimination, and fear of being unable to cope faced by travellers with disabilities (see Devile & Kastenholz, 2018; Hunter-Jones, 2004; Small, 2015). For the most part, these studies report on disabilities that are in some way discernible to others. Accounts of the travel experiences of people with an invisible disability are fewer in number. Matthews and Harrington (2000, p. 405) define 'invisible disability' as "one that is hidden: not to be immediately noticed by an observer except under unusual circumstances or by disclosure from the disabled person or other outside source". To date, tourism scholars have not considered the neurological condition of epilepsy and its potential effect on travel. Therefore, this paper seeks to explore the ways in which epilepsy may affect travel.

The term 'epilepsy' is "derived from a Greek word meaning to take hold, seize or possess" (Jacoby, 1992, p. 657). A person is said to have epilepsy if he or she has recurring epileptic seizures: the paroxysmal discharge of cerebral neurons. There are various seizure types and they can vary from brief lapses of attention to serious long-lasting convulsions. The condition is argued to be the world's most common serious neurological disorder affecting approximately 500 million individuals worldwide (Jacoby, 2002). The impact of epilepsy on an individual's life is multi-dimensional and can include physical and cognitive problems associated with seizures, side effects from medication, and "psychological and emotional problems, social isolation, and problems concerning education, employment, family life and leisure activities" (Bishop & Allen, 2003, p. 227).

Access to leisure, physical activity, transport and travel are important for the well-being of people with epilepsy. However, many previous studies commonly report the physical and psychosocial barriers to participation in sport and leisure for people with epilepsy (e.g. Arida, Cavalheiro, da Silva, & Scorza, 2008; Collard & Marlow, 2016; Han, Choi-Kwon, & Lee, 2011; Millett, Johnson,

* School of Hospitality and Tourism, Auckland University of Technology, New Zealand.

E-mail address: alison.mcintosh@aut.ac.nz.<https://doi.org/10.1016/j.annals.2019.102856>Received 24 March 2019; Received in revised form 2 December 2019; Accepted 13 December 2019
0160-7383/© 2019 Elsevier Ltd. All rights reserved.

Thompson, & Fish, 2001). Unsworth (1999) identified travelling as a leisure pursuit notably associated with a safety threat for people with epilepsy. In a first medical study of epilepsy and air travel, it was found that air travel can promote an increase in epileptic seizures after a flight for those who have a prior history of flight-related seizures (Trevorrow, 2006). Epilepsy/seizures have been reported as one of the top four reasons for flight diversion because of an on-board medical emergency (Drazkowski, 2007). Whilst most seizures do not need medical intervention, there can be irreversible neuronal injury and even death from prolonged convulsive status (Trevorrow, 2006). As such, the study of epilepsy has practical implications for examining and managing the health risks of travel, and in formulating policies, procedures and information to help in the medical management of those with epilepsy wanting to travel. From a social science perspective, there remains little knowledge about how the lived nature of epilepsy may affect the travel experience.

The travel propensity and experiences of individuals diagnosed with epilepsy, a population mostly neglected by tourism researchers, is the focus of this paper. There are many lenses through which we can look at the lived experiences of people with disabilities, including embodiment (Darcy, 2012; Small, 2015) and stigma (Goffman, 1963; Link, Wells, Phelan, & Yang, 2015). Whilst recognising these previous approaches, this paper adopts phenomenology as a theory as well as a scientific method of investigation. A further foundation for the paper is the social construction of disability and its personal lived experience (Oliver, 2009; Owens, 2015). Thus, it is recognised that it is not a person's condition that is disabling; rather, it is a form of social oppression caused by the hostile social environment (Bishop & Allen, 2003; Buhalis & Darcy, 2011; Darcy, 2012; Lehto, Luo, Miao, & Ghiselli, 2018). This provides the context for understanding the relationship between the individual's lived experience, society's attitudes and the focus on creating environments that enable independent, equitable and dignified participation. Whilst people with epilepsy lack an external signifier of disability, such as a wheelchair or guide dog (Dwyer & Darcy, 2011), their condition has the potential to unsettle the travel experience.

Literature review

Epilepsy and travel

There is a growing body of research on issues of disability and tourism (see, for example, the edited collection by Buhalis & Darcy, 2011). Consideration of independent travel for people with invisible disabilities is evident in the disability studies literature (for example, Stock, Davies, Wehmeyer, & Lachapelle, 2011). However, only a small handful of medical studies have evaluated the impact of epilepsy on travel (see Cummins & Schubach, 1989; Devkota & Karki, 2010; Drazkowski, 2007; Trevorrow, 2006). These previous studies have considered the medical link between epilepsy, air travel and driving. A much wider body of work has considered its impact on quality of life, including ability to participate in sports and leisure (see Bishop & Allen, 2003; Dubow & Kelly, 2003; Jacoby, 2002; Kobau, Luncheon, Zack, Shegog, & Price, 2012; Lim, 2010; Raty & Larsson, 2007). Epilepsy as a chronic condition is generally seen to reduce quality of life because it limits positive life experiences and sense of personal control. Of particular note, Baker et al. (2008) found that 37% of the children/teenagers in their study expected their condition to hinder their future opportunities for travelling and exploring. Despite the importance of understanding the subjective experiences of people with epilepsy (Collard & Marlow, 2016), discussion of the impact of epilepsy on the lived nature of the travel experience has not yet been taken up by tourism scholars, nor the expectation that the condition may hinder travel wishes and opportunities.

In the medical field, it is known that a person with epilepsy faces considerable challenges when it comes to using transportation (Drazkowski, 2007; Graf, Stuben, & Pump, 2012; Shand, 2000; Silverman & Gendreau, 2008; Skjenna, Evans, Moore, Thibeault, & Tucker, 1991). In relation to air travel, Trevorrow (2006) investigated whether flying is linked to an increase in epileptic seizures and found that seizures were significantly more common in the first few days after flying. However, those individuals had higher seizure frequency generally, held greater worry about having a seizure during a flight, and were more inclined to avoid air travel as a result. In terms of the flights, distance travelled, duration, time zones navigated and direction of the flight were not found to affect the occurrence of seizures. Those individuals with complete seizure control were found to be unlikely to experience post-flight seizures.

Air travel is said to affect the frequency of seizures because sleep rhythms are disrupted, oxygen desaturation of the cabin air may occur, along with hyperventilation, a lack of hydration, and increased stress – all seen to be triggers of epileptic seizures. Indeed, Devkota and Karki's (2010) study of three diagnosed cases of epilepsy on a long-haul flight revealed these to be triggers of epileptic seizures during the flight despite the individuals concerned taking their regular medication. As such, the study found air travel to play a role in exacerbating epilepsy causing in-flight medical emergency. Given the lack of validation and agreement about the likely effects of flying on precipitating seizures, previous scholars have called for more research in addition to guidelines for identifying individuals at risk of seizures related to air travel and for catering to their needs (Trevorrow, 2006).

