PERSPECTIVES ON EXPERIENCES OF TOURISTS WITH DISABILITIES: implications for their daily lives and for the tourist industry

ABSTRACT

This study attempts to understand how people with disabilities (PwDs) interpret the dimensions that they consider important when on holiday. By understanding these dimensions, it becomes possible to identify and remove barriers to holiday-making and improve customer satisfaction. In particular, the study focuses on a) what having a holiday means for PwDs and how travelling affects their lives; b) the process of decision-making when PwDs organise a tourist experience; and c) the roles played by travelling companions, associations and tourism companies. To that end, rich qualitative data was collected through 25 in-depth interviews with people with reduced mobility. Findings suggest that tourist experiences had a decisive impact on the perspective that PwDs have of their disability in their daily lives, with the feeling of independence being a crucial aspect. Factors such as limited negotiating scope, necessity of a care assistant, knowledge of the destination language or availability of state aid influence the decision-making process. For domestic tourism, the train is the most valued transport thanks to a particular service provided in Spanish stations. This study contributes to accessible tourism theory by providing insights into the complexity of travelling with a disability and its impact on people's daily lives, from a first-hand tale.

KEYWORDS: accessibility, disability, tourism experience, independence, barriers, social model

Introduction

It has been recognised that people with disabilities (PwDs) have the right to leisure and travel activities like everybody else (Buhalis & Darcy, 2011; Buhalis, *et al*., 2012). In recent years, PwDs have been identified as an increasingly lucrative market segment (Buhalis & Darcy, 2011; Buhalis & Michopoulou, 2010; Domínguez, *et al*., 2013) and yet, experience barriers in travel (McKercher & Darcy, 2018; Devile & Kastenholtz, 2018). Although accessible tourism is not a new phenomenon, there are factors fuelling its growth. According to the World Health Organization (WHO), more than a thousand million people (around 15% of the world's population) have some form of disability. This percentage will keep rising, mainly due to the population ageing and the increase in people suffering from chronic diseases (WHO, 2020). Likewise, new tourist facilities emerging in the market have improved accessibility, either to comply with legislation or

due to companies' greater awareness. This encourages more PwDs to travel and take holidays (Blichfeldt & Nicolaisen, 2011; Buhalis & Darcy, 2011; Lyu, 2017; Zhang & Cole, 2016). In Spain alone the latest figures available on disability, provided by the *Instituto de Mayores y Servicios Sociales* (Institute for Elderly and Social Services - IMSERSO), show that the number of people considered 'disabled' (with a disability level of 33% or higher) is almost 3 million. Of these, 56% have reduced mobility, defined as a person's difficulty in carrying out movements (COCEMFE, 2020).

'Tourism for all' or providing accessibility for tourists in order to address growing numbers of PwDs, is not only economically profitable but also has a beneficial impact for society and improves social inclusion. In the UK, the English Tourist Board developed Social Tourism, calling for the elimination of physical, economic and socio-cultural barriers hampering PwDs from making use of tourist resources (Baker, 1989; Minnaert, *et al.*, 2012; UNWTO, 2016). Tourism has the capacity to improve happiness and well-being, therefore, it is considered a right for everyone (McCabe & Johnson, 2013; McCabe, 2020; Morgan, *et al.*, 2015). Indeed, for people from a disadvantaged background a holiday offers the chance for a break from many of the challenging circumstances in offering a fresh perspective, opening up new ways to live, which may have a significant impact (McCabe, 2020). Promoting accessibility in tourism is not only beneficial for PwDs, but for everyone who needs it; for example senior tourists, people with temporary limitations (as a result of a surgery, accident…) or parents with children, making the space and services more comfortable and usable for all tourists (Alén, *et al.*, 2012; Buhalis & Darcy, 2011; Buhalis & Michopoulou, 2011; Domínguez, *et al.*, 2013; UNWTO, 2016).

However, despite the potential importance of PwDs for the tourism sector, there are few in-depth studies from the tourist's own perspective (Darcy *et al.,* 2020; McKercher & Darcy, 2018). This study aims to identify the aspects of travelling considered important by PwDs and to highlight the implications for both PwDs and the tourism industry. Enhanced knowledge of PwDs' tourist experiences will raise the awareness of the physical and socio-cultural barriers preventing their effective inclusion in the leisure and tourism spheres. This can enable actions aimed at reducing and eliminating such barriers or help to find alternative solutions through adapting products and policies to support tourism for all and, hence, enhance customer satisfaction and well-being for PwDs. The study analyzes the tourist experiences from 25 semi-structured in-depth interviews with Spanish informants with reduced mobility. In the context of this research 'tourist experience' refers to the retrospective, first-person narrative of the journey, beginning from the decision to travel and ending with the return to the usual place of residence. In particular, through the travel tale, this study considers (1) <u>what the holiday means to PwDs and how it affects their self-perception and daily lives</u>: what motivates them to travel, if traveling represents something special to them, if their life has changed after making a trip, how has both accessibility and barriers at the destination impacted their travel; (2<u>) the process of planning and decision-making when undertaking a tourist experience</u>: facilitators and barriers during the process of searching travel information and factors that influence the decision of taking or not a trip; and (3) <u>the roles played by travelling companions, tourist service companies and associations of PwDs on the whole tourist experience</u>: what they represent, how they (or have the potential to) facilitate travel and when they are considered a burden.

Literature review

Disability and accessible tourism

Accessible tourism is currently largely informed by the social model of disability. This new paradigm introduced the idea that limitations suffered by PwDs are consequences of the barriers imposed by society. Until that moment, the individual/medical model had prevailed in disability studies (Barnes & Mercer, 2010; Darcy & Buhalis, 2011; Swain *et al*., 2013). According to the medical model, PwDs' problems stem from the individual limitations imposed on them by their own disabilities. Thus, their difficulties are attributed to their "personal tragedy" and that this can only be remedied by medical intervention (Barnes & Mercer, 2010). The medical model prevailed until Paul Hunt published 'Stigma: The experience of disability' (Hunt, 1966), stating that the problem of disability lies not only in the individuals, but in their relationship with the non-disabled and with the built environment. The first analyst to theorise the distinction between the medical and social models of disability was Oliver (1990; 1996; 2013), one of the strongest advocates of the social model.

