

Flying into Uncertainty: Part 2 – Flying with Non-Mobility Disabilities

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... the research agenda has moved on from accessibility and disability as 'hidden conditions' become important due to legislative requirements on making tourism accessible for all, that transcends physical and visible conditions. (Connell & Page, 2019: 39)

Introduction

While the academic literature on the air travel experience of those with disability has tended to focus on mobility disability, and the required service delivery associated with this group, a growing number of researchers are examining the experiences of passengers with non-mobility disabilities, many of which are considered 'hidden' disabilities. Much of what has been written in Chapter 5 about mobility, mobility disability and the air travel experience, is relevant to those with other types of impairment, however, there will be differences unique to the specific impairment. Non-mobility disabilities considered in this chapter include vision and hearing impairments, cognitive impairments, such as dementia, autism and epilepsy and mental health conditions. It must be remembered that some passengers with non-mobility impairment may have additional non-mobility and/or mobility impairments. As in Chapter 5, a discussion of the passenger experience of air travel by people with impairments other than mobility is based on the premise that they have the same rights to citizenship as non-disabled passengers. This includes the right to safe and comfortable travel and the feeling of inclusion as a flying passenger, from first booking a flight, to the airport and onboard experience. Nevertheless, commissioned research by the UK's Civil Aviation Authority (CAA) suggests that '7 per cent of UK citizens avoid travelling by air because of a hidden disability – such as dementia,

autism or because they use a colostomy bag' (Berry, 2018). Indeed, those people with non-mobility impairments are among the least likely to travel by air. Despite having the same rights to travel, it is clear that the passenger's travel experience will vary according to their type and degree of impairment. As highlighted in Chapter 5, there are multiple forms of difference. The study of those with physical impairments highlights the multi-sensory nature of travel. For air passengers with sensory and cognitive impairments, other senses come to the fore such as the importance of touch for the blind. As many of the non-mobility disabilities are 'hidden disabilities', air passengers with these disabilities may face increased stress during flying. One of the important dilemmas faced by air passengers with hidden disabilities is the question of whether to disclose or conceal their disability – whether that will mean inclusion or exclusion.

In the United Kingdom, the Civil Aviation Authority (2016) has set out guidelines on how airports can support people with hidden disabilities, such as autism, dementia, mental health conditions and sensory impairment. These guidelines include: awareness and communication training for staff, information for the passenger regarding airport methods of identification (such as passenger lanyards or bracelets), the provision of a quiet waiting area and quiet route through the airport and clear images and messages to assist in the location of toilets etc. The CAA recommends that the person with disability is not separated from their companion when going through security and receives explanations by security staff about the security procedure. To facilitate familiarisation of the airport, detailed information and visits/open days are encouraged. Following guidance to assist people with hidden disabilities at airports, the Civil Aviation Authority (2018) has published guidance for airlines 'applicable to all flights from the UK and for flights to the UK on an EU registered airline' (Civil Aviation Authority, 2018: 4). The recommendations include: provision of information in an accessible format (prior to travel, at the airport and onboard the aircraft), assistance at the airport in areas for which the airline is responsible, assistance onboard the aircraft (such as accommodating seating requests) and assistance during flight disruptions. Training of airline staff to understand the needs of those with a hidden disability is essential. While a number of airports throughout the world have adopted procedures addressing the needs of those with hidden disabilities, these advances are not universal. In this chapter, we consider particular challenges for passengers with non-mobility impairments in their booking and information search, navigation of airports, boarding and in-flight experience, highlighting the particular embodied experience of those with non-mobility disabilities and the need for airports and airlines to explicitly cater for this group.

Non-Mobility Disabilities

Vision impairment

The logistics of travelling for those who are blind or with vision impairment are challenging. Small and Darcy (2010) report that this group is less likely to travel, especially internationally, than those with other disabilities (with the exception of those with mental illness). For those with vision impairment, senses other than vision come to the fore: touch, sound, smell, taste and kinaesthetic skills. Those with vision impairment are not a homogenous group, yet the sighted world treats them as such (Richards *et al.*, 2010). To understand the needs of a passenger with vision impairment one needs to consider the particular type of vision impairment (for example, macular degeneration, glaucoma etc.) and the degree of visual acuity and visual field. In a study of the tourist experiences of people with vision impairment (PwVI), Small *et al.* (2012: 949) conclude:

Vision impairment in itself is not a barrier to becoming a tourist and enjoying the benefits of tourism, yet PwVI are faced with a disabling environment specific to their embodiment. In particular, they are constrained by: access to information, wayfinding, knowledge or attitude of others and travelling with a guide dog.

Where there is no outward sign of disability (no cane or guide dog), there is the dilemma for the person whether to disclose their vision impairment to the travel staff. They have to make a judgement as to how the staff will respond. Will disclosure mean inclusion or exclusion? While much of the academic literature on disability has focused on mobility impairment, there have been several studies that have examined the air travel experiences of those with vision impairment.

