# **RESEARCH ARTICLE**

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# Rediscovering identity through leisure travel: Lived experiences of persons with disabilities

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**Introduction:** Travelogues for non-disabled travellers state that travelling offers an opportunity for constructing new identities. This meaning ascribed to travelling led the researcher to pose the question: What is the lived experience of travelling for people with disabilities? The objectives of this study were to describe and explore the experiences of travelling for people with disabilities, how they make sense of their experiences of travelling, and the meaning that travelling holds for them. The theoretical framework for the study is the Person-Environment-Occupation Model and the Model of Human Occupation.

**Method:** A qualitative, hermeneutical phenomenological research design was utilised. Through purposive sampling, six participants were selected and then interviewed using a semi-structured interview guide. Interpretative phenomenological analysis was applied to analyse data.

**Results:** Three themes emerged, namely: A *Double-edged sword*, which highlights the contradictory effects of travelling, followed by *People are part of the package*, which emphasises the participants' interpretations of the role that society plays in disability, and lastly the *Pilgrimage to self-discovery*, as travelling offers the means to rediscovery of self.

**Conclusion:** The study provides insight into how travelling, as a leisure occupation, facilitated discovery of a new identity for people with disabilities.

**Keywords:** hermeneutic phenomenology, leisure travelling, occupational identity, occupational performance, occupational being, Person-Environment-Occupation Model, Model of Human Occupation MOHO

#### INTRODUCTION

Joe Gebbia, the co-founder of the well-known company called AirBnB, alluded to the idea that travelling "is one of the most powerful forms of growth and learning that somebody can experience" Drawing on empirical research from travelogues (a journal where one logs travel journeys) of non-disabled travellers, it is reported that they attest to becoming "physically open and emotionally responsive to new experiences" and that they view their bodies not only as adaptable, but also as "flexible and contingent" It is exactly these characteristics that caused the researcher to

question if the experiences of non-disabled travellers would be the same for disabled travellers.

Occupational therapists consider humans to be occupational beings who are affected by what they do; occupation is therefore key to defining identity<sup>3</sup>. What one does relates to who one is. Occupation refers to any form of meaningful activity that people engage in to fill their time, therefore it is regarded as highly personal and unique to the individual<sup>4</sup>. One way in which occupational therapists classify occupation is by means of three categories, namely: productivity, self-care and leisure<sup>5</sup>. Leisure as an occupation provides

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opportunities for people to discover individual strengths and confers significance on everyday life. Therefore, it may be assumed that travelling provides an attractive option as a leisure occupation for people with disabilities. This calls for a more concerted analysis of the essence of travelling, specifically for people with disabilities.

People with disabilities have recently shown an increased interest in travelling, proving they have the same desire to travel and explore as non-disabled people<sup>7</sup>. According to a quantitative market study conducted on disability travel, Open Doors Organisation<sup>8</sup> reports that between 2018 to 2019, adults with disabilities took 81 million trips, an increase from 73 million trips in 2015. The European Commission states that people with disabilities in total took 17.6 million trips in 20129. Travelling in totality constitutes 10% (2015) to 10,4% (2019) of the world's Gross Domestic Product (GDP), which is about US \$9,25 trillion of the world's economy. Pre-COVID, 1,46 billion travel trips were recorded in 2019, with 81 million of these trips taken by people with disabilities9. People with disabilities represent 5,5% of international travelling, therefore it is evident that they are underrepresented in this industry<sup>10</sup>. This is partially due to barriers of inaccessibility and societal perception regarding disability. As society grows in disability awareness and people with disabilities proceed to assert positive identities, they are proving to be a growing, profitable target market for the tourism industry<sup>11</sup>. This emphasises the necessity of investigating the effect of travelling for people with disabilities, who currently comprise 15% of the global population<sup>12</sup>.

Although there is a growing interest in travelling for people with disabilities, a more complicated and contingent account emerges when we consider the limited accessible accommodation, stringent flying terms and conditions, and inadequate accessibility at public attraction sites - indicative of occupational injustice. For people with disabilities, going out into public spaces often entails overcoming these barriers. This challenge may lessen their occupational and community participation<sup>13</sup> and result in internalised oppression causing them to withdraw from society and leisure occupations such as travel. Given that travelling is such a powerful form of growth and learning for non-disabled people<sup>1</sup>, the question is whether travelling can improve people with disabilities' community participation and how this might influence their occupational identity. Therefore, this study addressed the following research question: what is the common or shared lived experience of leisure travelling for people with disabilities?

#### LITERATURE REVIEW

The following databases were reviewed: Science Direct, Credo, ERIC, SAGE Journals Online, Pubmed and EbscoHost. The review of literature revealed very little previous research by occupational therapists in the field of travelling as a leisure occupation amongst people with disabilities; therefore, there was a need to review literature from other fields such as Tourism, Sociology and Psychology.

How one defines disability is crucial when formulating ideologies and philosophies about life, particularly on as-

pects of impairment and disablism - a term used to characterise discrimination against people with disabilities<sup>14</sup>. Occupational therapists explicitly distinguish between impairment and disability. Disability is a state that occurs because of society restricting people with impairment from engaging in mainstream activities due to inaccessibility as well as discrimination and social exclusion. Recognising this. South Africa ratified the United Nations Convention on the Rights of People with Disabilities (UNCRPD) in 2009 to overcome these challenges and improve equality for all<sup>15</sup>. The Social Model and the Social-relational Model explain this perspective of disability well, as identity and ideology are interlinked with socialisation<sup>14</sup>. These two models affirm the societal and the personal impact of disability. The Social Model defines disability as "the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities"16:14. With society as the main cause of disability, the Social Model advocates that liberation involves networking with other people with disabilities, creating positive selfhood and developing an inclusive disability community whilst focusing on a just economic policy<sup>16</sup>. Consequently, the Social Model falls short of replacing negative thinking with healthy productive thought patterns. In this manner, the Social Model resists transformation, as little association is made between impairment and age, traditions, culture, and language, and fails to theorise the experiences of people with disabilities'17. The Social-Relational Model extends the Social Model as it argues that one should accept that society is generally inaccessible, and that living with an impairment is, in itself, the personal challenge of the individual. The Social-Relational Model insists on the importance of people with disabilities owning their inner struggles to heal<sup>14</sup>.