The stigma of epilepsy

A review of previous studies reveals the social representation of epilepsy: in addition to its clinical condition, which can cause physical harm to a person, epilepsy remains shrouded in misconceptions and negative stereotypes exist. As such, epilepsy has psychological and social impacts on an individual. People with epilepsy are negatively affected by its stigma (Hills & MacKenzie, 2002; Jacoby, 2002; MacLeod & Austin, 2003). Previous health science research links the effects of its stigma to increased rates of psychopathology and decreased social interactions (Dell, 1986; Jacoby, 2002). 'Stigma' is an attribute conceptualised by society as discrediting, signalling difference, outsider status or deviance (Becker, 1963; Goffman, 1963; MacLeod & Austin, 2003). The stigma is linked to a number of factors including poor seizure control, inadequate awareness of the condition, and under-resourced medical

services. Ultimately, it is not the person's disability that is the origin of stigma, but society at large and the associated labelling of undesirable differences that cause oppression and social rejection (Dattilo, 2017; Elliott, Ziegler, Altman, & Scott, 1982; Kurzban & Leary, 2001). Kurzban and Leary (2001) argue that social exclusion, which lies at the heart of stigma, is consensual and characteristic of human cultures around the world and throughout history.

Jacoby (2002) traces the stigmatisation, public attitudes, historical categorisation of epilepsy and the legal discriminations imposed on people with epilepsy. As epilepsy is a 'prescribed disability' in many developed countries (Jacoby & Austin, 2007), people with the condition are protected by law. Yet, like other people with disabilities, they still experience legal discrimination, especially in relation to employment and driving (Jacoby, 2002). Historically, epileptic seizures have been associated with sin, evil, demonic possession, or seen as a contagious disease; they are perceived as dangerous and threatening to the accepted social order and cultural norms (Bagley, 1972; Jacoby, 2002; Scott, 1972; Temkin, 1971). Even following biomedical explanations of the condition, studies link epilepsy to associations with and perceptions of aggression, criminal behaviour, abnormal sexual activity and hereditary degeneracy (Jacoby & Austin, 2007). Studies show that its social acceptability is greater now than in the past (Caveness & Gallup, 1980; Dell, 1986; Harrison & West, 1977; Jacoby, 2002). However, low levels of knowledge about epilepsy perpetuate the stigma, and the unpredictable, uncontrollable, inexplicable and distressing nature of seizures continue to arouse fear for the person witnessing the seizure as well as the sufferer (Hills & MacKenzie, 2002; Jacoby & Austin, 2007).

There exists a large body of literature about epilepsy and behaviour. For the person with epilepsy, the stigmatisation is often associated with the shame and guilt of "undesired differentness" (Jacoby, 2002, p. 11). The result of this is often for the individual to adopt the coping strategy of concealment: to keep one's condition of epilepsy a secret (Goffman, 1963; Jacoby, 2002; Schneider & Conrad, 1981). As such, there is evidence that people with epilepsy actively plan to avoid high-risk situations in which they may experience a public seizure, and develop strategies to cover public evidence of their condition – either through keeping their condition a secret or employing neutral terms when referring to their seizures, for example, terms such as "funny turns" or "dos" (Jacoby, 2002, p. 12). For the individual, stigma is ultimately related to the frequency of an individual's seizures, whereby more frequent seizures become visible and impact upon interpersonal interactions and informal control (Jacoby, 2002).

The stigma is also found to be a chronic self-limiting condition; even when the seizures are no longer occurring, the individual carries the fear of recurrence of the 'offensive behaviour' (Albrecht, Walker, & Levy, 1982). There is evidence that, in remission, epilepsy may cease to be a feature of everyday life but can never be cured with certainty, and as such it remains a 'spoiled identity' (Goffman, 1963). Resultantly, epilepsy is a stigmatising disorder associated with higher than typical rates of anxiety (Jacoby & Baker, 2000) and social isolation (Jacoby, 1992). Findings of previous studies attest that the fear of felt stigma (the fear and shame associated with being epileptic) is often of greater negative consequence to the individual with epilepsy than any actual incident of discrimination (Trostle, 1997). That is, the fear of felt stigma often leads people to hide their condition from others even if there is no evidence of discrimination against them (Jacoby & Austin, 2007). The concealment may also be supported by the negative view of epilepsy held by parents and other family members (Jacoby, 2002; Schneider & Conrad, 1981; West, 1979). As such, differing aspects of stigma, whether felt/experienced, imagined or internalised and managed through strategies to avoid stigma (Elliott et al., 1982; Link et al., 2015), are important considerations affecting social interaction in the tourism experience. The particular cultural and social environments in which stigma are experienced also warrant greater investigation.

Following the established knowledge of epilepsy in the health and leisure sciences literature, what remains to be known is the lived experiences of travel for people with the condition; of how it is to travel with epilepsy and the extent to which their travel experiences may be affected by seizure episodes, stigma and anxiety.

Study methods

The study used a phenomenological, qualitative approach that sought to understand the experiences of individuals with epilepsy in relation to travel. A phenomenological position was used because the study aimed to capture the unique and subjective lived experiences (Hegel, 1949; Moran, 2000; Willson, McIntosh, & Zahra, 2013) of those who live with the hidden neurological condition. This approach mirrors previous studies designed to provide insights into the nature of the lived experiences of people with disabilities in their own words (see, for example, Collard & Marlow, 2016; Darcy, 2012; Lehto et al., 2018; Sedgley, Pritchard, Morgan, & Hanna, 2017) and is grounded in health and leisure science research techniques. It is argued that qualitative methods are better suited to uncovering the subtleties and complexities of how epilepsy affects a person's life (Vaismoradi, Turunen, & Bondas, 2013).

The methods used to understand the potential impact of epilepsy on travel involved in-depth, conversational-style interviews that prioritised the respondent's voice. An open-ended approach was applied because it avoids a researcher-imposed framework thereby enabling the addition of new ideas and information (see Bishop & Allen, 2003). Because stigma, whether internally felt or actually encountered, is noted to be one of the greatest challenges faced by people with epilepsy, it is important to allow them the space and freedom to describe situations that may make them feel 'different' (MacLeod & Austin, 2003). Phenomenology requires respondents to be able to articulate and express their thoughts and feelings about the experience even if these are difficult to discuss.

Questions of what and how, and not why, were used to explore the individual's lived experience and avoid judgement (Collard & Marlow, 2016). To explore the 'why' questions, personal diaries could be provided to respondents in a follow up study to supplement the interviews and focus on the individual's experience away from perceived judgement. The interview opened with a general question asking the respondent to share how epilepsy affects their life and was followed by the questions "Has epilepsy ever affected your travel experiences? *In what ways?*" These questions were then followed by additional probing questions seeking clarification or elaboration. Each interview took place in the respondent's own home. The location was chosen by the respondent and determined by them as a comfortable and 'stress free' environment.

