

Unheard voices: The lived leisure travel experiences  
of individuals with Early-Onset Parkinson's  
in New Zealand

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## Abstract

This thesis aims to explore and interpret the lived leisure travel experiences of individuals with Early-Onset Parkinson's (EOP) in New Zealand. Parkinson's is a neurodegenerative brain condition, and EOP applies to those individuals diagnosed before 50 years of age. While Parkinson's and EOP are typically considered to be a 'disease' in the medical world, the World Health Organization asserts that the condition results in high rates of disability and thus the need for care. Hence, in this thesis, EOP is positioned as a disability, and simply referred to as EOP.

Tourism has been argued to be barrier-laden and exclusionary of people with disabilities (PwD), which can lead to marginalisation and social inequality. Yet, in an ideal world, tourism should be equally accessible to and inclusive of all people, including those who live with disability. Like people with different dimensions of disability, individuals with EOP are socially marginalised, yet they may still wish to participate in leisure experiences, including travel and tourism, as a means of enhancing their quality of life, physical health, psychological well-being, and social interaction. Research into the lived leisure travel and tourism experiences of people with different dimensions of disability is growing; however, this is predominantly focused on people with physical and sensory disabilities. While studies focusing on cognitive disabilities are emerging, there is a lack of work on EOP in existing scholarship.

This interpretive phenomenological study seeks to give voice to individuals with EOP and bring their lived leisure travel experiences to life. It employed semi-structured interviewing with 10 participants in New Zealand. Three key themes emerged inductively from the thematically analysed data, namely: (1) *(In)visibility of EOP in travel*; (2) *Sense of urgency to travel*; and (3) *Managing symptoms during travel*. *(In)visibility of EOP in travel* reveals how, within the context of travel, individuals with EOP experience the effects of their symptoms presenting as either invisible, visible, or both, to others. This can result in individuals expressing a felt need to disclose the cause of their EOP symptoms. *Sense of urgency to travel* reveals, among other things, that the urgency to travel for individuals with EOP is seemingly greater than for those with terminal illnesses, because of the time-bound physical and cognitive restrictions

that EOP creates. *Managing symptoms during travel* reveals the importance of accurate information for preplanning, and both the need and desire for a companion to accompany the travel of individuals with EOP.

As the only study at the time of writing to explore EOP within the burgeoning body of accessible tourism scholarship, either internationally or in New Zealand, this research augments existing understandings of PwD by adding a new body of information about another dimension of disability, EOP, that has not previously been considered and gives voice to the leisure travel experiences of those living with EOP. In exploring and revealing these experiences, it is hoped that unheard voices become heard, in both inquiry and industry alike, helping break the cycle of marginalisation of PwD in tourism, through increased awareness, understanding, and empathy.

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## List of Abbreviations

AUT	Auckland University of Technology
AUTEC	Auckland University of Technology Ethics Committee
DBS	Deep Brain Stimulation
EOP	Early-Onset Parkinson's
PwD	People with disabilities
SRM	Social relational model
UN	United Nations
*UN Tourism	United Nations Tourism

\*To note: In January 2024, United Nations World Tourism Organisation (UNWTO) rebranded to UN Tourism. For clarity, all references in this thesis are attributed to UN Tourism, including those published before the name change.

## Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgments), nor used artificial intelligence tools or generative artificial intelligence tools (unless it is clearly stated, and referenced, along with the purpose of use), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Chris Atkinson \_\_\_\_\_ 25 November 2024

## Dedication

This thesis is dedicated to my Dad, the late AB.

To an extraordinary life, well lived, and for being an amazing father. I hope you are happily 'sailing' somewhere warm and peaceful on your final journey.

Always in my heart.

## Acknowledgements

Like some before me, the sharp end of the research and initial writing of this thesis very sadly coincided with the death of my dearly loved father. He passed away, as I sat with him, on the 22<sup>nd</sup> of March this year. In fact, this year has been an appalling one for so many of my near and dear. But back to my acknowledgments...

Firstly, to my research participants who gave generously of their time and shared stories of their sometimes painful, sometimes hilarious, lived leisure travel experiences. Thank you for being willing collaborators in this exercise. This thesis would not exist without you.

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## Ethics Approval

24/8 Unheard voices: The lived leisure tourism experience of individuals with Early-Onset Parkinson's Disease.

Approved until 28 February 2027.

## Chapter 1 Prologue

In the words of my supervisor, because they are as succinct as it is possible to be, “I would like to open this thesis with a prologue, the intention being to foreground myself as situated researcher within this research” (Gillovic, 2019, p. 1), which is titled and explores ‘Unheard voices: The lived leisure travel experiences of individuals with Early-Onset Parkinson’s (EOP) in New Zealand.’

This thesis was driven by my passion for tourism and personal lived experience of EOP as a disability. With these two drivers, and considering the interpretive phenomenological approach this study takes, I acknowledge that my personal historicity has without a doubt shaped my interest in and decision to pursue this particular thesis topic (Tracy, 2010). Having declared the origins of my research interest, which I elaborate upon below, I also choose to let the reader know that most of the content in Chapter One, Prologue, and in Chapter Seven, Epilogue, consists of personal statements (Denzin & Lincoln, 1998), written actively in the first person rather than passively in the third person (Ateljevic et al., 2005; Westwood et al., 2006).

I was just 36 years old and pregnant when I noticed my right little finger randomly twitching. Post-pregnancy the tremor worsened, and I sought the advice of my GP, who referred me to a general neurologist. My journey to EOP was not a quick one. The neurologist was uncertain that my tremor was Parkinson's as my age belied the likelihood. For a second opinion, she referred me to New Zealand’s pre-eminent neurologist, Dr Barry Snow. We came to know each other well over the coming years. He, too, was reluctant to diagnose my symptoms as EOP, and for the first three years of our doctor–patient relationship, Barry continued to demur on a firm diagnosis. However, as the symptoms worsened, so too did the formal medical diagnosis come.

I consider myself ‘lucky’ in the scheme of things. EOP deteriorates more slowly compared with Parkinson's, which develops at a much later but more usual age range of late 50s to 60 plus (Parkinson’s New Zealand, n.d.). My main symptoms were tremors and dystonic twists. These symptoms are two of only a very few Parkinson's/EOP symptoms that can be treated with Deep Brain Stimulation (DBS) surgery. In layperson’s terms, DBS surgery involves electrodes being inserted deep into

the brain to stimulate the production of dopamine, which EOP depletes, and which is necessary to function without the symptoms of Parkinson's (Parkinson's New Zealand, n.d.).

So, after living with EOP for 18 years, I underwent DBS surgery. DBS is intensive and gruelling; it involves six hours of surgery while awake with your head bolted to the operating table, but it curtails symptoms instantaneously. It is not a cure, but it does give the recipient a step back in time of approximately 10 years, in terms of the severity of their symptoms. Unfortunately, I was one of just 3% of patients globally who developed a brain infection within six weeks of surgery. To recount the short version of the story, I had to have the entire operation reversed, and before I could undergo the surgery again, the COVID-19 pandemic hit. I then waited 18 long months to have the DBS surgery redone in September 2022. This time the operation was successful, apart from slightly slurred speech, which is a common side-effect of DBS surgery and of EOP itself. And so, my step-back-in-time improvement clock began its approximate 10-year wind-down... This is my personal historicity of EOP.

I come to this research as a 58-year-old, middle-class, European New Zealander who identifies as female. My lived experience of EOP over the past 22 years has been largely defining. However, before my diagnosis and for some years afterward, I worked in senior management positions within the New Zealand tourism industry. No longer able to work full-time in the area of my passion due to my EOP non-motor symptoms of fatigue, inability to multi-task, sometimes slurred speech and slight cognitive decline (Parkinson's New Zealand, n.d.), I felt the need to do something useful with my time, and something that would also be useful or important to others. While deciding whether to undertake a master's degree, I sought the advice of an old friend who is now involved in academia. His suggestion that I research an area that was related to my personal journey led me to develop the general study topic of EOP and tourism. With the help of my supervisors, Dr Brielle Gillovic and Professor Alison McIntosh, this was refined to a focus on exploring and interpreting the lived leisure travel experiences of individuals with EOP in New Zealand.

In researching my proposed topic, I saw there was a clear gap in scholarship on this subject. There also appeared to be a lack of awareness, understanding, and empathy

around the nature of disability, hidden or (in)visible disabilities in particular, and travel and tourism (McIntosh, 2020).

My own lived experiences strongly supported this. I recall a trip my partner and I took to Buenos Aires before the COVID-19 pandemic. It was also before I had DBS surgery. My EOP symptoms were generally under control with a high level of medication. However, I had one significant 'tell'. I was experiencing severe full-body dystonic 'twists' increasingly frequently. These completely disabling events arrived with less than a minute's warning, resulting in me falling onto the ground in a twisted, spasming heap and would last for between 45 to 90 minutes. On our return flight home to Auckland from Buenos Aires, and shortly after take-off, I experienced a 'twist'. My partner was wonderful with it as usual. However, the aircrew were totally unsure how to deal with me or the situation. They initially hovered around, querying my partner as to what was going on, all the while ignoring me. As my partner tried to explain, the crew continued to ignore me. Other passengers came over at times, curious and concerned, but again, only spoke to my partner. It was totally mortifying, and I felt absolutely undignified and unassisted by the crew, and embarrassed for both my partner and myself. The memory of this lived experience of EOP and the effect on my leisure travel, including the negative impact on my sense of dignity and self-esteem, together with the lack of extant literature on EOP and travel, were the deciding factors in the selection of my thesis topic.

Academic research is a relatively new and recent engagement for me. I completed an MBA (Honours) in my early 30s, and despite a weighty dissertation, neither this nor my undergraduate studies in tourism involved significant primary research. So, I came to this MPhil research as a novice, an old one at that, and my research was absolutely a dynamic and messy process, and certainly not a disembodied one (Ateljevic et al., 2005).

I come to this research with lived experience of EOP – that is, as an 'insider' (Dunn & Andrews, 2015). This is a situation where the researcher is very familiar with the research topic and/or the research participants, or where the researcher engages in a study on themselves, those like them, their family, or their community (Wilkinson & Kitzinger, 2013). Positionality as an 'insider' is not necessarily a negative. Milner and

Frawley (2019) acknowledge their “rightful place within research as experts by lived experience and agents of social change in their own right” (p. 2). Whilst this lived experience provided me with a commonality with my interview participants, helping rapidly build trust and connection (Tracy, 2019), it also unexpectedly caused me some discomfort. I closely related to many participants’ stories.

In hindsight, as a novice researcher, I believe this shared lived experience could have created a hurdle, as I instinctively knew my participant’s stories and therefore at times did not probe into statements or answers that a researcher without the common lived experience would have naturally asked or enquired about (Tracy, 2019). Bracketing, that is putting aside one’s own views or understandings of the phenomena in question (Chan et al., 2013) may have been a solution to the above dilemma. However, as noted by Dörfler and Stierand (2021), bracketing, as a theoretical construct, is not about achievement of objectivity – rather, it embraces subjectivity and puts it at the forefront. It is not concerned with removing pre-understandings but raising awareness of them, so that they can be explored, made use of, and explicitly incorporated (Dörfler & Stierand, 2021). With intimate knowledge of EOP, I was therefore able to add depth to the voices and reflections of the participants’ leisure travel experiences and offer but one possible interpretation of them (van Manen, 1990).

However, while I may be considered an insider, upon reflection (Tracy, 2019), it has become apparent to me that I also come to this research as an individual who has been reluctant to identify myself as someone who lives with a disability. By this, I mean that due to the slow progression of my EOP symptoms coupled with the massive improvement in said symptoms resulting from my DBS surgery in 2022, I have previously separated myself, mentally and emotionally, from other individuals with EOP/Parkinson’s. In some ways, I have tended to “other” these individuals (Darcy et al., 2020, p. 140), but I also see myself as “being with and for the other” (de Laine, 2000, p. 16), at least in part, in my own mind.

This realisation, brought about reflexively throughout the personal processes of the thesis journey for me (Tracy, 2019), will be unpacked further in Chapter Seven, Epilogue. But to begin...

## Chapter 2 Introduction

Being disabled should not mean being disqualified from having access to every aspect of life. (Emma Thompson)

### 2.1 Introduction

Tourism has been argued as being inaccessible to, and exclusionary of, people with disabilities (PwD) (Cockburn-Wootten & McIntosh 2020; Kastenholz et al., 2015; Michopoulou & Buhalis, 2013). This is largely due to its barrier-laden nature (Gillovic & McIntosh, 2020), often evidenced by tourism products, services, and destinations being designed by, and for, people without disabilities (Darcy & Dickson, 2009). This can lead to social inequality (Gillovic & McIntosh, 2020) and instances where PwD are “othered, omitted, overlooked, or ostracised” (Darcy et al., 2020, p. 140). Yet, in an ideal world, tourism should be equally accessible to, and inclusive of, all (Darcy & Dickson, 2009; Gillovic, McIntosh, & Darcy, 2024). One such marginalised group of PwD, overlooked by the tourism industry and tourism research alike, are individuals with EOP. This study aims to explore and interpret the lived leisure travel experiences of individuals with EOP in New Zealand. It provides a platform for their previously silent voices to be heard and understood (Deville & Kastenholz, 2020; Gillovic, McIntosh, & Darcy, 2024).

Research into disability-related tourism scholarship is burgeoning (Darcy et al., 2020), and the number of studies examining the lived tourism experiences of people with different dimensions of disability is also growing (Gillovic, 2019; McIntosh, 2020; Page & Connell, 2024). However, there remains a lack of academic scholarship focused on EOP and lived leisure travel experiences. It is expedient that the voices and lived leisure travel experiences of individuals with EOP are researched and shared, as this contributes to the development of greater awareness, understanding, and empathy with regard to individuals with EOP, together with PwD more broadly, by the tourism industry, other tourists, and society in general (Gillovic, McIntosh, & Darcy, 2024). Increased understanding helps facilitate the development of more appropriate tourism products, services, and experiences for individuals with EOP and a more accessible and inclusive approach to destination development (Deville & Kastenholz, 2020; Gillovic, McIntosh, & Darcy, 2024). This thesis is situated within accessible tourism scholarship,

and it contributes to the small but increasing body of research that focuses, in particular, on hidden disabilities. Previous studies in this area include, for example, a focus on intellectual disability (Gillovic, 2019), dementia (Page & Connell, 2024), and epilepsy (McIntosh, 2020).

Globally, it is estimated that between 1.3 (WHO, 2023) and 1.6 (The Return on Disability Group, 2024) billion people live with disability. In New Zealand, 24% of the population live with disability (Stats NZ, n.d.). This percentage is predicted to increase, primarily due to decreasing rates of mortality and the aging or 'greying' of global and local populations (Buhalis & Darcy, 2011), which brings with it changes in functionality, health, and well-being (Aubrecht & Krawchenko, 2016). Zola (1989, p. 6) highlights the significant relationship between aging and disability, stating that "everyone with a disability will age, and everyone who is aging will acquire one or more disabilities."

Surrounding this core and aging group of PwD are an estimated three billion significant others who are involved in their lives as carers, friends, or family (Return on Disability, 2014). This indicates that nearly half of the world's population is directly or indirectly touched by disability. Geographically, a significant proportion, close to 80%, of PwD live in least developed countries with limited access to what are considered the necessities of life, such as fresh water, nutritious food, medical care, education, and employment (Darcy et al., 2010), all of which are largely taken for granted in more developed countries such as New Zealand. However, life in New Zealand for PwD is still disadvantaged in comparison to people without disabilities. For example, the employment rate for 15–64-year-old PwD is 39.1%, compared with 78.5% of people without disabilities; 37% of PwD experienced discrimination in the past 12 months compared to 19% of adults without disabilities; 31% of PwD live in a mouldy home, compared with 20% of people without disabilities; and 11% of PwD found it difficult to access a doctor or medical centre, compared with 3.6% of people without disabilities (Stats NZ, 2018). These statistics indicate that despite being a developed country, PwD in New Zealand are still disadvantaged in many aspects of life.

Historically, PwD may have been regarded as a homogenous group, that is, considered a group with similar needs and traits (Daruwalla & Darcy, 2005; Richards et al., 2010). However, in reality, PwD represent a heterogenous group because the nature and

duration of disability can be permanent or temporary, sporadic, short-term, or long-term. There are different dimensions of disability, and how they are experienced is widely varied (Darcy & Dickson, 2009). Disability can affect a person's hearing, sight, cognition, memory, physiology, communication, and mental health (Darcy & Buhalis, 2011; Small & Darcy, 2011).

PwD also have a variety of unique wants, needs, motivations, and desired life experiences, which are as diverse as the concept of disability itself (Buhalis & Michopoulou, 2011; Michopoulou et al., 2015). These desired life experiences, including engaging in leisure travel, are of increasing personal and professional interest for a growing number of the world's population who have lived experience of disability, either directly themselves, or indirectly through their significant others (Darcy & Dickson, 2009). While it has been argued that PwD "have the same needs and desires for tourism as others" (Yau et al., 2004, p. 946), as mentioned earlier, tourism can still be exclusionary of, and inaccessible to, PwD (Cockburn-Wooten & McIntosh 2020; Kastenholz et al., 2015). This adds weight to the need for studies such as this, which contribute to the development of a greater understanding of different dimensions of disability and, thus, increased inclusion of PwD in both tourism and wider society (Gillovic, McIntosh, & Darcy, 2024).

Tourism is one of the largest industries in the world (Buhalis et al., 2023). It represents approximately 10% of global GDP and in 2023 the sector provided 27 million new jobs, representing a 9.1% increase compared to 2022, and only 1.4% below the 2019 level, (World Travel and Tourism Council, 2024). The access market has traditionally largely been ignored by the global tourism industry (Buhalis et al., 2005; Gillovic & McIntosh, 2015). However, the global tourism market of PwD has a range of significant, defining characteristics that make it an economically relevant and socially compelling market to deliver accessible tourism products and services to. These characteristics are explored in the next section.

## 2.2 Accessible tourism

There is a growing body of research into issues relating to disability, accessibility, and inclusion in tourism (Gillovic, McIntosh, & Darcy, 2024; McIntosh, 2020). Driving this body of research are social and economic rationales supporting the development of

accessible tourism (Darcy & Dickson, 2009). “Accessible tourism enables people with access requirements, including mobility, vision, hearing and cognitive dimensions of access to function independently and with equity and dignity through the delivery of universally designed tourism products, services and environments” (Darcy & Dickson, 2009, p. 34). PwD are not the only beneficiaries of accessible tourism; rather, the definition implies that tourism should be accessible to, and inclusive of, all people (Cockburn-Wootten & McIntosh, 2020). To this end, accessible tourism, specifically through the design and delivery of barrier-free environments (Ambrose et al., 2012), also benefits seniors, parents travelling with children and prams, and people with other access requirements (Darcy & Dickson, 2009). Thus, ‘access market’ is a term that can be used to encapsulate this wider group of people as potential beneficiaries of accessible tourism.

There is also a social case for ensuring PwD have the same right to travel as people without disabilities, which is affirmed in Articles 9 and 30 of the United Nations (UN) *Convention on the Rights of Persons with Disabilities* (Qiao et al., 2023). The UN (2006) *Convention on the Rights of Persons with Disabilities* recognises the citizenship rights of people with disabilities, and is underpinned by principles of respect and equality, access and inclusion. Article 30 refers to participation in all areas of ‘cultural life,’ including sport, leisure, and tourism. Participation in social and cultural life, especially tourism, is important to “help foster equitable and inclusive societies, where respect for human rights and human dignity, as well as equal opportunities, are realised” (Gillovic & McIntosh, 2020, p. 3).

Tourism participation is also seen as a source for enhancing general health, well-being, social interaction, and overall quality of life for socially marginalised groups, such as PwD and, in the context of this thesis, individuals with EOP (Blichfeldt & Nicolaisen, 2011; McCabe & Johnson, 2013; Page & Connell, 2024). Tourism is seen by PwD as a metaphor for recovery, in that it is a multi-dimensional activity through which individuals can demonstrate autonomy and regain some sense of control over their lives (Yau et al., 2004). This may involve motivations related to asserting their independence, enhancing their self-identity, searching for adventure and (controlled) risk (Shi et al., 2012), or even the desire to be temporarily freed from their role as “objects of care” (Kastenholz et al., 2015, p. 1264).

In relation to tourism, scholars agree that PwD still want to travel and have the money and the right to do so, but the access market has largely been ignored by the industry (Buhalis et al., 2005; Gillovic & McIntosh, 2015; Yau et al., 2004). The economic rationale supporting accessible tourism is based on a few key factors, namely, the accessible tourism market worldwide is significant and growing, due largely to an aging population (UN, 2015); PwD generally travel with family or a companion, so the average group size is larger; and as a market segment, PwD tend to spend more and stay longer (Gillovic, McIntosh, & Darcy, 2024). Globally, PwD and their families have a total spending power estimated at over US\$18 trillion (The Return on Disability Group, 2024). The economic and business case supporting accessible tourism is explored further in Chapter Three, Literature Review.

### 2.3 Parkinson's, EOP, and disability

As outlined by the WHO (2023) and Parkinson's New Zealand (n.d.), one form of disability is EOP. This is a degenerative brain condition that affects the nervous system and muscles. It has a wide range of motor and non-motor symptoms including tremors, rigidity, slurred speech, and problems with balance and coordination, along with cognitive decline, anxiety, and sleep disturbance, with the combination and experience of symptoms for every individual being unique (Parkinson's New Zealand, n.d.). There is currently no cure for EOP, although the symptoms can usually be managed for a period of time through various medications that artificially replace the dopamine that is lacking in the brain (Parkinson's New Zealand, n.d.). Exercise improves general health, and therapies such as speech and physiotherapy can also help manage symptoms. However, over time the effectiveness of these medications and therapies ceases to work (Parkinson's New Zealand, n.d.). This leaves the individual with the full effect of the symptoms described above.

EOP is universally understood as applying to those individuals formally medically diagnosed with Parkinson's at, or before, the age of 50 years (Upbeat NZ, 2021). In 2023, there were an estimated 10 million people with Parkinson's globally (Parkinson's New Zealand, n.d.). In the same year, it was estimated that there were around 12,000 people with Parkinson's in New Zealand (Dieriks, 2023), and 10% to 20% of this population are thought to have EOP (Upbeat NZ, 2021). The total number of people

with Parkinson's in New Zealand is expected to double by the year 2040, again due to an aging population (Pellegrino, 2022).

While the common medical term for Parkinson's/EOP is a 'disease,' the WHO (2023) states that the degenerative condition results in high rates of disability and the need for care. The symptoms of EOP progressively worsen over time and, at any stage, can result in the individual concerned experiencing physical or social impairment. An individual with EOP can be disabled by society through a range of factors including attitudes, stigma, and marginalisation (McIntosh, 2020). Parkinson's/EOP is therefore situated as a disability by the WHO and in this thesis is referred to as such.

Parkinson's/EOP is often perceived as an older person's disability (Upbeat New Zealand, 2021). Managing EOP can therefore be particularly challenging for a younger person and their family from a medical, psychological, and social standpoint (Upbeat New Zealand, 2021). Medically, the cost of private specialists for diagnosis and ongoing treatment can be prohibitive in younger family situations (B. Snow, personal communication, February 2019). Equally, the wait time for public specialists, particularly for an initial diagnosis, can create stress and psychological trauma for the younger person and their family (Parkinson's New Zealand, n.d.). For those individuals with EOP and their families, the manifestations of EOP, for instance, tremors, muscle freezing, lack of coordination, and speech slurring, amongst other symptoms, can produce significant negative impacts in social situations, with both the individual and their family members feeling anxious and stigmatised (B. Snow, personal communication, February 2019). Negative social impacts for individuals with EOP include having their symptoms, as outlined above, mistaken as something self-inflicted, such as being drunk. As discussed further in Chapter Five, this can cause extreme embarrassment and distress for the individual concerned. A diagnosis at a young age presents its own unique set of challenges as people are often still working, raising family, and juggling financial demands (Parkinson's New Zealand, n.d.).

Building on the above description of EOP as one dimension of disability, this chapter moves now to discuss important considerations in understanding disability and the relationship between disability and the tourism experience. It contextualises lived

experience and the notion of 'giving voice' to marginalised groups. It also articulates the significance and rationale for the study.

## 2.4 Understanding disability

"Language provides a unique capability to resist, strengthen and reframe identities of individuals and groups, yet can also reinforce, weaken and perpetuate dominant worldviews of disability" (Gillovic, McIntosh, Darcy., & Cockburn-Wootten, 2018. p. 1). Recognising this, defining and understanding disability is important because the language people use to describe PwD can influence their perceptions, expectations, and interactions with PwD (Barton, 2009). However, one of the difficulties in defining disability is due to the myriad of dimensions of disability, differing degrees of permanence, the spectrum of support needs required, and the circumstances in which an individual with disability lives their daily life (Darcy & Dickson, 2009; Zajadacz, 2015). The WHO and the World Bank (2011) define disability as an umbrella term that covers "impairments, activity limitations [and] participation restrictions" (p. 4). In this definition, "impairment" describes a problem in body structure or mental functioning, "activity limitations" relate to the problems associated with attempting a particular function, and "participation restrictions" describe problems related to involvement in normal daily activities (WHO & World Bank, 2011). The UN (2006) posits that, due to its evolving nature, there is no one single definition of disability.