Grounded in the Occupational Performance Model<sup>18</sup>. occupational therapists understand the impact that disability has on a person's identity. Viewed through the lens of the Person-Environment-Occupation (PEO) Model<sup>18</sup>, a disability causes an interruption in one's everyday life activities; this induces an imbalance between the person, how he/she views him/herself; environment - accessibility of the space and societal response and occupation - what the individual does, the method in which it is performed, and the meaning attributed to it. When an individual's life is altered following an injury, occupation will be redefined. altered, adapted and rearranged19. The PEO Model describes the interaction between person, occupation, and environment as an "enabling-disabling" process that assists one to adapt to change<sup>18</sup>. Ideally one wants to achieve a harmonious transactional relationship between the person, the environment and occupation<sup>18</sup>. The harmonious interaction between these three components endorses a balanced lifestyle and optimal occupational performance. One way this can be achieved is through altering one's environment as it can greatly influence one's occupational performance<sup>18</sup>.

Emphasising the person-specific approach within occu-

pational therapy, the Model of Human Occupation (MOHO) is useful when considering the environment, roles and routines, performance skill and personal interests from individuals' perspectives4. The MOHO asserts that readjusting to the environment as well as reviving normal occupational development<sup>20</sup> will assist one to reconstruct one's identity. This is supported by the view that occupations give meaning to one's life<sup>21</sup> and are fundamental to the construction and reconstruction of identity<sup>22</sup>. Furthermore, the MOHO guides insight into the influences of the environment. In this study, travelling occurs in a particular environment or setting, which could either offer or restrict opportunities for occupational performance. In this study we therefore assert that travelling, as a leisure occupation, can be used to reconstruct identity. As Taylor<sup>19</sup> states, "people create who they are through occupations which connect them to their world and culture" 19:23. Kielhofner 23:124 elaborates on how individuals are "occupational beings" who create meaning and construct identity through engaging in occupation. Adapting to life-altering circumstances is fundamental to an individual's well-being and engaging in meaningful occupations, such as leisure, can assist with transitioning through these life changes<sup>19</sup>.

Occupational science offers a useful lens to explore the concept of leisure travelling as an occupation, to provide scientific evidence to clinically apply occupation in practice<sup>24</sup>. Analysing and adapting activities to purposely apply these within the environment to optimise occupational performance and reconstruct identity, is firmly and exclusively the scope of occupational therapists. Travelling as a leisure occupation is a multifaceted phenomenon. In order to comprehend the therapeutic value of occupation one must consider occupation within its ethnographic context, considering its spatiotemporal dimensions as well as its significance to the client<sup>19</sup>. For an activity such as travelling to be classified as a leisure activity, it should allow the individual to have freedom of choice. To be able to choose one's leisure activities freely greatly contributes to a sense of control and identity<sup>25</sup>. Moreover, some leisure activities are more beneficial than others, so it is imperative to match personal interests with preference<sup>26</sup> which promotes autonomy. James Wise states that "if there is no chance for selection there is no freedom"27:21. Travelling, like leisure, must be intrinsically satisfying. Iwasaki<sup>28</sup> and Pagán<sup>29</sup> state that taking a vacation is important for people with disabilities to become self-reliant, independent, and confident. Solitary leisure provides an opportunity for self-reflection. which in turn contributes to identity development and aids in transcending negative life events<sup>25</sup>.

Learning as a result of travelling is personal and strongly tied to individual interests and motivations. The nature of learning from a tourist experience only emerges over space and time as an interpretation that these experiences transpire<sup>30</sup>. The tourism industry emphasises that it is their responsibility to "engage travellers in transformative learning experiences" <sup>30:920</sup>. However, in line with the client-centred approach of occupational therapy, the researcher wants to broaden this viewpoint and extend the responsibility to that of occupational therapists as well. Occupational

therapists are proficient in aptly aligning occupation to optimise growth and influence, not just for occupational performance, but for the occupational identity of the individual. Occupational therapists can engage clients in transformative learning experiences, such as travelling, as they are more credible and proficient in adapting occupation and the environment.

Apart from the health system viewing disability predominantly from a medical model perspective, the Social-Relational Model highlights the importance of facilitating agency in people with disabilities, promoting a positive selfhood and contesting society's stereotypes. Considering the science of occupation, leisure travel can be seen as a leisure occupation; a multifaceted phenomenon applied as a pleasurable distraction from sometimes negative life events that can facilitate reconstruction of occupational identity. Therefore, the 21st century leisure traveller seeks new learning experiences that are unequivocally linked to travelling and adventure and should also be available to people with disabilities. However, the review of literature revealed very little previous research by occupational therapists which explored the experiences of leisure travelling for people with disabilities.

#### **METHODOLOGY**

#### Aim and objectives

The aim of the study was to explore the lived experiences of leisure travelling for people with disabilities. The objectives of this study were to describe and explore the experiences of travelling for people with disabilities, how they make sense of their experiences of travelling, and the meaning that travel holds for them.