The adoption of the social model was supported by social mobilisations that demanded the same opportunities and rights for PwDs (Barnes & Mercer, 2010; Swain *et al*., 2013). The social model states that in spite of an existing individual limitation, a person would not be excluded from participating in daily life activities if society did not impose environmental, attitudinal or communicative barriers (Barnes & Mercer, 2010; Darcy & Buhalis, 2011; Oliver, 2013; Swain *et al.*, 2013). When this social dimension of disability is translated into tourism terms, it becomes clear that PwDs are limited when travelling as destinations were not designed with accessibility needs in mind (Darcy & Buhalis, 2011). McKercher, & Darcy (2018) re-conceptualise the barriers to travel for PwDs, proposing a four-tiered hierarchy to understand the complexity of accessible tourism and the effects of barriers, constraints and obstacles to travel faced by people with disabilities. Facilitating the tourism experience for PwDs through accessible infrastructure (hardware) and services (software) is critical for accessible tourism.

Accessible tourism experiences

PwDs' tourism experience research in social sciences is concentrated in the geography and business/economy fields, focusing on assessing compliance with requirements of tourist accessibility in physical (Agovino *et al*., 2017) and internet access (Eichhorn *et al*, 2008; Michopoulou & Buhalis, 2013; Darcy, *et al*., 2019). Research has also highlighted the benefits of accessible tourism for the economy (Buhalis & Michopoulou, 2010; Michopoulou, *et al*., 2012; Buhalis, 2015; Domínguez, *et al*., 2013; Figueiredo, *et al*., 2012), and for PwDs (Darcy, 2010; Kastenholz, *et al*., 2015; Michopoulou & Buhalis, 2013; Moura *et al*., 2018; Pagán, 2015). Sociological studies offer findings on the meanings of tourist activities, including the motivations, problems and feelings of PwDs.

A tourist experience for PwDs usually means escaping from their daily routine and, if the experience is satisfactory, it also allows them to feel included and capable (Blichfeldt & Nicolaisen, 2011; Kastenholz, *et al.*, 2015; Shi, *et al.*, 2012), constituting an opportunity to recognise self-identity (Eichhorn, *et al.*, 2013) and cope with stress (Moura *et al.*, 2018). Tourism represents a metaphor for recovery and social inclusion. The complex process of being a tourist with a disability requires a dose of personal initiative, an accurate assessment of one's own capacities, the ability to gather reliable information and manage the trip, self-administer and reflect on the experiences. Being able to travel is a significant undertaking through which PwDs show others that they can do things themselves and that they have regained control over their lives (Kastenholz, *et al.*, 2015; Pagán, 2015; Shi, *et al.*, 2012). Studies on travel interests and motivations among PwDs show that they are diverse (Figueiredo, *et al.*, 2012; Shi, *et al.*, 2012; Zhang & Cole, 2016). Although they largely coincide with those of other tourists (Pagán, 2015; Shi, *et al.*, 2012), 'independence' and 'adventure/risk' feature more frequently than other motivations since the trip is a difficult and challenging process (Shi, *et al.*, 2012). In relation to preferences, accessibility in accommodation is the most important factor for PwDs (Darcy, 2010; Lyu, 2017; Zhang & Cole, 2016).

Barriers to accessible tourism experiences

PwDs experience extra barriers and difficulties when travelling. There are many barriers and physical and architectural obstacles are only part of the problem (Agovino *et al.*, 2017; Loi & Kong, 2017; McKercher & Darcy, 2018). PwDs encounter barriers in accommodation (Darcy, 2010; Poria, *et al.*, 2011), tourist attractions (Cloquet *et al.*, 2018) and transport (Poria, *et al.*, 2010). Many are also limited by their financial situation, mainly due to their difficulty in finding work (Pagán, 2012). Poria, *et al.*, (2010) identify several problems with air transport. PwDs dehydrated themselves to avoid using the toilet on the plane, they worried about losing their wheelchairs and/or feeling humiliated by security and embarkation procedures. Similarly, service sector personnel are often not properly trained to attend PwDs and there is a lack of accessibility awareness in the tourism industry (Bizjak, *et al.*, 2011; Capitaine, 2016; Poria, *et al.*, 2011).

Barriers produce the need to gather information and to carefully plan every aspect of the trip (Blichfeldt & Nicolaisen, 2011; Darcy, 2010; Eichhorn *et al.*, 2008; Mayordomo-Martínez et al., 2019; Michopoulou & Buhalis, 2013). The processes of searching for information and decision-making gradually become less complex, as the PwD acquires more experience in travelling (Blichfeldt & Nicolaisen, 2011; Pagán, 2012). Michopoulou & Buhalis (2013) remark that although access to online information is essential, most tourist websites only contain general information, lacking detail and creating barriers. Associations for PwDs, however, play a crucial role, providing the necessary information and acting as specialised travel agents, organising package holidays and enabling PwDs to travel (Blichfeldt & Nicolaisen, 2011). Eichhorn, *et al.*, (2013) state that PwDs have an intrinsic desire to affirm their independent self. This leads them to reject PwDs' specialised trips organised by associations, as they want to see themselves like everyone else without their disability being the centre of their identity.

Despite the well-established right of PwDs to participate in leisure and travel activities UNWTO (2016), it is evident that there are still significant barriers and a deficit in the understanding of PwDs' requirements and tourism experience (McKercher & Darcy, 2018; Michopoulou et al, 2015). Although some aspects of PwDs experiences have been explored before [i.e from accommodation (Darcy, 2011) or destination perspectives (Ernawati & Sugiarti, 2005)] this study contributes to the accessible tourism knowledge by delving into the whole travel experience from a first-hand tale. It responds to calls by Tao et al (2019) for further research on travel experiences of people with reduced mobility and also by Nyman, Westin & Carson (2018) who extend the call to include such research in different countries. Understanding perceptions of real experiences can improve the accessibility of the tourism industry while increasing the opportunities for the social inclusion of PwDs in leisure and travel activities.