While disability might not have a single, unified definition (UN, 2006), helping to shape the understanding of disability are several key and well-established disability models. These models are continually debated among disability studies scholars (for example, Albrecht et al., 2001; Goodley et al., 2019; OToole, 2013) as well as within accessible tourism scholarship (see, for example, Blichfeldt & Nicolaisen, 2011; Buhalis & Michopoulou, 2011; Darcy, 2012; Zajadacz, 2015). Over the past 50 years the ontological basis of disability can be tracked to two prominent paradigms, those of the medical and social models (LoBianco & Sheppard-Jones, 2008). These two models lead society's understanding of, and attitude towards, disability, and largely depict how PwD are viewed. The medical model emphasises how disability is a problem of the individual, whereas the social model suggests disability is a result of the structures and systems of society (LoBianco & Sheppard-Jones, 2008). The two key models of

disability also have implications for the language of disability, which are addressed below.

The medical model of disability evolved when professionals such as doctors and scientists took over as society's 'cognitive authority' from religious leaders (Humpage, 2007). At the heart of the medical model is the belief that disability is the problem of the individual, and "its magnitude relates to the extent of the deviation from the normal" (Buhalis & Michopoulou, 2011, p. 146). This deficit focus suggests that disability, as a deviation from 'the norm', is undesirable, and requires medical intervention to fix or cure the impairment (Engel, 1977; Todorovska, 2019), which is the result of some physiological impairment due to damage or disease (Llewellyn & Hogan, 2000). According to Blustein (2012), the medical model purports that alterations to the physical landscape or to society would not provide PwD with opportunities equal to those without disabilities, who are deemed fit and healthy on a standard scale, because impairments are innately disabling. Brittain (2004) suggests that the medical model provides the view that the medical issues experienced by PwD stand apart from the broader environments in which we live.

The language of the medical model is impairment-first rather than person-first, underlining the belief that it is the disablement of the person that needs to be addressed, treated, or fixed (Gillovic, McIntosh, & Darcy, 2024). This language can be considered disabling and may contribute to enabling the stereotypes of PwD and perpetuating the idea of abnormality or loss (Darcy & Buhalis, 2011; Lynch & Groombridge, 1994, Oliver, 1990). This contrasts with the view and language of the social model in which disability is regarded as a socially constructed phenomenon "which disables people with impairments, and therefore any meaningful solution must be directed at societal change rather than individual adjustment and rehabilitation" (Barnes et al., 2010, p. 163). Hence, the language of the social model is person-first. Person-first language places the emphasis on the person rather than on the particular functional limitation. "It preserves the integrity of the person and does not equate the person with the condition they have. For example, individuals with epilepsy rather than epileptics" (Lynch & Groombridge, 1994, p. 18). The language of disability therefore plays an important role in helping to create, perpetuate, or justify attitudes

and behaviour, whether they are positive or negative towards PwD (Gillovic, McIntosh, Cockburn-Wootten, & Darcy, 2018).

Regarding the language of disability, it is appropriate at this point to highlight that I sought to respect and uphold the language choices made by my participants in both engaging with them and presenting their data. Therefore, if disabling or marginalising terms are used at times in this thesis, particularly in Chapter Five, Findings and Discussion, where verbatim quotes from the participants are used, it is due to my upholding of the language choices made by my participants.

The social model of disability originated from disability activism and research in the United Kingdom in the 1970s, and in 1983 was given the term now utilised (Oliver, 2009). It came about through the reaction to the limitations of the medical model and saw PwD calling for their rights to all areas of citizenship, including tourism (Woodside & Etzel, 1980). Scholars generally articulate the social model of disability as more progressive and inclusive when compared to the medical model (Grenier, 2011). The core assumption of the social model of disability is that disability is a socially constructed concept and not an embodied personal flaw (Zaks, 2023). Discourse around the social model of disability indicates that disability “only exists in so far as it is socially constructed and imposed on people with impairments” (Llewellyn & Hogan, 2000, p. 159).

The social model argues that it is society that imposes disability on individuals with impairments, with the terms disability and impairment separated (Bingham et al., 2013; Palmer & Harley, 2012). The difference noted between impairment and disability is familiar to both models. Impairment is thought to be the result of illness and disease as described under the medical model, with disability the outcome of impairment (Oliver, 1990). Discourse on the social model presents the idea that disability rather than impairment is the focus. Impairment, a physical manifestation, plays a secondary role to disability which is considered to be socially developed. Under the social model, disability is scrutinized in the context of socially marginalising issues. (Hughes, 2007; Oliver, 1990; Zola, 1989). As noted above, this is an important difference whereby the social model fundamentally suggests that it social ideas and pressures that create

limitations, not an individual's physical state, and that there is nothing fundamentally or innately disabling about having an impairment (Barney, 2012; Blustein, 2012).

In fact, social model proponents purport that it is the way PwD are isolated and excluded from complete community participation that creates the notion or actuality of disability in addition to impairments (Bingham et al., 2013; Brandon & Pritchard, 2011). The lack of removal of environmental barriers faced by PwD, through social neglect or inability, can create a by-product of felt isolation and rejection and the perception or actuality of PwD being less able to engage compared to others within their community (Forhan, 2009; LoBianco & Sheppard-Jones, 2008; Palmer & Harley, 2012). Developing solutions should therefore be focused on changes to social and political activity rather than on an individual's impairment (Bingham et al., 2013). As disability is socially constructed, a social solution also becomes possible (McIntosh, 2020).

A third model of disability, the social-relational model (SRM), combines the merits of both the medical and social models of disability. The SRM explains disability as the "experience of socialised impairment" (Haslett et al., 2017, p. 62). It overcomes the limitations of previous models by recognising that impairments have direct and immediate effects, for example, reduced function or physical weakness, and that, at the same time, socially engendered restrictions can arise in different forms, for example structural and attitudinal (Goodley, 2013). Martin (2013) evidenced this by suggesting that "impairments such as being physically unable to use one's legs, and social and environmental barriers can all operate simultaneously" (p. 2). That is, the SRM purports that PwD are impacted both physically, by their impairments, and by social barriers, such as discrimination (Shakespeare & Watson, 2001), indicating that PwD face barriers to both 'being' and 'doing' in their living environments (Thomas 1999, 2014).

Traditionally EOP has been viewed through a medicalised lens, with individuals considered by their specialists as having a disability that, while unable to be fixed or cured, requires medical interventions to help the individual with EOP function as close to the 'norm' as possible and for as long as possible (B. Snow, personal communication, February 2019). Whilst EOP has traditionally been seen and managed

through the lens of a (bio)medical model (Clarkin et al., 2024), this research study is framed by the third model of disability discussed, that of the SRM. The choice of SRM is aligned with the WHO (2023), which argues that EOP can be considered a disability. Individuals with EOP need to be recognised and understood as having physical impairments, such as tremors and dystonia, but at the same time they are affected by stigma and other social barriers. Hence, the lives of individuals with EOP are impacted by components of both the medical and social models. Simpson et al. (2013) outline that the SRM has been used to offer an alternative way of conceptualising EOP, by showing how stigmatising attitudes have contributed to the individual's experience of physical restrictions. Building on the context of the disability models discussed above, disability and EOP are now considered within the context of lived experience, both of tourism and disability.

## 2.5 Lived experience, tourism experience, and disability experience

A broad range of studies have described 'lived experience', and several of them are explored below. Darcy and Small (2010) take an embodied perspective, stating that lived experience is fundamentally a bodily experience. Similarly, lived experience has been explained as the following:

[lived experience involves] representation and understanding of a researcher or research subject's human experiences, choices, and options and how those factors influence one's perception of knowledge. [... It] responds not only to people's experiences but also to how people live through and respond to those experiences. [...] Lived experience seeks to understand the distinctions between lives and experiences and tries to understand why some experiences are privileged over others. (Boylorn, 2008, p. 490)

Lived experience is just one aspect of study that phenomenological enquiry is interested in, with the aim being to describe a lived experience in detail (Mapp, 2008). The phenomenological perspective indicates that one must have personally experienced phenomena in order to communicate about them to others (Todres & Holloway, 2004).

To summarise, lived experience represents how a person reflects on the significance of what has happened (a phenomenon) and how he or she works or interacts in attempting to make sense of it (Smith et al., 2009). Indeed, in relation to this study, the

lived experience of individuals with EOP is significantly influenced by the complexity and individuality of clinical manifestations of EOP, increasing experience of disability, and gradual decline in the ability to care for oneself (Bonner et al., 2020; Eatough & Shaw, 2019; Smith & Shaw, 2017). The statement above points to the breadth of the lived experience of individuals with EOP, as each person experiences a unique set of symptoms and, hence, a unique lived experience. This vagary is what makes EOP so hard to diagnose for the specialist (B. Snow, personal communication, February 2019), difficult to accommodate from a tourism service perspective (this is expanded on in Chapter Five, Findings and Discussion), yet fascinating and important to research from a social science perspective.

“The tourist experience, or what people experience as tourists, is unique to the individual; thus, there are as many forms of tourist experience as there are tourists” (Sharpley & Stone, 2012, p. 2). Very early scholarship defined tourism experiences as superficial and frivolous (Boorstin, 1964), meaning that the experiences were sought with little thought or depth of meaning in mind (Cornelisse, 2018). Conversely, MacCannell (1973) believed that tourism experiences were about people seeking authentic experiences. Both arguments hold some truth, as the tourism experience is as varied as people are themselves. That is to say, the motivations for a tourism experience and the desired outcomes vary from person to person (Israeli, 2002). People search for various aspects of well-being through participation in tourism experiences (McCabe & Johnson, 2013). These experiences offer the potential fulfilment of a range of human needs including learning, self-actualisation, relaxation, feelings of togetherness, and social acceptance (Aho, 2001).

Cohen (1979) suggests that people relate to tourism experiences as a means to define and, in some cases, redefine the self. Noy (2004) concurs, explaining the view that tourism experiences are told and retold as “well-stylised travel narratives, which culminate in the telling of a profound self-change that their narrators have undergone” (p. 9). The research into and analysis of memorable tourism experiences by Tung and Ritchie (2011) support the findings of Cohen (1979) and Noy (2004) by outlining the importance of four key aspects: affect, expectation, consequentiality, and recollection. Affect relates to emotions and senses and could be said to align to the ‘dreaming’ phase of tourism planning (Tourism New Zealand, n.d.). Expectations are around

planning and anticipation and tie into the desired or perceived presence of an outcome or result in terms of personal development or self-discovery, which is consequentiality (Tung & Ritchie, 2011). Finally, recollection pertains to the re-living or recollecting of the experience through storytelling, and looking at souvenirs, and photographs (Tung & Ritchie, 2011). The tourism experience can be viewed from a significant range of positions; however, the most important aspect is that it is as unique as the individuals, whether with or without disabilities, who engage in such experiences. There are some common needs that people seek to meet through participation in tourism experiences (see Aho, 2001), but the outputs or consequences of lived tourism experiences remain subjective and unique.

In reflecting on the concept of the lived experience of disability, it is useful to highlight the phenomenological notion of the 'lived body' (Merleau-Ponty, 1962):

As an embodied subject, I do not experience my body primarily as an object among other objects of the world. Rather than being an object for me as subject, my body as I live it represents my particular point of view on the world. (p. 70)

PwD, and those who regularly accompany them on their travels, necessarily come to view the world through the medium of the limits and possibilities of their own bodies and/or circumstances. For example, for an individual with EOP who has a hand or arm tremor, a bowl of soup is not simply "something to be eaten, it is a concrete problem to be solved" (Toombs, 1995, p. 13). Hence the notion of lived experience can be applied to disability as it can be to tourism. That is, each individual or PwD has a unique lived experience of both disability and tourism, based on their own unique set of circumstances.

## 2.6 The importance of 'voice' in accessible tourism

At time of writing, accessible tourism scholarship relating to the perspectives and experiences of individuals with EOP engaging in leisure travel is non-existent, while there is limited research on other (often) invisible dimensions of disability, including dementia (Page & Connell, 2024), intellectual disability (Gillovic, 2019), and epilepsy (McIntosh, 2020). Yet, it is vitally important to hear directly from these PwD, to give and "to represent their voices with integrity" (Gillovic, McIntosh, & Darcy, 2024, p. 1).

Providing platforms for the voices of PwD helps drive understanding of the factors that dictate and shape the leisure tourism participation and experiences of PwD more generally (Devile & Kastenholz, 2020) and, in this study, of individuals with EOP in New Zealand. Indeed, PwD have lacked power and voice and faced stigma, discrimination, and institutional barriers (Johnstone, 2001; Oliver, 1990; Oliver & Barnes, 2012). Thill (2015) posits that recognition of diversity amongst PwD is also important for valuing voice. This means that in order to be considered to be inclusive, tourism needs to recognise that PwD represent a heterogeneous group, and individuals with different dimensions of disability have both the need and the right to have their voices heard.

Enabling the voices of PwD through research is a critical contribution to developing more accessible tourist products, services, experiences, and destinations. It may provide the tourism industry with essential knowledge that increases the awareness, understanding, and empathy required to more appropriately address and accommodate the needs of PwD, especially those with hidden or invisible disabilities (Fisher, 2023). Overall, research can “make space for the marginalised” (Russell-Mundine, 2012, p. 4), and this helps promote and engender a more inclusive approach to tourism (Devile & Kastenholz, 2020). By giving individuals with EOP and, by extension, people with different dimensions of disability voice through research, we will likely increase the broader awareness of their experiences of disability and tourism, but also that of their family, friends, and carers (Gillovic, McIntosh, Cockburn-Wootten, & Darcy, 2018). This wider understanding can only be beneficial for increasing the inclusion and overall well-being of PwD, both in tourism and society at large (Devile & Kastenholz, 2020; McCabe & Johnson, 2013).

## 2.7 Significance and aim of the research

The rationale for this study is reflected in its aim of seeking to address the gap in research and practice by providing exploratory insight into the subjective lived leisure travel experiences of individuals with EOP in New Zealand. Specifically, it positions itself within accessible tourism scholarship and contributes to growing work within this field (Darcy et al., 2020), and especially to the smaller body of work that notes the invisibility of certain disabilities and the implications this has on tourism participation

and experience (for example, Gillovic, 2019; Gillovic, McIntosh, & Darcy, 2024; McIntosh, 2020).

Scholars are increasingly examining the lived leisure travel experiences of people with different disabilities and in particular those with hidden disabilities, for instance, epilepsy (McIntosh, 2020), dementia (Page & Connell, 2024), and intellectual disability (Gillovic et al., 2021). However, upon reviewing the extant academic literature, it is apparent that there is a complete absence of research at the nexus of individuals with EOP, lived experience, and leisure travel. Indeed, Shabu et al. (2022), in their medical travel study, recommended that future qualitative research is undertaken on the lived travel experiences of individuals with EOP and Parkinson's. This, in part, highlights the significant gap in research to date on the topic and lends itself to an indication of the originality and contribution of this study. The lived leisure travel experiences of individuals with EOP have not yet been explored in accessible tourism scholarship, either internationally or in New Zealand.

A significant contribution of this study is to give individuals with EOP a voice (Deville & Kastenholz, 2020). It contributes by exploring and interpreting their leisure travel experiences, albeit offering but one possible interpretation (van Manen, 1990). It helps prioritise wider and more inclusive understandings of the lived travel and tourism experiences of PwD in different dimensions of disability within accessible tourism studies, and tourism scholarship more generally, which thus far has largely focused on people with physical disabilities (Ray & Ryder, 2003) or sensory disabilities (Deville & Kastenholz, 2020; Richards et al., 2021).

This study revealed several key nuances of particular significance regarding individuals with EOP, which are explored in depth in Chapter Five, Findings and Discussion. The first was around the (in)visible nature of EOP, which gives rise to misunderstanding from others. Another was the progressive and disabling nature of EOP, which impacts the ability to travel by placing a perceived (and actual) time limit on travel participation, and this in turn increases the urge to travel now rather than later. The third key nuance relating to the significance of this research is the need to manage symptoms of EOP, which necessitates care. This problematises the assumption of independence in travel.

The aim of this thesis is to explore and interpret the lived leisure travel experiences of individuals with EOP in New Zealand. The supplementary research questions which this thesis intends to answer are:

1. What is the significance of EOP for individuals' lived leisure travel experiences?
2. What meaning do individuals with EOP ascribe to their lived leisure travel experiences?

## 2.8 Thesis structure

The thesis commenced with a short Prologue which foregrounded my positionality as the researcher and my rationale for selecting the thesis topic.

Chapter Two, Introduction, has introduced important background information relevant to the study topic, the significance of the study, and the thesis aim and supplementary research questions.

Chapter Three, Literature Review, provides a critical review of some of the existing literature relevant to the thesis aim. Specifically, it covers key themes of the case for accessible tourism (development); motivations, barriers, and constraints to tourism participation for PwD; and lived tourism experiences of people with different disabilities. Also reviewed is the participation of PwD in leisure and recreation. The gaps and questions that remain are noted.

Chapter Four, Methodology, begins with a discussion of some of the most common research paradigms and provides justification for the selection of an interpretive phenomenological approach for this study. Sampling procedures are outlined, followed by an explanation of the data collection and analysis methods of semi-structured interviews and thematic analysis. The historicity of the participants is provided, and the chapter concludes with methodological reflections and ethical considerations.

Chapter Five, Findings and Discussion, reveals the key findings inductively derived from the interview data and thematic analysis. Three themes emerge: (1) (In)visibility of EOP in travel; (2) Sense of urgency to travel; and (3) Managing symptoms during travel. These themes are then discussed with respect to the thesis aim and in relation to the wider literature.

In Chapter Six, Conclusion, key findings are summarised and the study's originality, significance, and contribution are shared, as are avenues for future research.

Chapter Seven, Epilogue, concludes the thesis with a short, personal reflection, which brings closure to the study.

## Chapter 3 Literature Review

### 3.1 Introduction

This chapter provides a critical review of key themes within the accessible tourism scholarship that are relevant to the thesis aim. Research gaps are highlighted, pointing to the need to give voice to individuals with EOP by exploring and interpreting their lived experiences of leisure travel. The key themes covered are: the case for accessible tourism (development); motivations for, barriers to, and constraints on tourism participation for PwD; and lived tourism experiences of people with different disabilities. Given the lack of literature on individuals with EOP in travel and tourism, the review concludes with a consideration of relevant themes relating to the participation of PwD in leisure and recreation.

### 3.2 The case for accessible tourism (development)

Much scholarship discusses the fact that the access tourism market has multi-faceted benefits to both the business and social case (Buhalis et al., 2012; Gillovic, McIntosh, & Darcy, 2024; UN Tourism, 2016a). A range of literature reviewed suggests that PwD, and other potential beneficiaries of accessible tourism, are a significant and lucrative market for the industry (see, for example, Darcy, 2006; Gillovic & McIntosh, 2020; Huh & Singh, 2007). The global access market is substantial in size and continuing to grow (Gillovic, McIntosh, & Darcy, 2024), primarily due to an aging population (UN, 2015), as already highlighted in Chapter Two, Introduction.

The business and social cases for accessible tourism have been researched both quantitatively and qualitatively (Darcy, Cameron et al., 2011; Return on Disability, 2014). The quantitative research includes statements regarding measures of the size, significance, and value of the access market (Gillovic, McIntosh, & Darcy, 2024). Literature reviewed posits that the business benefits of tourism operators providing accessible tourism include an increase in customer base size and in activity and occupancy, all of which have positive economic flow-on effects seen in improving profitability, leveraging competitive advantage, increasing market share, and enhancing destination competitiveness (Darcy et al., 2010; Gillovic & McIntosh, 2020; Stumbo & Pegg, 2005). Literature also indicates that PwD who find tourism operators

that actively meet their needs reward those operators with high levels of loyalty, word-of-mouth referrals, and repeat visitation (Darcy et al., 2010). This also has positive business flow-on effects (Gillovic & McIntosh, 2020; Stumbo & Pegg, 2005).

Some scholars argue that there are still tourism operators who want tangible proof of the benefits accessible tourism can bring before they engage in the full gambit of what creating or accommodating access looks like and means (Bizjak et al., 2011; Card et al., 2006). Making tourism accessible to PwD is regarded by some tourism operators and even destinations as an additional and, at times, unnecessary cost and hassle (Shaw & Coles, 2004; Shaw et al., 2005). Misunderstandings of this market, together with the perceived cost involved in potential changes required, as highlighted above, have often deterred such tourism operators and destinations from investing in accessible tourism development and adapting their offerings to address barriers and meet other needs of PwD (Lawthers et al., 2003). A circular pattern emerges as, with less attention from the tourism industry to the access market, the sense and actuality of inclusion for PwD declines, and they increasingly experience marginalisation and exclusion (Michopoulou et al., 2015).

PwD are progressively and publicly calling for a place in tourism activities (UN Tourism, 2016b). In response to this public position, and in contrast to tourism operators and destinations referred to above, others are already undertaking initiatives dedicated to adapting their products and services to meet the needs of different segments of the market, including PwD (Prescott, 2024). UN Tourism (2016b) notes that a lot of activity still remains to be undertaken for a high standard of accessibility and inclusion to become a reality for PwD, both by operators and destinations, particularly those considered emerging or located in least developed countries. By carrying out such activities, the competitiveness and growth of tourism operators and destinations is likely (UN Tourism, 2016b). The subject of this study, individuals with EOP, comprise an element of the business case for accessible tourism. They too could contribute to the economic growth and competitiveness of tourism operators and destinations (UN Tourism, 2016b), if their needs were better recognised and accommodated by the industry.

Darcy et al. (2020) explain that some destination regions around the world (for example Catalunya, Singapore, Flanders, and Cairns) are working to develop infrastructure, goods, services, marketing, and promotion to actively pursue accessible tourism, supporting the fact the access market exists both as a market segment and as “part of every market segment” (Dwyer & Darcy, 2011, p. 222). In this way, people with different dimensions of disability are slowly being included in destination development. However, Buhalis and Darcy (2011) argue that there is a need to facilitate development that goes beyond accessibility just being about accessible infrastructure, although this is important, to development that truly delivers the full sensory experience for PwD. Other scholars support the principle of full sensory development and, through a focus on embodiment, have improved the general understanding of the need to provide accessible destination experiences (Chan & Agapito, 2022; Soliman et al., 2023) that move beyond ‘the visual gaze’ (Small et al., 2012) to engage with PwD in ways that include not just sight but the other senses of feel, sound, taste, and smell (Efstathiou & Zippelius, 2019).

PwD are not the only group who have accessibility requirements and they are not the only recipients (Zajadacz, 2015). With a positive approach to addressing these requirements, tourism destinations will experience an evolution of their product and service offerings, which in turn will both create a more accessible tourism experience and improve the quality of life of not only their visitors but residents too. Destinations that invest money and other resources in providing appropriate facilities and other offerings for PwD can be characterised as competitive in this market (Liasidou et al., 2021). “For many destinations, the advent of smart tourism (particularly in the context of public transportation, visitor flow, augmented reality and the visitor experience, and visitor safety) has enhanced, and will continue to enhance, their destination competitiveness and their ability to sustain engagement with ever-more demanding tourists” (Fyall & Garrod, 2020, p. 167).

Within relevant literature, much has been written that relates, in part, to changing the tourism map to involve new people and places (Alén et al., 2012; Darcy & Dickson, 2009). This includes considerations of the tourism system at large, from destination management (see, for example, Fyall & Garrod, 2020; Gretzel, et al., 2015; Hayden et al., 2024) to the incorporation of the principles of universal design in tourism sites and

spaces. It also includes considerations of both the business and social rationales for accessible tourism, as articulated previously. In terms of destination management, “the need to achieve balanced economic growth that enriches the tourist experience, protects the natural environment and enhances the well-being of the host ‘resident’ community has become an overarching challenge for destination managers” (Fyall & Garrod, 2020, p. 165).

Universal design has been defined as

the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design. ... The intent of the universal design concept is to simplify life for everyone by making products, communications, and the built environment more usable by more people at little or no extra cost. The universal design concept targets all people of all ages, sizes and abilities. (Darcy & Dickson, 2009, p. 6)

Darcy et al., (2010) comment on the significance of Universal design, stating that providing accessibility for PwD, along with the rest of the population, requires knowledge and design structures that are inclusive for all citizens. PwD are participating more frequently in tourism activities as a result of their growing level of economic and social integration and due to the adaptation of services, products and destinations. However, there remain many and varied barriers that hinder access to tourism services, and these are explored below.

### **3.3 Motivations, barriers, and constraints to tourism participation for PwD**

Considerable attention has been focused on the fact that PwD are increasingly advocating for their right to travel, and their desire to do so (Cloquet et al., 2018; Packer et al., 2007), in recognition of their more frequent participation in tourism (UN Tourism, 2016a). There is much qualitative research that examines the access market from demand-side perspectives, specifically the needs, motivations, and behaviours of PwD and their participation in tourism (Burnett & Baker, 2001; McCabe & Johnson, 2013; Robinson et al., 2007). While tourism has been shown to provide positive effects on the quality of life and life satisfaction of PwD (McCabe & Johnson, 2013), the motivations to participate may differ among PwD according to various factors,

including the dimension and degree of disability, and the nature of the tourism experience sought (Bergier et al., 2010; Pearce & Lee, 2005).

For some people who live with disability, the concept of departing from known, daily routines and undertaking travel can result in a high degree of angst (Darcy, 1998). This is because in their everyday lives, through self-created routines, they can control or influence their everyday surroundings to varying degrees and hence deal with any difficulties that arise. However, they do not have prior knowledge of possible barriers resulting from the new experiences and environments encountered through travelling and how they might deal with them (Yau et al., 2004). Yet, leisure travel is thought of by many PwD as a metaphor for temporary recovery. A major effort, problem-solving skills, along with a high degree of self-awareness about one's own capacity and capability, are required for engagement in tourism for PwD. It also requires the tenacity and emotional and mental ability to source accurate, helpful information on a tourism destination and activities (Rubio-Escuderos et al., 2024). Due to this complexity, actually achieving the travel goal demonstrates to the individual with a disability and others that they are independent and capable of managing (and enjoying) travel, and this in itself can be reflective of a metaphor for their lives (Yau, et al., 2004).