#### Research approach and study design

In line with the philosophical worldview of social constructivism, individuals seek understanding of the world they live in<sup>31</sup> and subjective meanings are developed from the occupations in which they choose to engage. Therefore, a qualitative research approach with an interpretivist orientation was chosen for the study as this approach revolves around how people experience and make sense of their realities<sup>32</sup>. Creswell stated that the "reality of an object is inextricably related to one's consciousness of it"31:77. This enabled the researcher to gain an understanding of people with disabilities' travelling experience. As the participants reflected on travelling and conversed about the deeper meanings they attribute to it, their reality of the experience transpires. However, one can merely attempt to interpret the participants' lived experience as the true phenomenon can only be experienced by the participants themselves<sup>33</sup>.

The hermeneutical phenomenological design, innate to a qualitative research approach, allows for the researcher to become infused with the participants' discourses, in this case - their lived experience of travelling, while concurrently constructing their interpretations that engender a deeper understanding of the occupation of travelling particularly as someone with a disability. As people are unique

#### Table I: Semi-structured interview guide

#### 1. Tell me about yourself

Prompt: How would you describe yourself? What do you enjoy doing? How do you occupy your time?

#### 2. What is your motivation for travelling?

Prompt: Why do you travel? What does being able to travel mean to you?

#### 3. What is your focus for travelling?

Prompt: What did you want to experience out of travelling?

#### 4. How do you capture memories of your trip?

Prompt: Do you journal / Talk about it / Take photos? What are your thoughts and feelings about this?

#### 5. Tell me about a travelling trip you undertook lately?

Prompt: Pointing to a photo they brought, to the interview, from one of their travels. What stood out for you in this photo?

individuals and experience the world in unique ways, they create their own realities, consequently resulting in multiple realities<sup>34.</sup> In his view of phenomenology Heidegger<sup>35</sup> concluded that the essence of something, in this instance travelling, can only be discovered when it is consciously encountered and reflected upon by the individual<sup>35</sup>.

### Participant selection and recruitment

The study population was people with disabilities from South Africa who travelled for leisure Participant recruitment took place by contacting online travel organisations who specialise in travelling for people with disabilities, to request eligible referrals. Six participants were purposively selected according to the following inclusion criteria: 18 years or older, have a physical disability, have travelled to a new environment for a minimum of one night, and explored new activities while on holiday. People with mental and/or cognitive impairments were excluded from the study as this may have affected the recall of their travel experiences.

#### **Data collection**

With the focus being on extracting rich data from each participant during individual in-depth, interviews<sup>32</sup>, a semi structured interview guide was used to guide participants to reflect on, and articulate, their past experiences of travelling (see Table I, above). During interviews, reflective notes were made and active listening techniques such as paraphrasing, clarifying, reflecting, and summarising were utilised. Interviews were audio taped, and later transcribed. Interviews lasted approximately three hours.

# Data analysis

The principles of interpretive phenomenological analysis (IPA)<sup>32</sup> were applied during data analysis in an attempt to stand in the shoes of the participants and conversely to give a "third-person view of a first-person account" <sup>36:110</sup>. IPA is concerned with the ontological questioning of existence in itself<sup>32</sup> and in this study, the person who travels was regarded as the principal subject rather than travelling<sup>36</sup>. IPA comprises a dual interpretation process of, firstly, the participants' interpretation of the meaning they attribute to travelling, followed by the researcher's understanding of

# 6. Can you share some of the activities you enjoy performing when you travel?

Prompt: What do you value most about travelling? Why do you regard this as important?

# 7. How would you describe travelling to someone who has not experienced travelling before?

# 8. What do you think are the effects of travelling for you as a person with a disability?

Prompt: Would you say it is necessary to travel and why? How have you changed after you began to travel as a person with a disability?

# 9. What do you think is the purpose of travelling for people with disabilities?

Prompt: Would you travel again, why? Can you share some examples of this?

the participants' connotation of travelling<sup>32</sup>. The researcher made use of Pietkiewicz and Smith's 32:12 stages of IPA namely: 1) multiple reading and making notes, 2) identifying emerging themes, and 3) seeking relationships and clustering themes<sup>32:12</sup>. During stage 1, the researcher immersed herself in the data through transcribing, reading and listening to the audio-taped interviews a number of times, while noting anything of interest in the data, and specific thoughts and reflections by the participants about certain issues to gain a complete sense of each interview. During this time, distinctive phrases and insights were noted in the left-hand margin<sup>37</sup>. In stage 2, the focus shifted to identifying emerging themes from the researcher's notes<sup>32</sup>. This stage is repeated until the researcher is able to make a theoretical link with detailed and dynamic themes<sup>37</sup>. In stage 3, the connections between the themes were identified, clustered together, and labelled with descriptive titles to form the final themes<sup>32:12</sup>. Finally, a comprehensive description of the shared experience of travelling for people with disabilities was compiled.

#### **Trustworthiness**

To ensure trustworthiness, dependability was ensured by having an audit trail with transcriptions, audiotapes, field notes and journaling. Credibility was maintained through member checking where the participants confirmed the transcribed data and the analysis telephonically. Additional peer examinations were conducted with academic supervisors. Transferability was upheld through providing detailed descriptions of the participants and methodology to outline practical application in other contexts and confirmability was achieved by including rich quotes directly derived from the data collected<sup>38</sup>.