Method

The aim of this study is to analyse the tourist experience of people with reduced mobility. As it is an interpretative study, with the objective of finding dimensions deepening through the personal experience, it required a qualitative approach, and the use of semi-structured in-depth interviews. This approach is particularly suitable for the study of minority groups and PwDs (O'Day & Killeen, 2002). Since the dynamic of semi-structured in-depth interviews is conversation and interaction, there was no established standardized questionnaire, rather an interview guide that was followed according to the research objectives. A total of 25 in-depth interviews were carried out. Appropriate ethical research guidelines were followed relating to consent and confidentiality. The number of interviews was established by means of discourse saturation (Bowen, 2008). The main themes emerged upon reaching the fifteenth interview. The remaining interviews made possible to consolidate the main themes and add nuances that enriched these themes. The discussions and sharing of the research team (co-creation of meanings) were fundamental in the saturation process. In this coding process, for example, as we found that word "independence" and synonyms like "autonomy" or definitions/experiences related to travelling independently like "The first trip on my own, without anyone, without my parents or family, went fine. Obviously, I went with people who already knew where we were going and the problems there", we coded these kind of quotes as "independence". These quotes related to a certain code were interpreted by researchers following the kind of related experiences. The decision to discontinue the interviews was made when new interviews no longer altered the previous codifications or provided new relevant nuances. In order to avoid the point of saturation being reached too quickly due to a homogeneous sample, heterogeneity in the sample was sought with 1) different starting points for the snowballing technique (parallel networks) and 2) different characteristics of the sample followed by sex, age, place of residence and degree of mobility (from people who could not move their limbs, or only with great difficulty to people who can walk with the aid of a stick or even without any special aid but with difficulty).

With regards to different starting points, a range of PwDs' associations were contacted, since PwDs who travel tend to be members of a PwDs' association or tend to travel with them (Blichfeldt & Nicolaisen 2011). This contacting process was as follows: after preparing a list of associations in the province of Alicante, we began visiting their headquarters in person. We first talked to a social worker or someone else who was present in the association at that time. Once they agreed to collaborate to this study, they provided the contact details of some of their users. The associations that have collaborated in this study are: *Ocio y Turismo Accesibles*, *Centro de Apoyo al Estudiante* of the University of Alicante, *AHEBA*, *ADEMA* and *ADIFIA*. Second, in order to widen the sources of the sample we attended two seminars on disability held in Alicante city, namely: ''*VIII Jornadas Informativas de Esclerosis Múltiple*'' and ''*La diversidad en primera persona: pregúntame, que no muerdo*'', where we were able to contact new participants.

The main selection criterion of participants was to have some form of permanent reduced mobility (degree higher than 33%) and to have travelled at least once in their life. Once this general criterion was met, heterogeneity was sought in the sample to enrich the results, since different perspectives have been contributed from different ages, sex or type of reduced mobility (nuances of experiences following characteristics of participants -if any- are exposed on results). In the composition of the sample, there are 12 men and 13 women. The age of the participants ranged between 19 and 63. Given the age difference among the interviewees, there was also a wide variety in the travelling experience, from those who had travelled only on a few occasions to the most experienced. The majority lived in Alicante (19), while other participants lived in Valencia, Castellon, Madrid and Cadiz. Participants were anonymised and assigned a number according to the order of interview. These categories are also shown at the end of each quotation in the following order: sex (M = male, F = female), age, province of residence, type of technical aid used and the origin of the incapacity (acquired or congenital). Finally, most of them are wheelchair users and the origin of their disability was congenital. The summary of the interviewee's profile can be found in the Appendix. These characteristics were asked to each participant at the moment of the first contact.

The interviews were conducted face to face, at the disability associations' headquarters, in cafés selected by the interviewees and in their homes. The duration of the interviews was between one and two hours. During the interviews, a range of issues was explored. Interviewees were asked about their travel experiences, considering the first trip they remembered, and how these experiences were changing over time. Through these experiences, we introduced questions about how they took the decision to take the trip, how they planned their trips, if they used different agents (such as family, friends, tourist companies, associations...) for the trip and their experience with these agents during the trip. We also asked about what travelling meant to them and if they experienced changes in their beliefs and in their lives after travelling.

The content (audio) of the interviews was recorded for its subsequent transcription and analysis. The analysis of the interviews is based on the thematic analysis. This is an accessible and flexible analytical method, considered a methodological approach in its own right (Braun & Clarke, 2006). The six-step procedure favours a systematic treatment

of the data and the identification of themes through an inductive approach. A theme represents some level of meaning modelled within the data set and must be defined, named, revised, and refined ensuring that they form a consistent pattern. For the coding work, the computer program Atlas.ti was used. This program provides systematic tools for coding, annotation and localisation of qualitative data in text format, allowing, in turn, the evaluation and visualization of complex relationships between them.

The rigor and reliability of the investigation is provided by various means (Tracy, 2013): 1) by introducing a broad sampling strategy, with different starting points for the snowballing technique (parallel networks) that seek to minimise the risk of encapsulated networks; 2) by describing the issues in detail and supported by quotes (this transparently shows the complexity of the data and allows the reader to reach their own conclusions); and 3) by ensuring the same data interpretation and coding strategy by the members of the research team. Given the varied casuistry, the way of interpreting and coding the data was constantly shared and discussed in work meetings. In this way it was ensured that the data were interpreted in the same way regardless of the researcher and that any modification was previously discussed and, if accepted, adopted by all equally. This process ensured the co-creation of meaning from the data and an internal consistency in understanding the issues identified in the interviews (Miles & Huberman 1994).

Findings and discussion

The analysis of the interviews centres on investigating what the tourist trip means to the participants and how the journey affects their self-perception and daily life. It also examines the planning and decision-making process behind the tourist experience and the role played in this experience by fellow travellers. The PwDs associations and tourist service companies, particularly travel agents, hotels and transport services are also studied.

Motivations of tourism and consequences of the trip

Interviewees explained that, for PwDs, taking on a tourist trip means successfully tackling a personal challenge, which brings them closer to social inclusion. Similar to other studies (Kastenholz, *et al.*, 2015; Pagán, 2015; Shi, *et al.*, 2012), travelling meant "leaving home and tackling challenges" whilst enjoying "new adventures" for the interviewees.

> *Travelling means becoming a person, tackling stuff which you think*
> *you can't tackle when in fact you can. (P1: M, 60, Alicante, electric*
> *wheelchair/congenital)*

General motivations were consistent with the study of Shi, *et al.*, (2012): "Having new experiences", "visiting family and friends", "learning about new cultures and places", "experience life" and "enjoying independence". This research focuses especially on the

meaning of independence, because this motivation is the most frequently mentioned by interviewees and is reflected in every aspect of the tourist experience.