One such study by Small in 2016 (unpublished) involved in-depth interviews with 21 (mostly Australian) participants who were blind or vision impaired, investigating their domestic and international air travel experiences: pre-departure when planning and booking, at the airport (departure, in transit and arrival at the destination) and on board the aeroplane. It was found that those with vision impairment share common experiences with those with other disabilities but there are also experiences which are specific to them. Of those who participated in the study, most travelled by air at least once or twice a year for work or pleasure, with business travellers flying more often than others. Most business travellers flew unaccompanied while others travelled mainly with a family member or friend. In terms of aids, most participants travelled with a cane. However, it must be remembered that not all people with vision impairment use a cane or guide dog especially if they have low vision. For some, a sighted companion will be their aid.

At the pre-departure planning and booking phase, difficulties were reported with both the airline and airport websites: they were too complicated, multi-layered, with formats that regularly changed and not easily navigable using screen reading software (to convert on-screen text to speech output) (see Domínguez *et al.*, 2018; W3C, 2019). Due to the inaccessibility of the websites, most bookings were done by family, friends, executive assistants, travel agents or the person with vision impairment phoning the airline. Very few of the participants knew about the support services on the airport websites. They preferred to phone the airlines for information and to request support. Further problems awaited the person on arrival at the airport. Limited wait time for cars at the drop-off zone meant they could not be escorted to the check-in counter and could be left 'stranded' on the pavement. Inside the terminal, there were issues with wayfinding and checking in. The electronic check-in kiosks were not accessible for PwVI and, at times, there were few staff to assist (especially when using a low-cost airline). Most check-in staff at the desk were reported to be helpful and would arrange meet-and-assist support to the departure gate, but as one participant said, PwVI are often concerned about being dropped off at the departure gate by the meet-and-assist service and then forgotten. Some have missed flights.

The airport is difficult for those with vision impairment. By nature, airports are large, noisy and busy. Unstructured spaces with few direct paths can make navigation difficult especially when there are few wayfinding cues. Further, as illustrated in Figure 6.1, the positioning of objects can be hazardous for PwVI if preventing a clear pathway. The design of modern airports, especially large international airports with their reflective surfaces, can also be challenging for some PwVI; see Figure 6.2.

The participants in Small's study cited gate changes as problematic as the change was often publicised via a visual screen rather than an announcement. Foreign airports with language and cultural barriers could add to the difficulties. Some participants who travelled for business had joined the airport lounge facilities (at own expense) to have certainty with assistance. And yet, as one participant said, '*I also know that people who have opted for this solution.... have also been "forgotten" and missed their flight (... no announcements in these lounges)*'. The process of going through security could be problematic especially when security staff removed the cane from the traveller's possession. As participants explained, security staff need to recognise that the person's cane is their eyes.

Staff... need to explain what they are doing, why they are doing it, and what might be expected to happen next. For people travelling with guide dogs, separation of the person from their dog should be minimised and good communication practiced. It's unfortunate that dogs' harnesses always trigger security alarms, resulting in the dog's handler being patted down.



Figure 6.1 Display stands in a duty-free retail area at Doha Airport obstruct clear passage through the space (2019 © Jennie Small)



Figure 6.2 Lighting, glass and light-coloured floor tiles create reflection at Dubai Airport (2019 © Jennie Small)

Having valuable possessions removed from their immediate proximity during security screening could also be stressful for PwVI, as one participant explained,

... everyone has to part with their possessions during the security screening, however..., [usually] sighted passengers can see their possessions as

they go through the screening. Blind passengers, on the other hand, hand over their most precious and necessary possessions without being able to track what happens to them. Especially on international flights, this is a significant issue, losing contact with personal identity papers, tickets, foreign currency, credit cards, and having the possibility of things being added to one's luggage.

Graham Innes (2016), Australia's Disability Discrimination Commissioner from 2005 to 2014, similarly describes his experience, as a person who is blind, of having his bags opened without his knowledge or permission, and his cane put in a place where he could not find it. The participants in Small's study explained that moving through the security scanner can be cumbersome and the process degrading, for example, when pushed and pulled through the scanner.

Small found that, once on board, there were other challenges for those with vision impairment. Toilets were reported as problematic due to variable layout and difficulty working the buttons and levers. Touch screen in-flight entertainment was not accessible, so most PwVI need to take their personal electronic devices and their own entertainment. Other in-flight controls (such as the overhead light and flight attendant call button), if operated by a touch screen, were, thus, also inaccessible, taking away from the independence of the traveller. It was reported that meals could be difficult with lots of little packages, small trays and restricted space. Menus need to be screen readable but never are. Disembarking the plane was an easier process. However, if required to disembark last (as is often the case), the delay, for the business traveller, could mean arriving late for a meeting. In disembarkation, there could also be the indignity of being offered a wheelchair. This experience has been confirmed by others (Innes, 2016; Richards *et al.*, 2010). Innes (2016) offered his solution: 'When my requested guide turns up with a wheelchair for me, I usually thank them and place my carry-on luggage on it, as the thing I most want to do when I get off a plane is walk' (Innes, 2016: 81). The participants expressed the need for a better whole-journey experience from the point of drop-off to end of journey and for an airport-based assistance service rather than an airline-by-airline service. Participants felt that there was more assistance available in countries where disability standards and compliance are regulated.