The search for independence, adventure, and (managed) risk are a related set of specific drivers or motivating factors for PwD to participate in tourism (Shi et al., 2012). Similarly, Kastenholz et al. (2015) add that a main motivation for some PwD is the desire to be temporarily freed from their role as "objects of care" (p. 1264). In addition, tourism may be sought by PwD for its positive effects on social integration (Kastenholz et al., 2015), coping with stress (Moura et al., 2018), and opportunities for affirming oneself and identity (Eichhorn et al., 2013; Pagán, 2015), as well as self-efficacy and a sense of achievement (Gillovic et al., 2021). Indeed, previous scholars have suggested that, for PwD, tourism can minimise feelings of indifference, distress, or dependency that are often experienced in their everyday lives (see, for example, Innes et al., 2016; Valtonen & Veijola, 2011) and can provide a sense of 'normality' (Hunter-Jones et al., 2020; McIntosh, 2020). However, in contrast, Yau et al. (2004) highlight that negative experiences can lower PwD's self-esteem and confidence and lead to the decision not to travel again. What remains unknown is whether these

motivations and experiences, both positive and negative for PwD more generally, correlate with those of individuals with EOP.

While PwD are motivated to participate in tourism, barriers and constraints may prevent or restrict them from effectively doing so. A review of the relevant literature reveals that a significant proportion of accessible tourism scholarship is focused on highlighting and discussing the barriers and constraints faced by PwD in regard to their ability to participate fully in tourism (Avis et al., 2005; Daniels et al., 2005; Israeli, 2002; McKercher & Darcy, 2018; Smith, 1987).

Smith (1987) synthesises a variety of examples of barriers for PwD under the categories of intrinsic, environmental, and interactive. Intrinsic barriers are driven by the individuals' own "levels of cognitive, physical, and psychological function" (p. 376). The intrinsic barriers most likely to impact on PwD participating in tourism include lack of knowledge, health-related problems, social ineffectiveness, and physical and psychological dependency. Environmental barriers are considered to be those limitations that are externally imposed, and include physical barriers such as transportation and architecture, together with attitudinal barriers (Smith, 1987). Thirdly, interactive barriers result from the interaction between the tourist and the surrounding social situation (Smith, 1987). The primary interactive barriers that confront PwD are skill–challenge incongruities and communication barriers. Other scholars have frequently discussed the structural, interpersonal and intrapersonal constraints on PwD participation in tourism (Blichfeldt & Nicolaisen, 2011; Crawford & Godbey, 1987; Israeli, 2002; McKercher & Darcy, 2018). These three constraint categories closely align with the three synthesised categories of Smith (1987), that is, structural barriers align with environmental barriers, interpersonal with interactive, and intrapersonal with intrinsic.

Some scholars have argued that intrinsic or intrapersonal barriers or constraints are the most significant obstacles (Murray & Sproats, 1990; Smith, 1987). In contrast, other scholars argue that it is the structural or environmental barriers, and especially the social environment, that are the most profound and impactful deterrent to participation for PwD (Daniels et al., 2005; Daruwalla & Darcy, 2005; Innes et al., 2016). Eichhorn and Buhalis (2011) posit that it is physical access, negative attitudes

and lack of adequate information that create the greatest barriers to participation in tourism by PwD.

Devile and Kastenholz (2018) and Eichhorn and Buhalis (2011) suggest that barriers might be physical, communicative, informational, or attitudinal. Physical barriers are akin to infrastructural barriers, such as inaccessible accommodation or transport, or physically narrow spaces or staircases (Michopoulou & Buhalis, 2013). Information barriers occur with a lack of current or reliable information about the level of accessibility. This may be, for example, incorrect or old information on a website (Daniels et al., 2005; Darcy, 2010; Eichhorn et al., 2008), or information being hard to find or missing (Rhodda, 2012). In the case of accommodation, for example, what is advertised may not match the reality (Rhodda, 2012). The importance of information is stressed in the decision-making process for PwD and their travel companions (Blichfeldt & Nicolaisen, 2011; Yau et al., 2004). Communicative barriers, according to Figueiredo et al. (2012) and Kong and Loi (2017), are in a similar genre to informational barriers and relate to information that is hard to read or understand. This could include brochures with very small print, those not available in Braille, or video clips without subtitles.

Lastly, attitudinal barriers or constraints, like Smith's (1987) environmental and interpersonal categories, are about the lack of understanding, knowledge and empathy of tourism operators and broader society towards PwD (Daruwalla & Darcy, 2005; Zhang et al., 2019), and especially those groups with different dimensions of disability that may be less understood. Indeed, some scholars (Gladwell & Bedini, 2004; Jaeger & Bowman, 2005) partially coincide with Eichborn and Buhalis (2011), who argued that, while both physical and informational access are undeniably crucial, the single greatest barrier inhibiting accessibility is negative attitudes and interaction, whether it is pronounced or subversive, between people with and without disabilities.

### **3.4 Lived tourism experiences of people with different disabilities**

Most previous research has focused on the experiences of PwD whilst traveling. Yet, a key gap within accessible tourism research is around the lived leisure travel experiences of individuals with EOP. As a segment of PwD, it is important that their voices are heard as they constitute a group who, to date, have never had a platform

for their stories. As a group of individuals with a very individualised disability (Parkinson's New Zealand, n.d.), their diversity of lived experience will add to the body of knowledge accumulating around (hidden) accessible tourism.

Some extant studies have tended to regard PwD as a largely homogeneous group (McKercher & Darcy, 2018), "as if every person with a disability possessed the same constraints and has to overcome the same barriers" (Figueiredo et al., 2012, p. 534). In reality, they are a heterogeneous group, where constraints (Daniels et al., 2005) vary by dimension of disability and level of support needs required (Darcy, 2010; Darcy & Buhalis, 2011) and across the sectors of the industry (Buhalis et al., 2012). Historically, the focus has generally been on physical issues or mobility impairment (Ray & Ryder, 2003; Švagždienė et al., 2021) or people with sensory disabilities (Devile & Kastenzholz, 2020; Rochman et al., 2022), and particularly those with vision impairments (Packer et al., 2007; Small et al., 2012).

PwD with disabilities whose symptoms are hidden or (in)visible, such as neurological conditions like epilepsy (McIntosh, 2020), dementia (Innes et al., 2016) and intellectual disability (Gillovic, 2019), reflect the different dimensions of disability now being looked at. This more recent focus is because it has been found that the voices and experiences of those with different forms of disability have traditionally been missing for accessible tourism scholarship (Gillovic & McIntosh, 2020). This may be due in part to a belief that they are difficult segments to access or include in the research process (Gillovic, McIntosh, Cockburn-Wooten, & Darcy, 2018). If tourism is to truly be accessible to, and inclusive of, all (UN Tourism, 2016a), then a wider understanding of the perspectives of people with different disabilities "ought to be heard if the aim of scholarly inquiry is to conceptualise the tourist experience more comprehensibly and responsibly" (Poria & Timothy, 2014, p. 93).

Generally, in accessible tourism scholarship, it seems the focus is on disabilities that are in some way known or discernible to others. This might be through some 'disability marker', like, for example, a wheelchair, hearing aid, or guide dog (Dwyer & Darcy, 2011). Studies of the lived tourism experiences of people with hidden or invisible disabilities are much less common. Matthews and Harrington (2000, p. 405) define an '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.” A key conclusion reported in previous literature that may also hold significance for the present research concerns the invisibility of disability and its impact on the tourism experience (McIntosh, 2020; Nilsson, 2020).

It should also be noted that most, if not all, forms of disability suffer from stigma, real or perceived, and the individuals concerned may choose therefore to try and hide their symptoms from others (McIntosh, 2020; McKercher & Darcy, 2018). Often this strategy of concealment results in an inner tension and an internal struggle over if, when and to whom they should reveal their condition (Lingsom, 2008). Another implication raised in studies by Lingsom (2008) and McIntosh (2020) is that keeping a condition ‘hidden’ may have the ramification of creating ongoing lack of knowledge and societal bias around it. To avoid encouraging tourism to continue, in part, to be a place of oppression and discrimination for PwD there is a critical need for education, awareness raising and training within the industry and also the broader community (Daruwalla & Darcy, 2005; Jacoby, 2002). However, as discussed above, the perspectives and experiences of people with invisible disabilities, such as epilepsy and dementia, remain relatively unexamined in tourism scholarship (McIntosh, 2020). To date the lived leisure travel experiences of individuals with EOP have not been explored at all.

Also, of note among these studies, and of potential relevance to this current study, is the perspective that assumes the relationship between tourism and independence (Gillovic et al., 2021, Gillovic, McIntosh, & Darcy, 2024; McIntosh, 2020). Yet travel is not always independent, and some PwD are in a situation of dependency, where they need to and may rely on a companion or carer in order to travel (Devile & Kastenholz, 2018; Gillovic, 2019). In addition, recognition is being granted to the relational dimension of travel, with studies including carers, family members and companions of people with disabilities (Darcy, 2002; Lehto et al., 2018).

While accessible tourism scholarship is beginning to venture more into the space of cognitive and hidden disabilities, this does not yet extend to EOP. While this gap may exist, studies outside of tourism offer some potential insight, specifically, those that explore the participation of people with different dimensions of disability in arts, sport, leisure, and recreation (Evans et al., 2017).

### 3.5 Participation of PwD in leisure and recreation

Given the complete absence of any accessible tourism scholarship considering the lived leisure travel experiences of individuals with EOP, I now review literature about PwD and/or EOP and the lived experience, and the relevance of other (non-tourism) leisure and recreational activities to leisure travel within the context of the interpretive phenomenological framework of this thesis.

A key common theme relates to the benefits of leisure for PwD. Indeed, some scholars (Abrantes et al., 2012; Cruise et al., 2011; Grazina & Massano, 2011) have noted that participation in physical leisure activities can be helpful for PwD, in helping alleviate apathy, fatigue, and depression, and in particular, for individuals with EOP, in improving cognitive function and fine motor skills. Sabari et al. (2015) and Crew et al. (2015) note that for PwD, including individuals with EOP, involvement in recreational activities such as dance and tai chi have been found to improve balance and posture and deliver the benefits of social interaction. This includes feelings of inclusion and a sense of well-being (McCabe & Johnson, 2013). In fact, for individuals with EOP, involvement in regular leisure and recreational activities led to significant improvements in flexibility and an increased degree of facial and hand movements, together with the positive effects of the social aspects of interaction with others (Heiberger et al., 2011).

Cycling is another form of leisure and recreation that has specifically been studied in relation to Parkinson's/EOP. Tiihonen et al. (2021) undertook a review of the impact of cycling in relation to the management and/or improvement of the symptoms of EOP. Many individuals remain able to ride a bike regardless of gait and balance impacts as a result of their disability. Interestingly, this is often despite having significant trouble with these symptoms when not cycling. Tiihonen et al. (2021) concluded that cycling has positive impact on the motor versus cognitive symptoms of EOP/Parkinson's. Like other forms of recreational activity, it delivers a general sense of health and well-being for the individual.

Again, these findings are unsurprising, given the positive impact of involvement in recreational activities on quality of life for PwD (McCabe & Johnson, 2013). It improves self-management and self-efficacy for PwD, such those with as EOP, these people

having generally lost a degree of bodily motor control and, consequently, control over their lives (Brook & Booth, 2022). Despite a lack of explicit literature on EOP and travel, a comparison can be drawn between the positive benefits of involvement in leisure and recreational activities for PwD and those individuals with EOP, and involvement in travel. This is due to the similar nature of the activities both in terms of the use of a range of skills, motor skills, and the sense of inclusion and well-being that both recreation and travel produce (McCabe & Johnson, 2013).

### 3.6 Chapter summary

This chapter has provided a review of key accessible tourism studies literature, with a consideration of its rationales for market and destination development and the motivations, barriers, and constraints to participation for PwD in tourism, as well as leisure and recreation more broadly. As Darcy et al. (2020) posit, smaller numbers of PwD can enjoy these aspects of social life compared to people without disabilities. Critically, a review of the literature has also revealed that accessible tourism studies are increasingly examining the lived tourism experiences of people with different dimensions of disability, namely physical and sensory (Devile & Kastenholz, 2020; Ray & Ryder, 2003; Richards et al., 2021). There remains a lack of understanding about the experiences of people with other dimensions of disability, most notably among those with hidden disabilities (Gillovic et al., 2021; McIntosh, 2020). This study seeks to bridge this gap, by exploring the lived leisure travel experiences of individuals with EOP in New Zealand.

Chapter Four, Methodology, discusses the study methodology selected to deliver on the thesis aim and an introduction to the study participants. Ethical and methodological considerations along with research limitations are also explored.

## Chapter 4 Methodology

### 4.1 Introduction

The research reported in this thesis aimed to explore and interpret the lived leisure travel experiences of individuals with EOP in New Zealand. This chapter explains and justifies the research methodology utilised to do this. It commences with a discussion of several prevalent research paradigms, together with reasons why they were dismissed for this study. The chosen framework of interpretive phenomenology is then explained and justified for its relevance to the study's aim. Sampling parameters, including the recruitment and selection of participants, are described, and the methods of data collection and analysis employed to reveal the key themes are then outlined. In addition, a short introduction to the research participants, their demographics and their histories is shared. Ethical and methodological considerations along with research limitations are covered at the conclusion of the chapter.

### 4.2 Paradigms

Paradigms are frameworks or sets of beliefs and values, often described as being like a pair of glasses (Tracy, 2019); they help the researcher view their surroundings in a certain way. Different sets of glasses provide different lenses through which to view and understand the world, with researchers required to select the lens (paradigm) most appropriate and suited to the research topic and question(s) at hand. According to Tracy (2019), "paradigms are preferred ways of understanding reality, building knowledge, and gathering information about the world" (p. 38). The term 'paradigm' may be defined as "a loose collection of logically related assumptions, concepts, or propositions that orient thinking and research" (Bogdan & Biklen, 1998, p. 22).

All paradigms have particular ontological, epistemological, methodological and axiological assumptions (Creswell, 2013). Ontology is about the nature of reality, that is, it concerns answers to the question 'what is truth?' (Killam, 2013). There are two types of ontology, realism and relativism. Realism states that there is just one truth, and that truth is absolute, whereas relativism considers there are many realities or truths (Gura, 1992; Jenkins, 2010). Hence, multiple, contradictory but equally valid accounts of the world can exist (Killam, 2013). Epistemology relates to how we know

what we know and how knowledge is acquired (Audi, 2010). It is generally either objective or subjective, where the former refers to the acquisition of knowledge in a factual, non-personal way while the latter is based on or influenced by personal feelings, tastes, or opinions (Killam, 2013). Methodology “refers to the way we go about discovering knowledge in a systematic way” and axiology deals with what the researcher believes is valuable and ethical (Killam, 2013, p. 9).

Common paradigms utilised in research include positivism, social constructionism, and interpretivism, and one significant variation of interpretivism is interpretive phenomenology (MacKenzie & Knipe, 2006; Patton, 2002; Tracy, 2019). These paradigms or frames of reference are briefly described below, and arguments are given as to why they were dismissed or selected as the paradigmatic framework for this study.

The positivist paradigm, sometimes also called the realist paradigm, dictates that there is one true ‘reality’ that already exists and just needs to be identified, discovered, or made known. O’Leary (2004) and Tracy (2019) explain that positivists conduct research by aiming to test a theory using observation and measurement to establish hard, factual data. Positivist paradigms are most commonly associated with quantitative research projects (MacKenzie & Knipe, 2006; Tracy, 2019). This research study is qualitative. It is about sharing the subjective, lived experiences of individuals with EOP, recognising there are multiple realities at play, and thus offering but one possible interpretation of them (van Manen, 1990). Given the nature of this study and the fact that positivist paradigms regard one truth as absolute (that is, ontologically realist and epistemologically objective) (Kafle, 2011), positivism was rejected.

With regard to social constructionism, Crotty (1998) and MacKenzie and Knipe (2006) outline the view that meaning is created by humans as they experience the world and reflect upon their experiences. At the heart of social constructionism is the belief that the world is without meaning until or unless people interact with and describe it and, in this way, construct it (Detel, 2001). Social constructionism “holds that all tenable statements about existence depend on a worldview, and no worldview is uniquely determined by empirical or sense data” (Patton, 2002, p. 97). Ontologically relativist, meaning that there are many views of reality, and epistemologically subjective, social

constructionism explores external patterns and sociocultural views (Crotty, 1998). Social constructionism utilises qualitative and/or quantitative research methods. The aim of this thesis was focused on exploring and interpreting the subjective lived leisure travel experiences of individuals with EOP in New Zealand, rather than examining external patterns and sociocultural views on disability and/or tourism, and social constructionism was thus not deemed as being the most appropriate fit for this study.

Interpretivism is an “ontological point of view which looks at the reality or truth as a social formation or construct of the mind’s inner feeling” (Aliyu et al., 2014, p. 84). As such, it is ontologically relativist as there are as many realities as there are minds. Epistemologically subjective, the interpretivist paradigm tends towards being highly descriptive (Pervin & Mokhtar, 2022); it generally relies heavily on the views of participants on the subject being investigated, and is therefore highly contextual (Greene, 1990). These factors can lead interpretation to be more about espoused values rather than real actions (Scotland, 2012). As a paradigm, interpretivism is exploratory, socially constructed, and provides opportunities for the participant’s voice to be heard, with context and background being imperative for understanding the research (Tracy, 2019). Cronje (2011) suggests that “interpretivists believe that the human experience of the world is subjective, and they have a concern to understand it as it is” (p. 3); hence, their purpose is to describe situations. Given the highly descriptive nature of interpretivism and the fact that this study aimed to explore and interpret lived experiences, and their significance and meaning upon reflection rather than as they happened, I dismissed interpretivism as not being the sole paradigm for this research.

Reflection on the paradigms outlined above and their ontological and epistemological bases cements the conclusion that an interpretive phenomenological paradigm was the most appropriate for this research study for reasons which I outline below. Kafle (2011) describes phenomenology as “an umbrella term encompassing both a philosophical movement and a range of research approaches” (p. 181). From this statement, it is apparent that phenomenology can be theory and/or methodology. Phenomenology appreciates the diversity of subjective human experience and prioritises a need to delve deeper into that which is ordinary or taken-for-granted (McManus Holroyd, 2007). Descriptive phenomenology captures the essence of an

experience as it is lived, whereas interpretive phenomenology captures meaning upon reflection and the subsequent interpretation of that meaning (Kafle, 2011).

Interpretive phenomenological research is about “going back to people’s specific experiences and letting the concepts come from there” (Todres & Holloway, 2010, p. 183). It provides a way to see the world through a focus on the phenomenon being studied and assists in researching and interpreting life’s special and mundane events, or phenomena (Dahlberg et al., 2008). Interpretive phenomenology, or hermeneutics, looks beyond the description of experience or phenomena and aims to seek meaning (Dahlberg et al., 2008). “Interpretive phenomenology is used when the research question asks for the meaning of the phenomenon and the researcher does not bracket their biases and prior engagement with the question under study” (Reiners, 2012, p. 2).

Descriptive phenomenology was not appropriate for this study as the aim was to explore and interpret the lived leisure travel experiences of individuals with EOP in New Zealand through their reflections on those experiences, rather than to simply record a description of them as they happened. Interpretive phenomenology has been used in previous accessible tourism studies to give voice to tourists with disabilities, their perspectives, and experiences (see, for example, Gillovic et al., 2021; Gillovic, McIntosh, Cockburn-Wootten, & Darcy, 2024; McIntosh, 2020).

This study is exploratory as it is the first study of lived travel experiences of individuals with EOP, and the participant’s voice is central to it – both aspects of an interpretive phenomenological paradigm. Ontologically, the aim is steeped in relativism since multiple realities exist. For participants, truth is shaped by context, meaning that in this study, the lived leisure travel experience of each individual with EOP will be unique, and thus the truth of their stories cannot necessarily be generalised (Killam, 2013). As researcher interaction is necessary to gain an in-depth understanding around discovery of what is going on, and their influence is acknowledged (and maybe even embraced), the epistemology is subjective (Killam, 2013). Related to the role of the researcher in interpretive phenomenology, ‘bracketing’ is largely a theoretical and philosophical approach that “can be conceptualised as the researchers’ attempt to hold in abeyance their pre-understandings and assumptions to attain experiences before making sense of them” (Dörfler & Stierand, 2021, p. 778). However, Dörfler and

Stierand (2021) also note that bracketing, as a theoretical construct, “is not about the achievement of objectivity; quite to the contrary, it embraces subjectivity and puts it centre-stage” (Dörfler & Stierand, 2021, p. 778). Interpretive phenomenology is the paradigm of choice for this study because “the researcher does not just play back to the participants what they have told her/him but interprets the significance of their self-understandings in ways the participants may not have been able to see” (Grant & Giddings, 2002, p. 16).

Larkin et al. (2006) very succinctly summarises the overall methodological approach utilised in this research study as follows:

this means that an interpretive phenomenological study typically involves a highly intensive and detailed analysis of the accounts produced by a comparatively small number of participants. These verbatim accounts are generally captured via semi-structured interviews, focus groups, or diaries, and the analysis then proceeds such that patterns of meaning are developed, and then reported in a thematic form. (p. 104)

As described later in this chapter, and aligned with the description above by Larkin et al. (2006), the methods utilised for this study included a small group of participants whose stories were recorded through qualitative semi-structured interviews and produce rich textual data (Kafle, 2011). The resulting data were thematically analysed, and the inductively derived themes are explored in this thesis (Larkin et al., 2006) to provide but one possible interpretation (van Manen, 1990) of the lived leisure travel experiences of individuals with EOP.

### 4.3 Sampling and recruitment

A sample of 10 participants participated in this research, as a point of data saturation had been reached and a small sample size is not seen as a limitation in phenomenological studies (Bartholomew et al., 2021; Smith et al., 2009). This is primarily because the key objective is not to obtain a ‘general’ conclusion, but rather to illuminate the lived experience and context in as much depth as possible (Frechette et al., 2020). Smith et al. (2009) provide some direction regarding sample sizes in phenomenological studies, suggesting that “Master’s level research projects could be limited to three participants ... and sample sizes are best if they range from 4 to 10

interviews” (p. 52). However, they conclude by adding that “no right answer [exists] to the question of the sample size” (Smith et al., 2009, p. 52).

Potential participants were recruited based on predetermined criteria for their inclusion or exclusion from the study. These criteria included that they reside in New Zealand and that they had received a formal, medical diagnosis of EOP (regardless of their current age). Selecting participants based in New Zealand served to refine the scale of the research down to a manageable geographic site (Marx & Singh, 2013). The requirement of an EOP diagnosis for inclusion – that is, a formal, medical diagnosis of Parkinson’s disease by or under the age of 50 (Upbeat New Zealand, 2021) – was important as the aim of the research was to capture the lived leisure travel experiences of individuals with EOP in New Zealand. Two additional inclusion criteria were that participants had participated in leisure travel either domestically and/or internationally; and that said leisure travel experiences must have been in the past seven years, that is, since January 2017. The leisure travel focus was specified as it was considered that travel for business purposes was unlikely to produce the rich and varied experiences that travel for leisure purposes does (Leiper et al., 2008), and individuals with EOP, extending into Parkinson’s, are generally less likely to still be working, or working in the type of roles which involve business travel (B. Snow, personal communication, February 2019). This is due to the effects of EOP on individuals, including tremors, fatigue, muscle freezing (dystonia), and speech impairment, amongst other career-impacting symptoms (Parkinson’s New Zealand, n.d.). The time frame of seven years was based on five years being reasonable for recency purposes (Boto-Garcia, 2023), that is, to ensure key memories or stories were recent enough to make recall accurate. However, with the disruption of the COVID-19 pandemic and subsequent global border closures, two years were added to the time parameters to equate to the total amount of time New Zealand’s borders were shut.

Potential participants were recruited through two primary avenues. Firstly, an email and attached flyer were sent to key personal contacts of mine, as the researcher. I asked them to print the flyer and have it publicly available for viewing in their offices at Auckland Hospital and Auckland University, respectively. Simultaneously, I forwarded an email invitation to Parkinson’s New Zealand and to Upbeat New Zealand (the EOP chapter of Parkinson’s New Zealand), for inclusion in their monthly electronic

newsletters. I had previously been in touch with Parkinson's New Zealand to discuss my proposed research and to request access to their monthly newsletter as a vehicle for participant recruitment. Establishing a relationship with advocacy organisations such as Parkinson's New Zealand was a crucial element of my sampling and recruitment strategy. Building one's reputation and establishing trust that aligns with the values of organisations like Parkinson's New Zealand (Nicholson et al., 2013) who act as gatekeepers, open doors, and therefore provide access to a pool of pre-qualified potential research participants is important (Altinay & Paraskevas, 2008). Having the weight and credibility of advocacy organisations supporting my research helped the recruitment process proceed smoothly.

The 'snowball' method was also utilised. This is a recruitment technique where research participants are asked to assist researchers by identifying other potential subjects (Oregon State University, 2010). Noy (2004), in his study of backpacker tourists, notes that the snowball method is often effective for investigating organic social networks and marginalised populations, of which individuals with EOP are one. Those who viewed the flyer or advertisement, either in my key contacts' offices or in the Parkinson's New Zealand or Upbeat New Zealand newsletters, were also encouraged to forward the invitation to other potential participants who they believed might qualify for the research topic. Between the advertisement placed in the digital Parkinson's and Upbeat newsletters, the flyer placed in my key contacts' offices, and the effect of the snowball method, a final 10 participants were selected.