> *What motivates me is independence and I no longer have it. It motivates me to see new places, landscapes, other countries, meet other people, learn about other customs… It motivates me a lot. (...) I've told you before. It is very interesting. It's like reading books, but in reality. To live adventures. Things always happen when you are well and when you are not that well. (P6: F, 63, Alicante, electric wheelchair, acquired)*

This study establishes that independence is an essential aspect in every phase of the tourist experience. For PwDs, independence was not always related to doing things for themselves or travelling without the need of a companion. They were aware that their disability made the help of other people indispensable for basic tasks, such as getting dressed and attending to personal hygiene. Independence is about "not having to depend on those closest for help in the trip" (family or friends). Accessibility is vital to achieve independence and feel like just another member of the group, taking part in decisions and helping others to have a pleasant experience (we can see this extended in following sections: "role of travelling companions"). We have also seen the importance of accessibility reflected in the acquisition of this independence, so it is crucial in the decision to undertake a trip (also extended in following sections "Challenges in planning and taking the decision to embark on a tourist experience" and "The role of the tourism industry in the experience of PwDs").

> *And going to a travel site, autonomy would end. So, I start to assess and for now, autonomy gains. (P5: F, 61, Alicante, electric chair / acquired)*

Interviewees associated their tourist experiences with feelings of independence and the chance to see and do things that were special, since in their daily routines they may not attempt them or they were not possible (Kastenholz, *et al*., 2015; Pagán, 2015; Shi, *et al*., 2012). The holiday enabled them to "forget problems" and "leave the monotony of daily life behind". Table 1 summarises the findings of the motivations, meanings and consequences of the tourist experience of PwDs.

Table 1. Motivations, meanings and consequences of the PwDs trip

THEMES	RESULTS
MOTIVATIONS AND MEANINGS	● ACTIVITIES To do things that they like (sports, art, enjoying nature…)
	● VISIT FRIENDS AND FAMILY To visit family.
	● EXPERIENCE To learn about new cultures, history, food…/To have adventures and new experiences.
	● ESCAPE To forget monotony and daily problems/Escape from routine./ To see and do different things not possible in their daily routine.
BEFORE TRIP	● INDEPENDENCE Personal challenge /To feel independent./To prove they are capable (can do many things, new activities and travelling)./ Normalisation of lives.
	● MEDICAL To visit doctors.
	● ACCOMPANYING OTHERS (To please family.)

CHALLENGES IN PLANNING AND ACTUALISING A TOURIST EXPERIENCE *DURING THE TOURIST EXPERIENCE*	<u>IN RELATION TO PLANNING</u> ● PwDs establish autonomy in daily life ● The uncertainty about destination accessibility force dependences on others to travel. ● Lack of information about accessibility also makes PwDs rely on family or friends who live in the destination to check the veracity of published information and the accessibility conditions. <u>IN RELATION TO TRAVELLING COMPANIONS</u> ● When they depend on people closest to them for travelling (family or friends), they feel that they depend on the decisions of others during trip. ● This dependence makes them feel like a 'burden', that they delay the rest of the group, someone to have to take care of , centre of attention… ● Demand for professional assistance so as not to depend on relatives to travel. ● Overprotection of family makes PwDs feel that they can do less things than they actually can. After travelling without parents, they become aware of their real capabilities. <u>IN RELATION TO ASSOCIATIONS</u> ● Associations allow them not to depend on family and friends for travelling: o They free PwDs from the planning process. o They offer professional assistance and support from counsellors. o Counsellors encourage them to do what they do not dare to. o Possibilities to do unthinkable activities. ● Some promotion of social segregation: o Desire to choose who they want to travel with. o Do not want to be enclosed exclusively in the collective of PwDs. <u>IN RELATION TO TOURIST COMPANIES</u> ● Accessibility in the tourist industry is the best source of independence: o Through accessibility and specialised services, they are no longer dependent on friends/family and associations o Find good practice with Atendo. Assistance provided by Spanish train stations makes this feeling of independence possible. o Suffer from airport assistance service, as well as other tourist services. ● PwDs need a service that considers personal demands and requirements	
CONSEQUENCES TRANSFORMATIONS *AFTER TRIP*	IF TRIP IS SUCCESSFUL ● Desire to travel in the future. ● Introduce new activities in daily lives. ● Become aware of external barriers (social) and prejudices of others that affect them day by day. ● No longer feel guilty for doing normal activities ● Demand greater accessibility from companies and government in own cities.	IF TRIP IS **NOT** SUCCESSFUL ● Fear and anxiety to go on a trip in the future. ● Feel home as a safe zone.

Source: authors.

Tourism produces significant changes in both their self-perception (Eichhorn, *et al.*, 2013) and their future as a tourist. The results show that a good first experience is decisive for gaining confidence and diligence and encouraging further travelling. Participants who visited a destination that was more accessible than their normal place of residence for the first time became aware that their daily lives could be different if they could make suitable adaptations. Some reported that they "stopped feeling guilty for wanting to do certain activities" and to have "access to places that were normally barred" to them. In contrast, a bad experience and accessibility barriers to tourism created feelings of helplessness and loss of confidence (Lee, *et al.*, 2012) which discouraged further travel.

> *"Leisure travel no, because I don't dare. Because in the end you come across so many problems finding a hotel that's adapted. […] This was my*

experience on the plane where that stuff with my wheelchair happened. That was the first thing about the wheelchair. Since then I haven't travelled by plane again." (P5: F, 61, Alicante, electric wheelchair, acquired)

Results show that travelling has a transformative effect on PwDs. First, they explained that if the journey was perceived as 'satisfactory,' it empowered them to "introduce activities into their daily lives" which until then would have "seemed unthinkable". If they could travel, then they could do many other things in their daily lives. Second, during the journey they had to face a "new situation, disrupting many beliefs and convictions". This made them aware that their degree of disability not only depended on their physical/individual problems but was also an equation in which both the material (physical barriers) and the social (prejudices) environments played decisive roles. Taking a holiday contributed significantly to shifting them from the individual to the social perspective of disability. Thanks to this, some became more active in demanding the elimination of barriers in their own cities.