Findings from other studies have similarly exposed the anxiety and stress of air travel for passengers with vision impairment (da Silva *et al.*, 2019; Poria *et al.*, 2010; Small *et al.*, 2012). In a study of Brazilian air transport, da Silva *et al.* (2017) highlight the difficulties experienced by passengers with vision impairment at airports. Of note was the lack of guidance and information on arrival at the airport with most information in visual format. Information boards were difficult to read with low colour contrast, small font size, excessive information and high

positioning. Throughout the airport, hazard and directional signage was inadequate for the safety of those with vision impairment, leading to the risk of passenger injury. There were also issues with the service provided to PwVI due to the lack of knowledge of staff at check-in and boarding. Ensuring the person was allocated their preferred seat was often problematic. In sum, the study identified non-compliance with the required regulations. Poria *et al.* (2010), studying the experiences of Israeli passengers who were blind, also identified the inaccessibility of flight information when in visual format. Passengers were fearful that they would miss information about a flight or gate change, especially when connecting to another flight. Regarding on-board experiences, Poria *et al.* (2010), while identifying some challenges for those with vision impairment (finding the earphone outlet, differentiating between salt and pepper, understanding the safety information), concluded, 'Blind people reported almost no difficulties, noting that they usually travel with a companion and that attendants approach them appropriately' (Poria *et al.*, 2010: 221). However, at the same time, Poria *et al.* (2010) found problems in communication with staff. As reported in Chapter 5, there was often the assumption by the crew that the passenger with vision impairment also had a cognitive impairment. In addition, the crew often preferred to address the companion rather than the person with vision impairment (Innes, 2016; Poria *et al.*, 2010). Another identified barrier to travel concerns travelling with a guide dog. Individual service providers may lack knowledge regarding the rules for such travel (Small *et al.*, 2012). There may also be issues regarding space for the animal to be accommodated with the passenger on the aircraft (da Silva *et al.*, 2017). The absence of toileting facilities for guide dogs at airports has also been reported (Innes, 2016).

Amar Latif, director of Traveleyes (a travel company for blind and sighted travellers), and blind himself, confirmed in an interview (personal communication, 25 July 2016) the findings from the above academic studies that there are many travel difficulties for passengers with vision impairment, from booking flights, navigating the airport and using the facilities onboard the plane. However, as he reports, it may depend on the airport and/or airline whether one feels supported and enabled or 'herded like cattle'. On a positive note, he explains,

I guess the advantages of being VI [Vision Impaired] and travelling across the world is... you land in, let's say, Paris... interconnecting. You'll have this intimate relationship with assistance staff ... suddenly you touch base with a local and as they're guiding you, you ask them... 'oh what's it like living here'? 'How's your life'? And then, suddenly, you're on your plane and... you've landed in Singapore and again you've got that ability. Whereas, sighted folk probably don't speak to anybody. So there are advantages.

To allow a person with vision impairment to travel independently and free from anxiety, Latif recommends better education and training for staff. Here, Latif cites an example where better training might avert an uncomfortable situation.

[Going through Security] you're supposed to fold your cane and put it in the box but once you do that nobody knows that you're a VI so quite often... they'll eye you suspiciously 'cause you're... walking, you're feeling around a bit. And then your sighted guide needs to... just signal' to the person on the other side 'look, this person's blind that's coming through the security'... I don't know how to resolve that except more training for those guys.

Latif explains that while there are assistance programs at many airports, they are not seamless, for example, there is a gap in assistance between entering the airport and checking in, which he refers to as 'no-man's land'. Latif stresses the benefits of a technological solution, an app on the passenger's device, to improve the accessibility of air travel at all stages of the journey: from navigating the airport, managing the onboard facilities (for example, in-flight entertainment system and menu options) to locating one's luggage on the carousel at the destination. This would expand the experience of the passenger, giving them more control and independence, for example, they could access the airport shops rather than spending long periods waiting at the Gate. If travelling with a companion, such technology would also take pressure from the sighted guide and go some way to a true partnership between the blind and sighted traveller.

That new technologies can assist passengers with vision impairment to access their environment has been recognised by The Royal Society for the Blind (2020). It describes an app that, for the first time, allows wayfinding inside multilevel buildings. It is achieved through a combination of new positioning beacons that through algorithms are able to process location via smart phone-based apps. The app, which has already been deployed in universities and retail environments, could be suitable for airports. The Royal Society for the Blind (2020) explains: 'The program uses a simple audio system to describe where users are and what's around them, finding the best way to get to their chosen destination'.