Prospective participants were asked to email me directly, utilising my email address listed in the flyer or newsletter advertisement, to express their interest in being involved in the study or to ask any questions. When I received emails from prospective participants, I responded to their contact and sent through the detailed Participant Information Sheet and Consent Form, along with a request that they reply to me with any outstanding questions and/or sign and return the consent form. Inclusion criteria were applied at the time I received emails from potential participants expressing interest in being involved in the research study. This took the form of determining whether they met the inclusion criteria of having been formally, medically diagnosed with EOP (Parkinson's New Zealand, n.d.), having participated in domestic and/or

international leisure travel since their diagnosis, and having engaged in such leisure travel experiences within the past seven years.

Prospective participants had three weeks to consider the invitation. I considered that this was a reasonable period as potential participants would know immediately upon reading the advertisement or flyer whether they fitted the research criteria or not. The three weeks provided enough time for reflection on whether they had a predilection to being involved in this type of study, and to consult with friends and family if desired. Participants gave their consent by signing the consent form which was emailed to them and returned by them. As good practice, participants were also verbally asked for their consent at the time of interview (Tracy, 2019). The backup position was to sign a printed consent form at time of interview or provide voice-recorded consent before the commencement of the interview, as a separate audio file. Only one participant utilised the audio file option.

#### 4.3.1 The participants

There were 10 participants involved in this study (see Table 1, below). Six were female and four were male, with their current ages ranging from 47 to 66 years. They had all received a formal medical diagnosis of EOP between the ages of 41 and 50. EOP is commonly considered to be a formal medical diagnosis of Parkinson's by, or under, the age of 50 (Upbeat New Zealand, 2021). Seven of the 10 participants were Auckland-based, with one each from Tauranga, Gisborne, and Queenstown. Eight were married, one was in a long-term live-in relationship, and another was in a long-term, non-live-in relationship. Half of the participants were no longer working, directly due to the stress of living with EOP. Stress is a major symptom of EOP and often plays out as a general inability to cope with multi-tasking (Parkinson's New Zealand, n.d.). Three were still employed in full-time roles, and two were retired, although it should be noted that one of the two had to retire early, again due to the impact of their particular EOP symptoms on their ability to continue in their chosen career.

Table 1

*Summary of Participants' Profiles*

Pseudonym	Gender	Age when diagnosed with EOP	Current age	Employed	Family	Location	Interview method	Relative with Parkinson's
Penny	Female	50	55	No	Married	Auckland	In person	
Mike	Male	47	49	Full-time	Married	Auckland	Zoom	Mother, Great Uncle
Bryce	Male	50	56	No	Married	Queenstown	Zoom	Father
June	Female	50	56	No	Married	Auckland	In person	
Liz	Female	49	56	No	Partner	Auckland	In person	
Clyde	Male	48	57	No	Married	Gisborne	Zoom	
Peggy	Female	43	47	Full-time	Married	Auckland	In person	Grandmother
Georgia	Female	41	47	Full-time	Married	Auckland	In person	Father, Great Grandmother
Keith	Male	48	69	Retired	Married	Tauranga	Zoom	
Butterfly	Female	42	66	Retired	Partner	Auckland	In person	

The following section briefly introduces each research participant and their historicity. Historicity is the historical actuality of a person or event, the quality of being part of history instead of being a historical myth, legend, or fiction (McManus Holroyd, 2007). Hirsch and Stewart (2005) define 'historicity' as equating to 'historicality', referring to the past of all objects and all people. "Everything and everybody on earth has historicity in this sense, even if this historicity has not yet been articulated, and even if there exists (at present) no evidence on which to base the knowledge of this historicity" (Hirsch & Stewart, 2005, p. 261). The purpose of including the participants' historicity is to help the reader develop a deeper sense of who they are as individuals, and of their respective personalities, attitudes, and unique lived leisure travel experiences. It affords understanding, provides a degree of authenticity to their individual stories, and aims to help the reader really 'hear' their voices.

#### 4.3.2 Introducing the participants

**Penny** is married, aged 55, and was diagnosed with EOP five years ago. Her earliest symptom was long-term back pain which no osteopath or physiotherapist could fix. She requested a back x-ray from her GP and the same day her little finger started to tremble. The GP sent her to a neurologist. Penny did not realise the neurologist was putting her through a range of tests in her hour-long appointment. She was referred to a movement specialist and sent home to quietly research everything she could find out about Parkinson's. Six weeks later she knew, before her appointment, that she had EOP. Her main symptoms were depression, fatigue, and dyskinesia. She has since had Deep Brain Stimulation (DBS) surgery which has been life changing. Penny sees having EOP as a bit like having a job. She must exercise and look after her health and finds it hard to pace herself. She travels regularly with her husband and has a really positive, can-do attitude to making the most of life "*Because you never know when it's going to change.*" Penny tends to front-foot the issue of having EOP with others but believes the saying that "disabilities are not always visible" is very true and that EOP is often misunderstood.

A physically active, full-time self-employed Canadian, **Mike** was 47 when he was diagnosed two years ago. His journey to EOP started in lockdown, several years before that, when he noticed a pulse in his right wrist which he had somewhat ignored and wished would go away. An important part of his historicity is that his mother had

Parkinson's for about 28 years, before passing away a couple of months after Mike received his own diagnosis. His great-uncle also had Parkinson's. Believing it to be genetic, he says finding out he too had EOP was a *"tremendous blow"*, but on the flip side, he had spent so much time helping his Mum that he knew what to expect and his head was more in the right space. Currently, Mike's main symptoms are a tremor in his left hand and slightly slurred speech. He talks about a loss of confidence as he can feel changes happening in his body but doesn't believe they are visible to others now. Although it frustrates him, Mike tends to try and hide his tremor. His impacted left hand with its tremor plays havoc with daily keyboard work and makes his interest in martial arts difficult also, and it is getting worse. He is largely ambivalent about leisure travel, which he describes as *"enjoying but not lusting after"*. With prompting he does admit that travel and making memories adds richness to his life. Mike travels with his wife, Holly, several times a year, and she does all the trip planning.

**Bryce** was born in the USA and was 50 years of age when he was diagnosed in 2018. He says he was relieved to get his diagnosis because they had thought his father also had Parkinson's but had been diagnosed around 2013 with Lewy Body Disease, for which the cognitive decline was *"fast and brutal"*. Bryce keeps physically active by running and cycling. Oddly, when he isn't medicated, he can run better than he can walk. He likes to try alternative therapies in the form of natural remedies. Bryce used to be a drummer but finds it hard to play now, although he still loves music; he calls it his medicine. He is married and usually travels with his wife. He has a positive attitude to his life even with EOP, remarking that *"there's always someone worse off than you"*. Although Mike is becoming more aware of his restrictions and starting to feel a lot less independent. He is not sure whether he would travel by himself anymore.

**June** retired last year at the age of 56, primarily because she felt the need to just take time for herself and her health. She has two children and is a grandmother to one. She was diagnosed relatively quickly and somewhat surprisingly with EOP, during COVID-19 pandemic lockdowns. Her symptoms started with a left foot shake, but she just thought it was something to do with her previous knee surgery. Then her foot gait worsened, becoming a real slap when she walked. June's very proactive GP sent her to Auckland Hospital, where tests and an MRI diagnosed EOP. Her main symptoms now are weakness on the left side and severe lower leg cramps. June is quite open with people about her

EOP. She feels that with the invisibility of the disability, it is better to be up-front about her situation. She is married, and last year did a trial international trip to Canada with her husband. The purpose of this trip was to see how she coped with her medication regime in a different environment and time zone. The trial went well and now she and her husband are planning further travel abroad. June has a *“let's get on and do it”* approach to life and leisure travel.

**Liz** is 56 and retired from a senior role in the travel industry several years ago as her EOP symptoms became unmanageable. Her journey to an EOP diagnosis was not particularly swift. It began with a hand tremor but when she consulted her GP, was told not to worry about it, and that it was just an older age thing. Then she started having falls while walking to work. Her workmates suggested she go to a different GP, which she did, and he sent her to a neurologist. She was finally diagnosed with EOP. Now, when Liz is coming “off” her medication she has a bad tremor and suffers cognitive impairment, which impacts her ability to multi-task. As she continued to work for five years after her diagnosis, Liz would sit on her hands to hide the tremor when she had external meetings. She finds her tremor is often mistaken for being cold or stressed and that people are generally proactive and helpful. Liz also finds her lack of fine motor skills frustrating. She feels the need to bring her travel plans forward now and, although her husband isn't a traveller, she travels with and to please her daughter. Liz finds the apathy and anxiety because of EOP hard to deal with; however, she used to love variety and trying new things.

Married to Bonnie, who sat in on our interview, **Clyde** is a former multi-sporter who was diagnosed nine years ago. He is 57. His journey to finding out he had EOP started when one of his teammates called out to him and said, *“Have you had a stroke old man?”* This was due to his left arm hanging still by his side when he was running. He thought life was fantastic and still thinks it is – *“it's just different.”* His main EOP symptoms now are fatigue, arm tremors, pain and cognitive loss, or *“brain fog”*, as he calls it. In his search for something to improve his symptoms, Clyde has had four rounds of stem cell treatment which he has found miraculous, although the effects are gradually wearing off more quickly. He relies heavily on Bonnie to plan their life, including travel. They undertook a huge adventure trip last year with their seven-year-old daughter to Vietnam, India, and Bali. This required a massive amount of planning

from Bonnie. They hired a private driver and guide to ensure that they had control over, and flexibility around, their plans. They were motivated to do this trip while Clyde was still physically capable. Clyde is anxious about air travel now and will no longer fly long-haul. Whereas prior to living with EOP, tourism was seen as a reward for working hard, now he just finds the idea stressful. He was one of the participants who reported a significant incident of having his symptoms mistaken for being drunk. However, he strongly believes tourism activities should be created for people with EOP to undertake at their own pace and is happy to pay more for this feature.

**Peggy** is a Mum to four children including twin 18-year-old boys. She is 47, married, and works full-time. Her journey with EOP started about six years ago with what she thought was an ongoing shoulder injury. Eventually, after being treated without success by the physiotherapist, Peggy's GP sent her to a neurologist, who gave her the diagnosis of EOP. This came as a shock, as she just thought she was just getting older and pulling muscles. Her current symptoms are primarily Brakennesia, meaning her whole right side is slow-moving. She finds repetitive movements like stirring, whisking, chopping veggies, and brushing her teeth challenging but manageable with medication. Peggy knows some of her symptoms are visible to others, especially the walking, as people she doesn't know often ask, *"Have you injured yourself?"* She also experiences frozen face. She enjoys the outdoors and travelling with her husband and is glad she can still be active at the moment. She does admit that she does do a lot more planning around travel these days to put her mind at rest, knowing that she will cope with the change of environmental conditions and her medication regime, in particular. Leisure travel for Peggy is about quality of life, having adventures and creating memories with her husband and family while she still can. She is a highly independent person but is very focused on others, saying her motivation to travel now is primarily to have adventures with her husband for whom, she appreciates, life is going to become much more restricted and challenging in the future, as he assumes the role of her carer as her EOP progressively worsens.

**Georgia** is also 47 and has had EOP for six years. She is married with two children and works full-time as a florist. Her father also has Parkinson's as did her grandmother. Like Peggy, her symptoms started with a sore shoulder which no physiotherapist or osteopath could fix. Then she began to get a shake in one finger. She was seen by two

neurologists before the eventual EOP diagnosis came. *"You think your world has crumbled,"* she said. But she now has a pretty positive outlook on life adding, *"you've got to live life and do things while you can."* Her current symptoms are tremors down her right side, which she is aware people can see. Georgia usually asks others for help; for instance, when she's out socialising, she will always ask someone else to carry the drinks. Her kids are also now well versed in helping her when needed, like being at the airport and needing to find and show tickets. The biggest challenge for Georgia around travelling is the anxiety she feels getting organised pre-trip and then the actual flying. The more anxious she gets, the shakier she gets.

**Keith's** wife, Bev, was the first to notice that Keith's legs had *"gone funny"*. Shortly after that, while he was out running an unknown guy running towards him said, *"Mate, you've had a stroke"*. Medical staff quickly thereafter diagnosed him with EOP. He was 48. Keith had been working full-time but was eventually forced by his symptoms to resign. His symptoms now include impacted walking gait, and slurred speech; also, his right-side drags, and he has cognitive decline, all of which are very obvious to others. He underwent DBS surgery in 2016 which had an enormously positive impact on his initial tremor and his full-body spasms, although just in the last 12 months the effects of the operation have begun to deteriorate. Keith and Bev have done a lot of campervan travel over the past 20 years, particularly around Europe, which they have enjoyed both for the scenery but also for the socialising. Keith now finds it frustrating that the majority of the workload, from pre-trip planning to the actual campervan driving, falls on Bev due to his cognitive and physical decline. But he also experiences an uplift in emotion during travel, which he describes as, *"a sense of achievement, I guess. I can do it!"*

**Butterfly** is 66. She retired last year at 65 and has a 29-year-old daughter. She was about 42 when she first noticed her thumb and fingers start to quiver and then got pain in her legs. She took the usual trip to the GP who referred her to a movement disorder specialist and the diagnosis of EOP came back. She too had a brain operation in 2016, but it was a very different one. She was part of a medical trial which inserted pig cells into the brains of a treatment group. Unfortunately, the trial was inconclusive. Her current symptoms are *"a bit of everything"*; tremor, dyskinesia, back pain, fatigue, and cognitive impact or *"fuzzy brain."* She has a long-term, non-live-in partner with

whom she has travelled quite extensively with throughout Asia and the USA. She has also travelled quite a bit with her daughter. She has found travel increasingly difficult as her symptoms have worsened, particularly with her medical regime in different environments and time zones. Her lack of strength means that travelling on her own is now problematic as she can't lift her suitcase. Like most people, Butterfly likes travel, but *"it just doesn't like me!"*

#### 4.4 Data collection

To effectively explore and interpret the lived leisure travel experiences of individuals with EOP in New Zealand within an interpretive phenomenological framework, qualitative interviews were selected as the overarching method of data collection. Westwood (2007) and Tracy (2019) suggest that qualitative interviewing provides the researcher with the ability to seek a depth of meaning and mutual discovery through the common use of open-ended questions and probes, which other forms of qualitative data collection do not offer. Other possible qualitative data collection methods are explored and rejected in the discourse below. Face-to-face or virtual semi-structured interviews were employed for the data collection.

Semi-structured interviews are one form of qualitative research method (Patton, 2002) that combines a pre-determined set of open questions (questions that prompt discussion) with the opportunity for the researcher to explore particular themes or responses further (Kvale, 2006). Semi-structured interviewing uses a guide with questions and topics that should be covered. The researcher has some discretion about the order in which questions are asked, but the questions are standardised, and probes may be provided to ensure that the researcher covers the correct material (Tracy, 2019). This type of interview collects detailed information in a conversational style (Kvale, 2006). Semi-structured interviews are one method that is often used when the researcher wants to delve deeply into a topic and to understand thoroughly the answers provided (Harrell & Bradley, 2009). Semi-structured interviews were chosen for the present study because there was a need to get specific information to meet the research aim and supplementary questions (Patton, 2002). Previous accessible tourism studies have also utilised semi-structured interviews as a way of

obtaining participants' perspectives and experiences (see, for example, Gillovic, 2019; Gillovic & McIntosh, 2015; Nyanjom et al., 2018).

Semi-structured interviews were selected instead of other qualitative interview methods such as surveys, focus groups, observation, or diaries (Tracy, 2019). This was because I considered that semi-structured interviews were the most effective means to give voice to the participants and their stories, produce the rich textual data that interpretive phenomenology demands (Kafle, 2011), and subsequently reveal the depth and richness of the participants' personal and unique lived leisure travel experiences (Brinkmann, 2013; Jennings, 2005). "Open-ended questions and probes, as two tools of semi-structured interviews, yield in-depth responses about peoples' experiences, perceptions, opinions, feelings and knowledge. Data consists of verbatim quotations with sufficient context to be interpretable" (Patton, 2015, p. 14). A survey, even one constructed with open-ended questions, would not have delivered the frank interplay of conversation with the opportunity for me to probe further into particular answers for elaboration or additional insight into stated experiences (Brinkmann, 2013). Diaries were discounted for similar reasons as surveys, that is, they did not offer the two-way conversational exchange that ensured a depth of data around experiences, and the ability to probe further (Patton, 2015). I also considered focus groups as a tool; however, I felt that the key driver was to privilege and honour the individual voice of each research participant, rather than potentially have these voices clouded by group discussion (Bartholomew et al., 2021; Gillovic, 2019).

The interview questions were designed to deliver data pertinent to the research aim, this being to explore and interpret the lived leisure travel experiences of individuals with EOP in New Zealand. The questions were divided into four main categories. The purpose of the first category, 'soft introduction', was to put the participant at ease and build rapport (Tracy, 2019). Once I had introduced the research aim, covered the time anticipated for the interview, as well as privacy and consent issues (Rabionet, 2011), participants were asked to tell me a little bit about themselves, and their journey to a formal medical diagnosis of EOP. The second category of questions, 'lived experience', focused on the participant's specific experience(s) of leisure travel since their EOP diagnosis. I was seeking to ascertain whether having EOP altered their experience, or perception of it. Questions included, for example, "Since your EOP diagnosis (and

within the past seven years) please would you describe for me one particular leisure trip that comes to mind?” Prompts included: “How come this particular trip came to mind? What motivated you to take this particular trip? How did that make you feel?” The third category of questions, ‘tourism operator advice’, moved away from rich emotional data (Kafle, 2011) and asked several questions about advice the participant may have for New Zealand tourism industry operators regarding service delivery for other individuals with EOP. The final category of questions, ‘an ideal future’, included two concluding questions that asked the participant to imagine the future or “pose an ideal” (Tracy, 2019, p. 166) and outline their own and their carer/companion’s leisure travel aspirations and what they hoped the future of leisure travel could look like for other individuals with EOP. Table 2, below, summarises the four categories of questions, their purpose, and literature references that support the theory behind the question construction. The full set of interview questions is attached as Appendix E.

*Table 2*

*Research Question Construction Main Categories*

Category	Purpose	Literature support
1 Soft introduction	Put the participant at ease and build rapport.	Rabionet (2011), Tracy (2019)
2 Lived experience	Participant’s specific experience(s) of leisure travel since EOP diagnosis.	Frechette et al. (2020)
3 Tourism operator advice	Advice the participant may have for New Zealand tourism industry operators around catering for individuals with EOP.	Kafle (2011)
4 An ideal future	Aimed at getting participants to imagine the future. A way of winding up the interview.	Tracy (2019)

Six of the participants I interviewed in person were Auckland-based. The remaining four participants’ interviews were conducted over Zoom. The interviews ranged in duration from 35 to 63 minutes. The critical factor for me during the course of the interviews was to develop and maintain good rapport with the participants and to treat each individual and their stories around the impact of EOP on their leisure travel experiences with the utmost focus and respect. Botterill and Platenkamp (2012) discuss the “radical sense of openness” (p. 30) that is required to acknowledge the opinions, perceptions, and realities that were being offered. At the end of each interview, I thanked the participant, said how much I had enjoyed the interaction, and

affirmed that they had done well (Lincoln & Guba, 1985). I reminded them that they would be receiving their transcript for review and either gave them the koha (a \$50 gift voucher) or arranged to send the koha to them, if the interview had been over Zoom.

#### 4.5 Data analysis

Thematic analysis was selected for this study. It is a method for “identifying, analysing and interpreting patterns of meaning (‘themes’) within qualitative data” (Clarke & Braun, 2017, p. 297). Thematic analysis offers “a way of making sense out of seemingly unrelated material, a way of analysing qualitative information, a way of systematically observing a person, an interaction, a group, a situation, an organisation, or a culture” (Boyatzis, 1998, p. 4). Thematic analysis is often blurred with content analysis and the two terms are frequently used interchangeably. Both are qualitative approaches that aim to develop an understanding of a particular phenomenon from the perspective of those experiencing it. They involve analytically examining the data of life stories by breaking text into smaller units or pieces of content and then applying a descriptive treatment to them (Sparker, 2005). Content analysis is based on taking a very systematic approach to the data, seeking to reduce a lot of verbiage into a smaller number of content categories (Krippendorff, 1989; Weber, 2004). The focus includes noting the number of times specific words, phrases, images or themes occur within the data to enable the identification of trends or patterns. Quantification or counting of frequency of times a theme was mentioned was not seen as a useful element to analysing the data in this study.

Thematic analysis is more focused on the underlying meanings and concepts that are present within the data, rather than the width of the application (Clarke & Braun, 2017). Thematic analysis provides a purely qualitative, rich, detailed account of the data and its nuances and complexities (Braun & Clarke, 2006). While both methods hold significant similarities and it is clear from the above discussion why there is some blurring between the two, thematic analysis rather than content analysis was selected for this interpretive phenomenological study. An interpretive phenomenological approach requires an elucidation of the establishment of meaning and, therefore, this thematic approach not only describes the meaning of the data but also offers a deeper, more extensive involvement with the data at an underlying level (Braun &

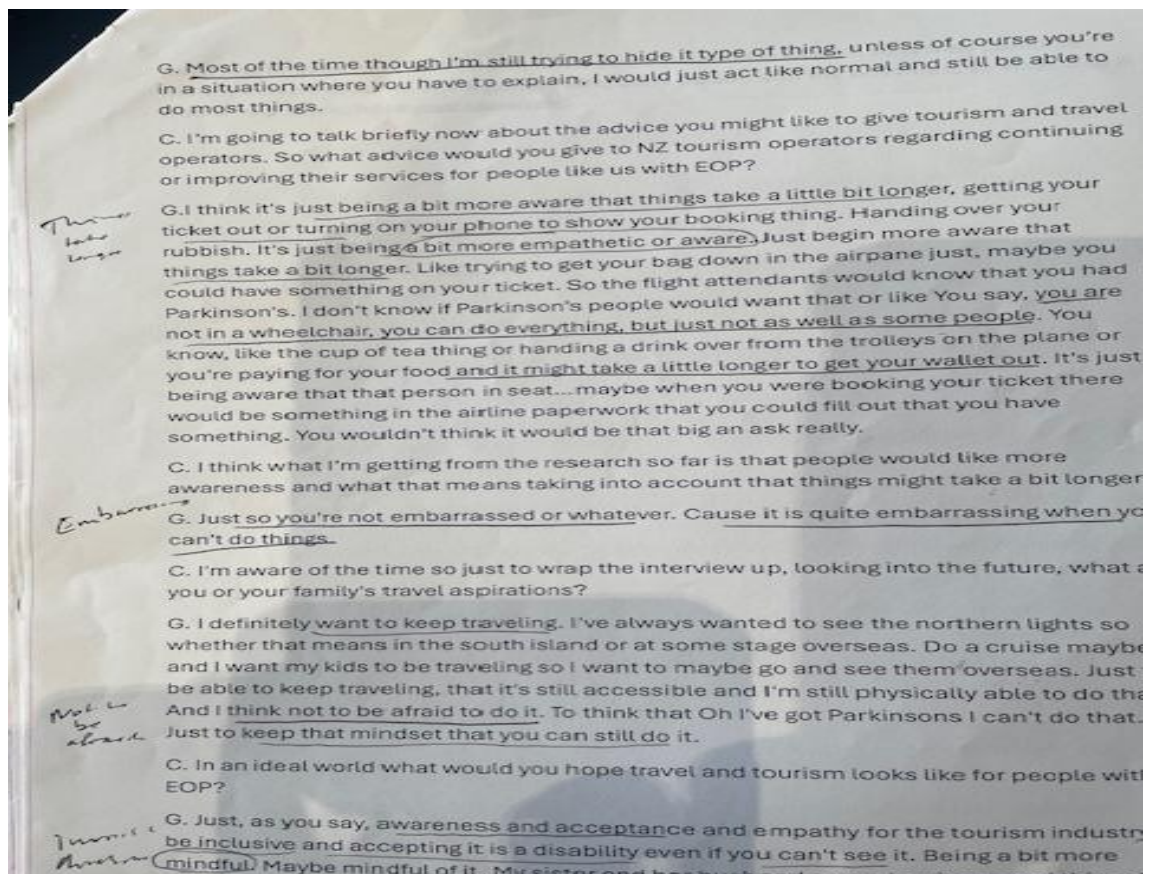
Clarke, 2006; Joffe, 2011). Thematic analysis is used in cases where there are no previous studies dealing with the phenomenon, such as the lived leisure travel experiences of individuals with EOP in New Zealand, and therefore the coded categories are derived directly from the text data (Hsieh & Shannon, 2005). The strength of thematic analysis as a method comes from establishing a set of steps that will ensure each transcript is coded consistently and in a way that will allow another researcher to pick up the framework and either assist with the study in question or apply it to their own research (Braun & Clarke, 2006).

I employed Braun and Clarke's (2006) six-step process for conducting a thematic analysis. The rest of this section consists of a description of this process. The first step, 'familiarising with data', is about transcribing data, reading and rereading the data, and noting down initial ideas (Braun & Clarke, 2006). Following the audio recording of each interview on my phone, I manually transcribed each of these audio files into typed form using Microsoft Word (Bryman, 2012). I emailed a copy of each interview transcript to the respective participant as soon as I had completed the transcribing and did this as I worked my way through the interview schedule. In this way, I immersed myself constantly in the data (Braun & Clarke, 2006). Additionally, I noted down initial ideas from each interview straight after the interview. To begin with, I did this in my messy handwriting, in the margins of each participant's interview guide. However, recalling how unintelligible my earlier notetaking had been due to my Parkinson's-impacted handwriting I rapidly changed to recording additional ideas in a Microsoft Word document. I added to this when I had completed the initial transcription and again when the interview transcripts were returned. Throughout this stage of the process, I became very familiar with the data. It was particularly interesting to note the little additional 'gems' which were added as after-thoughts when participants reviewed their transcripts. For example, Georgia added a note about an experience she had meant to share, which was the frustration of filling in arrival documents for the whole family for entry into Rarotonga and how she could no longer do this as her tremor was too bad. The positive reflection or reflexivity (Tracy, 2019) for Georgia in this situation was that her children transformed into young adults, stepping up and helping out by filling in the forms when she could not.