Table 1
Profile of respondents with epilepsy.

Pseudonym	Gender	Age	Employment	Family
Jane	Female	70	Retired	Married
Jenny	Female	65	Retired	Married
Lorraine	Female	72	Retired	Married
Tom	Male	22	Unemployed	Single
Bill	Male	55	Part-time	Married
Betty	Female	54	Unemployed	Married
Martha	Female	56	Employed	Married

A total of seven in-depth interviews were conducted, each between 50 and 75 min in duration; all were audio-recorded and transcribed. Whilst seven respondents may appear a small number, in phenomenological research, rich insights can emerge from a small number of interviews to provide clarity on an under-researched topic such as the unique, lived emotional experiences and nuances of travel for individuals with disabilities (May-West, Craig, & Wilder, 2018; Sedgley et al., 2017). Previous qualitative studies of the leisure or sport experiences of people with epilepsy have included samples of between one and four (e.g. Collard & Marlow, 2016; MacCosham, 2017). One respondent worked as an advisor with an epilepsy charitable trust located in the North Island of New Zealand. The other six were individuals with epilepsy recruited through the author's relationship with the trust via a letter circulated to the trust's members with details of how to opt-in to the research. The sample of respondents thereby comprised a convenience sample of those who were willing to disclose their condition, recruited through the author's trusted relationship with the charitable organisation, built over a period of about two years. Trust is a key pillar in the success of qualitative research with people with disabilities who historically have had an uneasy relationship with research (Tregaskis & Goodley, 2005).

The demographic profile of respondents is provided in Table 1 to allow readers to gain a sense of the interviewees. As epilepsy is a spectrum of disorders with about forty different seizure types, each respondent lived with varying frequencies of seizures, severity and medication types. Most of the respondents had epilepsy fairly well controlled. The study does not claim to be representative of different types or severity of seizures, nor does it treat epilepsy as a homogenous condition. It should also be noted that the perspective of disability provided in this study is one located within a western cultural setting where individuals with disabilities experience a higher standard of living (Lehto et al., 2018) and levels of stigma may differ from those in the developing world (Jacoby, 2002).

Each interview began after written and/or verbal consent had been gained following an approved ethical process. Interviews were audio-recorded with the permission of the respondents to ensure accuracy of the data captured and to allow the respondents the opportunity to validate their transcript. At the request of the respondents, their details were kept confidential and their names were replaced with pseudonyms. All the respondents were controlling their epilepsy with regular prescribed medication; however, the epilepsy advisor remained on-call to advise and support the researcher in case of a seizure emergency (this did not occur).

Following interview transcription, thematic analysis began. Thematic analysis using Braun and Clarke's (2006) process was conducted to unveil the rich illustrative narratives in addition to the identification of key themes. The transcripts were then read again to confirm that no other themes were present (see Vaismoradi et al., 2013). The findings reported below are the most common themes across each respondent's narrative (Table 2). Every individual with epilepsy is unique concerning the type, frequency, severity and impact of his or her seizures (Arida et al., 2008). For this reason, the findings of this exploratory research cannot be generalised for every individual with epilepsy; moreover, as phenomenology rejects the positivistic paradigm the study was not concerned with generalising concepts (Hegel, 1949). There is a need, therefore, for further research to build on the exploratory insights reported here.

The hidden side of travel

Despite all the respondents claiming that epilepsy had altered their lives dramatically, they were all active participants in domestic and international travel. Yet their reported travel experiences masked certain hidden elements. Analysis of the data revealed three main themes relating to the experience of travel for the individuals with epilepsy: *seizure episodes*; *invisibility of the condition*; and *managing anxiety*. These three themes will now be discussed.

Table 2
Thematic spread across each interview subject.

Pseudonym	Seizure episodes	Invisibility of the condition	Managing anxiety
Jane	✓	✓	✓
Jenny	✓	✓	✓
Lorraine	✓	✓	✓
Tom	✓	✓	✓
Bill	✓	✓	✓
Betty	✓	✓	✓
Martha	✓	✓	✓

Seizure episodes

In this first theme, respondents explained how epilepsy can influence the ability to travel because of the possibility of seizure episodes. Martha's quote typified the response:

For travel, if you have no seizure control and you worry about the type of epilepsy that you have, that could restrict your ability to enjoy life, from catching a bus, going to a bank or a café, or to travel.

Despite having different frequencies and severity of seizures, all the respondents spoke of their active participation in travel. This is also despite the fact that all of the respondents had been legally prevented from driving because of their condition, and some reported difficulties with biking, exercising and holding down employment. Their active participation in travel may be due to all in the sample having epilepsy that was well-controlled. Thus, seizure episodes do not necessarily impede participation in travel as it has been shown in other types of leisure (see Collard & Marlow, 2016; MacCosham, 2017).

The desire to live a life as "normal" as possible was expressed by all the respondents. They chose to participate in travel as it contributed to their quality of life and tried not dwell on the fact that they might have a seizure: "*If it happened, it happened ... I'm still going to lead the life I want to live and not let this control me*" (Jane); "*I had to get on with it. You can stay at home and sit inside your own four walls and have one seizure every so often, or you can go away and live*" (Jenny).

That said, Jenny and Tom did report incidents that had left a memorable impact on them, highlighting the potential disruption and uncontrollability that seizures can cause. As Jenny recalled:

Once I had to go to the motel people and say, "Oh look, um, I've had a seizure and ..." because I had been incontinent of urine when I had the seizure. Now I will always be a little bit prepared while I'm away, put the towel underneath me when I go to bed.

Tom also reported how his epilepsy affected his ability to travel:

If there is a long wait for transport, that is the biggest way it has affected me. I have atonic seizures which means that I lose muscle control, but that mainly shows up as just blipping and falling over and losing balance. Sometimes more than that, but it's very rare. I also have photo epilepsy and a few other things, being frightened of loud noise, sudden change in contrast of light.

Incidences of seizure were generally characterised as starting with feelings that 'something is not quite right'; 'an uneasy feeling'; 'feeling a little bit confused'; 'daydreaming'; 'like a zombie'. Respondents reported they were often unaware that they had experienced a seizure. As Jenny explained:

Usually I would wake up, I'd have had a tonic-clonic [seizure] and woken up about an hour later, and I'd just know I'd had one because I may have been incontinent or I have this urgency to move my bowels because everything's gone haywire in there and it's affected everywhere else.

The stigma of epilepsy was also found to disrupt the travel experience. For example, Lorraine recounted an incident involving her assistance dog:

A woman came along and sat a two year old on her [the dog's] back. I said, "Excuse me, she's a service dog." She said, "Oh I don't care, if you've got your dog in public, I can do what I want." I said, "I'm an epileptic and it's important that I have my dog because she will alert people or me that I am going to have one." She said, "I don't care, if you're that bad you should stay at home."