Hearing impairment

There has been little in the academic travel and tourism literature concerning those whose impairment is solely hearing although there have been some studies on the travel experiences of deafblind travellers (Dann & Dann, 2012; Hersh, 2016). More specifically,

there is scant information on the experiences of *air* travellers with a hearing impairment. Nonetheless, we can take the information from the more general travel experience studies as a starting point to understand their air travel experience. Darcy (2012) explains that the requirements for alternative information provision for people with hearing impairment are consistently ignored throughout the travel chain. Travellers with hearing impairment often rely on attendants to explain important information and interact with staff. Since travellers may have varying degrees of hearing impairment, there is a need for quiet travel environments in which announcements can be heard. This is relevant when considering noisy, busy airports where announcements may be in a foreign voice. Both Hersh (2016) and Dann and Dann (2012) highlight the importance of the sense of touch for those who are deafblind. Indeed, Elizabeth Dann, in her qualitative analysis of her own sensory experiences as a deafblind person, calculated 'that the sense of touch accounts for 42.9% of all my sensory experiences of tourism' (Dann & Dann, 2012: 135). From studying the experiences of deafblind travellers, Hersh (2016), too, highlights the importance of tactile information. She also cites the variability of her participants' ability to represent space and form mental maps, important in navigation. When we consider air travel and navigation of airports, such cognitive skills may prove particularly difficult where a terminal is unfamiliar due to it being foreign or constantly remodelled (see Chapter 2).

One study which has reported the air travel experiences of a traveller with hearing impairment is the autoethnographic study of Jain (Jain *et al.*, 2019). This study highlights the importance of visual communication strategies (facial expressions, body language signing and gestures) for someone with a hearing impairment. Due to Jain's particular hearing disability, he cites difficulties when experiencing insufficient visual cues, high frequency sounds and background noise:

*[when I was seated in a window seat on a plane] it was terribly difficult to communicate drinks or food choice. I couldn't hear the attendant very well. [...] And since I can't hear my own voice well, I did not know how loud I was speaking. Thus, the crew also had a hard time understanding me. Somehow, through gestures and repetitions, we made it work but I skipped one meal and compromised with cold water instead of the hot water (which I wanted). (Flight from Milan to Sharm el sheikh, Mar'17) (Jain *et al.*, 2019)*

As with travellers with other hidden disabilities, there is the dilemma of disclosing or concealing hearing disability. In this autoethnographic account, Jain explains how he used a speech-to-text translator for

in-flight announcements, communicating with the flight crew and immigration staff (situations with high background noise).

I found that I could access a range of information that was previously inaccessible (e.g., flight safety briefings, information about [the] destination such as weather and sightseeing details, information about in-flight service such as food and drinks). (Jain et al., 2019)

Nonetheless, there were difficulties associated with this method such as the unnaturalness of two-way conversation due to the transcription delay.

Eghtesadi *et al.* (2012) describe the development of an accessible in-flight entertainment system specifically for people with sensory disabilities. For passengers who are deaf or have hearing limitations the system provides access to content through user selection caption display. The system also provides options for those who are blind or have low vision to access content through talking menus and descriptions of key visual content. Under the Air Carrier Access Act of 1986, the U.S. Department of Transport (DOT) has established the accessibility requirements of people with disability as they relate to air travel. However, this legislation has limitations. Beyond the aircraft safety information, there is currently no requirement to make other information or entertainment services accessible to those with vision or hearing impairments (Eghtesadi *et al.*, 2012). However, from the perspective of service provision, this is an area where significant improvement can be made using currently available technologies.

Cognitive impairment

Cognitive impairment has also not received the travel and tourism research attention that more visible types of impairment have attracted. Although researchers' definitions of disability may recognise intellectual disability, there has, for the most part, been little or no analysis of this impairment (for example, Ancell & Graham, 2016). The airline industry, too, has tended to ignore those with cognitive impairment. While it has disability access policies for physical disabilities, 'most do not explicitly cater for people with cognitive impairments such as dementia' (O'Reilly & Shepherd, 2016). Rosenkvist *et al.* (2010: 132) explain that cognitive functional limitations 'can mean difficulties to remember, to orientate in time and space, to solve co-ordination problems, to express oneself verbally etc.'. Those with cognitive functional limitations may also have other impairments, such as mobility or vision. In a study of experts' perspectives on the mobility of those with cognitive impairment, Rosenkvist *et al.* (2010: 138) made the point that moving around in the world can be exhausting as 'this group of people requires tranquillity

to cope with decision-making on the basis of a lot of information'. Familiarity with the environment can provide confidence and lessen stress, anxiety, and fear. Qualitative research undertaken in the United Kingdom by the Civil Aviation Authority (2015) noted that those with cognitive disabilities and mental health conditions required help and support to access air travel due to numerous issues and stressors when travelling by air. 'These include anxiety, strong personal preferences, difficulty interacting with people, difficulty processing and retaining information, difficulty navigating spaces etc.' (Civil Aviation Authority, 2015). For those with such limitations, strength and stamina can vary day by day. Rosenkvist *et al.* (2010) also highlight that, amongst this group, individuals vary in awareness of their cognitive capacity – what they can or cannot manage. While their study was focused on mobility in public environments, the findings are no doubt also relevant for air travel.