# **Ethical considerations**

Prior to commencing the study, ethics clearance was obtained from the Humanities and Social Sciences Research Ethics Committee at the University of the Western Cape – (HS/16/6/17). Participants were fully informed about all aspects of the research, took part in the study voluntarily and provided written consent. To ensure anonymity, pseudonyms were assigned and by means of an identification key, the researcher was able to link the participants' interviews

#### Table II - Participants' demographic information

| Participant | Gender | Race  | Age  | Type of Disability | Acquired or<br>Congenital<br>disability | Years living with a<br>disability | Current<br>Work |
|-------------|--------|-------|------|--------------------|---|-----------------------------------|-----------------|
| Guusje      | Female | White | 65yr | Polio              | Congenital                              | 64 years                          | Pensioner       |

Guusie's leisure travel pattern:

Guusje has always been an avid traveller and has therefore enjoyed many trips nationally as well as abroad. Countries she has visited include The Nederland, Italy, France, Great Britain and Norway. Following her second diagnosis as post-polio, she needed more motivation to travel as it remains a battle to find wheelchair accessible accommodation therefore extensive planning and often frustration entails such endeavours. More recently Guusje and her husband have travelled to George, Cape Town and Johannesburg for more or less 5-8 days with their preferred mode of transport being their car.

| Letz | Male | Black | 23yr | Above Knee<br>Amputation<br>Motorbike accident | Acquired in 2011 | Eleven years | Paralympian<br>Entrepreneur |
|------|------|-------|------|--|------------------|--------------|-----------------------------|
|------|------|-------|------|--|------------------|--------------|-----------------------------|

Letz's leisure travel pattern:

Initially Letz used to view travelling as an activity only for the affluent. However, following his growing career in sports and his own business in producing various leather products, he is required to travel more regularly especially to European and African countries. Competing in events abroad presents as an opportunity for leisure travel and further exploration as well. When his schedule allows him to break away he visits places around Cape Town such as Robertson but more recently he took vacation to go to Namibia where he hiked the Fish River Canyon.

|   | Di      |      | 3445.21 | 27   | Spinal Cord Injury |                  | <del>-</del> | B           |
|---|---------|------|---------|------|--------------------|------------------|--------------|-------------|
| 1 | Phoenix | Male | White   | 21yr | C6-C7              | Acquired in 2012 | Ten years    | Paralympian |
|   |         |      |         |      | Gymnastic accident |                  |              |             |

Phoenix's leisure travel pattern:

Being only 16yrs old when he acquired his impairment, Phoenix did not have an extensive travel pattern prior to his injury. He has visited many provinces in South Africa and European countries with specific mention of Prague, Czech Republic. He prefers to travel with someone who understands his needs so his father or Biokineticist often accompanies him on his journeys.

| Grey | Male | White | 26yr | Spinal Cord Injury - 2014 T6 Car accident | Acquired | Eight years | Paralympia<br>Student |
|------|------|-------|------|---|----------|-------------|-----------------------|
|      |      |       |      | Car accident                              |          |             | Stude                 |

Grey's leisure travel pattern:

Travelling for sport, business and leisure alike, Grey has visited Australia, Europe and most of South Africa's provinces. For Grey to pack-up and visit friends or family in another province alone is no challenge. He is well adapted and equipped to travel independently whether it is by car, train or a plane.

| Flight | Female | White | 23yr | Cerebral Palsy | Congenital | 23 years | Student |
|--------|--------|-------|------|----------------|------------|----------|---------|
|        |        |       |      |                |            |          |         |

Flight's leisure travel pattern

Flight is used to travelling, via motor transport, to rustic and remote places in Africa, often reaching out to the locals. Always travelling with her family who understands her specific requirements, they would enjoy the local activities. Without a doubt she will not stand back for any available activity, as she will want to explore everything.

| Dali | Male | White | 26yr | Spinal Cord Injury<br>- 2008<br>Level T8 Car<br>accident | Acquired in 2008 | Fourteen years | Professional<br>Surfer<br>Entrepreneur |
|------|------|-------|------|--|------------------|----------------|--|
|------|------|-------|------|--|------------------|----------------|--|

Dali's leisure travel pattern:

Dali's favourite trip aboard was when he visited the USA - California. As surfing is one of his greatest passions, he recently made a road trip all along South Africa to raise awareness of adaptive surfing and to enjoy the Atlantic Ocean all around to the Indian ocean. Being fully equipped to travel independently in his own vehicle, he will regularly go away for the weekend to nearby coastal towns in the Western Cape.

with their profiles. To ensure confidentiality, transcripts were saved on password-protected files and the audio recording of interviews are stored in a password-protected folder on the researcher's external hard drive.

#### **RESULTS**

The participants' interpretation of the meaning of travelling is interlinked with their personal journeys and life experiences; hence, getting insight into their worlds is imperative to gain a deeper understanding of their interpretation of the meaning of travelling. Therefore, a summary of each of the six participants' stories is presented together with their demographic information (Table II, above. This is followed by the three themes that emerged from the data analysis.

During data analysis, three themes emerged which represent the unique lived experiences of travelling for the participants. Each theme, together with its related subthemes and categories, illustrates the phenomenon of travelling for people with disabilities. The first theme - Double edged sword - highlights the contradictory effects travelling can have. Theme 2 - People are part of the package - emphasises the immense role society plays in the travelling experiences of people with disabilities The last and most prominent theme - Pilgrimage to self-discovery-highlights how each participant had their own motives for travelling, but collectively they mentioned how travelling enabled them to experience self-discovery.