> *"I thought that the problem was my disability, and having a disability, how could I expect to do many things? But when I went to Vancouver I discovered that disability isn't the problem, because there in Canada […] I discovered that you can go everywhere on your own in your wheelchair, because you see lots of wheelchairs out in the streets. There I realised that the problem wasn't my disability, but the barriers that society puts in your way. So I came back to Alicante really fired up" (P24: F, 36, Alicante, electric wheelchair/congenital).*

Challenges in planning and taking the decision to embark on a tourist experience

The complex process of travelling requires extensive planning and information search (Blichfeldt & Nicolaisen, 2011; Darcy, 2010; Eichhorn *et al*., 2008; Mayordomo-Martínez et al., 2019; Michopoulou & Buhalis, 2013). PwDs need to have the "courage to take the decision", accurately assessing their own capacities in relation to the destination and plan appropriately in order to be able to cope beyond their comfort zone (Shi, *et al*., 2012). Often support and encouragement is required.

> *"My mother said, 'Either you're going or you're going,' so I had to go. I was a bit annoyed because I didn't know how I was going to feel. But as soon as you get there, the next day I forgot all the stuff I had in my head and then you start having a good time. Now it's been ten or twelve years since I've been going and it's completely normal for me". (P12: M, 37, Alicante, manual wheelchair/congenital)*

The perception of risks, the difficulty of planning and decision-making process diminished as the person acquired experience (Blichfeldt & Nicolaisen, 2011; Pagán, 2012). Before travelling, they assess both their own capacities and their specific needs at the destination, so they could search for information on accessibility accordingly.

Errors made during this process would possibly mean that the tourist had to tackle unforeseen problems which could lessen their enjoyment of the holiday. Because of this, the need for detailed information on what exactly 'accessible' or 'adapted' meant was crucial (Blichfeldt & Nicolaisen, 2011; Buhalis & Michopoulou, 2011; Darcy, 2010; Michopoulou & Buhalis, 2013). However, PwDs explained that the main problem they found when looking for information was scarcity and accuracy, so they made calls to hotels to request photographs and to ask specific questions on physical and architectural conditions. Some interviewees even contacted family or friends living in the destination and requested them to inspect and confirm *in situ* the accessibility information gleaned from the Internet.

> *Checking that the hotels are adapted is critical for me, because a lot of them say that they are, but they're really not. Well, for example in Aranda del Duero and in Salamanca as well we made a complaint because they said that they were adapted and then they were nothing of the sort. (F, 61, Alicante, one or two sticks/acquired)*

Travelling abroad is more complex for PwDs due to language and communication barriers. Lack of knowledge of the holiday destination's language represents a greater risk for PwDs. If there is an incident, most likely due to the PwD's needs, "foreign languages are a barrier to seeking help or communicating in general":

> *I talked to loads of hotels abroad and none of them offered someone to help me or to contract a company to do it. Here in Spain I'm not scared because if I have to look for someone myself, it's much easier to communicate in your own language with a company or to look for companies (P16: M, 34, Cádiz, electric wheelchair/congenital)*

The interviews revealed that prejudices and overprotective families can discourage PwDs from travelling. This could make PwDs feel that they "cannot do many things autonomously". This directly affects the confidence and the risks perceived of the trip and the assessment of their own possibilities to face them.

> *'You're not going to be able to do this, you can't do that,' and me, what did I think? I thought they might be right. But then you try it out and you realise that it's not true, that if you decide to do it, you can. (P8: M, 24, Alicante manual wheelchair/congenital)*

The budget available also has an influence on the planning and decision-making process for the trip. Economic reasons have considerable weight for PwDs in deciding whether to travel or not, since they have to take on large additional costs for the journey. Interviewees affirmed that the scarce availability of adapted tourist products makes the price of accessible facilities higher in general, especially accommodation. PwDs encounter less scope for negotiation and/or accessibility only in high-end products. Often, they have "few alternatives that are suitable" and "accessibility rather than price is the first priority".

Another factor that increased the price of the trip was the need for some PwDs to be accompanied by a care assistant, for whom they have to pay compensation and travel expenses. Although there is a state benefit in Spain specifically for this purpose, it was seen "insufficient or incorrectly applied". Also, the "need to hire this person 24 hours a day during the trip" makes the economic load very high. The high economic cost of the personal assistant collides with a "low disability pension that does not stretch to these extra expenses".

> *With my career, going out round the city, it's fine. But if I had to travel, that means I'd have to pay that person for a lot of days and it's a lot of money. In the end, you have to go with your family, and since I'm not young and my parents are elderly now, we've reached the point where it can't be done. I'd like to travel more, but I don't for economic reasons. As I said, I only have a disability pension and I don't have so much money that I could pay. My pension enables me to eat, the basic necessities and not a lot else. (P23: M, 34, Alicante, electric wheelchair/congenital)*

The role of travelling companions in the tourist experience

Travelling accompanied is usually a necessity for PwDs. Travelling companions can help PwDs to cope with risks and barriers during travelling. These travelling companions can be fellow travellers or carers who can help to avoid, solve or mitigate potential problems stemming from lack of accessibility. The vast majority of interviewees explained that they had "never travelled alone since acquiring disability". Some were autonomous at home and in their daily lives, but uncertainty about accessibility in destinations meant that they needed to travel with others. Even when reduced mobility did not stop them from walking, a carer can offer the security and confidence needed to overcome particular barriers, such as "carrying luggage", "getting up a particularly high step", or "avoiding falling in the underground".

In some cases, PwDs chose to spend their holiday time visiting friends and relatives. In this way, they made sure that they had company, help and understanding during their stay away from their normal residence. But, those who felt that they depended on their family and friends to travel felt that this also created "dependence on the decisions of others", and thus they "did not enjoy freedom of choice".

> *Since my life has changed a lot, I depend a lot on what the rest want. From my travel companions, right? (P19: F, 43, Castellon, manual chair or crutch/acquired)*

For this reason, although many interviewees needed continuous assistance, they preferred that this should be provided by professional staff hired especially for the trip. In this way, their travelling companions did not have to carry out the work of the carer and therefore did not grant themselves a certain superiority in decision-making.

> *I travel only when I have personal assistance. So, for example, if I know you, we have liked each other and we say ``we want to go to Galicia for a few*

days'', well, we are going, but I will take my personal assistant who is a person who is working for me, and that will mean that you are yes and only yes, colleague. Not that suddenly, even if you like me very much, you have to say ''oh! Well, I'm going to be the person who takes care of her''. Well, no. (P11: F, 44, Madrid, electric wheelchair/congenital)

The role of the tourism industry in the experience of PwDs

PwDs require the entire tourism system, including travel agents, transport companies and hotels, to offer suitable services so as to ensure that their trip remains trouble free. Interviewees felt that little progress has been made and many of their complaints coincide with those reported in previous studies (Agovino *et al.*, 2017; Bizjak, *et al.*, 2011; Capitaine, 2016; Poria, *et al.*, 2011). Furthemore, companies were also criticised for the lack of information on accessibility on their websites and travel guides (Darcy, 2010; Michopoulou & Buhalis, 2013). Nevertheless, interviewees felt that PwDs' **associations** work tirelessly to improve their tourist experience and to fill the gap in the market.