Dementia

An increase in the number of those with dementia, associated with ageing populations, should attract the attention of the travel and tourism industries. Among researchers, a slowly emerging interest in dementia and tourism is based on the belief that 'helping people to live well with dementia through tourism can have positive benefits' (Connell & Page, 2019: 39). To date, there has been some focus on the dementia 'friendliness' of tourism destinations (Connell & Page, 2019; Page *et al.*, 2014), tourism attractions and venues (Connell *et al.*, 2017) and the broad tourism product (Klímová, 2018). What we know is that there are many common problems faced by people with dementia in the visitor economy. According to Klug *et al.* (as cited in Connell & Page, 2019: 29), these include:

...mobility issues (e.g. getting to the venue, moving around the venue, disorientation caused by background noise, patterned décor and shiny surfaces, fear of getting lost or not knowing where to go); memory-related problems (e.g. ... finding the right words to communicate with people); problems of visual perception or spatial awareness (e.g. bumping into things, responding to visual interpretation in unexpected ways and the effect of low light levels on perception); and, impaired ability to interact with the environment and problems with paying for goods and services (e.g. counting money or remembering chip and pin numbers).

We know that much of the above is likely to be common to the air transport experience. As for those with sensory or other cognitive impairments, 'Airports and aircrafts can be noisy and confusing environments for people with dementia' (Dementia Australia, 2018). Nonetheless, there have been few studies whose focus is the air travel

experience of those with dementia. From medical research, we are informed of the potential medical problems for those with dementia: passengers with dementia face a possible danger of delirium in long-haul travel (Kelly & Kaplan, 2009; McCabe, 2017) with McCabe reporting that length of flight or descent from high altitude can increase the possibility of deterioration. Writers (such as Kelly & Kaplan, 2009; McCabe, 2017) have made the point that airline screening for fitness to fly is concentrated on a physical check, rather than cognitive check. In one of the few studies of air travel that has included the perspective of those with dementia and their carers, Australian researchers, O'Reilly and Shepherd (2016) found that the most challenging aspect of the air travel experience was navigating the airport, 'such as finding restrooms and the correct boarding gate, hearing announcements, checking in, reading information on signboards and bag screening'. Once on the aircraft, the small size of the lavatory was problematic with no room to accommodate a second person. The researchers cited instances of passengers with dementia becoming agitated during the flight. However, they noted that: 'Most companions said that once they were on the plane they were able to relax... flight crew had been very polite and able to accommodate their needs'. Similarly, a UK group of researchers at Plymouth University (Warren *et al.*, 2019) identified the issues that can be problematic for those with dementia: the security checkpoint (lack of communication, being separated from carer, pressure of queuing), assistance (lack of clarity in entitlement to assistance or the level of assistance offered), staff awareness (inconsistent approaches by staff even when the passenger had disclosed their dementia) and information (range of practical information difficult to find).

O'Reilly *et al.* (2017) likewise stressed the challenges of security and immigration procedures for those with dementia. Planning is considered the key to a positive flying experience. See below the air travel tips, as outlined by O'Reilly and Shepherd (2016) for people with dementia.

Box 1: Air Travel Tips for People with Dementia

- Talk to the airline about the assistance they can offer people with disabilities. Some airlines will escort you through the security and immigration checkpoints and on to your boarding gate. Find an airline you like and stick with them. Familiarity with the airline may help reduce anxiety.
- Book a flight that leaves at a quiet time of day. For example, some airports are very busy between 6am and 10am and 4pm and 7pm. It will be a lot easier for you to find your way and access assistance if you are traveling outside of the busy period.

- Plan to arrive at the airport an hour and a half early to allow unforeseen delays. Go through the security checkpoints straight away and then find somewhere to relax.
- You can often find information about the seating configuration of the airplane online. Find the best seats for you, for example, many people choose aisle seats close to the toilets.
- Find out about the airport prior to the day of your trip. You can visit the airport beforehand to get your bearings and look for information on the airport website. For example, there may be special parking zones for people with a disability that you can use.
- Don't be afraid to ask for help and explain your medical condition.
- Keep hand luggage to a minimum.
- If you wear a lanyard with a pocket on it around your neck, you can safely tuck away your travel documents in a place that is easy to access when you already have your hands full.
- Long haul travel can be the most difficult, particularly during the stop-over. Schedule flights which enable you to rest and give you plenty of time to meet your connecting flight. If possible, travel with two carers.
- Some people with dementia get agitated at particular times on the flight, such as when everyone is boarding, during the take-off or landing. The use of distraction techniques such as using noise cancelling headphones to listen to music, or eating a favourite snack can reduce anxiety.