#### Theme 1: Double-edged sword

The first theme - Double-edged sword - highlights the contradictory effects that travelling can have (Figure 1, above). It deals with the participants' mixed feelings and ambivalence about travelling. The participants encouraged

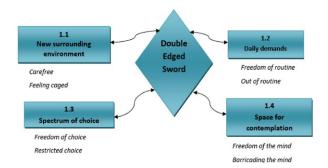


Figure 1: Theme One - Double-edged sword

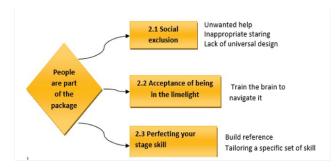


Figure 2: Theme Two - People are part of the package.

people with disabilities to travel but at the same time they pointed out the risks involved. It soon became evident that, akin to the two sides of a doubled edged sword, travelling can cut both ways.

#### **New surrounding environment**

The most prominent element of travelling is that it positions one in a new surrounding environment. The new environment has an unfamiliar layout with new surroundings bringing different challenges and opportunities. The participants' experiences of travelling endorsed feelings of freedom and being carefree especially since they were not surrounded by their familiar stressors.

Travelling can be an exhilarating experience that grants the participants much delight and excitement, but it can also lead to despair and feelings of inadequacy. Participants had to face new environments of inaccessibility which restrict their choice and cause other stressors. One of the participants said:

"Travelling has two extremes. It can make you feel free, like free from things that bind you and boundaries, or on the other side it can constrict you more and make you feel out of place in circumstances where it is not accessible" (Flight).

Guusje also stressed the importance of therapists recognising that travelling can build or break one's perception of 'self':

"As therapist you must realise that it (travelling) can go both sides. So if you don't want that they have the feeling that actually they are special persons (person with disabilities) ... don't let them go on holiday on their own. And make sure that they go to a place where they can be a normal being" (Guusje).

#### **Daily demands**

Another component of the double-edged sword raised was that travelling provides opportunity to escape one's routine. When travelling to a new environment the familiar space changes to an unfamiliar space and so do one's daily routines.

"...to travel is to break the routine of what you normally do at home or from where you are from. Because for a moment you can forget about everything and just lock the house, to leave everything and just go travel, it can be refreshing" (Flight).

#### **Spectrum of Choice**

Here participants reiterated the importance of having freedom to choose to travel where they wanted to and not just where it is accessible enough to travel to. The freedom of choice is part of the liberating experience obtained when travelling. In the words of one of the participants, she highlights the importance of freedom of choice:

"I need to go where I want to go. Not where you are telling me to go" (Guusje). It is just that you want freedom of choice to go and see what you want to see and not on terms and conditions ... Not because you are telling me to go, no, because my own mind is telling me to go.

### Space for contemplation

Through travelling the participants were faced with time and a new space to contemplate deeper matters which either liberated their minds or barricaded them more. Having sufficient space and time to think, allowing the mind to explore fundamentally frees the mind. One of the participants had to make an important decision regarding a difficult operation. She decided to go on holiday before deciding her way forward.

"I can put my mind straight. Here (at home) I have to think what are we going to eat and I have to look after the dog. He (husband) is doing it but in my mind I'm doing it. And I have to clean my house I have to go to my neighbours I've got all these things to do. If I'm on holiday I can be relaxed I can read a book and in the meantime I'm thinking" (Guusje).

Travelling is without a doubt a double-edged sword; it entails some sacrifices to be made and risks to be taken but there is also the possibility of experiencing freedom.

# Theme 2: People are part of the package

Theme 2 - People are part of the package - emphasises the participants' interpretations of the immense role that society plays in disability (Figure 2, above). Furthermore, being human inevitably links us to society. This concept was raised when participants depicted some challenges in travelling as a person with a disability. Throughout their journeys the participants discovered that people can make them feel more accepted and included, but people can also ostracise one another. Participant Dali feels that it is society and people that uphold disability:

"As I say, disability is not a disability; it is the people around you that are the disability. And you must learn how to handle those people. At the end of the day rehabilitation isn't a personal thing; it is a freaking general thing. You must learn how to handle people. So firstly, accept yourself and then learn how to manage yourself and then be able to maintain it consistently, maintenance around other people" (Dali).

#### Social exclusion

Despite those with disabilities having to accept their own impairments and fighting daily battles regarding inaccessibility, it is people that often cause them to feel more disabled. Dali became conscious of the fact that people with their inappropriate responses can make him feel more disabled. Since people are a part of life and a part of society it is difficult to avoid them wholly. For this reason, they had to learn to deal with people, they had to learn to manage their own responses and maintain a constant mentality pertaining to social discrimination. Travelling poses as a method through which one can develop such skilfulness to effectively manage inappropriate responses from people. Through travelling and being exposed to a variety of people and their responses, it helps people who have disabilities to build not only a reference of inappropriate actions by non-disabled people, but also in assisting to develop a repertoire of responses. Dali continues to use travelling as an opportunity to improve his skill in dealing with social discrimination and exclusion:

"I can perfect my stage skill with strangers. Like the things I say I'll observe how they respond ... okay maybe I should state it differently next time and watch how they respond then. To the next person I will say the same thing just in a different way. Okay I think this way works better. So, when you travel you can do more of this type of thing" (Dali).

#### Acceptance of being in the limelight

After the participants shared their travel encounters from various parts of the world, it became apparent that the bulk of society acts in ways that are not conducive to social inclusion. Some examples mentioned by the participants include that people have fallen on their lap and started praying and telling them they just have to believe enough and then they will be healed; people staring at them inappropriately; and regularly being bombarded with acts of assistance, which mainly rendered the participants feeling helpless and inadequate. Accepting that being a person with a disability consequentially places one in the limelight, is pivotal in dealing with the inappropriate responses from society. When the researcher asked Letz about his response when he experienced that people inappropriately stared at him whilst on holiday, he replied:

"I used to take it (as an) offense but now I've taken it as a blessing, maybe I'm a celebrity so you can look now. But I used to be very shy... Now, I don't feel anything - maybe my leg is so awesome that they want to look at it. I don't mind whatever ... As long as I'm walking ...