Indeed, all the respondents mentioned the (mis)understandings of epilepsy they felt and faced, as the following quotes illustrate. *When people find out I've got epilepsy, they can be a little stand offish, until they get to know that they're not going to catch epilepsy. They may be frightened that I am going to have a seizure in the middle of the hotel and scare people away.*

(Bill)

I've known people who in their seizure pattern have looked drunk and disorderly and have been marched out of the restaurant for being drunk and disorderly, when in fact they are just having a seizure.

(Martha)

Ultimately, despite living with seizures, the respondents had mostly learned to manage the effects of their condition and chosen not to let it stop their ability to live a 'normal' life as they wanted to live it, which included their ability to participate in travel. The desire to travel for a sense of the 'normal' or ordinary life is a finding echoed previously (Lehto et al., 2018; Small, 2008). Hunter-Jones (2005), for example, in her study of cancer and tourism found that travel facilitated a sense of escape from the normality of everyday life but also instilled a sense of normality into life for a defined period of time. Many previous studies have similarly concluded that leisure and travel are a means to positively enhance quality of life for people with disabilities (e.g. Lehto et al., 2018; Small, 2015; Stock et al., 2011). Travel may also signify an act of resistance (Eichhorn et al., 2013) or a way to ignore the full impact epilepsy may have on their life (Collard & Marlow, 2016).

The findings presented here also confirm that travel can be influenced by the prevailing incidence of felt and perceived stigma associated with the condition (Deville & Kastenholz, 2018; Hunter-Jones, 2005; Jacoby, 2002; Jacoby & Austin, 2007). In short, whilst not affecting travel motivation, living with the unpredictable nature of seizures is found to impact on the nature of the tourist experience, albeit not necessarily by seizure episodes per se but rather through social and internalised stigma. This is in contrast to previous leisure studies that have shown stigma to have less impact on participation in other leisure activities (e.g. Lim, 2010; MacCosham, 2017; Unsworth, 1999). Whilst this finding requires further validation, it may be useful for understanding how an individual maintains engagement in travel, and is influenced by their condition, despite being stigmatised.

Invisibility of the condition

The second theme relates to epilepsy as an invisible condition. Sometimes confused with a mental health condition (Oliver, 1980), epilepsy is instead a neurological condition. As one respondent described, “*it's invisible because you haven't got anything to show for it*” (Jane). As such, a key finding of this study was that most respondents chose not to disclose their condition unless a seizure happens or until there is perceived to be a need for others to know. “*It's a need-to-know basis*” (Martha); “*I never really bring it up*” (Jane). The condition, therefore, can be seen as a hidden element that may affect the travel experience.

It is a hidden disorder, and some people appear quite alert that are having a seizure, but appear odd. They might start tapping their feet. They might decide they can smell something or that their senses have been heightened; their awareness has been heightened and so they might feel a bit disconnected for a period of time.

(Martha)

It's not very visible, a lot of people, people I know, they don't know that I've got it [epilepsy], because it's not something that you need to say.

(Jenny)

It can be kept hidden because “*there's nothing to show you have a hidden condition, unlike the wheelchair sign*” (Martha). Comments made by respondents referred to the fact that people with epilepsy prefer to keep it hidden because of the stigma and lack of awareness of the condition. The following quotes demonstrate this:

Most people I don't think really understand it and they think if you've got epilepsy your whole intellect is the same.

(Jane)

I don't know why it came up that I actually said, “I have epilepsy”, and I told them this particular day, and she said, “Oh you don't look as if you have”, and I said, “Well what am I supposed to look like?” and she sort of stood there and stood back.

(Jenny)

Martha held the position that most of the stigma is related to fear of the condition:

I think there is fear still. It's something that people don't want to get too close to. It's a health and safety issue for some people. In some quarters, it's a possession of the spirit. It's the fear of the unknown and I think that unknown is because people only see one type of seizure, which is the convulsive seizure. They don't actually understand that there are thirty-nine other seizure types, and so everyone is lumped into the same category. I think people feel powerless too when they witness someone having a seizure. It looks painful.

When asked about instances where they would consider disclosing their condition during travel, respondents commonly mentioned that they would disclose it if they were travelling alone. That said, none of the respondents had travelled alone. One further reason was if the situation necessitated it, as shown in the following quotes:

If we'd just gone into a restaurant for a meal, unless I had a seizure right in the middle of the meal, we probably wouldn't say anything. If someone on the next table had a seizure, then, yeah, we would probably go over to them and say, we'll give you a hand if you want, I know what to do. Unless it's relevant to the situation, we probably wouldn't say.

(Betty)

The only times I do it is when there is a photo epilepsy issue, that's a stand-out one. I've had to walk out of places because of their strobe lights ... gives me motion sickness and I need to go and sit outside.

(Tom)

The findings thus provide evidence to confirm that epilepsy is not only an invisible condition prone to disrupting participants' lives but also one shrouded in concealment (Jacoby, 2002; Schneider & Conrad, 1981). The coping strategy of concealment may involve not disclosing their situated identity in a given social interaction and adopting assimilative behaviours (Elliott et al., 1982). Strategies to proactively anticipate and avoid stigma have similarly been reported among people with a mental health issue (e.g. Link et al., 2015; Sedgley et al., 2017). Baker et al.'s (2008) study of children/teenagers with epilepsy found that one third of them, and a quarter of parents, kept their epilepsy a secret from other people out of a fear of being treated differently, because witnessing seizures can be ‘scary’ for other people and there is a general belief that people should not know. The fear of being stigmatised therefore acts as a significant barrier to disclosure and reinforces the wish to not want to be different from peers; secrecy becomes a key means of adaptation (Jacoby, 2002; Valeras, 2010). Concealment has been found to result in reduced self-esteem and reduced quality of life; it is a sign that self-identity is threatened (Hills & MacKenzie, 2002; MacLeod & Austin, 2003). Indeed, confirming previous studies of the condition, this study similarly provides some evidence that the concealment comes with an overriding feeling of anxiety that burdens the individual (Jacoby & Baker, 2000). As Martha explained: “*It's a condition that fills people with fear and dread and stigma, prejudice in some cases.*”

Managing anxiety

The third theme relates to the respondents' strategies for managing their ‘anxiety’ associated with the condition whilst travelling. The noted anxiety that accompanies not knowing when a seizure will happen was the reported reason why all of the respondents talked about the need for non-disclosure and to have ‘epilepsy seizure plans’ so that they feel secure about travelling. “*They plan to get on with their lives knowing that they are in amber alert*” (Martha). The following quote by Tom illustrates the worry and anxiety of travel:

There's always things I worry about. There's exertion, like how much exertion I've done, how much stress am I putting myself through. To minimise stress I've gone through and made a full itinerary.