Source: O'Reilly and Shepherd (2016)

Connell and Page (2019) highlight the poor publicity that the air transport sector has attracted in the past in relation to dementia but see progress in the United Kingdom, as evidenced in the House of Commons debate on issues raised by the Prime Minister's Dementia Challenge Group for Air Transport (UK Parliament, 2016). As explained by Warren *et al.* (2019), the Prime Minister's Group 'is changing how the aviation industry sees people living with dementia and is improving how airports and airlines support them, and those who travel with them, so they can remain engaged in air travel'. In 2016, London's Heathrow Airport announced it was the first 'dementia-friendly' airport in the world (Miles, 2016). In the same year Gatwick Airport received a dementia innovation award for introducing passenger lanyards for staff to recognise those with hidden disabilities who might need assistance (Gatwick Airport, 2016). Reviewing UK airports from 2016 to 2019, Napolitano (2020) found that, by 2019, 90% of airports were offering some form of support to passengers with dementia. In Australia, Brisbane Airport was the first dementia-friendly airport with a guide developed for users of the airport (Dementia Centre for Research Collaboration, 2017).

Autism

For those with autism and their attendants, travel, including air travel, can be a challenging experience. Sedgley *et al.* (2017), in their study of the tourism experiences of mothers caring for a child diagnosed with Autism Spectrum Disorders (ASDs), reported that much groundwork had to be done by the mothers prior to travel by air as the airline websites lacked information for passengers with cognitive impairments. 'The need for tranquillity make airports and aeroplanes highly challenging environments for these children, not only as noisy and frenetic places but also as sites of surveillance, which require well-ordered behaviour (Morgan & Pritchard, 2005)' (Sedgley *et al.*, 2017: 20). They also reported the anxiety experienced by mothers due to the heightened security and the stress experienced by delays and long flights.

To limit the overwhelming sensory impact of air travel and, in particular, the airport environment, a growing number of airports are now providing 'multi-sensory' rooms or quiet rooms around the departure lounge (Poling, 2017). Following the release of guidelines in 2016 by the CAA which encouraged airports in the United Kingdom to provide greater support to passengers with 'hidden disabilities', such as autism and Alzheimers (Civil Aviation Authority, 2018), Ireland's Shannon Airport became the first airport in Europe to provide a multi-sensory room. The room includes 'such calming features as an aquatic bubble tube, an undulated wavy wall, color changing LED's and a wheel projector' (Poling, 2017). Similar spaces have also been established at a number of US airports in recent years. Harpaz (2017) reports that Delta airlines opened a multi-sensory room at Hartsfield-Jackson Atlanta International Airport in April 2016 in partnership with The Arc, an Autism advocacy group. Similarly, a quiet room opened at the Myrtle Beach Airport in South Carolina, USA, following a request from a local mother and founder of the Champion Autism Network for the airport to 'provide some sort of support for families' when flying with children with autism. To enable staff to identify and interact appropriately with passengers with autism and other hidden disabilities, a growing number of airports have introduced 'discreet' lanyards, wristbands, caps etc. to be worn by the passenger. At Vancouver International Airport in Canada, a special sticker on the passenger's boarding pass helps staff and crew identify passengers with autism and provide appropriate assistance and support when required (Poling, 2017).

For families with a member with autism, some airports and airlines also offer an opportunity to become familiar with the airport experience (including the often-stressful sights and sounds associated with air travel) – a 'rehearsal' – through a program called 'Wings for All'. This program has operated successfully at a number of airports in the United States and has recently been implemented at Perth Airport in Western Australia (Tetlow, 2017). The program allows children with autism and sensory

processing disorders to experience a 'run through' of the process of air travel, from check-in, through security and boarding, to onboard service (Adams, 2018; Poling, 2017; Tetlow, 2017). The program also provides staff training, to develop staff empathy and understanding for such travellers.

Cerdan Chiscano (2021), in her study of families of children with autism spectrum disorder, found that (a) communication about the airport experience, (b) usage of the airport (such as, sensory rooms, priority check-in, easy wayfinding and boarding) and (c) service (staff awareness of autism, appropriate language and empathy) were all critical to ensure a successful inclusive airport experience design. She reinforced the importance of stakeholder involvement, the use of value co-creation, to design positive air travel experiences.

Epilepsy

The neurological condition of epilepsy can pose hazards for a person's use of transportation, especially air travel (Cummins & Schubach, 1989; Shand, 2000; Silverman & Gendreau, 2009; Skjenna *et al.*, 1991; Trevorow, 2006). Indeed, air travel has been described by some as a potential 'safety threat' for people with epilepsy (Unsworth, 1999). Epilepsy is recognised as a complex spectrum of disorders with about 40 different seizure types. People living with epilepsy can experience differing frequencies and severity of seizures. Researchers have found that air travel may be linked to an increase in the occurrence of epileptic seizures in the first few days after a flight, especially among air passengers who have a prior history of flight-related seizures and experience a higher frequency of seizures generally (Trevorow, 2006). In addition, epileptic seizures have been reported as one of the most frequent reasons for flight diversion (Drazkowski, 2007). Most seizures do not require immediate medical intervention, but prolonged convulsive status can lead to irreversible neuronal injury, and even death. It is thus important that attention be given to the medical management of air travel for passengers with epilepsy (Trevorow, 2006).