> *I learned to look after myself because in the end you save money and also, you're going to do the same because most of the travel agents aren't prepared for dealing with disability issues. […] They think that if a hotel complies with the law then it's adapted and if it just has a few bars then it's certified. (P16: M, 34, Cádiz, electric wheelchair/congenital)*

With regards to **transport**, the most convenient and accessible vehicles for interviewees were adapted buses that are often used in group trips with an association, and private cars, which were adapted to the needs of each person. They were preferred as they offered "door to door and destination transportation" and "utter flexibility". They confirmed that adapted buses catered to individual needs principally by transporting technical aids (such as hoists, crutches, manual wheelchairs...) in the baggage hold and they have spaces for anchoring wheelchairs and lifting platforms:

> *It's much more convenient because you can go anywhere in a car and that's all you need, because you get to the destination and, OK, you get off the train, but then you have to find an adapted taxi, etc. Apart from that, when I travel I need to take a hoist as well because it's a technical aid that enables me to get from the bed to the wheelchair, and obviously the hotels don't have them. (P11: F, 44, Madrid, electric wheelchair/congenital)*

In the area of public transport, trains were the most highly regarded by interviewees. Those with less mobility and those needing wheelchairs had a better experience and expressed their preference for the train due to the "freedom and autonomy" it afforded them. They explained that "railway stations in Spain offer an assistance service" which accompanies them, easing their passage "through the building, carrying luggage, and

get on and off the train using platform ramps" and anchoring the wheelchair in the specially designated area:

> *So I wouldn't have to get my mother to come and take me from Alicante to Albacete, which is a hell of a long trip, I'd get the train and go there myself instead. I'd pack my own bag, go to the station (...), give my bag to the* Atendo *people, and they'd put me in place, help me fold the wheelchair if I had to, and if not they'd fix me to the special place for disabled people and it was fine. (P8: M. 24, Alicante, manual wheelchair/congenital)*

Accessibility in both trains and stations was also criticised. Interviewees pointed out that "no more than one person can travel in a wheelchair" since "each train had only one tie-down system" for that purpose. In addition, "accessibility is absent in the Spanish suburban stations", so people who do not live in large cities cannot reach the central stations by train.

Interviewees were not particularly keen on aeroplanes, because of restrictions on movement and difficulties to use toilets. In particular, electric wheelchair users found difficulty in transporting them. At the airport, they were obliged to transfer, with the help of an assistant to another wheelchair specifically designed for aeroplane access, while their own was taken apart and stowed in the hold with the rest of the luggage with a high possibility the wheelchair is damaged or lost. This was described as a "nerve-racking experience". On boarding the plane, "being physically lifted and placed in the seat" caused discomfort and embarrassment for some. They stated that "they pick you up like a sack of potatoes" instead of "using a crane for the transfer". During the journey they had to "sit without access to the toilet for hours" because they "could not get up from their seat". In addition, there are limitations on the batteries used in electric wheelchairs and on pieces of basic equipment (orthopaedic, medical, etc.), or "having to pay for two seats for one person, in case the extra seat is needed". These findings about air transport are consistent with those of Poria, *et al.*, (2010).

> *Planes are really difficult for us because, firstly, they put you on board with a chair that seems like it's for loading luggage, then in the plane itself you can't move, you can't go to the toilet because they have to get you the little chair again... Then, often they wreck your wheelchair when they load it with the luggage. They cause problems with electric wheelchairs because of the batteries. Also, depending on what type of battery you have, they let you on the plane or not, with the excuse of security. It's humiliating. (P15: F, 38, Valencia, electric wheelchair/congenital)*

Many of the problems faced by PwDs when travelling are related to **accommodation** (Poria, *et al*., 2011). All the people interviewed, regardless of their degree of incapacity, needed a certain level of adaptability. Hotels have a decisive role in the success of the trip and the experience of PwDs. Their success depends on their ability to empower travellers and to co-create memorable experiences within their context (Buhalis &

Sinarta, 2019). PwDs do not like to find themselves in a situation of uncertainty or even dangerous situations which cannot be resolved making them "feel powerless to react". The reality experienced by interviewees is unsatisfactory and often triggers extreme anxiety. Inaccuracy of published information and the tendency of companies to simply comply with the most basic regulations meant that a tourist experience could be spoiled by unforeseen issues related to accessibility. All interviewees concurred that "a lot of hotels say that they are accessible when they're not". Similarly, service sector workers were seen as not having the necessary knowledge of how to treat the PwDs or of their needs, which created continual arguments, complaints and bitterness towards the hotel sector. PwDs perceived their experiences in hotels as "extremely limiting" and spent an "incredible amount of time searching for information, planning and decision-making" due to the lack of preparedness by the hospitality sector.

> *I was anxious about what would happen. If I was going to get really tired, if I was going to be able to get into places, if if if. I was a bit anxious, but it's that fear we have of the unknown, of not knowing exactly where we're going and what we're going to find there. (P19: F, 43, Castellón, manual wheelchair or crutch/acquired)*

Finally, many interviewees concurred that journeys organised by PwD **associations** were, up to now, the best way of travelling. Travelling with an association can be the only possible way for PwDs to go on holiday. This is particularly the case when social tourism initiatives are supported by the government. When they choose an organised trip, they "avoid the arduous process of looking for adapted facilities" and the "uncertainty that this brings". As the PwD associations understand their needs and requirements they ensure that hardware and the software is appropriate, so they can enjoy tourist activities and experiences that they would otherwise never envisage undertaking. The interviewees agree with Blichfeldt & Nicolaisen (2011): that the associations act as specialised travel agents. However, there was no evidence that PwD associations provide the relevant information to create forums where PwDs can learn from each other.