Researcher: "But you had to travel, you had to go through quite a journey to get to that point?"

Letz: "Ja it was difficult at first. Ja, it was difficult. I just felt, initially I use to feel like I'm being looked at as less of a man, less of a human being. Coz everybody is looking at you. I mean you wouldn't look at just a normal person walking by. When they look like that like it's a weird thing you know" (Letz).

Letz highlights that even though travelling laid emphasis on his appearance, it was also through this journey that he could train his mind to not let societies' offenses break him down.

### Perfecting your stage skill

This subtheme marks the words of Dali when he mentioned that through travelling, he can:

"...perfect his stage skills with strangers" (Dali).

As mentioned previously, able bodied people tend to have inappropriate actions to people with disabilities. The participants felt that it is the responsibility of people with disabilities to acquire self-assertiveness in dealing with these inappropriate responses from society. Travelling poses as a method through which one can develop such skilfulness to effectively manage inappropriate responses from people. Through travelling and getting exposed to a variety of people and their responses, it helps people who have disabilities to build not only a reference of inappropriate actions by non-disabled people but also assist in developing a repertoire of comebacks.

"You see, what happens is at the beginning you try to convince people that you are actually okay. But then, eventually you reach a point where you realise that you don't have to convince people anymore, but that you have so many different stories you can use instead. So you already have a solution to every scenario, for every response from people. That is a skill and you can only get trained in it when you travel. You are not going to become skilled in it around your friends and family as they handle you in the same way. They are biased towards you" (Dali).

## Theme Three - Pilgrimage to self-discovery

Theme 3 - Pilgrimage to self-discovery - entails the physical journey of exploring new activities and the steps to discovering a new self (Figure 3, page 63). The participants elaborated that travelling prompts them to take chances and to step out of their places of safety, where they had to learn how to deal with incidents, and it is travelling that endorses exploration of new activities and growth. Travelling exposed the participants to a higher occurrence of incidents in unfamiliar spaces and inaccessibility which could be very discouraging. They could either confront or steer away from these challenges, which unfortunately cannot be avoided.

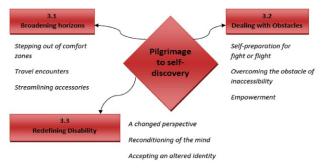


Figure 3: Theme Three - Pilgrimage to self-discovery.

However, if they do decide to adapt to the inaccessibility, they feel that they have mastered the task at hand and are left with a sense of empowerment. Travelling essentially allowed them to learn and grow from overcoming obstacles which in turn lead to accepting an altered identity. In the words of one of the participants:

"Is leisure travel leisure travel? Or is it a pilgrimage where you discover yourself because that is pretty much what you are going to do every time you travel. It is a pilgrimage, it's a journey of discovery" (Dali).

#### **Broadening Horizons**

Many participants said that travelling required them to enlarge their place of safety and explore through broadening their horizons. Travelling exposed the participants to something outside of their familiar environment. It prompted them to expand and stretch beyond their realms of safety and once they have stepped out of the familiar environment, away from the familiar responses and the familiar faces, they started seeing new things; discovered new things about who they are. However, despite one's comfort zone being accessible and safe all the participants encouraged travelling to broaden their horizons. Letz said:

"Aaaah travelling, you are expanding your boundaries first of all. I'll motivate them to do that because at the end of the day if you start travelling you overcome fear of the unknown" (Letz).

#### **Dealing with Obstacles**

Travelling does not come without challenges. Despite the anxiety and stress paired with stepping outside of their comfort zones, the participants exposed themselves to new activities and new places that are mostly inaccessible. The participants had to face obstacles from physical challenges like having to navigate their wheelchairs on uneven terrains and pivot onto curbs as well as emotional challenges like having to stay calm when an incident happens. The participants consider dealing with these types of obstacles as helping them to grow and increase their level of independence. For example, Dali stated that he sees travelling as the perfect opportunity to practically apply what he was taught during rehabilitation in a clinical environment:

"...apply what I was taught in Rehab...which was how to do

ADLs to make life easier ... it can be seen as post rehab, because now you have to practically apply it" (Dali).

#### **Redefining disability**

Through travelling they confronted their perspective of disability and how they viewed themselves, thus redefining disability for themselves. They had to be innovative and adapt on the spot, but when they succeeded it created a feeling of mastery. This was the case with Phoenix as travelling showed him alternative perspectives to his disability; it showed him the unique side of his disability:

"...you learn a lot about yourself and the how you adapt and how society has adapted to you. You find the unique side of your disability. So psychologically, you know with assistance, it can be very empowering personally" (Phoenix).

The identified themes can be traced (and highlighted) in the words of one of the participants as stated below:

"...one should travel for leisure, because if you don't put yourself outside of your everyday normal activities (stepping out of your comfort zone - Theme 3), you are not going to test your abilities and see what your actual skill is (streamlining and dealing with obstacles - Theme 3) doing new things, new adaptations. You are familiar with the people around you and close to you (people are part of the package - Theme 2), so you are in a comfort zone in your everyday living. Therefore, the more you travel and do not have to concentrate on your responsibilities (freedom of the mind, routine and stressors - Theme 1), but can just relax and look at what is around you (experiencing new encounters which cannot be found in a book - Theme 3); the quicker and easier you'll adapt to your new situation and sudden disability (accepting an altered identity - Theme 3)" (Dali).