Martha explained that *"epilepsy is a very individual thing, so it's understanding what is important for a person to have a quality of life around their seizures"*. For the respondents, this meant feeling confident and safe whilst travelling by always travelling with someone they know who is going to look after them if they have a seizure. *"I've always had issues with anxiety and won't travel alone"* (Tom). It also meant sticking to routines, ensuring medication was taken routinely 12 h apart and avoiding their personal triggers such as tiredness, stress, diet, caffeine, sugar, alcohol and dehydration. *"I stay very thoughtful of my triggers and avoid them at all costs"* (Tom).

Respondents explained that overseas travel can become problematic in this sense because of managing routines, taking prescriptions for medication to different countries, language barriers, connecting flights, different time zones and jetlag. *"It takes a brave person to travel on their own in some cases"* (Martha). This sentiment was echoed by all the respondents and is illustrated in the following quote from Jane's interview:

I've always travelled with [my husband] you see. I would never travel alone, never. And even though I am pretty well controlled, I would never travel alone.

Due to the possible stresses of travelling, all the respondents described the careful planning they put in place before their trip to ensure their safety should they have a seizure whilst travelling. Getting to know timetables, having a medic alert bracelet, doctor's clearance to travel, carrying a form of identity, having emergency phone contacts, carrying a prescription and plenty of medication, taking snacks, drinking plenty of water, ensuring a designated 'sanctuary' space out in public, and knowing the location of the closest hospital, were all important to having *"some form of back-up plan should you have a seizure, and feel secure about it"* (Martha).

On the whole, respondents described how they try and stick to their normal routines whilst they travel, as the following quotes demonstrate:

If I can board a plane near to sleep time or the evening, I am in the same sleep pattern as I would be at home ... I'm still keeping the same pattern as what I would do. I have had no repercussions of that.

(Jane)

It's just a matter of perfect timing and keeping in your routine.

(Lorraine)

Travellers with epilepsy are therefore faced with a range of emotional and practical challenges whilst away from the familiarity and routine of home. Anxiety has previously been reported in people with epilepsy's experiences of leisure, wherein the frustration or fear of recurring seizures was found to prevent exercise, causing the feeling of 'being held back', symptoms of depression and increased social isolation (Collard & Marlow, 2016; Han et al., 2011; Jacoby & Baker, 2000). For people with disabilities, emotions and anxiety are similarly found to amplify during travel due to the unfamiliarity of the tourism environment (Deville & Kastenholz, 2018; Lehto et al., 2018; Sedgley et al., 2017; Small, 2015). These emotions are compounded by the social discrimination of their disability (Darcy, 1998), yet remain in contrast to the more commonly reported positive emotional stimulation and hedonism of travel (Krippendorff, 1987). Ensuring one is always with another person, careful planning and the need to create familiar routines and structures whilst travelling have similarly been previously reported as coping strategies for travellers with disabilities (Deville & Kastenholz, 2018; Lehto et al., 2018; Sedgley et al., 2017; Small, 2015; Unsworth, 1999).

Discussion and conclusions

Most previous attention to disability in tourism research has focused on the experiences of travellers with visible disabilities (Deville & Kastenholz, 2018; Sedgley et al., 2017; Small, 2015) rather than the nature of travel for people with invisible conditions. Connecting to the established work in disability studies, health and leisure sciences, this paper provides a snapshot of how an individual with epilepsy's travel experiences may be influenced by his or her hidden condition and its social stigma despite a lack of visible signs of 'discredited difference' (Goffman, 1963). In this way, the study found that having epilepsy is far more than simply having seizures. Indeed, *"To have epilepsy is to open oneself to the full force of past and contemporary social prejudice and misunderstanding"* (Trostle, 1997, as cited in Jacoby, 2002, p. 17). Jacoby (2002) argues that although social attitudes toward epilepsy have improved, people with epilepsy still cannot anticipate what they can expect of their social interactions with other people. As a result, a key finding from this exploratory study was the desire of travellers with epilepsy to keep their condition hidden in order to avoid perceived stigma and discrimination and to ensure their feelings of confidence and safety. In psychology, this has been termed 'symbolic interaction stigma' wherein people who are stigmatised anticipate the negative reactions of others that are potentially harmful (even if they do not occur), conjure what may transpire and strategise to manage the situation in the best way they can (Link et al., 2015). Indeed, previous studies of stigma attest to its disruptive impact and the strategies used by the stigmatised to cope with it (e.g. Elliott et al., 1982).

Whilst not impeding motivation to travel, the study illuminated the pronounced influence of stigma on the travel experience for people with epilepsy, despite it being a hidden condition. The findings thereby lend credence to previous studies of epilepsy wherein the effects of the stigmatising of the condition, and the degree of fear and shame felt by those with the condition, were found to be more pronounced than the effects of seizure episodes (e.g. Jacoby, 2002). On a general level, the findings lend support for previous studies of disability and travel that have revealed the embodiment of disability differentiates the travel experience for people with disabilities compared to those without disabilities (e.g. Small, 2015; Stock et al., 2011).

There is also some evidence to suggest that travel experiences may differ according to the type of disability, raising the need for

further understanding of the plurality of lived experiences of disability (Owens, 2015). Specifically, the inconsistency of the occurrence of seizures, the ability to not disclose the condition, and its perceived stigma, renders the condition of epilepsy distinct (Baker et al., 2008). Whilst future research should consider the experiences of travellers with less well-controlled epilepsy beyond the more controlled sample of respondents reported here, the findings potentially dismiss previous claims that it is the visible (physical) signs of a disability/illness that generate the most tension for travellers (Darcy, 1998; Devile & Kastenholz, 2018; Eichhorn et al., 2013; Hunter-Jones, 2004). This conclusion, whilst needing further validation, stands to potentially challenge the existing dominant discourse around visibility in respect to the disablist social environment of tourism, wherein people with disabilities become objects for the gaze of others (Eichhorn et al., 2013).

Although the condition of epilepsy may not be obvious to others, the study findings reinforce arguments of disability as a social construct (Oliver, 2009). The nature of epilepsy is both medical and social (Baker et al., 2008; Bishop & Allen, 2003). Its associated social perception is generally related to its visibility and its controllability (Jacoby, Snape, & Baker, 2005). The study also draws attention to how this is experienced by those with epilepsy; that is, through the reported social restrictions perceived by travellers living with epilepsy that result in them keeping their condition hidden. To have disclosed their condition would have rendered them visible and hence vulnerable. As such, the invisibility of their condition was for the discernment of others – an attempt to ‘pass for normal’ (Joachim & Acorn, 2000). What becomes apparent is that, for the individual, this situation plays out in an inner anxiety, or ‘covert conflict’ (Hunter-Jones, 2004), in negotiation with the tensions of the wider problem of societal prejudice wherein their experiences might not conveniently ‘fit in’ with what society perceives to be ‘normal’ (Hunter-Jones, 2004; Jacoby, 2002).