> *The first trip on my own, without anyone, without my parents or family, went fine. Obviously, I went with people who already knew where we were going and the problems there, but even so it was a bit difficult. I went with an association and with people who came along to help us out. (P12: M, 37, manual wheelchair/congenital)*

In Spain, the associative network plays a key role in tourist trips because state federations are responsible for managing the requests for the IMSERSO programme. The programme subsidises up to 80% of tourism and thermalism activities for PwDs and their companions. These activities consist principally in group trips with counsellors organised by a state federation.

One of the negative factors mentioned in the interviews about PwDs group trips is that they promoted the social segregation of PwDs. Eichhorn, *et al.*, (2013) stated that

specialised trips for PwDs make them feel as if their disability was the centre of their identity, when they want to affirm their own identity through tourism. The participants in this study expressed their desire "to travel with people from other social backgrounds" and "not only with people that they did not know" and with "whom their main point in common was their disability". Not depending exclusively on PwD associations to travel is a way to overcome this social segregation and tourist services companies should play a fundamental role to achieve this.

> *Because I'd like to go with people I have something in common with, not just a physical circumstance. (P10: M, 40; Valencia, electric wheelchair/congenital)*

Elaboration of key themes

This study explores experiences of PwDs from their own perspective. This research explains the motivations, meanings and consequences of the trip for PwDs highlighting the importance of independence throughout the whole tourist experience. The interviewees associated independence mainly with not depending on family and friends for assistance when travelling. Tourists with a disability seek, first, not to be seen as a burden and, second, to gain freedom of choice. When they depend on professional assistance and are freed from the help of their travelling companions (family and/or friends), PwDs are placed on a more even level of interaction, where they can relate to their travelling companions on an equal basis, taking part in group decisions and contributing to creating pleasant travel experiences.

A number of critical factors and different actors are involved that influence the planning and decision-making of the trip for PwDs. Figure 1 summarises the factors affecting the planning process and decision-making for PwDs .

Figure 1. Factors affecting the planning process and decision-making for PwDs.
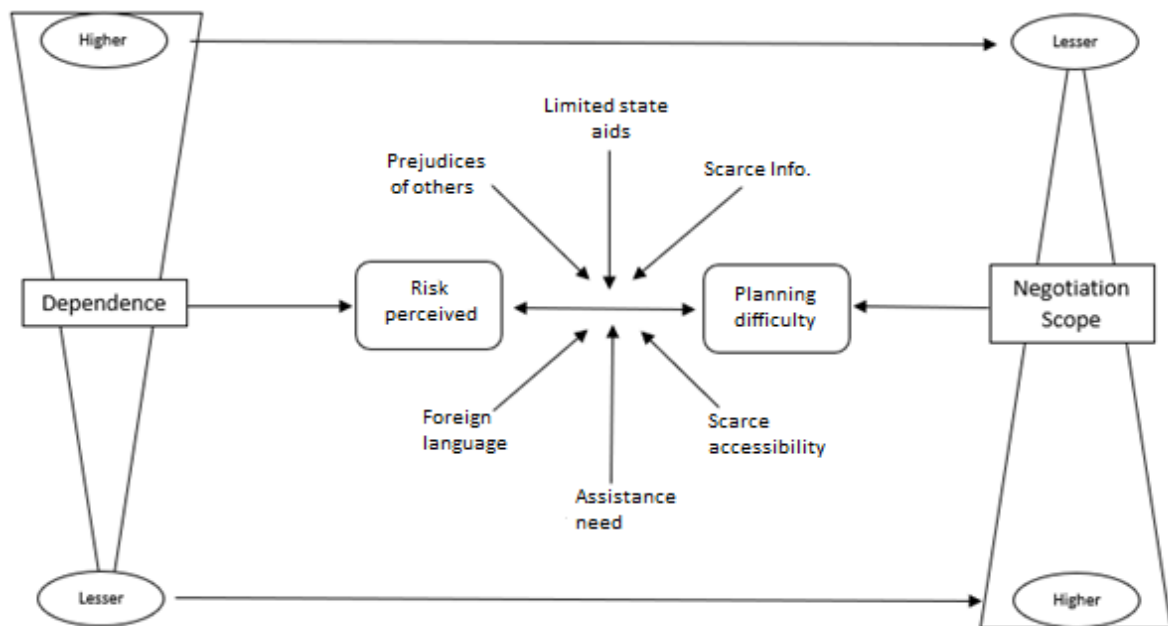
Source: authors.

Perceiving risks and planning difficulties is critical when taking the decision to travel. The level of dependence has a significant effect on how PwDs assess the difficulties to be faced in the trip and, hence, determine the difficulty of the planning process. The lack of negotiating scope of PwDs also affects this planning process, as they do not have enough market options that address their needs. The lack of accessible supply or the presence of these facilities only in expensive, high-end products makes travelling unaffordable for many PwDs. When PwDs cannot find affordable and suitable products, they are discouraged from travelling, or they are forced to seek holidays where family and friends can accompany and support them. The greater the PwD's dependence, the lower the negotiating scope and the greater the planning difficulties. Likewise, other limitations that influence the relationship between risk perception and the difficulty of planning include: availability and richness of information, other people's biases, the need for a care assistant, the knowledge of the language spoken at the holiday destination and the availability of state aid (specifically for travelling or dependence benefits).

Understanding the transformational consequences of travel for PwDs demonstrates the importance of tourism. Interviewees faced new situations during trips which transformed their self-perception and views in life. Travelling has very important impacts on their daily lives, their future as tourists and on their role as citizens. If they have a positive experience, they gain confidence and empowerment. Interviewees suggested that this enables them to become bolder in their daily lives, integrate more in their societies and become more active in demanding the elimination of barriers in their own cities.

Tourist service companies play an important role in the success of the trip and in the PwDs' feeling of independence. However, the lack of awareness of the PwDs' needs

often results in deficiencies in accessibility and travel experiences. With regard to the means of transport used, PwDs prefer private cars or adapted buses as they offer more controllable accessible options and flexibility. Trains are also favoured by PwDs due to the assistance services provided by the Spanish railway stations and the ability to move independently during the journey, using their own wheelchair, without depending on family or friends to assist them either in the station or on the train. The least valued option is air travel due to a significant number of factors: the lack of control is much greater; many perceive their treatment by airport staff during the security check and the embarkation procedures as offensive or humiliating; the inability to use the aircraft's toilets and the serious mobility restrictions during the flight. The fear of wheelchairs getting lost or damaged while in the baggage hold and the inconsistency in the regulations for transporting batteries for electric wheelchairs are also critical factors.