The second step was the 'generation of initial codes' (see Figure 1, below). This involved coding important and interesting features in the data across the complete data set and collating data relevant to each code (Braun & Clarke, 2006). As previously noted, my initial draft coding was undertaken in the margins of the transcribed interviews when I read through them the first couple of times. I also underlined key phrases or points that stood out to me.

Figure 1

An Example of My Generation of Initial Codes



Following the initial coding, I worked through each typed transcript to pull from the text data extracts, termed 'units of meaning'. I then copied each unit of meaning into a spreadsheet. Units of meaning could be a single word or two, a phrase, or a paragraph or several (Kleiman, 2004). I then reflected on what core or key idea was at the heart of each unit of meaning and how I could summarise that into several words. These words then became my key ideas coded for. From there, I refined the key ideas coded for into a single representative word or two. An example of my recording of units of meaning is given in Table 3, below.

Table 3

*Units of Meaning Sample Recording*

Pseudonym	Unit of meaning	Key idea coded for	Code
Liz	I have a daughter who lives in MEL. So obviously wanting to see her as much as I can.	Travel motivation	Motivation
	Then came back to work for 5 years before my Parkinson's made it too stressful for me to keep working in the job I was in.	Impact of stress on employment	Stress
	Then I did a couple of falls while walking to work and I didn't understand why I was falling.	Tremor and falls	Falls  Tremor
	Tremor, slowness of movement when I'm coming off the meds, inability to think about more than one thing at a time. I used to be really good at multi-tasking and now I can't multi-task when I'm coming off the meds.	Slowness of movement	Movement impacted
		Inability to multi-task	Non multi-tasking
	When my tremor's going, yes. When my tremor isn't going, I think it's pretty hidden that I have Parkinson's.	Disability hidden	Invisible disability

'Searching for themes' is the third step in Braun and Clarke's six-step thematic analysis process. This involved collating codes into potential themes and gathering all data relevant to each of these (Braun & Clarke, 2006). During this step, I transferred the units of meaning and their associated 'key idea/s coded for' into a new document. I could now grade or sort the various codes into draft overarching and key themes (Gillovic, 2019). These overarching and key themes arose from my in-depth thinking about what I felt each interview participant was really trying to tell me and what I interpreted as being perceived by the participants as important. I was seeking not only commonalities but also the outlier comments. However, it was the commonalities that largely formed the codes and eventually, therefore, the draft themes (Patton, 2002). An example of my search for themes is shown in Table 4, below.

Table 4

*Example of 'Tentative Overarching Theme', 'Key Themes' and 'Key Ideas Coded For.'*

Tentative overarching theme	Key themes	Key ideas coded for
How symptoms of EOP are managed during travel	Managing symptoms	Familiarity of environment Control Safety
	Planning	Sourcing accurate information Significant other Cognitive decline Travel companion
	Need more time	Fine motor skills impacted Asking for help Consideration Empathy

'Reviewing themes' in relation to the coded extracts and the entire data set (Braun and Clarke, 2006) was the fourth step. This step of the data analysis was fundamentally about ensuring that the overarching or key themes selected were the most authentic and effective fit for the entire data set. Whilst thematic analysis rather than content analysis was selected as the analytic tool, this stage required a logical review to ascertain whether the overarching themes selected were in fact representative of the key and most important lived tourism experiences of the participants. In some cases, this meant that the code or theme was in fact the most often repeated.

The fifth step was 'defining and naming themes' (Braun & Clarke, 2006). This involved ongoing analysis to refine the aspects of each theme and to clarify the overall story that the analysis tells. It also included generating clear names and definitions for each theme (Braun & Clarke, 2006). The analysis involves a constant moving back and forth between the entire data set, the coded extracts of data that are being analysed, and the analysis of the data that is being produced. Writing is an integral part of analysis, not something that takes place at the end, as it does with statistical analyses (Patton, 2002; Tracy, 2019). The refining and naming of themes resulted in three key themes relating to the thesis aim, these being: (1) (In)visibility of EOP in travel; (2) Sense of urgency to travel; and (3) Managing symptoms during travel. These overarching

themes were distinctly obvious from the units of meaning and ideas coded for, but also had elements of blurring between them.

Table 5, below, shows the thematic spread of participants who commented on the three key themes listed above.

*Table 5*

*Thematic Spread*

Participant	Theme 1 (In)visibility of EOP in travel	Theme 2 Sense of urgency to travel	Theme 3 Managing symptoms during travel
Penny	✓	✓	✓
Mike	✓	✓	✓
Bryce	✓	✓	✓
June	✓	✓	✓
Liz	✓	✓	✓
Clyde	✓	✓	✓
Peggy	✓	✓	✓
Georgia	x	✓	✓
Keith	✓	✓	✓
Butterfly	✓	x	✓

‘Producing the report’, as the sixth step of the thematic analysis (Braun & Clarke, 2006), was the creation of this thesis, with the findings revealed in Chapter Five, Findings and Discussion, and Chapter Six, Conclusion. The key themes and the underlying aspects of each of them illustrate the originality of this study, being the only study, at the time of writing, to explore and interpret the lived leisure travel experiences of individuals with EOP in New Zealand and the contribution it makes in filling what is currently a gap in accessible tourism scholarship.

#### 4.6 Ethics approval

Approval for this research study was obtained from the Auckland University of Technology Ethics Committee (AUTEC) prior to commencing the recruitment process. The guidelines and principles established by AUTEC were applied with dedication and consistency throughout all aspects of the research process, from participant

recruitment and interview design to data collection and analysis. There were several specific aspects for ethical consideration. These are revealed and explored briefly below.

The first aspect is that of “on us, with us, by us” (Streed et al., 2023). Franits (2005), shares that in relation to this topic, the saying “Nothing about us without us” probably had its roots in the 1970s/80s disability rights movement in the United Kingdom and has since become the slogan of many disability rights advocacy groups to communicate that individuals with disabilities should be at the forefront of any decision or policy-making that affects their lives. Nonetheless, having PwD at the forefront, or meaningfully included in decision-making, does not necessarily ensure equality or redress on structures or policies which are unfavourable to them.

Smart (2001) avers that people without disabilities cannot have the degree of understanding about issues that impact PwD, in comparison to those who live with disability. Because of this, the experiences of PwD are significantly more valued than any other sources of information from outsiders. Outsiders in this instance are people without disabilities. The development of more PwD assuming the role of researcher in disability or accessible tourism studies is positive. In this study, as the researcher, and an ‘insider’, I am an example of this. This does not deny people without disabilities the absolute right to research topics about disability; however, it does have implications for choice of research method. For people without disabilities there is a strong underlying need to select a method that facilitates their ability to really listen to the voices and the experiences of PwD, to remain focused on the individual to listen for any challenges to assumptions, and “thus provide avenues to deepen (our) overall understanding of disability experience” (Franits, 2005, p. 577). Research methods that facilitate this depth and quality of listening and interaction between the participant and the researcher include in-person or virtual interviews, focus groups and, potentially, diaries with follow-up interviews. For the reasons previously outlined in this chapter, the interpretive phenomenological framework of this research study lent itself to the use of in-person and virtual one-on-one qualitative interviews as a means of ensuring the quality of the listening and the production of rich textual data (Franits, 2005; Kafle, 2011).

Another ethical aspect of this study was that the research involved the selection and interviewing of a vulnerable, marginalised group of participants, being individuals with EOP in New Zealand. I considered my answers to this section of the AUTEK Ethics Application (Form EA1) very carefully. As an individual who has EOP, I do not personally regard myself as either vulnerable or marginalised. However, I consider myself 'fortunate' to have been eligible for DBS surgery two years ago, which was life changing. My positionality as the researcher is shared in more detail in Chapter One, Prologue and Chapter Seven, Epilogue.

Regardless of my positionality, in interviewing 10 individuals with EOP I needed to ensure that they felt safe and respected at all times. Hence the selection of whether the interviews were conducted face to face or via Zoom, and, if in person, the choice of venue was entirely my participants' (Tracy, 2019). As it eventuated, six of the 10 interviews were in person, with two of these conducted within the homes of the participants and four at their choice of local café. The choice of in-home interview ensured the participant was in a comfortable, known and safe environment (Tracy, 2019). As required by AUTEK, a researcher safety plan was in place for the two in-home interviews. This involved a third party being made aware of the participant's address and the expected timeframe of the interview. Once I had completed the in-home interview, I called my nominated contact to let them know I was safe and had left.

In relation to working with vulnerable or marginalised groups, Wolf (1996) urges that researchers "need to critically and self-consciously examine their positionality, if only to better understand their role in the global arena or their self-appointed 'dogooder' role" (p. 35). Additionally, "running exploratory research with the constraints associated with conducting research on these groups should ensure we conduct our research in a sensitive manner and ensure that our research will have beneficial outcomes – particularly for those who are marginalised" (Scheyvens et al., 2003, p. 191). The relevance of this for the present study is that I, the researcher, was very conscious of conducting all interviews in a particularly empathic and sensitive manner. I also remain committed to ensuring that the key relevant findings are shared with the New Zealand tourism industry with the aim of having beneficial outcomes for individuals with EOP.

Finally, given the relatively small cohort of individuals with EOP in New Zealand, maintaining the confidentiality of participants was paramount so that identities were not divulged. The Participant Information Sheet (Appendix C) detailed how collected data would be utilised and how participant identities would be kept confidential. The key to maintaining confidentiality was assigning participants a pseudonym.

#### 4.7 Methodological reflections

Research trustworthiness is an important topic. Anney (2014) and Lincoln and Guba (1985) are among several scholars who outline four criteria for the trustworthiness of qualitative research, these being credibility, transferability, confirmability, and dependability. These four aspects are briefly addressed below, in relation to the study. Credibility is about the accuracy and truth of the research (Amankwaa, 2016). In this research study, key Parkinson's professional contacts were utilised to launch the snowball sampling method, which ensured that those interviewed fitted the inclusion criteria; that is that they were individuals with EOP who had travelled in the past seven years for leisure purposes. The questions were designed to deliver in-depth, quality data (answers) that delivered on the research aim. Each individual participant shared their 'truth'. Member reflections (Tracy, 2010) also assisted with ensuring data accuracy as participants were sent their interview transcripts and asked to add or clarify information, and to ensure it accurately reflected the answers they gave.

Transferability refers to the degree to which the results of qualitative research can be transferred to other contexts with other participants – it is the interpretive equivalent of generalisability (Bitsch, 2005; Tobin & Begley, 2004). However, in qualitative studies "findings are highly context and case dependent" (Patton, 2002, p. 563). In relation to this research, it was important to describe in as much detail as possible the context and setting of this study, which was done in Chapter Two, Introduction, and Chapter Four, Methodology, so readers/researchers can decide if any of this research and its approach are relevant to their own projects. However, it is likely that the study methodology and findings would be transferable to other individuals with EOP engaging in travel and tourism.

Confirmability demonstrates the neutrality of the researcher in the findings of the research (Amankwaa, 2016). The research findings must be shown to have come from

the data, not from any bias on the part of the researcher or from any source other than the participants. My interpretation, as the author, offered through the framework of interpretive phenomenology was not bracketed but rather held front and centre (Dörfler & Stierand, 2021).

Dependability is about making sure the findings, interpretation, and study recommendations are all supported by the data received from the informants of the study (Cohen et al., 2014; Tobin & Begley, 2004) or, in other terms, dependability is demonstrated in the consistency of the research process (Amankwaa, 2016). In this instance, the data received was run through an established process for thematic analysis outlined in six steps by Braun and Clarke (2006). This helped ensure the consistent treatment of each interview transcript (Anney, 2014). The project supervisors (that is, those that had some knowledge of the research project) also reviewed a sample of the transcripts to check the consistency of the researcher's work. Finally, 'member checking' (Tracy, 2019), which involved each of the participants checking their own transcript, added another level of dependability.

#### 4.8 Methodological limitations

This research study was conducted within the framework of interpretive phenomenology. As a qualitative study based on semi-structured interviews (Patton, 2002; Tracy, 2019) with just 10 participants, the findings provided rich textual data (Kafle, 2011) and revealed the depth and quality of their experiences. However, a possible limitation of this research was the sample size; in interpretive phenomenology it is perfectly acceptable (Bartholomew et al., 2021) but it may be seen as limiting in its ability to generalise to a wider population of individuals with EOP.

However, I believe there needs to be a follow-up with the participant group to gain further insights. In its current form and as an exploratory study, this research thus represents but one possible interpretation of the meaning and significance of the lived leisure travel experiences of this group (van Manen, 1990). Such follow-up could take the form of surveys or diaries, which would allow the participants to expand on their stories in their own time (Tracy, 2019). Alternatively, new qualitative research could be undertaken with a different and larger group of individuals with EOP, to explore a

greater number of stories and lived experiences of EOP in leisure travel in New Zealand.

Semi-structured interviews using open-ended questions and prompts are generally effective for qualitative research and serve to allow the researcher the ability to delve more deeply into various questions through probing (Tracy, 2019). The open-ended nature of such an approach is positive in that the researcher can receive information or examples that might not otherwise have been captured. However, a limitation of this research method is that it requires the interviewer to have the skill to effectively probe, a skill that is not that common in novice researchers (Tracy, 2019).

The use of interviews could be considered a limitation. Focus groups may have elicited richer data as participants may have tended to 'bounce off each other' in terms of their recollections (Tracy, 2019). However, in this study I felt it was more important to honour the individual voices of the participants (Bartholomew et al., 2021; Gillovic, 2019). In the context of interpretive phenomenology, the most important objective was to really hear each individual participant, and then to offer but one possible interpretation of their experiences (van Manen, 1990).

#### 4.9 Chapter summary

This chapter has provided a review of key accessible tourism studies literature, with a consideration of its rationales for market and destination development and the motivations, barriers, and constraints to participation for PwD in tourism, as well as leisure and recreation more broadly. As Darcy et al. (2020) posit, smaller numbers of PwD can enjoy these aspects of social life compared to people without disabilities. Critically, a review of the literature has also revealed that accessible tourism studies are increasingly examining the lived tourism experiences of people with different dimensions of disability, namely physical and sensory (Devile & Kastenholz, 2020; Ray & Ryder, 2003; Richards et al., 2021). There remains a lack of understanding about the experiences of people with other dimensions of disability, most notably among those with hidden disabilities (Gillovic et al., 2021; McIntosh, 2020). This study seeks to bridge this gap, by exploring the lived leisure travel experiences of individuals with EOP in New Zealand.

## Chapter 5 Findings and Discussion

### 5.1 Introduction

This chapter first presents the key themes that emerged inductively from the data to reveal the lived leisure travel experiences of individuals with EOP in New Zealand. The three key themes are: (1) (In)visibility of EOP in travel; (2) Sense of urgency to travel, and (3) Managing symptoms during travel. These findings are described, explained, and evidenced directly from the data, and discussed in relation to the wider literature.

### 5.2 Theme one: (In)visibility of EOP in travel

The first theme that emerged inductively from the data was centred on the '(In)visibility of EOP in travel'. That is, EOP is a disability "*not always being visible*" in the context of travel or, in short, it is an invisible, or sometimes visible, disability. For clarity, the dynamic around this duality of the term (in)visibility is to indicate to the reader that individuals with EOP can, within the context of travel, experience the effects of symptoms of EOP that are invisible, visible, or both. The theme also explored the inherent tension that some individuals with EOP feel around if, and when, and how and to whom, to reveal their disability. Additionally, what also emerged were the sometimes positive, but more usually negative, impacts on individuals with EOP of having their visible symptoms misunderstood as either something self-inflicted, for example, "*being drunk*", or having others misinterpret their symptoms as another form of disability rather than EOP. These three interrelated strands of Theme One are explained and evidenced below.

The "*invisible disability*" aspect of this theme is about understanding that for the participants in this study, the expression of their EOP in the form of symptoms including (mild) "*tremors*", "*fatigue*", "*depression*," and "*cognitive impairment*" is often not visible to others around them. In the context of travel, 'others' are either fellow tourists or tourism operators. There are several reasons why symptoms are not that visible or are even unnoticeable to the onlooker: the individual with EOP is in the very early stages of the disability, and therefore their symptoms are not yet that pronounced; their medication still works very effectively and masks their symptoms; and/or they are well-versed in managing or hiding their symptoms. For individuals with

EOP, this *“invisible disability”* can have both positive and negative impacts on their lived leisure travel experiences. Bryce believes he benefits from the invisibility of EOP in travel from tourism providers at this stage of his EOP, as evidenced by the following comment: *“I can’t really say I’ve had any different experience (other than good), but I guess I’m not really at a point yet where I need special ‘accommodation’ so I can’t really speak to that just yet.”*

By contrast, during their interviews, nearly two-thirds of the participants recounted personally experiencing some form of negative impact from the (in)visibility of EOP in travel. Giving voice to this, when the symptoms of individuals with EOP, such as *“depression”* or *“fatigue”*, which is often evidenced by *“a lack of energy”*, are invisible, meaning, for example, *“when I’m not feeling well, when I’m feeling really down and can barely get to the supermarket, close to the hotel”*, the emotional toll of EOP comes into play. Participants reported the felt need to disclose their EOP to others in an attempt to counter the potential reactions from onlookers, operators, or fellow tourists. As Penny explained, *“and I park in that park (the disabled park) and I get the looks ... and have to explain. ... We may not drag our leg but you can still be having a really bad day and it’s not visible.”* This felt need to make the invisible visible through disclosure is consistent with the conclusions of other accessible tourism studies, for example, McIntosh (2020) and Nilsson (2020).

Lack of understanding of the (in)visibility of EOP in travel by the tourism industry, and other tourists, was an often-repeated sentiment from participants throughout the interviews. For example, June was on the receiving end of the sceptical reaction of a fellow tourist when she was given a lift in the support van on a cycle tour, after having EOP-related cramping, and reflected as follows:

*That was kind of interesting ‘cause there was quite a steep hill and we got to the top (me in the van) and the guy (a fellow tourist) was kind of joking, but not. Like “You got out of that one, didn’t you? The things you do to get out of going up the hill.” He had no idea, but it was a bit of a dig.*

A number of the participants commented on the need for more awareness, education and understanding from the tourism industry about the invisibility of EOP in travel. Liz stated:

*'cause it's quite a hidden one oftentimes and they don't know what's going on in your head and the struggles, the effort you are having to make to do something that for a normal person would be quite easy to do.*

Mike reflected on whether he had noticed any impact on his travel experiences and the associated service levels from tourism operators since being diagnosed with EOP. He stated, *"It's been fine. I don't think they have known that I have an issue."* This raises the point of whether, and how, tourism operators or others can know that accommodation of an (in)visible disability may be required when symptoms are not obvious and/or are not voiced by the individual. The possible education of the tourism industry and others around EOP is addressed later in this chapter.

There is a positive global travel industry initiative around invisible disability which was mentioned by two participants. This initiative is the Hidden Disabilities Sunflower Scheme, which is an international programme that offers people with non-visible disabilities "a discrete way to indicate to staff at participating organisations that they have a hidden disability and may need a little extra support, guidance, understanding, or time" (Civil Aviation Authority of New Zealand, n.d., para. 1.). June and Liz both reported on the Hidden Disabilities Sunflower Scheme, as follows:

*I've noticed this thing. I took a picture of it in Queenstown airport and haven't done it yet but it said "If you are disabled but don't have obvious symptoms you can go to the airport counter and get a sunflower symbol on a lanyard." This is a globally recognised disability symbol. It's a programme designed to help (tourism) service staff be more empathetic around invisible disability. (June)*

*There's a lanyard you can get with a sunflower on it. But I haven't got it yet. I might get one if it does mean you go through queues faster 'cause sometimes I find waiting at the airport, and security queues have been really bad at Auckland lately, like 45 minutes, and for me to stand for 45 minutes is really difficult so I'm thinking of getting one to see if that would mean you could get through queues a little bit faster. (Liz)*

The fact that two of the participants commented on the Hidden Disabilities Sunflower Scheme indicates a felt need for a greater level of empathetic service from travel providers and the right to not have to disclose the details of what is otherwise largely an invisible disability.

In relation to the (in)visibility of EOP in travel, Penny recounted the following:

*I remember being in Wellington on a trip and hopping on a bus and there was a little sign by the disability seat, saying 'disabilities are not always visible.' I think that's such a big thing. I think a lot of people need to hear things like that.*

The above comment from Penny and the two separate mentions from June and Liz regarding the global Hidden Disabilities Sunflower Scheme indicate positive steps by a range of corporate entities, particularly in the travel, transport, and aviation sectors, together with the international disability community to undertake such initiatives. The impact of initiatives, such as the Hidden Disabilities Sunflower Scheme for this study's participants, is about engendering a sense of dignity and inclusion without people necessarily having to disclose their invisible disability. Such schemes mean they are less likely to experience stigma and marginalisation (McIntosh, 2020) in their lived leisure travel experiences.

Penny recalled a time when she was on the receiving end of the invisibility of EOP in travel, following her DBS surgery in Australia. This situation emphasised a lack of understanding by a sector of travel operators who had been trained in just one response to a perceived situation. Crucially, it also indicates the significantly negative emotional impact that unhelpful interactions with others can have on an individual with EOP, as the quote from Penny below shows:

*Well, it was when I had my operation and I was coming back through immigration in Australia and Mike sort of got separated from me, off the other way and they said to me, "Can you walk through the machine" and I said, "No, I can't" and they said, "Well you can" ... I said, "Because I've got a pacemaker for my brain." They said, "The heart pacemakers can walk through." I said, "I've got electrodes in my brain and I've had a brain operation three weeks ago. So I can't walk through." They said, "You can walk through because we've been told that everyone can walk through." And I said, "Well I'm not going to." So they went and got the supervisor and what they did was they turned the machine off and they made me walk through the machine. And I just thought that was so pathetic. Really pathetic and I was just at the point where I had my scarf on and I felt like ripping it off and showing them the scar.*

For Penny, this experience at Australian immigration, which was caused by the invisible aspects of her DBS surgery ("I've got electrodes in my brain"), resulted in her feeling

angry, frustrated, and marginalised. There was no understanding shown that her invisible symptoms were different to those with another form of disability (for instance, those with heart pacemakers). As alluded to earlier, her frustration and the emotional impact of the encounter left Penny feeling the need to have to disclose her condition by revealing a visible, physical symptom, her head surgery scar, which at the time was being hidden behind her scarf.

Many tourism operators do undertake staff training to develop and encourage disability awareness and understanding. However, it is the (in)visibility of some symptoms in the early stages of EOP that make it a difficult disability to train for and manage. Complicating the (in)visibility of symptoms is the dimension around the uniqueness of every individual's set of EOP symptoms. Mike reflected on this point regarding the difficulty of tourism industry training for EOP given the individual uniqueness of symptoms. He commented:

*The problem is taking something that is so uniquely individual and translating it into quality service on the other side. It's tricky, I'm not sure how you do that. Except to have service providers with great empathy and communication skill.*

Yet, as found with other types of disability, education, awareness raising, and training within the travel industry is crucial to avoid perpetuating tourism as a site of marginalisation (Devile & Kastenholz, 2020; Gillovic & McIntosh, 2020). This desire for 'sameness' or to not be marginalised was alluded to by Bryce regarding getting around airports, "and I'm just not ready up here [in his mind] to sit in a wheelchair and be pushed around." In this statement he implies that being "pushed around" in a wheelchair is not considered 'normal' and lacks a certain degree of dignity. He also explained his feelings of "being different", of not being 'normal', and an overall sense of embarrassment and loss of dignity when he relayed the following story:

*I took a trip when I was in Osaka. I rode my bike out to the mountains on the edge of the city and stopped to get a bottle of juice at a local tourist spot. I was fumbling with my change 'cause I was having an 'off' (coming down off medication cycle) time. While I was fumbling for my change there was a palpable frustration from the people behind me in the queue. The person at the register seemed fine. It could all have been in my head, that's certainly possible. But I eventually just handed her the coin purse and said, "Would you mind taking out the right amount?" But it was embarrassing feeling the*

*antagonism and judgment of the people behind me in the queue and I felt undignified, fumbling around with my change.*

Again, the visibility of Bryce's EOP symptoms was partially obvious in this situation, with his hand tremor as a result of coming into an "off" medication stage, yet it was unexplained or unrecognisable to those in the queue behind him. His invisible EOP symptoms of "brain fog" together with the visible symptoms of tremor resulted in other tourists expressing frustration, and left Bryce feeling "judged" and "undignified", or, in other words, marginalised.

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." It is unsurprising, then, that many participants in this research study described their lived experience of either the positive or, more often, the negative, impacts of "invisible disability". These study results support the findings of previous accessible tourism literature and, in particular, the experiences of individuals with other forms of hidden disabilities, such as intellectual disability and epilepsy (see, for example, Gillovic, 2019; McIntosh, 2020).