Previous health and disability scholars have commented on ‘hidden distress’ wherein people with epilepsy increase the stress of managing their condition for fear of encountering stigma, with the result that the stigma has a far more disruptive effect on their life (Jacoby et al., 2005; Link et al., 2015). People with epilepsy must live with the anxiety of not knowing if or when their condition may reveal itself, and the likely impact, including the embarrassment of being caught out and discredited (Goffman, 1963; Joachim & Acorn, 2000). How managing the influence of stigma by the respondents in this study may compare to the lived experiences of travellers with other types of disability requires further investigation.

Invisibility was found here to become the internal coping strategy in tourism environments for travellers with epilepsy as they were able to set aside the label ‘epileptic’ (Jacoby, 2002). Prompted by fear, concealment has been shown to lead to social withdrawal and isolation (Link et al., 2015; Raty & Larsson, 2007). Whilst future research is needed to examine the longer-term implications of concealment, the findings presented here provide some evidence to show that the travel experience can become fear-laden and inauthentic. That is, that travellers are not able to be themselves because they are protecting their self-identity (Eichhorn et al., 2013; Valeras, 2010). In effect, people with epilepsy fall between (and disrupt) the dichotomy of disabled and nondisabled (Valeras, 2010); hence more understanding of disability identity and travel is required.

Concerns about autonomy and freedom, especially through the ability to travel, were found to be important aspects of a person with epilepsy’s perceived quality of life. This confirms previous suggestions that independence and autonomy are particularly valued and salient for people with epilepsy because they may be threatened or restricted by the occurrence of seizures (Bishop & Allen, 2003). Findings of this study confirm that travel is not only a marker of quality of life but also a signifier of a ‘normal’ life and autonomy. In this way, travel facilitates temporary escape from the restrictions faced in everyday life and the opportunity to traverse into a perceived realm of the ‘ordinary’ or ‘normal’. Indeed, the ability to travel has been viewed as a form of resistance that can be seen as a means to overcome oppression affecting people with disabilities (Eichhorn et al., 2013; Lehto et al., 2018; Tribe, 2007). However, the important need for travellers with epilepsy to stick to usual routines and also create ‘home-like’ structures whilst away to facilitate predictability, familiarity and safety (similarly found in Lehto et al., 2018; Sedgley et al., 2017) remains in contrast to previous tourism scholarship that attests the ‘home and away’ experiences of travel (Krippendorf, 1987). For these travellers, therefore, there is mounting evidence to support the need to reconceptualise travel and tourism.

The unfamiliar tourism environment was found to have produced heightened anxiety for these travellers with epilepsy, as has been similarly found for travellers with other disability types (e.g. Darcy, 1998; Small, 2015). It also created a situation of dependency. The fact that travellers with disabilities are accompanied by a travel companion is well documented (see Darcy, 1998; Devile & Kastenholz, 2018; Lehto et al., 2018; Unsworth, 1999). However, the fact that respondents in this study never travelled alone was distinct from perhaps the case of travellers with severe disabilities who might not be able to travel without the assistance of an aide or companion (Smith, 1987). Rather, for these respondents, it was a personal choice driven by the anxiety of their condition. It was also dependent on having a travel companion; not having this support would otherwise reduce the opportunity for travel and compromise feelings of autonomy (Bishop & Allen, 2003). This finding is significant because most tourism scholarship perpetuates travel as independent. In fact, the findings of this study reveal that dependency for travellers with epilepsy appears more pronounced during travel than it may be in the home environment as risk is heightened and routines harder to follow, causing greater anxiety. There is a need, therefore, to advance understanding of dependency and/or independency in tourism scholarship, noting in particular the critical role of carers or travel companions, the concept of ‘care’ in travel, and the relational and emotional entanglements of lived travel experiences.

As a condition that can often effectively be managed with medication, the study findings provided some evidence to suggest that, in contrast to travellers with other types of disabilities, people with epilepsy may face fewer barriers in accessing and participating in travel. However, they similarly face careful planning and decision-making processes (see Darcy, 1998; Sedgley et al., 2017). Whilst the study findings are helpful in understanding how individuals with epilepsy stay engaged in travel, there remains an important need for the tourism industry to provide information to help support travel planning for people with (invisible) disabilities, a need echoed in much previous accessible tourism research (e.g. Buhalis & Darcy, 2011; Buhalis & Michopoulou, 2011; Eichhorn, Miller, Michopoulou, & Buhalis, 2008). Previous medical studies show that transportation issues, in particular, remain a major concern for

people with epilepsy. Yet there remain very few studies of the best-practice advice to give to people with epilepsy using transportation, or information on how to avoid problems after arriving at a destination (Drazkowski, 2007), such as in hospitality settings (Boxall, Nyanjom, & Slaven, 2018; Darcy, 2010). In addition to the provision of information, the travel industry could provide better accessible experiences through improved training and management, medical management advice, accessible product and service design, and practices based on consideration of the social approaches to disability to ensure equity, dignity and independence (Darcy, 2012; Darcy & Dickson, 2009; Daruwalla & Darcy, 2005). There may also be the opportunity to consider the potential of new technologies to support and assist independent travel, as has been raised by studies of people with intellectual disabilities (e.g. Dattilo, 2017; Stock et al., 2011).

An implication of this study is that keeping a condition 'hidden' may also have the likely consequence of perpetuating ignorance and social stigma around the condition. As found with other types of disability, the need for education, awareness raising and training within the industry and also wider society is thus crucial to avoid perpetuating tourism as a site of marginalisation (Daruwalla & Darcy, 2005; Jacoby, 2002). Notably, the significant impact of social stigma evidenced in this study warrants further attention, as it is an important predictor of quality of life (Jacoby & Austin, 2007). Future research could investigate stigma in the context of a tourist trip, or the tourism industry in general. With respect to tourists with epilepsy, future studies could examine their social interactions with other tourists and possible stigmatisation. There is also a need to consider self-stigma interventions designed to reframe the travellers' perceptions and interpretations of others' attitudes and behaviours within their own consciousness and resulting affective behaviours to help alleviate symbolic interaction stigma. As the findings of this study cannot be generalised to all types (and frequencies) of epilepsy, there is also a need for further investigation into the risks of epilepsy and strategies to cope/adapt during travel. Future research could also examine the travel experiences for people with other invisible disabilities – for example, diabetes, hearing loss, brain injuries, and invisible chronic illnesses – whose narratives remain unheard in tourism scholarship. The relationship between visibility and invisibility in disability, stigma, and the complexity of disclosure and non-disclosure remains poorly understood (Joachim & Acorn, 2000). Ultimately, there remains a need for emancipatory research to tackle disablist society and 'normalising' discourse (Oliver, 1992, 2009), as well as the social and internalised perceptions of stigmatised conditions, so that travellers can remain true to themselves in their quest for quality of life.

Declaration of competing interest

None.

Acknowledgements

The author would like to thank the anonymous reviewers for their valuable and constructive feedback on the manuscript. Special thanks to the respondents who gave generously of their time to take part in this research.