All the participants suggest and recommend that people with disabilities should travel. Travelling forces one to find alternative means to overcoming inaccessibility, and the participants agree that the more one travels the quicker and easier one will redefine an altered identity.

#### **DISCUSSION**

The aim of this study was to gain an in-depth understanding of the lived experience of travel for people with disabilities. The researcher drew on the components of both the Person-Environment-Occupation Model<sup>18</sup> and the dynamic human open system of the Model of Human Occupation<sup>40</sup> in order to discover the essence of travelling for the participants. In line with the phenomenological approach, the researcher found it necessary to merge these two models and develop the Integrated Model (see Figure 4, page 64) to suit the hermeneutical perspective and interpret the environment not only in actuality but from the participants' perspective.

Principally, the Integrated Model demonstrated that individuals are viewed as open systems which interact with

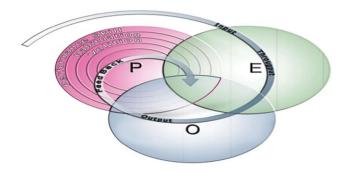


Figure 4: The Integrated Model.

their environment by means of input, throughput, output and feedback<sup>23, 40</sup>. This dynamic interaction, described in the MOHO, can gradually bring the three spheres of Person, Environment and Occupation closer together for an improved occupational fit, or conversely, diverge it. This shows that an individual can experience "change by the environment and can cause change in the environment" <sup>20:244</sup>.

At the hand of the Integrated Model, it can be seen how the participants' human open systems changed and improved their occupational performance as they embarked on their travel journey. Firstly, they were exposed to an unfamiliar environment, whereby they received new information - equating to a changed input. By exploring the new environment, they received new responses from friends and the community. Receiving an encouraging response rather than a voice of warning from family and therapists, encouraged them to explore their own boundaries, resulting in experiencing new activities. This prompted the participants to revaluate their own perspective - equating an altered throughput - by redefining their interests, values, roles and habits in a new light<sup>40</sup>. Partaking in a new action ensued a different action - equating an altered output. Often the participants' travel stories entailed managing challenging obstacles such as a kayak capsizing, being left in an inaccessible space or other situations that they had hoped to avoid. However, in facing these challenges and mastering them, they were able to establish an altered feedback. Stepping out of their comfort zones and exploring and mastering new travel-related activities brought about new confidence which led them to reorganise their human open system <sup>20:245</sup>. Thus, the "system is constantly changing, unfolding and reorganising itself through engagement"42:1. Perceiving their abilities in a different light assisted them to accept their disability and alter their occupational identity.

Consequently, travelling initiated a change in the human open system by providing a new environment and new sensory information. This new environment, due to travelling, is seen as the prompt which led the participants to readjust their human open system, resulting in convergence of the three circles of the Person-Environment-Occupation Model<sup>18</sup>. The relationship between who they are – person, how they do things – occupation, and the environment elicited a better occupational fit. Through the process of optimising their occupational performance and readjusting their human open system, the participants were able to

rewrite the essential qualities of their occupational identity.

# The purpose of travelling for people with disabilities

Despite having unique reasons for travelling, it emerged that the participants could self-direct their destination of choice and choose what meaningful travel activity they wanted to experience. This is analogous with leisure as travelling as well as a "self-directed activity, which holds meaning and is intrinsically motivating to the individual" <sup>38:109</sup>. Travelling is a medium in which activities can be shaped to match the individuals' character and requirements. This highlights travelling as a person-orientated activity that is chosen and directed by the individual.

All the participants considered travelling as a form of rehabilitation, or in other words, as real-time therapy. Being in control of which destination they wished to visit allowed them to exert freedom of choice - something they felt robbed of when they received post-acute rehabilitation. The shared experience by the participants is confirmed by Shi et al.'s study wherein she stated that "being able to travel after an injury is a method of rehabilitation" 11:37, highlighting how travelling, for people with disabilities, promotes autonomy and endorses taking control of one's own destiny.

## People with disabilities' experiences of travelling

The participants shared a collection of travel experiences relating to activities such as abseiling, safaris, hiking, kayaking and other diverse activities. During their travels they engaged in experiential learning instead of being forced to follow a clinical routine led by a therapist. As the participants shared the events and happenings, their stories were entangled with tales of inaccessibility. The obstacles pertaining to inaccessibility made it less likely that travelling revolved primarily around fun. The participants mentioned in theme three: 'Pilgrimage to self-discovery' that they had to be prepared to deal with obstacles such as inaccessibility when they travelled. Their stories highlighted how people with disabilities are marginalised by disablism. The emotional impact of disablism on the participants surfaced when activities they encountered during their travels put an emphasis on exclusion and discrimination. While these aspects might seem invisible to the fellow non-disabled traveller, disablism is generally interwoven into society's assumptions towards people with disabilities<sup>39</sup>.

Participants had to learn not to be limited by society's discrimination and injustice, as people are inevitably part of the package when undertaking travelling. It was through travelling that they learned to appreciate being different in a 'walking' society. Travelling empowered them to not only build a repertoire in dealing with these offences but also provided them with the opportunity to perfect their skills in navigating society's conventional thoughts of what it is to be considered 'normal'. This growth in self-assertiveness built their confidence in navigating being different and managing disablism.