In the studies just mentioned, Gillovic (2019) and McIntosh (2020) both found that the nature of the (sometimes) invisible conditions of intellectual disability and epilepsy resulted in generally negative impacts on the individual during travel. As an example, in her study, McIntosh (2020) revealed that a long wait for transport at an airport brought on atonic (loss of muscle control) seizures for one of her participants. This was clearly a negative impact for the individual concerned, who moved from having no visible symptoms of their condition to the very visible, negative experience of having a seizure.

The second strand of the theme '(In)visibility of EOP in travel' which emerged inductively from the data was the inherent tension of actively hiding EOP symptoms while engaging in leisure travel. For those whose symptoms are not yet pronounced, invisibility in the early stages of EOP can have a positive outcome for the individual. This is because, as their condition is "unknown" or "unnoticed," participants commented that they are not "treated differently" or are not treated "like a disabled

person,” and hence do not experience feelings of being marginalised (McIntosh, 2020), “excluded” or “discriminated against.” EOP, like other hidden or invisible disabilities such as epilepsy, carries stigma with it (McIntosh, 2020), at least in the mind of the individual with the disability. The fear of “judgement”, being stigmatised or, as some of the interview participants commented, being “treated differently”, acts as a disclosure barrier which can lead to either deliberately hiding symptoms or avoiding being upfront about their EOP. Previous findings reported by McIntosh (2020) indicate that people with epilepsy are often negatively affected by its stigma, whether felt, experienced, imagined, or internalised. In relation to stigma, Peggy reflected: “I don’t like the term disabled. There’s a part of me that doesn’t want to be treated any differently”. Clyde commented: “I’d hate to think that the tourism industry would start excluding people with Parkinson’s because of fear. ... I would hate to be discriminated against” and “I just don’t want to be excluded.” The findings of this study around EOP support McIntosh’s (2020) findings about the nature and effect of stigma. 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 that the individual adopts a coping strategy of concealment (Elliott et al., 1982; Link et al., 2015).

Mike commented that he gets frustrated with himself due to this concealment, yet does it anyway:

*My Mum spent the first 10 years of her having Parkinson’s trying really hard to hide it from everyone and I understood it, but I thought it was a huge waste of energy. And yet I find myself doing the same thing. I mean if somebody says, “Oh I notice your hand is trembling, do you have something,” I’m more than happy to have that conversation but I don’t like standing in front of somebody with my hand trembling, so I do try and hide it even though I don’t mind talking about it, which is kind of strange.*

Individuals with an invisible disability are constantly faced with a tension between explaining or concealing their condition. Considered the foundational author on the topic of stigma, Goffman (1963/2009), articulates in detail, and with many examples, this tension between concealment or explanation of their condition due to perceived or actual stigma regarding people who are unable to conform to the standards society

calls 'normal'. The findings reported by McIntosh (2020) also address the nature of stigma in relationship to travel:

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. (p. 5)

Individuals with EOP face the dilemma of if, when, how, and to whom they should reveal or not reveal their disability (Lingsom, 2008). Concealment, then, can be utilised as a core tool for adaptation (Jacoby, 2002; Valeras, 2010). However, Hunter-Jones (2004) explains that coping strategies such as concealment come with their own set of complexities as they create inner anxiety.

Previous disability studies (Hills & MacKenzie, 2002; MacLeod & Austin, 2003) have shown that concealment can result in reduced self-esteem, and as a product of this, reduced quality of life; it is a sign that self-identity is threatened. Lingsom (2008) suggests it is possible to divide disability into visible and invisible. There is a wide body of academic scholarship on visible disability and accessible tourism (see, for example, Blichfeldt & Nicolaisen, 2011; Kim & Lehto, 2013; Luo, 2014); however, there is still limited research into invisible aspects of disability in relation to tourism (Gillovic, 2019; McIntosh, 2020). At the time of writing there is no literature on EOP and its impact on lived leisure travel experiences.

Another strand of the theme of the '(in)visibility of EOP in travel' has to do with the misunderstanding the participants often face. EOP itself is an *"often misunderstood"* neurological condition, as described by the participants. When symptoms such as *"balance issues"*, *"slurred speech"*, *"tremors"*, or *"dyskinesia"* for individuals with EOP are obvious, they can be misinterpreted by tourism operators and other onlookers as either a *"self-inflicted condition"*, such as *"being drunk"*, or the operator or onlooker *"assumes they know"* what disability the symptoms represent *"without checking"* and then acts on their (often) incorrect assumption. For tourism operators or other tourists, the situation of visible EOP symptoms can also be a tricky issue to navigate. Again, without detailed education about EOP and/or dialogue with the actual individual in any given situation, symptoms can be misinterpreted. Even hand or arm tremor, which is the most well-known EOP/Parkinson's symptom (Parkinson's New

Zealand, n.d.), can be misinterpreted as the individual *“being cold or nervous.”* Having a tremor mistaken for being *“cold or nervous”* can result in feelings of *“embarrassment”* for individuals with EOP and, potentially, *“the need to explain”* what the tremor actually is, as participants described. As Georgia commented, *“Most of the time though I’m still trying to hide it type of thing, unless of course you’re in a situation where you have to explain.”*

A common issue for the participants that became apparent from the data was having their visible EOP symptoms misinterpreted as *“being drunk.”* The impact of having their condition considered *“self-inflicted as drunk,”* in particular, was met with *“horror”* and a deep sense of *“embarrassment”*. This situation was recounted by Bryce in relation to friends of his, who also live with EOP, who were holidaying in Japan and were on *“more than one occasion accused of being drunk”* when they were actually embodying EOP symptoms such as stilted gait, *“slurred speech,”* or *“balance issues”*. Keith described a similar experience when coming out of a hospital in Germany having been admitted for three days for Parkinson’s treatment and feeling *“embarrassed”* trying to get a taxi to take him and his wife, Bev, back to their camper van. He recalled, *“They basically ignored us. I tried three or four taxis. I don’t know if they thought I was drunk ... or quite what it was.”* Other tourists are often the ones who misinterpret EOP symptoms, as Penny and Liz, respectively, articulated in the following comments: *“um, lot of, a few sideways looks as if I was drunk and ‘has she done it to herself or is it something that’s happening to her’; You sort of get that look”* and *“I know there are people with EOP who have been in worse situations where people have thought they’ve been drunk or something.”*

Clyde explained a poignant example when he shared his feelings of *“horror”* and *“embarrassment”* around being mistakenly considered drunk by a tourism operator:

*Well, the worst experience I’ve had was when people have confused my EOP condition with me being drunk – with the slowness of speech, not being stable on my feet or even the tremor. That actually happened in front of my two sons a few years back and I was just horrified. In fact, it was the very first drink of the night and I was refused service because I was ‘drunk’ and actually kicked out of [tourism venue], the bar up there, because they thought I was drunk. And I was saying, let me just show you on my phone, I have a letter from a neurologist that can explain I’ve got EOP. And they said, “It’s*

*too late we've made the decision, you're out." It was horrific in terms of embarrassment.*

On a lighter note, Liz offered a fascinating and, in this instance, fortunately harmless situation of having her EOP symptoms misinterpreted while travelling, as the following quote illustrates:

*Last time I went to Melbourne the timing was off and I was in between my medications when I was checking in and I didn't want to take my meds early as I wanted to be Ok on the plane. So, I was shaking quite dramatically during the time I was using the kiosk and the Air NZ rep came up to me and said "Are you Ok?" "Yeah, yeah I'm fine, I know how to work the Kiosk" But she hovered near me, and I thought "That's interesting". And when I finished getting my boarding card she came over and said, "I think that you should go with that group over there." And I said, "What's the group?" And she said "I think you'll be fine to go with that group. You'll miss all the security queues and the customs queues, and you'll go through really quickly." Oh, that's a good idea and I was really into it. So I went over to the group and another girl came along that was joining the group, and we set off, there were about four passengers and one Air NZ rep and we did, we just went flying through like the crews do, down the side, and they moved all the ribbons out of the way and we were at the gate in about three minutes, it was fantastic. And as we were going along, I realised this was the fear of flying group and they'd obviously thought I was really nervous about flying and they were worried I'd have a panic attack or something. I got to meet the pilots before they went on board. They do that with the fear of flying group to give them some reassurance. It was a really great experience but completely not what I needed.*

The recounting of this experience provided an excellent example of the visibility of EOP in travel and the subsequent misinterpretation of the disability, which thankfully did not result in a negative experience for Liz. It was, however, a very clear example of an operator "assuming" they knew what the embodiment of a symptom, in this case, significant tremor, meant and acting on that assumption without any conversation or clarification with her.

Another strand of the inductively derived theme of the '(in)visibility of EOP in travel' is when there is a visible symbol of disability, such as a wheelchair or a guide dog (Dwyer & Darcy, 2011). In this case, it was the use of a wheelchair that was met with derision, leaving the individual with EOP feeling judged and "misunderstood." In this particular instance, Butterfly commented on the sceptical reaction of fellow tourists at

Disneyland, when she and her daughter hired a wheelchair for her some 14 years ago, highlighted in the following quote, *“I found it hard, the people that looked at me like ‘What’s she in that for, are they just doing that to get to the front of the queue, are they?’ Some people aren’t very understanding – they don’t realise.”*

For PwD, such as those with EOP, leisure tourism can provide a pathway to enhanced general well-being, better social interactions, improved self-perception, and an overall positive sense of dignity (Blichfeldt & Nicolaisen, 2011; McCabe & Johnson, 2013). The lived leisure travel experiences shared by the participants and the findings from these, as articulated above, support previous findings from a range of accessible tourism studies. For example, McIntosh’s (2020) study highlights similar feelings of stigma and loss of dignity among people with epilepsy who engage in leisure travel, as well as the similar felt tension of the participants with EOP in this study regarding if, when, and how to reveal their (in)visible condition. This present study implies that, as is the case with other types of invisible disability (Baker et al, 2000; Gillovic, 2019; McIntosh, 2020), keeping EOP ‘hidden’ during leisure travel may also have the likely consequence of perpetuating ignorance and social stigma around the condition.

In summary, the first theme inductively derived from the data, that of ‘(In)visibility of EOP’ in travel, revealed a range of strands. These included the fact that EOP is a disability *“not always being visible”* in travel situations. Also explored was the inherent tension that some individuals with EOP feel around if, how, when, and to whom to reveal their disability (Lingsom, 2008). Additionally, the misunderstanding or misinterpretation of EOP symptoms and the generally negative impact of this misinterpretation on individuals with EOP was revealed.

### 5.3 Theme two: Sense of urgency to travel

The second key theme that emerged inductively from the data was a ‘sense of urgency to travel’. This uncovers the innate urgency that some individuals with EOP feel, post-diagnosis, to bring their travel plans forward. This is due to feeling that time is running out and that the individual will, at some point, no longer be capable of undertaking leisure travel. The second strand of this theme was around a concern for their future carers and wanting to make (travel) memories whilst they are still able to do so. Most interestingly, the sense of urgency to travel appears greater for individuals with EOP

when compared with the findings in studies of those with terminal illnesses. Finally, conflated with the confrontation of one's likely eventual circumstances with EOP, participants were divided in the meaning they now ascribed to leisure travel. The three strands of Theme Two are explored in turn, below.

For participants, the first strand of this theme was most significantly focused on the reported increased *"sense of urgency"* to bring travel plans *"forward"* in time, following their diagnosis with EOP. This increased time imperative, which nine out of 10 interview participants commented on, was driven by the reality of confronting one's declining condition and concerns for the future. When prompted, research participants explicitly indicated that their leisure travel motivation was now focused on *"bringing forward"* their plans, as Liz and Peggy, respectively, explained: *"because the EOP is going to deteriorate and if I want to enjoy the travel, I need to do it sooner rather than later"* and *"it's just brought forward the desire to start doing some of these trips sooner rather than later while I'm physically capable."* Other participants related how they had thought they *"had a lot of time but now needed to get on and do it"* and a quote from Bryce indicated he felt travel was now *"a little more urgent, because how long have I got?"* The various quotes from Liz, Peggy, and Bryce all display their underlying fear and emotions about the future and how EOP will undoubtedly negatively impact upon their ability to travel. Mike commented: *"I guess I just value the trips a bit more because I'm not sure how long I'll be able to do them."* Clyde's view was that he and his family were *"motivated to do it [travel] now rather than wait, whereas before I think we would have waited, and [said] we'll do it later."* These comments indicate the reprioritisation of travel as a key item in 'to do' list of the family or the couple, as they come to terms with what the future scenario may look like.

The data that emerged inductively around the sense of urgency about travel was focused on a concern about the future and still being *"physically capable"* of participating in leisure tourism. There was an expressed sense of fear about the impact of physical decline, but also an implied sense of fear of cognitive decline on the individual's ability to cope with, and therefore enjoy, the leisure travel experience. Comments to this effect from Clyde were: *"I just get muddled very quickly...I'm very lucky to have Bonnie because I couldn't do it without her. ... I'll get dates completely*

*wrong, and I just get confused.*” Cognitive decline and dementia are side effects of EOP and Parkinson’s (Parkinson’s New Zealand, n.d.). In relation to leisure travel, Butterfly calls the cognitive decline her *“fuzzy brain”* and says that she needs to *“write everything down. If I don’t write it down it doesn’t happen, type of thing.”* Keith commented on his sense of *“frustration”* and of *“feeling a bit useless”* that, with his physical and cognitive decline, *“all the work [for and on the trip] fell on Bev’s head.”*

What is particularly interesting and potentially unique about this theme is the urgency focus; the strong and emotional desire, as Georgia commented, *“to do it now before you can’t do it.”* It could be thought that this *“sense of increased urgency”* to bring travel forward may be a finding commensurate with that of people with terminal illnesses. However, in a search of leisure travel, cancer, terminal illness and bucket list travel (see, for example, Aisporna & Erickson-Hurt, 2019; Zascerinska et al., 2024), the sense of *“urgency”* to undertake travel, whilst important, arguably, does not come through as strongly as it did in this present research study. This is posited as being because for individuals with EOP, their physical and potential cognitive decline is not terminal, but it is time-bound, over a relatively extended period (Parkinson’s New Zealand, n.d.). Hence, the participants described the sense of urgency to bring travel forward while they still feel they can achieve it.

Willson et al. (2023) identify that the motivation for an individual with a terminal illness to travel may be prompted by a distinct purpose such as a desire to connect with their loved ones, create memories together, and achieve their dreams, before they die. Willson et al.’s (2023) findings are supported by an interpretation of findings from this study. Aside from the emotional urgency motivation, it is my interpretation, which is but one possible interpretation (van Manen, 1990), that for some of the research participants, there exists an unrecognised level of motivation. This is about an ‘other’ (de Laine, 2000) focus and was around ensuring their future carers (their partners and other family members) get the opportunity to experience things and to create memories with the individual. The following quote from Peggy reflects this:

*So, our plan is to go as far away as possible, which is why we’re going to Europe, right, ‘cause I’m only going to go downhill right? I’m certainly not going to get any better, unfortunately. And I’m ok with that for now, so it’s just about maximising the opportunity not just for me but also for my husband who’s going to be my carer and for*

*whom life will probably get pretty challenging for him and restrictive so it's about going now and experiencing things together and having some fun while I can.*

Peggy also shared that travel was undertaken *“so my family have got something to look back on, creating memories.”*

It is the unfortunate reality that, while you do not die from EOP, there is currently no cure, and it is a neurologically degenerative disease (Parkinson's New Zealand, n.d.). There is no escaping the harsh reality of the impact that EOP will have, as individuals with EOP will eventually end up acquiring significant physical disabilities and, in many cases, cognitive disabilities as well (Parkinson's New Zealand, n.d.). Consequently, for some participants, particularly those whose EOP diagnosis was some years ago and whose symptoms and disability are therefore more advanced, the meaning ascribed to leisure travel experiences was generally negative, that is *“feeling useless”, “tiredness”* and suffering *“anxiety”*. Conflated with the negative meaning ascribed to leisure travel as a result of the increasing symptoms of EOP was a lowered self-esteem or self-perception, which has been seen in other studies on the motivation of PwD to engage in tourism (Yau et al., 2004). Other participants also revealed the relational aspects associated with the sense of urgency to travel now rather than later. Clyde spoke of his knowledge of this fact and the underlying motivation to travel now to create family memories, stating; *“We wanted to make sure we did it while I was still able and to get a big family thing done.”* Mike reflected on the value of such experiences, commenting: *“Holly and I have great shared memories of the trips away, so it absolutely adds to my life.”*

Another strand of this theme of ‘sense of urgency to travel’ which emerged was an offshoot of the physical and cognitive decline experienced by individuals with EOP. These are the symptoms of general *“fatigue and lethargy”* and the *“inability to make an independent decision”* or to *“multi-task.”* Liz explained that *“Before it was my own desire to experience new things, I loved variety, I loved experiencing new things. Now it's about what my daughter wants to do. I do it if she wants to do it.”* She further commented, *“also the apathy and anxiety that comes with EOP prevents you from doing travel sometimes.”* These comments by Liz allude to several points. Firstly, it speaks to the fatigue and lethargy that commonly overcomes individuals with EOP. As

a result of this state, along with cognitive decline, it becomes harder, if not impossible, for the individual to make decisions about anything, in this case what leisure travel experience or activity to engage in. Secondly, Liz's comment reinforces the essence of my deeper interpretation about the motivation to travel.

To reiterate, some travel, following a diagnosis of EOP, becomes about or is driven by an 'other' focus. That is, the individual's travel motivation is about the needs of their family and making sure that the partner and/or wider family are living their best (travel) lives, as the future has a bleak outlook for the restrictions that their loved one's EOP/Parkinson's disability will eventually place on them, as the carer(s). This concern for significant 'others' bears close resemblance to findings reported by Gillovic (2019), where she explores how the carers ultimately wanted to give the adults with intellectual disabilities a good life, and felt that travel, despite its inherent difficulties for the carers, was one means to achieve this. "It seemed experiences of care, then, were about prioritising the needs of other (individuals with intellectual disability), ahead of self (carer)" (Gillovic, 2019, p. 155).

Tourism scholarship shows that PwD generally have the same desire to travel and explore as people without disabilities (Yau et al., 2004). Much literature investigates the travel motivations of both PwD and people without disabilities. Generally, motivations for undertaking travel and tourism for people without disabilities include engaging in new and different experiences, visiting family and friends, expanding horizons, learning about other cultures, a break from work, and physical and mental health (Huang & Hsu, 2009; Yousaf et al., 2018). For PwD, travel takes on additional meaning in regard to the improvement of well-being and quality of life (see, for example, Blichfeldt & Nicolaisen, 2011; McCabe, 2009).

The third strand of this theme which emerged inductively was about the change in the meaning ascribed to travel due to this sense of urgency to travel, which itself is related to the confronting nature of EOP as a condition. June described the development of a new "*let's just do it*" attitude to leisure travel experiences, having had a successful trial trip to Canada last year with her husband. She explained:

*He is likely to retire next year and that was one of our life goals was to travel so now it's like "What does that look like for us?" We did a*

*trip to Canada last year and that was almost like a test case. It was a direct flight and how's it going to go? How is it going to affect the meds, etc.? There was that fear of how's it gonna go? And it did go ok, so it's given us that sense of, right! Let try further afield. Let's just do it!"*

Despite a decline towards the inevitable future condition of EOP, Keith now ascribes a "sense of achievement" to his tourism experiences of motor homing around Europe over the past 20 years with his wife, Bev. Even though his contribution to the trips has declined over time and he now does not do any of the driving, he can still "do it". He commented that "a lot of people we talk to with EOP won't travel at all. It's just too hard for them." For Georgia, having come to terms with the confronting nature of EOP as a condition, what she ascribed to the meaning of her tourism experiences was "bucket list things. Do it before you can't do it!" She talked about "walking the Tongariro crossing with some friends" and her desire to keep travelling and to "see the Northern lights". Bucket list things extended to "wanting her kids to travel" and for her to go and visit them overseas.

With this sense of urgency to travel, conflated with the confronting nature of EOP as a disability, over half of the research participants ascribed negative meaning to their tourism experiences. These negative emotions were driven by the actual symptoms of EOP and confronting their likely future. Bryce described how he now sees tourism experiences as "a yardstick of your level of independence and I'm definitely feeling more aware of my restrictions." Clyde talked about the association of "stress" that he now has with tourism experiences. He reflected:

*Anything that causes me stress. Anytime I'm under pressure, be it in turbulence or if I was going to do a bungy jump again, my tremor just takes over my whole body, my brain fog becomes debilitating. There is also the association of being in unfamiliar surroundings. I know a number of people with Parkinson's who find the stress of being in unfamiliar surroundings (from travelling) too daunting for them to consider and that has a major impact on their life.*

A number of other participants also talked about the association they now hold or the feelings or meaning they ascribe to leisure travel in terms of "tiredness", "anxiety about air travel" and a general "loss of confidence". Clyde expressed that; "whereas

*before it [leisure travel], appears as a treat or a reward, now with EOP I find the whole thing quite daunting, and it also forces me to acknowledge my condition."*

Bryce reflected on a new loss of confidence, *"it definitely starts to make you feel a lot less independent. Yeah, like I don't know if I would go by myself places anymore."*

Georgia said she experienced a duality. On one hand she ascribed positive meaning to leisure travel because she *"could still do it"*. Still being able to travel provided her a strong sense of identity. Yet, in the reverse, her self-identity was undermined by her anxiety that she *"wasn't going to be able to do things ... 'cause it's quite embarrassing when you can't do things."*

Self-identity is central to individuals' creation of meaningful experiences (Bond & Falk, 2013). A sense of self-identity and, as part of this, self-belief is acquired by some individuals with EOP as part of their tourism experiences. Peggy describes her leisure travel experiences now as *"quality of life and for me that means adventures and having some fun and experiencing new things while I can ... pushing myself so I know that I'm not just going to lie down and let this take over."* The outlier of my research participants was Mike, who felt that the confronting nature of EOP had not had any impact on his ascribed feeling about leisure travel or a sense of urgency to travel. He commented that this was *"because although I enjoy travel, I don't lust after it. ... It's not super important to my life so I don't think there has been any change around EOP and travel."* However, when probed further and asked if he felt leisure travel experiences contributed to his quality of life or self-development, he admitted to a slight movement in position. He stated:

*My gut answer is I don't think they do, but as I say that I think that's probably rubbish because even though I don't really lust for and plan trips away, Holly and I have great shared memories of the trips away, so it absolutely adds to my life. ... I don't think I've ever thought about how much it adds to my life.*

Overall, the data revealed that regardless of whether the ascribed meaning was positive or negative, and therefore the associated self-perception was likewise, the key finding was around the sense of *"urgency"* to travel. The most fascinating point about this was that this sense of urgency seemed to be greater for individuals with EOP than for individuals with terminal illness.

#### 5.4 Theme three: Managing symptoms during travel

The third and final theme that emerged from the data was about ‘Managing symptoms during travel’. This theme had several strands to it. The first major strand was around the need for an increased level of pre-trip “*planning*” to try and alleviate emotional “*anxiety*” and “*stress*”, and provide a level of comfort and control of the unknown (travel) world for individuals with EOP. The second strand was about the extra time for tourism-related activities that individuals with EOP require in order to manage their symptoms during travel. The third strand was about the relational dimension, regarding how travel is now usually undertaken with a significant other (or others), and how that person is often the one who does all “*the pre-trip and trip planning.*”

The first aspect of this theme speaks to the importance of, and need for, more “*detailed planning.*” Planning in the context of leisure travel for PwD is related to access to information and the importance of that information being accurate (Eichhorn et al., 2008; Michopoulou & Buhalis, 2013). Eight out of 10 of the research participants discussed a need for a greater level of planning for leisure travel following their EOP diagnosis. The critical factor that drove this was the desire to be in as much control as possible of unfamiliar environments. This control of one’s environment was required to alleviate stress as far as practicable. Participants commented as follows to this effect: “*Sure it might take a bit more planning,*” “*And I mean I had done a lot of preparation before,*” and “*We did a lot of preparation for this trip, so we could make our own trips very flexible.*” Clyde further reflected on the unpredictable nature of his EOP symptoms and the impact of trying to manage them whilst being in a new environment, as illustrated in the following quote:

*I was forever in fear of how I would be in an hour from now. It didn't matter when the 'now' was. 'Cause I can be very fluid in my talking and very functional with my walking or whatever and an hour from now I can be very, very different. So the, when I'm in familiar surroundings I can manage that and when I'm with familiar people I can manage that. But when you are well outside your comfort zone in Northern India ...*

Control was partly driven by the medical requirements of the participants. It was about being able to access accurate and detailed information to ensure they felt prepared and knew how to adapt their medicine regimes, or “*meds*”, in particular, while in new

environments. Peggy talked about her need to now undertake detailed planning, commenting, *“I just need to make sure I’ve got my meds with me, that I’ve got access to clean water so I can take my meds and stay hydrated.”* She elaborated on this:

*Just with the tramping side of things. I probably spent more time checking out what the distances were, how long the walks were, what the terrain was like, what the weather was doing because if it was going to be a bit muddy it would make it much harder and again, making sure I had access to clean water so I could keep up with my medications if I needed to ... definitely more planning required. Along with the planning, where is there to stop if you were driving for long periods of time. Somewhere to stop and rest and just take a moment to nap.*

Peggy was an outlier among the participants in this study in that she was still actively engaged in her own trip planning. Bryce also commented on the change in his behaviour driven by this recently acquired need to plan travel, as the following quote illustrates:

*Even going back a couple of years I would never have thought twice about jumping in the car and going somewhere. And now I’m like, do I have my meds, I’ve got to time this right. I don’t take a lot of protein when I’m doing my meds so that dictates what I’m going to eat and where I’m going to eat.*

Butterfly was another of the participants who voiced her increased need to plan in more detail now, versus before having EOP, stating: *“I actually got, I managed to dig up a little thing that I’d done that was trying to plan when, I found this notebook in the cupboard, so that was my little plan, as it were.”* In this quote Butterfly was referring to a little notebook she had found and which she showed me. It was a plan of when and where to take her doses of medication based on local time zones and airports. This was for a trip she had taken with her partner and his brother to Asia for his nephew’s wedding. She assured me the written plan was a new approach compared with previous trips and that the pre-planning had helped considerably in managing her medical regime; *“Yes, it seemed to work. We went from Singapore to South Korea. South Korea to Hong Kong and back to Auckland and that’s quite a bit of flying.”* Similarly, June and her husband undertook a ‘trial’ long-haul flight to Canada last year as a specific test case, *“It was a direct flight and how’s it going to go? How does it affect the meds, etc.?”* Clyde commented about the impact of unfamiliar travel

surroundings and loss of control and the potentially devastating impact of this. He reflected on

*being in unfamiliar surroundings. I know a number of people with EOP and Parkinson's who find the stress of being in unfamiliar surroundings too daunting for them to consider and that has a major impact on their life. We met a couple whose only child lived here in Gisborne, and they live in Canada ... but he's now refusing to travel because of the physical impact on his condition. And, unfortunately, his wife can't leave him, she's his caregiver. So, they've resigned themselves to not seeing their daughter.*

The above quotes collectively reveal how the management of EOP symptoms can be disruptive and alter behaviour for the individuals concerned. To follow on from an example already shared above, where previously Bryce would not have *"thought twice about jumping into his car"* and heading off for an unplanned road trip, such a trip now required detailed thought and pre-planning around medication, food stops, and overall timing for his 'on' and 'off' periods. This change for some people is frustrating and emotionally laden. This need to plan in detail carries with it a sense of loss of freedom as evidenced in particular by the quote above from Bryce.