References

- Albrecht, G. L., Walker, V. G., & Levy, J. A. (1982). Social distance from the stigmatised: A test of two theories. *Social Science and Medicine*, 16, 1319–1327.
- Arida, R. M., Cavalheiro, E. A., da Silva, A. C., & Scorza, F. A. (2008). Physical activity and epilepsy: Proven and predicted benefits. *Sports Medicine*, 38(7), 607–615.
- Bagley, C. (1972). Social prejudice and the adjustment of people with epilepsy. *Epilepsia*, 13, 33–45.
- Baker, G. A., Hargis, E., Hsieh, M., Mounfield, H., Arzimanoglou, A., Glauser, T., ... Lund, S. (2008). Perceived impacts of epilepsy in teenagers and young adults: An international survey. *Epilepsy & Behavior*, 12, 395–401.S.
- Becker, H. (1963). *Outsiders: Studies in sociology of deviance*. New York, NY: Free Press.
- Bishop, M., & Allen, C. A. (2003). The impact of epilepsy on quality of life: A qualitative analysis. *Epilepsy & Behavior*, 4, 226–233.
- Boxall, K., Nyanjom, J., & Slaven, J. (2018). Disability, hospitality and the new sharing economy. *International Journal of Contemporary Hospitality Management*, 30(1), 539–556.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Buhalis, D., & Darcy, S. (Eds.). (2011). *Aspects of tourism series*. Bristol, England: Channel View Publications.
- Buhalis, D., & Michopoulou, E. (2011). Information enabled tourism destination marketing: Addressing the accessibility market. *Current Issues in Tourism*, 14(2), 145–168.
- Caveness, W. F., & Gallup, G. H. (1980). A survey of public attitudes towards epilepsy in 1979 with an indication of trends over the past thirty years. *Epilepsia*, 21, 509–518.
- Collard, S. S., & Marlow, C. (2016). The psychosocial impact of exercising with epilepsy: A narrative analysis. *Epilepsy & Behavior*, 61, 199–205.
- Cummins, R. O., & Schubach, J. A. (1989). Frequency and types of medical emergencies among commercial air travelers. *Journal of the American Medical Association*, 261, 1295–1299.
- Darcy, S. (1998). *Anxiety to access: Tourism patterns and experiences of New South Wales people with a physical disability*. Sydney, Australia: Tourism New South Wales.
- Darcy, S. (2010). Inherent complexity: Disability, accessible tourism and accommodation information preferences. *Tourism Management*, 31(6), 816–826.
- Darcy, S. (2012). (Dis)embodied air travel experiences: Disability, discrimination and the affect of a discontinuous air travel chain. *Journal of Hospitality and Tourism Management*, 19, 1–11.
- Darcy, S., & Dickson, T. (2009). A whole-of-life approach to tourism: The case for accessible tourism experiences. *Journal of Hospitality and Tourism Management*, 16(1), 32–44.
- Daruwalla, P., & Darcy, S. (2005). Personal and societal attitudes to disability. *Annals of Tourism Research*, 32(3), 549–570.
- Dattilo, J. (2017). *Inclusive leisure services*. Urbana, IL: Sagamore-Venture Publishing LLC.
- Dell, J. L. (1986). Social dimensions of epilepsy, stigma and response. In S. Whitman, & B. P. Hermann (Eds.). *Psychopathology in epilepsy: Social dimensions* (pp. 185–210). New York, NY: Oxford University Press.
- Deville, E., & Kastenholz, E. (2018). Accessible tourism experiences: The voice of people with visual disabilities. *Journal of Policy Research in Tourism, Leisure and Events*, 10(3), 265–285.
- Devkota, A. R., & Karki, A. R. (2010). Seizure precipitated during long haul flight. *Journal of the Institute of Medicine*, 32(3), 59–61.
- Drazkowski, J. F. (2007). Driving and flying with epilepsy. *Current Neurology and Neuroscience Reports*, 7, 329–334.