While the probability of having a seizure during a flight is low (Devkota & Karki, 2010), passengers with poorly controlled epilepsy may be refused transport, or only permitted under certain conditions (Graf *et al.*, 2012). For example, if a person has experienced a tonic-clonic seizure less than 24 hours before flying, many airlines will require that person to provide medical clearance as set out by the guidelines of the International Air Travel Association (IATA). In general, flying with epilepsy requires health counselling and common-sense consideration of an individual's fitness to cope with the environmental and physiological demands of air travel on the human body (Drazkowski, 2007). The physiological challenges of flying are related to the exposure to reduced

atmospheric pressure inside the cabin, oxygen desaturation, low humidity, high levels of cosmic radiation, postural immobility and jet lag from crossing time zones. In addition to disrupting sleep patterns, air travel also disturbs eating patterns. All of these variables can trigger epileptic seizures (Devkota & Karki, 2010).

While there appears no conclusive direct link between the occurrence of seizures and air travel in relation to flight distance, time zones and duration of the flight, air travel holds a theoretical risk for passengers, meaning that it is impossible to claim that a seizure will never be triggered by these variables (Shand, 2000). Air passengers with epilepsy worry about having a seizure during a flight with the potential for the occurrence of seizures reducing a person's sense of control. The unpredictable, uncontrollable and distressing nature of epileptic seizures can arouse fear in both the sufferer and those witnessing the seizure (Jacoby & Austin, 2007). Seizures are described as starting with 'feelings that "something is not quite right"; "an uneasy feeling"; "feeling a little bit confused"; "daydreaming"; "like a zombie"' (McIntosh, 2020: 5). Many people are unaware they have had a seizure until it is over (McIntosh, 2020). Devkota and Karki (2010: 60) report the medical account of a 29-year-old female who had a generalised tonic-clonic seizure during a long-haul flight:

After 16 hours flight, one hour before landing in Paris she fell down in the corridor while she was trying to go to toilet. Her body was stiff lasted for about one minute; she had up rolling of eyes but no frothing, tongue bite or incontinence. She did not have any external injury or injury to head. After the episode she was confused for few minutes. Her vitals were stable and oxygen saturation was maintained. Oral diazepam 5 mg was given and she slept well. Remaining flight was uneventful.

Some air passengers manage complete seizure control through regular medication. That said, careful travel planning to stick to usual routines becomes important in maintaining control over seizures during air travel. A respondent in McIntosh's (2020) study explained:

If I can board a plane near to sleep time or the evening, I am in the same sleep pattern as what I would be at home. Going to England which we've done three times, we'd stop off, it would be in Asia, and you were in a plane, what, ten hours. We stop over there for three to four days and then we catch a flight again at night time. So I'm keeping the same pattern as I would do. I have had no repercussions from that.

Planning for travel may include getting clearance from a doctor, wearing a medical identification bracelet, knowing the details of the travel itinerary, having emergency phone contacts, carrying plenty of snacks, water and medication, carrying a prescription and local hospital details and knowing a safe space to go in the event of the onset of a

seizure, usually the closest restroom (McIntosh, 2020). The potential for personal physical harm, as well as the stigma and anxiety of having seizures in public, may mean that some people avoid air travel altogether (Jacoby, 2002). Alternatively, it may mean that some people will only travel accompanied with someone who can look after them, and/or their support service animal (McIntosh, 2020). Flying accompanied by a support person or 'carer' is required by some airlines if the person with disability is deemed not to meet 'independent travel criteria' or there is a legitimate safety risk (Darcy, 2012; Qantas Airways Limited, 2020). In her study of epilepsy and tourism, McIntosh (2020) found that, due to the often hidden and stigmatising condition of epilepsy, travellers concealed their condition, keeping it secret as a coping strategy, and/or avoided situations that might risk them experiencing a seizure in public. This was despite medical advice that it is better to inform airline crew as to how they can help in the event of a seizure during the flight than not to disclose (Shand, 2000). Given the series of constraints, there is a need for research to examine further the stigmatising nature (the fear and shame) of epilepsy and tourism. As an invisible and often uncontrollable condition, there is a greater need to examine the impact of the neurological condition on the air travel experience, the ways in which it may be managed in-flight and the ways to support travel planning.

Mental health conditions

When examining the propensity to travel amongst disability groups, it was found that those with mental illness were the least likely to travel (Small & Darcy, 2010). There is little documentation on the air travel experience for this group. However, there is evidence that air travel is stressful for those with mental health conditions. Seeman (2016: 79), in discussing the travel risks for those with a serious mental illness, claims: 'Travel, even when embarked on for the purpose of relaxation and enjoyment, can prove so stressful for individuals with pre-existing severe mental illness that it can result in psychotic relapse'. In particular, she cites reports, since at least the 1950s, 'of travelers with psychiatric illness suffering travel-related psychotic decompensation, during air travel especially' (Seeman, 2016: 76). Lack of sleep, disruption of circadian rhythms, dehydration, nausea and sharing a close space with unfamiliar people are some of the stressors of flying. It is thought that those with serious mental illness can be particularly anxious when events are perceived as out of their control. However, Seeman concludes that there are many ways to prepare the person for travel and obviate potential stressors.