Another strand of 'managing symptoms during travel' was the need for individuals with EOP to be able to take a little more time than other tourists. This is due to the impact of EOP on fine motor skills, decreasing levels of strength, or stress-related issues (Parkinson's New Zealand, n.d.). Liz commented on this need for extra time in terms of managing symptoms:

*Something I should have mentioned earlier is that my fine motor skills aren't as strong as they used to be, like getting a credit card out of my wallet or getting a boarding pass out of my bag is harder than it used to be and I find that really frustrating 'cause it used to be so easy.*

Georgia had experienced similar situations. She commented about the ideal need for tourism operators and other tourists *"being a bit more aware that things take a little bit longer, getting your ticket out or turning on your phone to show your booking thing."* Penny suggested that the tourism industry could help with the stress aspect of EOP symptom management by providing *"somewhere quiet to go in stressful situations*

*such as airports”, and Keith added a suggestion for “Later checkout times in hotels because it does take you longer.”*

These interview findings regarding the need for a greater level of planning, in aiming to avoid the stress of unknown travel situations for individuals with EOP, support previous literature findings (see, for example, Darcy, 1998; Yau et al., 2004). Darcy (1998) outlines that, for PwD, the concept of departing from known, daily routines and undertaking travel can result in a high degree of angst. This degree of uncertainty is based on the fear of the loss of control with which PwD can generally approach their known world. Through self-created routines, PwD can control or influence their everyday surroundings to varying degrees and hence deal with any difficulties that arise. However, when travelling they are unlikely to have prior knowledge of possible barriers resulting from the new experiences and environments encountered through travelling and how they might deal with them (Darcy, 1998). Indeed, leisure tourism is thought of by many PwD as a metaphor for recovery (Yau, et al., 2004). Major effort, problem-solving skills, and a high degree of self-awareness about one’s own capacity and capability are required for engagement in travel activities for PwD. It also requires the tenacity and emotional and mental ability to source accurate, helpful activity and destination information. Due to this complexity, achieving the travel goal demonstrates to the individual with disability and others that they are independent and capable of managing (and enjoying) travel, and this in and of itself is about a metaphor for their lives (Yau et al., 2004).

Alongside the increased need for planning, particularly related to medical regimes and the need for more time, was the relational strand of this theme of ‘managing symptoms during travel’. This was based on the fact that for all 10 participants, following an EOP diagnosis, travel was now undertaken with a significant other or others. Participants made comments such as, *“I went with my partner and his brother and we went to a nephew’s wedding”* and *“we took the family and we went to Rarotonga and we also went with my Mum and Dad.”* Peggy mentioned that what was most memorable about a trip was being able to travel with her significant other: *“it was age and stage. My husband and I got to do it, just the two of us.”* This strand of the theme relating to travel now being or needing to be undertaken with a significant other is an interesting juxtaposition of thought. Blichfeldt and Nicolaisen (2011) and

Kastenholz et al. (2015) very accurately reflect the feelings of PwD regarding travel facilitating a sense of temporarily being freed from their role of “objects of care” (p. 1264). However, in contrast, the findings of this research study indicate that the reality of travel now only being undertaken with a significant other, in order to help manage symptoms during travel, actually indicates a need (or want) for assistance and, therefore, that the participants are indeed “objects of care”, rather than being freed from this state. Gillovic, McIntosh, Cockburn-Wootten, and Darcy (2024) explain that previous considerations of care in relation to travel have predominantly viewed it as a health aid, rather than a socially motivated leisure activity.

In two-thirds of the participants’ cases, the significant other that they now travelled with also became responsible for the trip planning. Clyde articulated this aspect of the theme very well, commenting: *“I can’t be involved in organising the itinerary because we’d be flying home from somewhere when we haven’t even got there yet! I get the whole thing mixed up.”* Mike also travels with his wife and relies on her to undertake all the planning: *“I usually leave it to Holly to organise where we are going. We have a chat and then she is great at organising stuff.”* Keith is another participant who relies on his wife Bev to do all their trip planning as he is not capable of independently making decisions about where to go, as a result of his EOP-related cognitive decline. Chung and Lee (2019) identify a strong relationship between travel companionship, well-being, and meaningfulness, finding that PwD travelling with their spouse or partner, children and other family members and friends were much happier than when travelling alone. The findings of this study support Chung and Lee (2019); however, for individuals with EOP, the need or desire for a (family) travel companion has an added level of complexity, as outlined above. Both Darcy (1998) and Small (2015) discuss how an unfamiliar tourism environment results in increased anxiety for PwD and that it also creates a dependency situation. This dependency relates to the common and well-documented situation where PwD are accompanied by a significant other or travel companion (see Darcy, 1998; Devile & Kastenholz, 2018; Lehto et al., 2018). McIntosh (2020) sheds light on the difference between those PwD who cannot travel alone without a carer and those who choose not to, which appears to be the case for individuals with EOP or epilepsy. She explains:

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. Rather, for these respondents, it was a personal choice driven by the anxiety of their condition. (McIntosh, 2020, p. 8)

The findings of people with different disabilities situated within the barrier-laden (McIntosh, 2020) nature of leisure tourism has been widely covered (see, for example, Daruwalla & Darcy, 2005; Gillovic & McIntosh, 2020; Gillovic, McIntosh, Cockburn-Wooten, & Darcy, 2024; McIntosh, 2020; Smith, 1987). These studies have detailed the “mobility restraints, physical barriers, lack of access to information, discrimination, and fear of being unable to cope faced by travellers with disabilities” (McIntosh, 2020, p. 1). The barriers listed above are all common themes for individuals with EOP. This interpretive phenomenological study aims to contribute new insight on the lived leisure travel experiences of individuals with EOP and, as it is an (in)visible disability, the findings of this study are positioned alongside those of studies on intellectual disability (Gillovic, 2019; Gillovic et al., 2021) and epilepsy (McIntosh, 2020).

## 5.5 Chapter summary

This chapter has revealed the three key themes that inductively emerged from the data: (1) (In)visibility of EOP in travel; (2) Sense of urgency to travel; and (3) Managing symptoms during travel. It has explored the various, and often interrelated strands that comprise each of these themes and discussed them in connection with both the thesis aim and the wider literature. Whether an individual’s EOP symptoms were invisible and/or visible to others influenced how they were perceived and treated. Consequently, individuals might feel compelled to conceal or disclose their condition (Jacoby, 2002; Lingsom, 2008) due to potential experiences of stigma, which is a challenge found to be shared by other people with hidden disabilities (Gillovic, 2019; McIntosh, 2020). Individuals with EOP felt a strong need to bring their travels forward due to the degenerative nature of their condition. This stemmed from the desire to travel while they had time and were able to create meaningful memories with their significant others who would later become their carers. This sense of urgency appeared even greater than that of people with terminal illnesses (see, for example, Aisporna & Erickson-Hurt, 2019; Willson et al., 2023; Zascierinska et al., 2024). Finally,

individuals relayed the practical and relational aspects of managing their EOP symptoms during travel, which required pre-trip planning, allocating extra time for activities, and the assistance and companionship of significant others. This was tied to the stress and anxiety of navigating an uncertain and unfamiliar tourism world (Darcy, 1998; Yau et al., 2004) and thus creates a situation of dependency (Devile & Kastenholz, 2018; Lehto et al., 2018). Despite these inherent challenges, travel was perceived as both a significant and meaningful experience for individuals with EOP.

Chapter Six, Conclusion, follows. It includes a summary of the key themes and further discussion of the most significant findings. The originality, significance, and contribution of this study is explained. This is followed by future research suggestions and Chapter Seven, Epilogue, concludes the thesis.

## Chapter 6 Conclusion

### 6.1 Introduction

This interpretive phenomenological study sought to explore and interpret the lived leisure travel experiences of individuals with EOP in New Zealand. Cuthbertson et al. (2020) suggest that the exploratory qualities of interpretive phenomenology provide the potential for insight into topics of which little is known. Indeed, little, if anything was previously known about the lived leisure travel experiences of individuals with EOP either globally or in New Zealand.

The findings of this study augment existing understandings of PwD by adding a new body of information about another dimension of disability, EOP, that had not previously been considered in tourism scholarship and gives voice to the leisure travel experiences of individuals with EOP. The study intended to give voice to individuals with EOP, as a marginalised group, through hearing, interpreting, and sharing their experiences through qualitative semi-structured interviews with 10 participants (Tracy, 2019). Several scholars have drawn attention to the need to give voice to PwD to achieve a more in-depth understanding of their feelings and perspectives as they relate to their lived leisure travel experiences (Blichfeldt & Nicolaisen, 2011; Devile & Kastenholz, 2020; Richards et al., 2010).

Yet, beyond increasing understanding, the wider significance of giving voice to PwD is to help counter their marginalisation in tourism and in society (Gillovic, McIntosh, & Darcy, 2024; McIntosh, 2020). Giving voice aims to help empower PwD, including individuals with EOP, and increase their agency. It is hoped that increased agency and traction will result in the increased presence and contribution of PwD as key stakeholders in the overall tourism system (Hayden et al., 2024), outlined in Chapter Three, Literature Review, and – by extension – wider society.

This study was situated within the burgeoning scholarship of accessible tourism studies. Such scholarship has increasingly explored the tourism experiences of people with different disabilities, mostly physical and sensory, for example, mobility (Ray & Ryder, 2003) and hearing (Nilsson, 2020), and increasingly in different dimensions, such as cognition, for example, intellectual (Gillovic, 2019); however, this research

addresses an area with a paucity of study, namely the lived leisure travel experiences of individuals with EOP. Chapter Six concludes this thesis by first summarising the key study findings and discussing them in relation to extant accessible tourism studies literature. The originality, significance, and contribution of this study are explicated, and future research possibilities are highlighted. Concluding remarks are followed by a short, personal reflection in Chapter Seven, Epilogue.

## 6.2 Significance of the findings

This study revealed three key themes about the lived leisure travel experiences of individuals with EOP. These were: (1) (In)visibility of EOP in travel; (2) Sense of urgency to travel; and (3) Managing symptoms during travel.

The first theme, '(In)visibility of EOP in travel', explored both the positive and the negative effects on participants of the invisible, visible, or (in)visible symptoms of EOP as a disability and within the context of travel. It also revealed the inherent tension of the (in)visibility, or the active hiding of symptoms by participants in the early stages of EOP during their travel. Perhaps most significant within this theme was the participants' degree of felt tension between deciding whether to conceal or disclose their EOP, and if, when, and to whom to reveal it (Lingsom, 2008). Many participants clearly expressed the view that they felt stigmatised, marginalised, and unheard, particularly by fellow tourists or other onlookers, because their symptoms were not necessarily obvious as a disability and were, in turn, misunderstood or misinterpreted.

These findings, particularly that of the felt tension around concealment or disclosure, and stigma, support a small number of other accessible tourism studies on hidden disabilities within tourism, particularly studies relating to epilepsy (McIntosh, 2020), intellectual disability (Gillovic, 2019) and dementia (Page & Connell, 2024). As other dimensions of disability, particularly those that are visible or have indicators or markers, such as a guide dog or wheelchair (Dwyer & Darcy, 2011), have been previously studied (see, for example, Buhalis & Darcy, 2011; Nilsson, 2020; Ray & Ryder, 2003), it seems that the tourism industry is, in some small part, more acclimatised to visible disabilities and therefore better able to accommodate them. However, stigma, whether real or perceived, has a huge effect on hidden or invisible disabilities, in that those individuals who feel stigmatised may be unlikely to engage or

continue to engage in leisure travel and tourism. Without knowledge of hidden or invisible disabilities, tourism operators, other tourists, and society more broadly, have a greater propensity to act in a marginalising way, even if unintentionally (Darcy, 1998; Gillovic, McIntosh, & Darcy, 2024).

It seems likely that it is the nature of the unpredictability of symptoms and the management of them, and how they present as (in)visible to others, that aligns the travel experiences, and the associated emotions, of individuals with EOP or epilepsy more closely together than with other dimensions of disability. 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). In the quote above, the description of the problems associated with epilepsy could easily be applied to EOP and would remain largely accurate.

Hence, the two neurological conditions can rightly be assumed to be very similar in nature regarding the (in)visibility of symptoms and the censoring of this, for and by others, along with the challenges that come with managing symptoms and medications whilst travelling (McIntosh, 2020; Parkinson's New Zealand, n.d.). These two neurological conditions share unique challenges for leisure travel, but both have largely been ignored in accessible tourism scholarship, aside from the McIntosh (2020) study on epilepsy and travel and the Shabu et al. (2022) study on health advice for medical travellers with Parkinson's. From a wider perspective, unveiling the hidden aspects of some dimensions of disability can only serve to improve equity and dignity, and decrease the felt and actual marginalisation of PwD within the wider tourism industry and society as a whole (Daruwalla & Darcy, 2005; Michopoulou et al., 2015). In practice, this affirms the need for disability awareness training (Gillovic & McIntosh, 2015) or an education campaign like the Hidden Disabilities Sunflower Scheme (Civil Aviation Authority of New Zealand, n.d.).

The second theme, 'Sense of urgency to travel', revealed among participants a strong need to bring their travel plans forward, following their EOP diagnosis. This was based on coming to terms with the reality of the condition and related concerns for the

future. Given the projected growth in the aging population, and therefore the numbers of PwD, including those with EOP and Parkinson's, in both New Zealand and globally (Buhalis & Darcy, 2011; WHO, 2023), this sense of urgency to travel for individuals with EOP creates implications for the tourism industry. Increasing pressure will be brought to bear on the supply of products and services and the development of destinations that are or will need to be designed and delivered with PwD/EOP in mind. Hence there is need for a matching increase in empowerment, advocacy, and agency by PwD, in the field of accessible tourism (Gillovic, McIntosh, & Darcy, 2024).

The 'sense of urgency to travel' was perhaps the most significant finding of this study. When likened to individuals with terminal illnesses, it may have been expected that their motivations would reflect a higher level of urgency to travel than individuals with EOP, due to the finite nature of terminal illness. However, this was not apparent when reviewing bucket list travel and terminal illness literature (see, for example, Aisporna & Erickson-Hurt, 2019; Willson et al., 2023; Zascerinska et al.; 2024). Exploration of the data revealed a potentially higher level of urgency to travel for individuals with EOP. This is suggested as being due to the combination of EOP not actually representing the threat of mortality but having the *fait accompli* of serious physical and, potentially, cognitive decline. Hence the common sentiment expressed by the participants regarding the driver behind their travel motivations was "*do it now while I still can.*" However, the underlying thought behind the sentiment was actually about *perceived* mortality rather than continuing a sense of normality through social functioning.

This theme was also about an underlying motive of concern for their future carers and also wanting to make (travel) memories whilst they were still able to, thus compounding the sense of urgency to travel. This finding complements study findings by Gillovic (2019) and Gillovic et al. (2021) about carers wanting to provide a good life for adults with intellectual disabilities in their care. Of note, however, is one key difference between this study and that of Gillovic (2019), in that, for carers of adults with intellectual disabilities there is no time constraint. The findings concerning individuals with EOP making (travel) memories support those of Willson et al. (2023) about the importance for those with terminal illness of making travel memories with family while they are still able to do so. The making of memories with family for those with EOP is about creating memories for the wider family and ensuring that loved ones

are living their best (travel) lives. Together with this study, these studies elucidate the important emotional and relational dimensions of leisure travel experiences for PwD and the carers and companions they travel with.

The third and final theme, 'Managing symptoms during travel', also comprised several strands. Notably, there was an important need for an increased level of pre-trip planning to alleviate stress, by providing a level of comfort and control of the unknown tourism world for the individual with EOP. This was particularly relevant when individuals were out of their (medication) routines and was tied to their recognition of the need for extra time when participating in leisure travel, due to the impact of EOP on fine motor skills, stress, and decreasing levels of strength (Parkinson's New Zealand, n.d.). This finding supports those of other accessible tourism studies (see, for example, Buhalis & Darcy 2011; Darcy, 1998; Darcy & Buhalis, 2011; Yau et al., 2004). For example, Darcy (1998) outlines how for PwD, the concept of departing from known, daily routines and undertaking travel can result in a high degree of angst. This degree of uncertainty is based on the fear of the loss of the control with which they can generally approach their known world. Maintaining a sense of control during travel is an important emotional and mental synonym for life for PwD, and while tourism is considered an integral part of modern life, for PwD it is not always accessible or inclusive (Shaw & Coles, 2004). PwD are not always able to partake in tourism due to its barrier-laden and socially exclusive nature (Daruwalla & Darcy, 2005; Smith, 1987).

This theme also comprised a notable relational dimension that raised the importance of travelling with a significant other. While Kastenholz et al. (2015) have suggested that, for some PwD, participating in tourism allows a temporary escape from being "objects of care" (p. 1264), the individuals with EOP in this study wanted to travel with their significant other, and were in need of being cared for. While their significant other was their travel companion, they arguably became their carer to some degree too. This caring activity comprised not only the practical elements, like the significant other doing all of the planning, both before and during travel, or assisting with medication regimes, but also the emotional elements, like supporting them through their anxiety. This finding points to the important practical, emotional, and relational dimensions of the lived travel experiences of some PwD, and problematises the

common assumption of independence in travel, which other scholars have raised (Gillovic, McIntosh, Cockburn-Wooten, & Darcy, 2024; McIntosh, 2020).

### 6.3 Research contribution

The originality and contribution of this study are outlined below, along with reference to wider accessible tourism scholarship.

This interpretive phenomenological study, 'Unheard voices: The lived leisure travel experiences of individuals with EOP in New Zealand', commences the process of filling what is, to date, a complete void in previous tourism and accessible tourism scholarship on this topic, both globally and in New Zealand. Thus, as the first of its kind, this study is undoubtedly original. It contributes to existing understandings of PwD by adding a new body of information about another dimension of disability, EOP, that has not previously been considered in tourism literature, and it gives voice to the leisure travel experiences of those living with EOP. Specifically, the study reveals that individuals with EOP experience similar impacts to other PwD through the felt stigma of an often (in)visible disability (McIntosh, 2020) and the misunderstandings that can result from this. The research findings also contribute the information that individuals with EOP feel a sense of urgency, post-diagnosis, to bring their travel plans forward, due to concerns about their future capabilities and the desire to make memories with significant others while they still can (Willson et al., 2023). Also revealed, and thus contributing to the body of knowledge about PwD with different dimensions of disability, is that for individuals with EOP, like other PwD, the need to pre-plan travel increases the importance of access to accurate travel-related information. This study, like others (see, for example, Gillovic, 2019) reveals the importance of the relational aspect of travel and the need and desire for a travel companion to assist with care.

The population of individuals living with EOP in New Zealand is small (Pellegrino, 2022), and this being a phenomenological study meant the sample of participants was also small (Frechette et al., 2020). Despite these two factors, the contribution of the study is severalfold. The originality and key contribution of this study is that, until now, the perspectives and experiences of individuals with EOP have not been considered in tourism scholarship and, as such, their voices have remained unheard. Several scholars

provide insight into the importance of giving voice to PwD in tourism (see, for example, Blichfeldt & Nicolaisen, 2011; Devile & Kastenholz, 2020; Richards et al., 2010). Giving previously unheard groups of PwD, like individuals with EOP, their voice helps increase awareness, understanding, and empathy among people in the tourism industry and tourism researchers alike, and may contribute to a more inclusive (tourism) world (Gillovic, McIntosh, & Darcy, 2024). Increased awareness and understanding within the tourism industry will likely lead to an increased sense of empowerment and agency among PwD, including individuals with EOP, and, through this, more ability to advocate effectively for changes, including in global and country-specific policies relating to tourism products and services, and the actual delivery of such products and services, and also the development of destinations that are inclusive of all (Gillovic, McIntosh, & Darcy, 2024, Hayden et al., 2024).

There is a need to prioritise wider and more inclusive understandings of the subjective lived travel experiences of people with different disabilities (Gillovic, McIntosh, & Darcy, 2024). Existing accessible tourism scholarship has focused mainly on physical disabilities, such as mobility impairments (Ray & Ryder, 2003), or sensory disabilities, such as hearing or vision impairments (Nilsson, 2020; Qiao et al., 2023), and, increasingly, cognitive and hidden disabilities, such as intellectual disabilities and epilepsy (Gillovic, 2019; McIntosh, 2020). Missing from these considerations has been the perspectives and experiences of individuals with EOP. This study goes some way in addressing such a knowledge gap.

Ultimately, this study reaffirms the views of Devile and Kastenholz (2020, p. 267) who state:

there seems to be a need to develop new attitudes that encourage and support accessible tourism practices, identified as very beneficial for these individuals (those with visual disabilities) personal development, social inclusion and overall wellbeing. In this context, accessible tourism may present itself as a vehicle to promote individual and social well-being, not only for directly benefiting participants – a typically socially marginalized group – and their families, but also for society as a whole, by increasing social and family capital within the aforementioned groups, who in turn may become more empowered and active within the multifold dynamics of society at large.

The relevance of the quote above to this study is that, like for those with visual disabilities, the positive impacts of participation in leisure travel for individuals with EOP are significant. As their participation increases, so too might the awareness, understanding, and empathy of the tourism industry grow – and, potentially, that of wider society, too – hopefully, countering experiences of exclusion and marginalisation (Michopoulou et al., 2015). In summary, the contribution of this research is significant in that it adds to the small but growing body of academic knowledge around hidden disabilities in accessible tourism.

#### 6.4 Future research opportunities

As the only research study at the nexus of EOP, accessible tourism, and lived leisure travel experiences that is known to exist at the time of writing, either globally or in New Zealand, there is an obvious need for further research to expand and advance on the findings explored in Chapter Five, Findings and Discussion, and summarised in this chapter. Some of the key opportunities for related future research are outlined below.

Firstly, Shabu et al. (2022), while examining medical travel for individuals with EOP, recommended that future qualitative research is undertaken to extend beyond a focus on travel for medical purposes for individuals with EOP, acknowledging that they may also participate in travel for leisure reasons. They do not elaborate further on their reasoning but by inference, this is due to a dearth of research and literature on the lived leisure travel experiences of individuals with EOP. While this study begins this process, there is an obvious need to build on this initial, solitary work and to further validate its findings.

While EOP is a disability experienced globally, this research was just based on individuals who reside in New Zealand. This was done deliberately to ensure that the study was geographically manageable. However, it may be interesting to investigate whether the research, if repeated in other countries, would deliver different findings. The nuances that may impact the outcome of geographically different studies are in whether attitudes and actions of others towards people with invisible disabilities differ by culture. Alternatively, there is an opportunity to conduct quantitative research just in New Zealand but on a larger scale, or qualitative or co-designed research on

different but related topics, which would add to the overall picture of lived leisure travel experiences of individuals with EOP, which has just begun to be explored.

Various scholars (see, for example, Benjamin et al., 2022; Gillovic & McIntosh, 2020; Jacoby & Austin, 2007; McIntosh, 2020; Moufakkir, 2015) discuss the significant impact of stigma on the tourism experiences of PwD. These findings were also reflected in this study on EOP. The significant impact of social stigma on equity and dignity as evidenced in these studies is suggested as an opportunity for future research attention as it is an important predictor of quality of life (Jacoby & Austin, 2007).

There is a limited, albeit increasing, number of studies on the carers' perspective and the care experience in accessible tourism scholarship (see Bauer, 2018; Eusébio et al., 2023; Gillovic, 2019; Gillovic, McIntosh, & Darcy, 2024). This is an important avenue to consider given the importance of significant others, as carers, in supporting the leisure travel experiences of individuals with EOP, and the practical, emotional, and relational elements within this. As Gillovic, McIntosh, and Darcy (2024) outline, "as international travel includes the crossing of different geographic and cultural spheres, future accessible tourism research could examine demographic, cultural, social, economic, and political dimensions of the care experience during travel" (p. 63).