Taking a holiday organised by a PwD association as part of a group saves them from the arduous process of looking for properly adapted facilities and ensures that transport, accommodation and tour activities will be more accessible and less expensive. At the same time, they can count on the support and assistance of counsellors and travel companions. Because of the obstacles in the tourist sector and the key role of PwD associations in the management of public aid, many respondents saw travelling with associations as the only way for them to enjoy a tourist experience. However, they would prefer the option of travelling independently or with people from other social backgrounds and with whom they share similar interests. They would like to avoid travelling exclusively with PwDs and the stigma associated with that. As the interviewees praised the train assistance service ('Atendo') provided by the Spanish railway company (RENFE), it would be interesting to explore the processes used and transfer the best practices to other transportation services in other countries and contexts to improve the satisfaction of PwDs.

Conclusions

This paper explores the motivations for PwDs to engage in tourism, the key consequences of the whole travel experience and the challenges they face in the planning and decision-making involved in taking a trip. The interviewees discuss the different meanings that the experience has for them and its impact on transforming their views and ways of living. PwDs face significant challenges and barriers when planning a trip as there is insufficient information available. Most premises, tourist attractions and accommodations lack an architectural design that can satisfactorily cater to all PwDs' needs, leading to insecurity, frustration, inconvenience and, ultimately, dissatisfaction. The role of travelling companions in the tourist experience is also explored and it is evident that although PwDs appreciate the assistance offered by family and friends they often feel that this is at the expense of their independence and their ability to be equal decision-makers in a travelling party. Interviewees express frustration "vis-à-vis" the tourism industry, as there is still a lack of understanding of their needs, due to insufficient training of staff in PwDs' needs. Evidence from travel, trade, transport, accommodation and PwD associations demonstrate that some industry

members have come a long way in tending to PwDs' needs but overall there is still room for improvement. The interviewees state that insufficient efforts have been made to satisfy their requirements in terms of design for all. More importantly, it is evident that the tourism industry as a whole still lacks a PwD-friendly attitude and it is still not fully prepared to attract this lucrative market. The positive impacts of social tourism and the support of governmental funds for travelling is appreciated and is connected with the beneficial transformational capabilities of tourism and with the improvement of quality of life.

The theoretical contribution of the study is twofold. First, it brings to the front the notion of *independence*. Whilst other studies may have briefly touched upon this (i.e moving freely/unassisted within and between spaces), this study delves deeper into the concept and reveals aspect not yet fully explored [i.e. a) independence in relation to negotiation scope, b) independence as an enabler of equal decision making within the travel group and c) independence as a personal challenge to prove and feel capable]. Second, it highlights the multi-layered difficulties of travelling with a disability. By unpacking the complex relationships between PwDs and a wide range of actors within the tourism system, we are able to better comprehend the tourist experience and its inherent conditions. Enhanced knowledge of PwDs' tourist experiences and conditions assists us in identifying and (hopefully) removing barriers to tourism and leisure, ensuring social inclusion and increasing benefits for all; the individual, society and the industry.

Managerial implications

The study's results also have significant implications for practitioners. Findings of this research provide significant PwD insights that can help improve their tourist experience and open new market possibilities. This will have a positive effect on tourism companies and destinations, as they can create new customised business opportunities for the different segments of the PwD markets. Furthermore, the ageing of the population and the growing participation of active elderly people in leisure and travel make the production of knowledge on accessible tourism extremely useful. Gaining a better knowledge of disabled tourists and their preferences should enable the industry to make reasonable adjustments in their hardware and software and offer appropriate services. Tourism education and training programmes should also improve the understanding of PwDs' needs, the effectiveness of tourist information systems, the adaptation of premises, the provision of services and, most importantly, help to foster a more professional and empathic treatment of the PwD customer. Similarly, the positive effects of tourism for PwDs must also be taken into account by associations, politicians and public administrations to promote PwD independent tourism, and seek to establish a legal framework that continues to extend the number and nature of compulsory accessibility requirements for the tourist companies.

Limitations and future research

However, this study has some inherent limitations. In this study, only the tourist experience of the population with reduced mobility has been investigated, leaving out of the analysis other types of disabilities such as sensory or intellectual disabilities. Given the heterogeneity of the disabled population we took the methodological decision to narrow the sample and the research, to that particular type of impairment, in order to avoid compromising our goals of carrying out an in-depth analysis of their tourist experience. Future research should focus on other other types of disabilities to understand different kinds of experiences. Future research should also look into other geographical locations, as this study focused in Spain only. The viewpoints of other stakeholders within the accessible tourism system, (for instance carers and associations), should also be examined in order to develop a better understanding of the underlying social dynamics and identify the hindrances and enablers of tourism participation.

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APPENDIX

Table 2. Profile of participants

Participant	Sex	Age	Province of residence	Physical impairment	Origin of impairment
1	M	60	Alicante	Electric wheelchair	Congenital
2	F	62	Alicante	Electric wheelchair	Acquired
3	F	61	Alicante	Crutches	Acquired
4	F	63	Alicante	Manual wheelchair	Acquired
5	F	61	Alicante	Electric wheelchair	Acquired
6	F	63	Alicante	Electric wheelchair	Acquired
7	F	19	Alicante	Manual wheelchair	Congenital
8	M	24	Alicante	Manual wheelchair	Congenital
9	F	22	Alicante	No special aid	Congenital
10	M	40	Valencia	Electric wheelchair	Congenital
11	F	44	Madrid	Electric wheelchair	Congenital
12	M	37	Alicante	Manual wheelchair	Congenital
13	M	32	Alicante	Manual wheelchair	Congenital
14	F	29	Alicante	No special aid	Congenital
15	F	38	Valencia	Electric wheelchair	Congenital
16	M	34	Cádiz	Electric wheelchair	Congenital
17	F	33	Alicante	Manual wheelchair or crutches	Congenital
18	M	37	Alicante	Manual wheelchair	Congenital
19	F	43	Castellón	Manual wheelchair or crutches	Acquired
20	M	46	Alicante	Manual wheelchair	Congenital

21	M	48	Alicante	No special aid	Congenital
22	M	46	Castellón	Manual wheelchair or crutches	Acquired
23	M	34	Alicante	Electric wheelchair	Congenital
24	F	36	Alicante	Electric wheelchair or manual	Congenital
25	M	34	Alicante	Crutches	Acquired