- Dubow, J. S., & Kelly, J. P. (2003). Epilepsy in sports and recreation. *Sports Medicine*, 33(7), 499–516.
- Dwyer, L., & Darcy, S. (2011). Economic contribution of tourists with disabilities: An Australian approach and methodology. In D. Buhalis, & S. Darcy (Eds.). *Accessible tourism: Concepts and issues* (pp. 214–240). Bristol, England: Channel View Publications.
- Eichhorn, V., Miller, G., Michopoulou, E., & Buhalis, D. (2008). Enabling access to tourism through information schemes? *Annals of Tourism Research*, 35(1), 189–210.
- Eichhorn, V., Miller, G., & Tribe, J. (2013). Tourism: A site of resistance strategies of individuals with a disability. *Annals of Tourism Research*, 43, 578–600.
- Elliott, G. C., Ziegler, H. L., Altman, B. M., & Scott, D. R. (1982). Understanding stigma: Dimensions of deviance and coping. *Deviant Behavior*, 3(3), 275–300.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Graf, J., Stuben, U., & Pump, S. (2012). In-flight medical emergencies. *Deutsches Arzteblatt International*, 109(37), 591–602.
- Han, K., Choi-Kwon, S., & Lee, S. (2011). Leisure time physical activity in patients with epilepsy in Seoul, South Korea. *Epilepsy & Behavior*, 20, 321–325.
- Harrison, R., & West, P. (1977). Images of a grand mal. *New Society*, 40, 762–782.
- Hegel, G. (1949). *Phenomenology of mind*. B. Baillie, Trans. (2nd rev. ed.). New York, NY: Humanities Press.
- Hills, M. D., & MacKenzie, H. C. (2002). New Zealand community attitudes toward people with epilepsy. *Epilepsia*, 43(12), 1583–1589.
- Hunter-Jones, P. (2004). Young people, holiday-taking and cancer – An exploratory analysis. *Tourism Management*, 25(2), 249–258.
- Hunter-Jones, P. (2005). Cancer and tourism. *Annals of Tourism Research*, 32(1), 70–92.
- Jacoby, A. (1992). Epilepsy and the quality of everyday life: Findings from a study of people with well-controlled epilepsy. *Social Science and Medicine*, 34(6), 657–666.
- Jacoby, A. (2002). Stigma, epilepsy and quality of life. *Epilepsy & Behavior*, 3(Suppl), S10–S20.
- Jacoby, A., & Austin, J. K. (2007). Social stigma for adults and children with epilepsy. *Epilepsia*, 48(9), 6–9.
- Jacoby, A., & Baker, G. A. (2000). The problem of epilepsy. In G. A. Baker, & A. Jacoby (Eds.). *Quality of life in epilepsy: Beyond seizure counts in assessment and treatment* (pp. 1–12). London, England: Harwood Academic.
- Jacoby, A., Snape, D., & Baker, G. A. (2005). Epilepsy and social identity: The stigma of a chronic neurological disorder. *The Lancet Neurology*, 4, 171–178.
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32(1), 243–248.
- Kobau, R., Luncheon, C., Zack, M. M., Shegog, R., & Price, P. H. (2012). Satisfaction with life domains in people with epilepsy. *Epilepsy & Behavior*, 25, 546–551.
- Krippendorff, J. (1987). *Holiday makers*. London, England: Butterworth-Heinemann.
- Kurzban, R., & Leary, M. R. (2001). Evolutionary origins of stigmatization: The functions of social exclusion. *Psychological Bulletin*, 127(2), 187–208.
- Lehto, X., Luo, W., Miao, L., & Ghiselli, R. F. (2018). Shared tourism experience of individuals with disabilities and their caregivers. *Journal of Destination Marketing & Management*, 8, 185–193.
- Lim, K. S. (2010). Sports and safety in epilepsy. *Neurology Asia*, 15(1), 25–27.
- Link, B. G., Wells, J., Phelan, J. C., & Yang, L. (2015). Understanding the importance of “symbolic interaction stigma”: How expectations about the reactions of others adds to the burden of mental illness stigma. *Psychiatric Rehabilitation Journal*, 38(2), 117–124.
- MacCosham, B. (2017). Negotiating leisure constraints: The case of an amateur musician with epilepsy. *Leisure Studies*, 36(6), 825–837.
- MacLeod, J. S., & Austin, J. K. (2003). Stigma in the lives of adolescents with epilepsy: A review of the literature. *Epilepsy & Behavior*, 4, 112–117.
- Matthews, C. K., & Harrington, N. G. (2000). Invisible disability. In D. O. Braithwaite, & T. L. Thompson (Eds.). *Handbook of communication and people with disabilities* (pp. 405–421). Mahwah, NJ: Lawrence Erlbaum.
- May-West, E. M., Craig, P. J., & Wilder, A. (2018). The meaning of cross-country skiing for persons with significant visual impairment: A phenomenological study. *Therapeutic Recreation Journal*, 52(4), 349–373.
- McCabe, S., & Johnson, S. (2013). The happiness factor in tourism: Subjective well-being and social tourism. *Annals of Tourism Research*, 41, 42–65.
- Millett, C. J., Johnson, A. L., Thompson, P. J., & Fish, D. R. (2001). A study of the relationship between participation in common leisure activities and seizure occurrence. *Acta Neurologica Scandinavica*, 103, 300–303.
- Moran, D. (2000). *Introduction to phenomenology*. London, England: Routledge.
- Oliver, M. (1992). Changing the social relations of research production? *Disability, Handicap & Society*, 7(2), 101–114.
- Oliver, M. (2009). *Understanding disability: From theory to practice*. Basingstoke, England: Palgrave Macmillan.
- Oliver, M. J. (1980). Epilepsy, crime and delinquency: A sociological account. *Sociology*, 14(3), 417–440.
- Owens, J. (2015). Exploring the critiques of the social model of disability: The transformative possibility of Arendt's notion of power. *Sociology of Health & Illness*, 37(3), 385–403.
- Pagán, R. (2015). The contribution of holiday trips to life satisfaction: The case of people with disabilities. *Current Issues in Tourism*, 18(6), 524–538.
- Raty, L. K. A., & Larsson, B. M. W. (2007). Quality of life in young adults with uncomplicated epilepsy. *Epilepsy & Behavior*, 10, 142–147.
- Schneider, J. W., & Conrad, P. (1981). Medical and sociological typologies: The case of epilepsy. *Social Science & Medicine*, 15A, 212–219.
- Scott, R. (1972). A proposed framework for analyzing deviance as a property of social order. In R. Scott, & J. Douglas (Eds.). *Theoretical perspectives on deviance* (pp. 9–35). New York, NY: Basic Books.
- Sedgley, D., Pritchard, A., Morgan, N., & Hanna, P. (2017). Tourism and autism: Journeys of mixed emotions. *Annals of Tourism Research*, 66, 14–25.
- Shand, D. (2000). The assessment of fitness to travel. *Occupational Medicine*, 50(8), 566–571.
- Silverman, D., & Gendreau, M. (2008). Medical issues associated with commercial flights. *Lancet*, 373, 2067–2077.
- Skjenna, O. W., Evans, J. F., Moore, M., Thibeault, C., & Tucker, G. (1991). Helping patients travel by air. *Canadian Medical Association Journal*, 144(3), 287–293.
- Small, J. (2008). The absence of childhood in tourism studies. *Annals of Tourism Research*, 35(3), 772–789.
- Small, J. (2015). Interconnecting mobilities on tour: Tourists with vision impairment partnered with sighted tourists. *Tourism Geographies*, 17(1), 76–90.
- Smith, R. W. (1987). Leisure of disabled tourists: Barriers to travel. *Annals of Tourism Research*, 14(3), 376–389.
- Stock, S. E., Davies, D. K., Wehmeyer, M. L., & Lachapelle, Y. (2011). Emerging new practices in technology to support independent community access for people with intellectual and cognitive disabilities. *NeuroRehabilitation*, 28, 261–269.
- Temkin, O. (1971). *The falling sickness*. Baltimore, MD: Johns Hopkins Press.
- Tregaskis, C., & Goodley, D. (2005). Disability research by disabled and non-disabled people: Towards a relational methodology of research production. *International Journal of Social Research Methodology*, 8(5), 363–374.
- Trevorrow, T. (2006). Air travel and seizure frequency for individuals with epilepsy. *Seizure*, 15, 320–327.
- Tribe, J. (2007). Critical tourism: Rules and resistance. In I. Ateljevic, A. Pritchard, & N. Morgan (Eds.). *The critical turn in tourism studies: Innovative research methodologies* (pp. 29–40). Oxford, England: Elsevier.
- Trostle, J. (1997). Social aspects: Stigma, beliefs and measurement. In J. Engel, & T. A. Pedley (Eds.). *Epilepsy: A comprehensive textbook* (pp. 2183–2189). Philadelphia, PA: Lippincott-Raven.
- Unsworth, C. (1999). Living with epilepsy: Safety during home, leisure and work activities. *Australian Occupational Therapy Journal*, 46, 89–98.
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15, 398–405.
- Valeras, A. (2010). “We don’t have a box”: Understanding hidden disability identity utilizing narrative research methodology. *Disability Studies Quarterly*, 30(3/4).
- West, P. (1979). *Investigation into the social construction and consequences of the label epilepsy*. Bristol, England: University of Bristol.
- Willson, G., McIntosh, A., & Zahra, A. (2013). Spirituality and tourism: A phenomenological analysis. *Annals of Tourism Research*, 42, 150–168.

Alison J. McIntosh is a professor at Auckland University of Technology, New Zealand. In her research, Professor McIntosh focuses on critical understandings of the tourism and hospitality experience, with particular focus on issues of accessibility, equity and advocacy. A central theme of her research is that experiential, qualitative and social justice analyses reveal subjective, emotional and neglected aspects of tourism experiences, prioritising otherwise unheard voices, personal dimensions, and tourism in marginalised contexts.