# People with disabilities' understanding and sense-making of travelling

The experience of travelling in its totality is more than mo-

mentary excitement or just a singular sensuous experience. Travelling signifies something larger than the event itself and embeds growth for the individual. The participants perceived their travel experiences as a medium for breaking barriers, broadening perspectives, and gaining a greater sense of mastery. They could break the mould of disablism that society had assigned to them; they gained a new perspective on how to streamline their daily activities; and through mastering some travelling activities their perception of their own abilities changed. Travelling therefore created opportunities whereby the participants could mould and evolve their perspective of their realities. Their perspectives regarding their own disability as well as their concept of 'self' were amended through a process of cognitive reflection, describing travelling as a journey or rather a pilgrimage to self-discovery, which assisted them to restore their occupational performance.

As they travelled, they experienced new occupations which shifted the balance between person, environment, and occupation. Gaining new information from different communities and occupations amended their perspective of self and their disability. The process of stepping out of their comfort zone through to mastering a new activity broadened their horizons and compelled them to do introspection, resulting in a different perspective on disability and disablism. After travelling, the participants could not go back to their old dimensions of doing everyday activities as they had expanded their perspective about accessibility, explored a greater variety of occupations and experienced different and enabling perspectives of disability. The pilgrimage, as elaborated in Theme Three: 'The pilgrimage to self-discovery', led them to amend their own concept of disability through reconstructing their identity. Therefore, it became evident that as the participants made sense of their travel experiences, it facilitated them in re-discovering their new self. Initially they undertook travelling for leisure but, in essence, they embarked on a pilgrimage of introspection, readjusting internal perceptions and growth in their occupational identity.

# The meaning that travelling has for people with disabilities

The findings showed that for decades travelling has been associated with expeditions, societal development, and learning, and the findings confirmed that to travel, is to embark on a pilgrimage<sup>41</sup>. It can be argued that embarking on this pilgrimage serves as a catalyst for growing and a form of learning that the participants could choose themselves. They could discover who they were and who they wanted to be. In essence through adjusting their human open system on their travel journeys, the participants narrated their life stories and reconstructed their occupational identity.

### Limitations

The main limitation was that four out of the six participants were professional athletes of which three were Paralympians and one a professional surfer. This selection was unintentional and purely coincidental, although it could be indicative of a higher level of determination and ability to

travel among professional athletes in comparison to other people with disabilities.

#### Implications for practice

It was evident from this study that it is of great value for occupational therapists to recommend and encourage their clients with disabilities to engage in travelling as a leisure occupation. Therefore, the following implications for practice are to be considered:

- Occupational therapists should recommend client appropriate leisure activities. It is of great importance that occupational therapists firstly, do not neglect leisure as a valuable part of therapy when focusing on identity restoration as it facilitates personal transformation; and secondly, leisure travelling has proven to be a self-directed activity that aids in buffering the impact of disability and assists in reconstructing occupational identity.
- Travelling is a form of free-choice learning and a means of learning from experience. It provides new information to all senses involved and requires active participation in occupations that hold meaning for the participant. Recommending this type of experiential learning as a therapeutic intervention will promote autonomy and independence.
- As part of community integration occupational therapists can include planning a leisure travel trip with eligible clients who have recently been disabled.
- Occupational therapists should provide support to online sites such as Trip Advisor, Travelstart, Lonely Planet, AirBnB etc. to promote greater accessibility for travelling for people with disabilities.
- Accessibility and disability are still broad terms within South Africa. This requires more definitive legislation pertaining to inclusivity and accessible tourism for people with disabilities. A task team should be appointed in order to draft a protocol to ensure that accessible tourism becomes a mainstream activity in South Africa.
- Further research is needed to analyse how travelling influences neuroplasticity in people with disabilities. In addition, as hermeneutical phenomenology only allowed the researcher to interpret the participants' interpretations of their experience linguistically, travelling with the person with a disability whilst documenting his/her experiences through participant observation would allow for real-life context. The researcher recommends that an ethnography design involving participant observation be conducted.

#### CONCLUSION

This study highlights the importance of occupations and how they give meaning to one's life. Engaging in leisure travel promoted a dynamic transaction between self, environment and performance. For the participants, the freedom to travel as a leisure activity promoted feelings of mastering the environment, thus contributing to redefining their identity. Essentially, occupation proved to be fundamental in the construction and reconstruction of identity, with leisure travel providing a greater platform to experiencing various occupations.

This research provides an understanding of how travelling facilitated people with disabilities in developing a new identity. It further provides new insights into how travelling assists in the discovery of individual strengths and the generation of positive emotions. Lastly, it encourages occupational therapists to promote appropriate leisure programmes as a means of therapeutic intervention to enhance occupational identity and promote optimal occupational performance.

The shared lived experience of travelling for people with disabilities is that it is a pilgrimage of self-discovery, whether it is discovering one's own boundaries, discovering alternative means of doing daily activities or discovering a fresh perspective on one's disability. Travelling expanded their sensory, physical, and emotional parameters which enabled them to view themselves and their disability in a new light. The participants in this study did not engage in travelling merely for fun, but for self-discovery. By facing the obstacles pertaining to inaccessibility, they learned to appreciate being different in a one-dimensional society and grew stronger in their autonomy by taking control over their destiny. Therefore, travelling proves to be one of the most influential forms of growth and is essential to transform one's occupational identity.

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#### DATA AVAILABILITY STATEMENT

Upon reasonable request, the data is available from the authors at vdwyolanda@gmail.com.

## **DECLARATION OF CONFLICTING INTERESTS** AND FUNDING DECLARATION

The authors declare that there are no trading, legal, financial, or any other opposing interests that may affect this study.

#### **AUTHOR CONTRIBUTIONS**

The first author conducted the study and wrote the article under the supervision of, and with input from, the second and third authors, as part of a Master's degree.

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