A number of passengers with mental health conditions travel with emotional support animals. While limited academic research has been undertaken, some significant media reporting has occurred in the United

States around the carriage of emotional support animals on planes (Dombroff, 2018; McGonigle, 2018; Wood, 2018). Unfortunately, while the original intent of airlines in regard to such carriage was positive, the practical application of the regulations has often caused difficulties for both airline operations and other passengers. Media reports explain that airlines in the United States have been struggling to deal with the impacts of the rapidly increasing numbers and types of emotional support animals on flights. Delta Airlines reported ‘a 150 percent increase in passengers bringing animals onto planes since 2015, with an attendant 84 percent jump in incidents such as people being bitten or attacked, or animals urinating or defecating during flights’ (Dombroff, 2018). In response, the U.S. Department of Transport has undertaken a review of the rules around emotional support animals and limited the definition in its regulations to dogs, reversing the previous policy that permitted a wide range of other animals to fly (U.S. Department of Transport, 2020; Vann, 2020). See Chapter 3 for further discussion.

Other media reports relating to mental health and travel concern travel insurance. Recently, the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) launched an investigation into the major travel insurance companies, concluding that the companies did not have the right to discriminate against people with mental health conditions by implementing blanket bans, as they have done in the past (Bainbridge & Florance, 2019). While insurance companies are able to discriminate on a variety of grounds involving previous health conditions, challenging their right to discriminate against people with episodic mental health conditions can lead to change. Other disability groups, including those with previous health conditions, may be able to leverage other travel insurance challenges from this case.

Conclusion

Consideration of the air travel experiences of those with disability requires extending the definition of disability to include those with non-mobility related disabilities that are often hidden. While passengers with any type of disability have the same rights to citizenship as non-disabled passengers, people with non-mobility impairments may be among the least likely to travel. This chapter highlights the significance of sensory, cognitive and mental health impairments in the embodied experience of those who do take to the air. There are particular challenges for passengers with non-mobility disabilities at airports when visual or audio cues are inappropriate, background noise is high, information is inaccessible due to lack of provision of alternative formats, and wayfinding is difficult, especially in multilevel buildings. Additional challenges may occur during customs checks (in international travel) and on board the plane. Here, the physiological effects of air travel

can exacerbate certain conditions. In addition, the potential for unexpected experiences and uncontrollable triggers resulting from a 'hidden' condition may increase stress and anxiety during air travel. Certainly, the knowledge and attitudes of staff can 'make or break' the travel experience. A key to a positive flying experience is to plan ahead. While there will be some commonality in experience, there will also be differences depending on: the type and degree of impairment, the required communication supports and whether the person travels independently, in a group and/or with an assistant animal. Throughout the journey, we can see the corporeal interaction of the passenger with the materialities of the airport and the aircraft – the signage, check-in desks, baggage carousel, passenger seat, in-flight entertainment system, toilet cubicle, lighting and so on.

Highlighted in this chapter is the disabling environment of air travel, specific to the embodiment of a person's non-mobility disability. For passengers with a hidden disability, there is the added dilemma of whether to disclose their condition, and the likely consequence of doing so (or not). This is particularly so with people who may have a psychosocial or mental health-related condition. Judgements need to be made as to how others will respond: will disclosure pre-boarding lead to inclusion or exclusion? It is important to recognise that the difficulties faced by the passenger with a non-mobility disability are not limited to that person but shared by companions, for example, the sighted companion trying to navigate the blind partner (Small, 2015) through a busy terminal or the companion communicating to security staff on behalf of the passenger with hearing impairment. More attention is required to raise awareness of the needs of the companions, in addition to those with non-mobility disabilities, and the ways in which airline staff can be trained, and technologies employed (Bosch & Gharaveis, 2017) to provide greater support to both groups of passengers.

da Silva *et al.* (2019) conclude that transport accessibility is the responsibility of multiple organisations from airport operators, airline staff, aircraft manufacturers and regulatory agencies. Recommendations by the Civil Aviation Authority (2016) and initiatives by various airports to provide for passengers with hidden disabilities are positive steps in making the airport experience inclusive for all. It is hoped that similar guidelines and initiatives might be extended to airports in other parts of the world. Sensitivity to the needs of those with non-mobility disabilities are also required before arrival at the airport (at the information search/booking stage) and on the aircraft, as Civil Aviation Authority (2018) recommends, if the individual (and their companion/s) are to have a fully inclusive air travel experience. The following chapter introduces another group of individuals who may be excluded from the air travel experience or for whom air travel is an anxious experience – those with a fear of flying.

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