Making memories with significant others who are likely to take on the future role of carers when the symptoms of EOP invariably worsen is a key travel motivation revealed in this study. The concept of changes to travel motivations of PwD as, or if, their symptoms worsen, is suggested as another possible area for future research. Related to this, Zascerinska et al. (2024) suggest that "the bucket list has become culturally symbolic, a widely accepted form of 'shopping list' of desired experiences that people, irrespective of their life-stage, wish to achieve" (p. 230). A focus for future research might therefore be around how such lists are constructed, and how the significance of goals (touristic or otherwise) within it might vary according to individuals with EOP, and in comparison with other dimensions of disability or chronic health and pain conditions.

Lastly, given the importance of increasing the awareness, understanding, and empathy of the tourism industry towards PwD, and particularly people with invisible disabilities, another area for future research may engage various tourism stakeholders to

determine their perspectives on, and experiences of, seeking to accommodate this group and, in particular, research might consider the nature of dignity for PwD, and how to acknowledge, respect and uphold it.

## 6.5 Concluding remarks

This interpretive phenomenological study has explored and interpreted the lived leisure travel experiences of individuals with EOP in New Zealand and, in doing so, has given voice to a previously unheard population in accessible tourism scholarship. Through an inductive process, I have revealed what is most significant about the participants' lived leisure travel experiences, which centres around the '(in)visibility of EOP in travel', a 'sense of urgency to travel', and 'managing symptoms during travel'. Yet, despite what might be presented as inherent challenges within the leisure travel experience, individuals with EOP still wish to participate in such experiences because they are meaningful. They perceive leisure travel as a means to enhancing general health, well-being, social interaction, and overall quality of life (Blichfeldt & Nicolaisen, 2011; Innes et al., 2016; McCabe & Johnson, 2013). Indeed, like other people with different disabilities, individuals with EOP also see leisure travel as a multi-dimensional activity that represents a metaphor for recovery through which they can demonstrate autonomy and regain (temporary) control over their lives (Yau et al., 2004).

Devile and Kastenholz (2020) remind us that a lack of education can result in tourism being a site for marginalisation for PwD. It seems that invisible disability, in particular, may amplify this, as it is fraught with complexity. Lingsom (2008) explains that people with invisible disabilities have a propensity to hide their challenges for fear of attracting unnecessary attention or judgment from others, or exclusion by others. For both tourism operators and society in general it is critical to be aware of and understand the tourism needs and expectations of people with different disabilities, including those that are hidden and may present as somewhat invisible (Nilsson, 2020). The implications of this need lead to a circular debate highlighted previously in Chapter Five, Findings and Discussion. That is, people with invisible disabilities often have a felt tension as to whether, when, and to whom to disclose their lived experience of disability (Lingsom, 2008). However, without either the individual with invisible disability disclosing and/or wider awareness and education of both the tourism

industry and society about disability and its different dimensions, it is extremely difficult for appropriate accommodations and caring service to be provided. By giving voice, albeit through research, to PwD more broadly and, in this instance, to individuals with EOP, it is hoped the sometimes exclusive and marginalising nature of tourism may be countered so that the qualities of equity and dignity inherent in Darcy and Dickson's (2009) definition of accessible tourism may be upheld to engender a tourism that is truly accessible to, and inclusive of, all.

As I started this thesis with a quote it seems appropriate to finish with one. This quote, from one of the participants, Peggy, encapsulates the significance and meaning leisure travel experiences hold for her, and is representative of a view held by many other participants, as individuals with EOP:

*I think for me it's about quality of life and for me that means adventures and having some fun and experiencing new things while I can. So that I've got something to look back on, my family have got something to look back on, creating memories and a certain level of capability and independence still. Pushing myself so I know that I'm not just going to lie down and let this take over.*

## Chapter 7 Epilogue

### 7.1 Introduction

This chapter brings this interpretive phenomenological thesis, which explored and interpreted the lived leisure travel experiences of individuals with EOP in New Zealand, to a close with a short personal reflection. It completes my story, to date, of lived experience of EOP, which I began in Chapter One, Prologue, and which led me to this point in my research journey.

### 7.2 Reflections in a mirror

One day I took a hand glass and went to a long mirror to look at myself, and I went alone. I didn't want anyone ... to know how I felt when I saw myself for the first time. But there was no noise, no outcry; I didn't scream with rage when I saw myself. I just felt numb. That person in the mirror *couldn't* be me. I felt inside like a healthy, ordinary, lucky person—oh, not like the one in the mirror! Yet when I turned my face to the mirror there were my own eyes looking back, hot with shame ... when I did not cry or make any sound, it became impossible that I should speak of it to anyone, and the confusion and the panic of my discovery were locked inside me then and there, to be faced alone, for a very long time to come. (Goffman, 1963/2009, pp. 14-15)

The relevance of the quote above relates to the personal reflections I saw in the figurative mirrors of my participants and the initial feelings I experienced from my own reflexivity upon listening to, and interpreting, their stories, and on my thesis journey as a whole.

I chose to keep much of my story, my lived experience of EOP, and then, more recently, my lived experience as a qualitative researcher engaging in semi-structured interviewing with 10 unique and brave research participants, until the end (Tracy, 2019). This was not to hold in abeyance my own views or feelings (Dörfler & Stierand, 2021), so much as it was to place the lived experiences of my 10 individuals front and centre of this thesis so that their voices might clearly be heard (Devile & Kastenholz, 2020).

So, to continue the story of my thesis research journey... After receiving AUT faculty approval, and then following due process, receiving AUTEK research approval, I blithely commenced my research interviews. The theory and practice of tourism is a passion for me. It is in my blood. And, due to DBS, my EOP symptoms are largely under control. As such, and arguably with my 'othering' hat on (Darcy et al., 2020), I did not expect to find the interviews confronting. However, they were. In fact, I had previously accounted for the possibility that my research topic may give rise to a range of emotions because of my lived experience of EOP. I had done this through my ethics approval application by acknowledging that the interviews may be confronting and indicating that I was willing to attend counselling and/or to use journalling to work through any confronting issues.

The first interview was slightly nerve-wracking, as I found my feet, although not confronting. However, the simultaneous feeling of both familiarity and terror began to grow with each successive interview. It was like looking at my reflection in a mirror. I knew, understood, and related to the stories that unfolded as each participant shared their perspectives and experiences, and was simultaneously slightly horrified by some of their symptoms and the state of some of their conditions that were reflected back at me. I explain two such 'reflections' in more detail, below.

EOP is 1,000 different diseases. The set of symptoms of every individual is unique (Parkinson's New Zealand, n.d.). Whilst this is the case, and therefore the images that were being reflected at me, through the 'interview mirror', were unique in their own right, most were familiar enough to me, having lived through 18 years of EOP, prior to my effective DBS operation in 2022.

Reflexively (Tracy, 2019), I was shocked by the degree to which I felt confronted. Here was I, researching and writing a thesis on accessible tourism, the lived leisure travel experiences of individuals with EOP in New Zealand and recognising the need for increased awareness, understanding, and empathy, yet I was experiencing some emotional turmoil at the view presented to me. The fact that I was potentially, probably, hearing, seeing, and interpreting what my future looked like, had escaped my perception in the academic-focused lead-up to the interviews.

Throughout the data collection process, I used a journaling technique (Meyer & Willis, 2019) to assist with managing the confrontation I felt. That is, after all the interviews, I used a book to write down my feelings and thoughts regarding my sense of confrontation, as well as about each interview and the thesis topic, more generally.

Adams (2013) articulates the value of journaling as follows:

Writing and wellness are natural allies. When approached in a purposeful and intentional way, journal writing can be an agent for healing and change. Writing thoughts and feelings in a journal develops insight, compassion for self, and body awareness. Writing organises cognition, articulates intuition, and regulates emotion. (p. 176)

The journaling of my emotions assisted me significantly in working through and negating any potential negative impact of the 'mirror reflections' I felt from the various interviews I undertook as part of my research.

Reflections on two participants, in particular, were profoundly impactful. The experience of the first of these interviews, which I conducted in person, I found particularly daunting as the individual was wracked with tremors and dyskinesias (sudden, sharp movements) throughout the hour we spent together. She spoke of her "*fuzzy brain*" and of not being physically capable of lifting bags anymore when travelling. Both symptoms I personally experienced before my DBS operation and the cognitive impact (or fuzzy brain) had slowly been starting to make itself felt again, already. Yet the sense of humour and positiveness this participant displayed was a sage reminder to me about the power of positive thinking.

The second of my particularly confronting interviews was with a participant who had lived with EOP for quite some years. His speech was affected, amongst other things. This made it slightly challenging to understand answers at times but also gave me pause for thought as it reflected to me how I must sound to others. Indeed, when transcribing the recorded interviews I was affected by how slurred I perceived that I sounded. But again, the positive impact that leisure travel had on this individual's self-perception was uplifting.

I was reminded by a comment Clyde, one of my other participants, made during our interview, about my own experience when first diagnosed with EOP, some 22 years

ago and attending my first (and only) Parkinson's monthly coffee catchup. His quote, below, were my exact feelings, another reflection in the mirror...

*I refuse to attend the Parkinson's monthly coffee groups. I find it too confronting. I refuse to put myself in. I have a sense of compassion for the people there, but it's not good for my state of mind for me to associate myself with the challenges that I'm physically seeing in the room.*

As explained in the Prologue, I had been reluctant to associate myself with other individuals with EOP or to consider myself as having a disability. DBS surgery had helped in perpetuating this view, as I generally do not present with many immediately noticeable symptoms of EOP. Yet, the journey of this thesis has opened my eyes to the need to join my voice with others in my 'tribe', my EOP cohort, if I, or we, are to make a difference to enabling more awareness and understanding of PwD, and empathy for PwD, including individuals with EOP, by and in society (Gillovic, McIntosh, & Darcy, 2024).

I am honoured to have had the opportunity to explore, interpret, and share the lived leisure travel experiences of my 10 research participants with EOP, and to provide them with a platform for their voices to be heard. As much as I found the interview process personally confronting, I thank them all for the learning opportunity they each provided me, through metaphorically holding up a mirror that enabled reflection on my own demons and instilling in me a sense of the hope that only an experience like leisure travel can bring to a sometimes disabling and marginalising world.

I come to the end of this research no longer ashamed to say that I am an individual with EOP and committed to using my voice wherever possible to further contribute to engendering the social change needed to ensure that tourism is truly accessible to, and inclusive of, all.

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## Appendices

### Appendix A Ethics Approval



**Auckland University of Technology Ethics Committee  
(AUTEC)**

29 February 2024

Brielle Gillovic  
Faculty of Culture and Society

Dear Brielle

Re Ethics Application: **24/8 Unheard voices: The lived leisure tourism experience of individuals with Early-onset Parkinson's Disease.**

Thank you for your responses to AUTEC's conditions.

Your ethics application has been approved for three years until 28 February 2027.

**Non-Standard Conditions of Approval**

1. Please ensure the Information Sheet includes the AUT logo and the date that the Information Sheet was produced on.

Non-standard conditions do not need to be submitted to or reviewed by AUTEC unless requested but must be completed before commencing your study.

**Standard Conditions of Approval**

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTEC.
2. All public facing documents must have the AUTEC approval number and be of a high standard of spelling and grammar. Dates on the Information Sheet(s) and Consent Form(s) must be consistent.
3. Any amendments to the project must be approved by AUTEC prior to being implemented.
4. A progress report is due annually on the anniversary of the approval date.
5. A final report is due at the expiration of the approval period, or, upon completion of project.
6. Any serious or adverse events must be reported to AUTEC, this includes unforeseen issues that might affect continued ethical acceptability of the project.
7. AUTEC grants ethical approval only. You are responsible for obtaining management permission for access from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

The application number and title need to be referenced on all correspondence related to this project.

All forms are available online <http://www.aut.ac.nz/research/researchethics>


For any enquiries, please contact [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz)  
(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat  
**Auckland University of Technology Ethics Committee**

Cc: Chris.atkinson1003@gmail.com; Alison McIntosh

Auckland University of Technology, D-88, Private Bag 92006, Auckland 1142, New Zealand.  
T: +64 9 921 9999 ext. 8316; E: [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz); [www.aut.ac.nz/researchethics](http://www.aut.ac.nz/researchethics)

## Appendix B Email Invitation



**An Invitation**

**Do you have Early-onset (or young-onset) Parkinson's and engage in leisure travel?**

If you were diagnosed before the age of 50 (regardless of your current age) and you would like to be involved in a small research project, I would love to hear from you!

My name is Chris Atkinson. I am a postgraduate student at AUT, and I have Early-onset Parkinson's Disease (EOP).

I would like to invite you to participate in a study which I am doing for my Master of Philosophy degree.

It is about the experiences of individuals like us, who, despite a diagnosis of EOP, continue to want to engage in life activities such as leisure travel and tourism. I am keen to hear how you have experienced travel and tourism since your diagnosis.

If you are keen to know more about this study, and perhaps share your experience of tourism and travel (since you were diagnosed with EOP and where the travel or tourism experience has been in the past seven years ) please email me by 26 March 2024 on: [Chris.atkinson1003@gmail.com](mailto:Chris.atkinson1003@gmail.com)

I will send you back a detailed Participant Information Sheet which answers many potential questions about the study and then I will be in touch shortly after that to see if you are keen to participate. If you are, and it is entirely your own choice, I will send you a consent form and I will then arrange an interview time that suits you, either in person at a public meeting location in Auckland, or online if you reside outside of Auckland or would prefer online to in-person. The interview will take approximately one hour.

If you know someone who you think fits the research criteria and would be interested in sharing their experiences, please do forward this invitation to them and ask them to contact me directly.

Many thanks and I look forward to hearing from you!

Chris Atkinson

*Approved by the Auckland University of Technology Ethics Committee on 29 February 2024. AUTEK Reference number 2408.*

## Appendix C Participant Information Sheet



**AUT**  
TE WĀNANGA ARONUI  
O TĀMAKI MAKĀU RAU

### Participant Information Sheet

**Date Information Sheet Produced:**  
2 March, 2024

**Project Title**  
Unheard voices: The lived leisure tourism experiences of individuals with Early-onset Parkinson's Disease (EOP).

**An Invitation**

Hi. I am Chris Atkinson. I am a master's student at AUT, and I live with Early-Onset Parkinson's Disease (EOP). When I was diagnosed 21 years ago at the age of 36, I found there was a fair amount of information about Parkinson's but very little regarding early, or young, onset Parkinson's and specifically, none in relation to leisure travel and tourism experiences. My research aims to help fill this gap.

I would like to invite you to participate in my research project about the experiences of individuals like us who, despite a diagnosis of EOP, continue to want to engage in life activities such as leisure travel and tourism. Leisure travel and tourism is a term that covers any travel, or engagement in tourism offerings or products undertaken for personal reasons and not for work purposes. I am keen to hear how you have experienced leisure tourism since your diagnosis. The timeframe for my research project is travel or tourism that has taken place since January 2017.

This research is part of my studies toward a Master of Philosophy degree.

**What is the purpose of this research?**  
There is a growing body of research into issues relating to accessibility, tourism, and disability. While the impact of leisure and recreation on Parkinson's and EOP has been lightly examined it has been mostly from a medical perspective. The actual leisure tourism experiences of those of us with EOP have not yet been explored, either here in New Zealand or internationally.

This study aims to address this gap in research and practice by providing exploratory insights into the lived leisure tourism experiences of individuals with EOP in New Zealand and whether and how such experiences influence our self-perception, including our sense of equity and dignity.

It is intended that the research findings will contribute to the body of research surrounding access and inclusion in tourism, provide important insights about EOP for New Zealand tourism operators and potentially inform future research agendas. The findings of this research may be used for academic publications and presentations.

**How was I identified and why am I being invited to participate in this research?**  
You are receiving this information sheet either because you noticed a flyer in one of my key contacts, Adele McMahon (Nurse Specialist, Neurology Department, Auckland City Hospital) or Dr Tara Coleman (School of Environment, Faculty of Science, University of Auckland) offices and have proactively contacted me via email, someone has forwarded the flyer or invitation to you or you have responded to an advertisement in your Parkinson's or Upbeat newsletter.

It is entirely up to you whether or not you choose to continue contact with me and whether you express interest in being involved in this research. To be clear, neither my initial key contacts (Adele McMahon or Tara Coleman), Parkinson's New Zealand or the Upbeat chapter of Parkinson's New Zealand will know if you participate in this study as you are contacting me directly and the study will de-identify all participants (you will not be named).

To be eligible for my research you need to meet the following criteria:

- A diagnosis of EOP;
- Have undertaken leisure tourism since January 2017, domestically and/or internationally; and
- Be comfortable sharing your experiences.

I am only seeking 10 participants. If by chance I receive email contact from more than ten potential participants by the 26<sup>th</sup> March, 2024, the ten will be randomly selected.

If you know someone who meets the study criteria and might be interested in participating, please feel free to forward this information to them.

**How do I agree to participate in this research?**

If you think you may like to be part of this research please email me on [chris.atkinson1003@gmail.com](mailto:chris.atkinson1003@gmail.com). We can discuss any questions you have and if you decide to participate arrange a convenient interview time and location.

I will send you a consent form to complete.

The consent form is a physical one that simply requires you to tick some boxes, sign and send or scan back to me. If you are unable to complete the physical form for whatever reason there is a verbal, audio-recorded option that we can complete before commencing the actual interview. This verbal consent is recorded as a separate audio file to the interview.

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

**What will happen in this research?**

Your participation in this research will be in the form of an interview. For those in Auckland, where I live, these can be face-to-face in a public space we can both easily access (such as a library meeting room). We will discuss accessibility requirements before meeting to ensure the location is convenient and comfortable. You are welcome to bring a support person if desired or needed. For those outside Auckland, a zoom interview will be scheduled for a time that suits us both.

The interview itself will take no more than an hour and be conversational in nature. The questions will ask you a little about yourself and your EOP, and then your tourism experiences. There will be an opportunity for you to share stories and perspectives. You can choose not to answer any question, without explanation.

The interview will be audio recorded so I have an accurate record of our conversation. I will transcribe (type up) the interview and send you a copy by email. At this point you have an opportunity to add to, delete, clarify, or alter your comments in any way.

While the data I gather from the interviews will be used in the thesis I produce for my degree, it may also be utilised in other academic publications or presentations. It is also my intention that the findings of this research will form a set of operational suggestions for the New Zealand tourism industry.

None of the data or findings from this research will identify you or any other individual (or business). Pseudonyms will be used, the key outcomes of the interviews will be summarised generically and any personally identifiable information will be removed.

**What are the discomforts and risks?**

It is not the intention of this research to cause discomfort, but you might find recounting some of your experiences upsetting. You will be free to stop the interview at any time, or to refuse to answer any questions. Before we meet you may wish to think about which experiences you are comfortable sharing.

Please note that I am looking for positive stories and experiences too!

If you are having a face-to-face interview, we will discuss accessibility issues beforehand. I will endeavour to create a comfortable environment for the interview, and you are welcome to bring a support person with you.

**How will these discomforts and risks be alleviated?**

It is entirely up to you which of your tourism or travel experiences you choose to share during our research interview. However, if you do find that recounting an experience (s) does cause discomfort or distress AUT Student Counselling and Mental Health is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

- drop into our centre at WB203 City Campus, email [counselling@aut.ac.nz](mailto:counselling@aut.ac.nz) or call 921 9292.
- let the receptionist know that you are a research participant and provide the title of my research and my name and contact details as given in this Information Sheet.

You can find out more information about AUT counsellors and counselling on <https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health>

**What are the benefits?**

Benefit to participant; you may gain satisfaction from sharing your stories and experiences and reflecting upon these. It is your chance to have a voice!

Wider benefits; One of the outputs of the research will be a summarised set of operational suggestions, sent to the wider New Zealand tourism industry which aims to help improve the accessibility, equality and dignity for all, of tourism and travel opportunities in New Zealand. Although indirect, your involvement in my research may result in modifications to the way New Zealand tourism and travel operators train staff and present their products and services.

Benefits to the researcher; I hopefully achieve my degree.

**How will my privacy be protected?**

The New Zealand Parkinson's community is small and the EOP cohort even smaller. Your privacy is of utmost importance in this research study. Your name will not be used in this research – you will be assigned a pseudonym. I will not include in my thesis or any other publications from this research any details that may directly or indirectly identify you.



As the sole researcher, I and my two Masters supervisors, will be the only people who will have access to the data collected during our interview. The data will be saved on my password protected computer network drives. Your consent form, which will include your name, will be stored by my supervisor separately to the data and will be destroyed after a period of six years.

**What are the costs of participating in this research?**

The cost of participating in this research is your time, for a face-to -face interview with me, at a public location of mutual convenience in Auckland - or via a zoom interview if Auckland is not your home location or if you prefer zoom to an in-person meeting. You will also have an opportunity to check your transcript, which may take a further half hour or so.

**What opportunity do I have to consider this invitation?**

I would love to hear from you as soon as possible if you are interested in participating in this research, but ideally no later than 3 weeks after you receive the invitation and information sheet.



**Will I receive feedback on the results of this research?**  
Yes, absolutely! A copy of the summary of the research results will be emailed to you once it is available.

**What do I do if I have concerns about this research?**  
Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Brielle Gillovic on [brielle.gillovic@aut.ac.nz](mailto:brielle.gillovic@aut.ac.nz) or 021 178 8926.  
Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz), (+649) 921 9999 ext 6038.

**Whom do I contact for further information about this research?**  
Please keep this Information Sheet and a copy of the Consent Form (when provided by email) for your future reference. You are also able to contact me as follows:


**Researcher Contact Details:**  
Chris Atkinson  
[Chris.atkinson1003@gmail.com](mailto:Chris.atkinson1003@gmail.com)

**Project Supervisor Contact Details:**  
Dr Brielle Gillovic  
[brielle.gillovic@aut.ac.nz](mailto:brielle.gillovic@aut.ac.nz) or 021 178 8926

Approved by the Auckland University of Technology Ethics Committee on 29 February 2024, AUTEK Reference number 2408.

# Appendix D Consent Form

e: RC



TE WĀNANGA ARONUI  
O TĀMĀKĪ MĀKAU RAU

## Consent Form

*Project title:*                    *Unheard voices: The lived tourism experience of those individuals with Early onset Parkinsons Disease*

*Project Supervisor:*        *Dr Brielle Gillovic*

*Researcher:*                    *Chris Atkinson*

- I have read and understood the information provided about this research project in the Information Sheet dated 2 March 2024.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I agree to take part in this research.
- I wish to receive a summary of the research findings (please tick one): Yes  No

Participant's signature: .....

Participant's name: .....

Participant's Contact Details (if appropriate):  
.....  
.....  
.....  
.....

Date: .....

*Approved by the Auckland University of Technology Ethics Committee on 29 February 2024.2408 AUTEK Reference number 2408.*

*Note: The Participant should retain a copy of this form.*

## Appendix E Semi-Structured Interview Guide

### Interview Questions for MPhil Research

#### Unheard voices: The lived leisure tourism experiences of individuals with Early on-set Parkinson's Disease

#### Opening the interview

#### Introductory

1. Please would you tell me a little bit about yourself? Anything that comes to mind is fine.
2. Please would you tell me a little about your journey to being diagnosed with Early-onset Parkinson's Disease (EOP)?
3. What are your main EOP symptoms currently?
4. Would you share with me a little about how EOP/ Parkinsons affects your daily life now?

#### I'm now going to ask a few Specific Questions About your Experiences of Leisure Travel and Tourism

5. Please would you tell me how you would personally define leisure travel / tourism, and what it means to you?
6. Since your EOP diagnosis (and within the past 7 years), please would you describe for me one particular leisure trip or tourism experience(s) that comes to mind?
7. Please would you tell me what differences, if any, you noticed about this particular travel/tourism experience compared to tourism experiences you can remember from before your diagnosis?
8. How did this make you feel?
9. Since your diagnosis with EOP please would you talk to me about any particular meaning you give to, or associate with, leisure tourism experiences now?
10. Since being diagnosed with EOP, in what ways do your travel/tourism experiences impact on your self-perception? .
11. What motivates you to undertake travel or experience tourism activities now? Are your motivations different from prior to your diagnosis?

I'm now going to ask you a few questions relating to Dignity, Equity and the role of tourism providers in your experiences. By tourism providers, operators or the tourism industry I mean people who work for airlines, tourism experiences, hotel staff etc.

12. Please would you tell me if, and how, leisure travel/ tourism experiences contribute to your quality of life or self-development?
13. Are your EOP symptoms generally visible to others?
14. Please would you tell me a little about how you have experienced service from tourism / travel operators since being diagnosed with EOP?
15. Does it feel like you (and your family / travelling companions if you had them) received the same service level as those without EOP? If not, please would you describe how you perceived the difference?
16. In comparison with a non-EOP person, do you believe you have experienced a loss of travel /tourism opportunities?
17. In terms of the tourism industry, how prepared were they, or able to provide, appropriate services and support for people like us, with EOP?
18. In terms of other tourists you encountered, how did they perceive or respond to you while travelling? How did you feel?
19. Were there any instances where you felt excluded or unwelcome? If so, please would you tell me about them? How did you feel?
20. Since EOP diagnosis, while travelling, what were/are some of the emotions you felt or experienced?

We're now going to talk briefly about the advice you might like to give to tourism / travel operators

21. What advice would you give to NZ Tourism operators regarding continuing, or improving their services for individuals such as us, with EOP?

22. How could the travel/tourism industry facilitate more positive travel experiences, or better compensate for the negative ones?

**And just to wrap the interview up .....**

23. Looking into the future, what are your personal/family's travel/tourism aspirations?

24. What would you hope the future of leisure travel/tourism looks like for other people with EOP?

Is there anything I have not asked or understood that you feel I should know or that you would like to clarify?

Do you have any questions for me?