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Research paper

## Shared tourism experience of individuals with disabilities and their caregivers

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## ABSTRACT

This research took a phenomenological approach to delineate shared tourism experiences of people who need assistance when traveling and their caregivers. If travel represents a temporary escape of everyday routines for an average traveler, travel for this group was found to represent a magnifying everydayness as they continue to be challenged with limitations as a result of disability. As demonstrated in the intensity of emotions and the mixed nature of them, tourism represents an extraordinary experience for this traveler segment despite the ordinary nature of their travel activities. Important insights are drawn with relation to the role of travel in the development of resistance strategies adopted by individuals with disabilities and their caregivers, as well as their value tendency for eudaimonic wellness.

## 1. Introduction

Individuals with impairment usually travel with caregivers who assist with their needs. Research in the area of tourism and disability has focused on travelers with disabilities, encompassing topics such as travel barriers/constraints (McKercher, Packer, Yau, & Lam, 2003), travel needs/motivations (Ray & Ryder, 2003), and benefits of tourism participation (Kim & Lehto, 2012). The need for recreational respite for caregivers, especially informal caregivers, has also been brought to the attention of researchers in the caregiver literature (Pinquart & Sörensen, 2007). Research in this area is nascent as informal caregivers are regarded as one of the most underappreciated and under-researched travel segments in the context of medical tourism (Casey, Crooks, Snyder, & Turner, 2013). It is also note-worthy that the existing studies related to caregivers have been mostly conducted in the western cultural setting, and are comprised of populations from white and middle-class backgrounds (Mactavish, MacKay, Iwasaki, & Betteridge, 2007). Further, despite the fact that individuals with disabilities in general tend to travel with their caregivers, rarely are there studies dedicated to the shared travel experience of this companionship. One such effort was made by Kim and Lehto (2013), where the researchers attempted to examine shared tourism activities of parents and their children with disabilities, albeit from the perspective of parents.

The lack of research concerning the shared tourism experiences of disabled individuals and their caregivers was a motivating factor for the current study. Examination of the shared tourism experiences of disabled travelers and their caregivers is a timely endeavor. In recent years, 'hopeful tourism' scholars have posited that tourism promotes social capital and social inclusion (Pritchard, Morgan, & Ateljevic, 2011) and that it plays a role in creating a more just and sustainable world (e.g. Pernecky, 2012). This perspective is important for individuals with disabilities and caregivers as they tend to be excluded from many tourism situations (Morris, 2001; O'Grady, Pleasence, Balmer, Buck, & Genn, 2004).

One specific population that deserves scholarly attention is Chinese travelers with disabilities and their caregivers. There are approximately 85 million people living with disabilities in China (China Disabled Persons' Federation, 2012). Although large in size, little research has been dedicated to this population. China has been making significant strides in improving the quality of life for individuals with disabilities, such as government mandates for the provision of accessible facilities for public services and other regulations to protect their employment and educational opportunities. Despite these efforts, there has been a paucity of attention on the tourism experiences of this population, and even less is known regarding their caregivers.

This research aimed to provide a nuanced depiction of what constitutes a memorable shared tourism experience of Chinese travelers

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with disabilities and their caregivers. The unique and often extensive nature of caregiving responsibilities in the travel context entails a close examination of such a joint experience from the perspective of caregivers, alongside that of travelers with disabilities. This approach is consistent with recent calls for greater efforts to understand subjective meaning-making of tourism experiences in contexts rather than to isolate and generalize experiences based on quantitative measures.

## 2. Literature review

According to the Sixth China National Sample Survey 2010 and the Second China National Sample Survey on Disability 2006, there are approximately 85 million people living with disabilities in China (China Disabled Persons' Federation, 2012). In other words, 6.34% of the population live with a disability. Among these, 14.86% have a visual disability; 24.16% have a hearing disability; 1.53% have a speech disability; 29.07% have a physical disability; 6.68% have mental retardation; 7.40% have a mental disability, and 16.30% have multiple disabilities. China has been making significant strides in improving the quality of life for individuals with disabilities in recent years. One of these efforts involves governmental regulations that mandate public service and provision of accessible facilities for this population. Governmental regulations implemented to accommodate individuals with disabilities in China include the 1997 Regulations on the Education of Persons with Disabilities, the 2008 Law on the Protection of Persons with Disabilities, the 2008 Regulations on the Employment of Persons with Disabilities, and the 2012 Regulation on the Construction of Accessible Environments.

China has held two international sporting events for persons with disabilities: the Beijing Paralympic Games in 2008 and the Guangzhou Asian Para Games in 2010. These events helped bring attention to the need to improve the lives of persons with disabilities in China. However, there has been little research about the barriers and constraints that impede participation of the Chinese disabled population in leisure travel, despite the recognition that they generally encounter more challenges than those without disabilities when it comes to recreational pursuits and facilities. In fact, research about the leisure and tourism experiences of disabled individuals, their families and other caregivers is virtually non-existent. This research represents an effort in bringing attention to this often neglected population segment.

### 2.1 Travelers with disabilities and wellness

Although some ambiguity exists in the definition, disability has been generally understood from three perspectives: medical, functional, and social. While some consider disability as a disease, the social model propellers regard individuals with disabilities as normal persons living with a unique life style. The social model views disability as being created by environmental and attitudinal obstacles (Crow, 1996). Cultural differences are deemed as important in understanding the quality of life and social status of individuals with disabilities (Coleridge, 2000). In the tourism area, there has been an increasing attention devoted to the disabled population. These studies have investigated tourism experiences of disabled individuals from angles corresponding to different sectors of the hospitality and tourism industry, including in-flight, museum, hotel, ferry, and restaurant experiences (Bell, 2011; Chang & Chen, 2012; Chung & Lue, 2012; Khatri, Shrestha, & Mahat, 2012; Poria, Reichel & Brandt, 2010). These efforts have provided insights in how to better serve this travel segment. Research has shown that the impact of travel on travelers' wellbeing can be both direct and indirect (Bergstad et al., 2011; Currie & Delbosc, 2010). The indirect impacts are derived from participation in activities that satisfy elemental maintenance needs. The direct impacts are derived from satisfaction with a travel experience

itself. Tourism's role in the reduction of negative affect, such as sadness and isolation, is another stream of research within the disabled population literature (Bergstad et al., 2011; Currie & Delbosc, 2010). These suppositions corroborate with the belief that travel could be, in and of itself, a necessary element of life for travelers with disabilities (Mokhtarian & Salomon, 2001; Páez & Whalen, 2010). Researchers have also brought to light issues related to psychological and physical barriers to leisure travel by this travel segment (Ray & Ryder, 2003; Shaw & Coles, 2004).

Researchers have examined accessible tourism in relation to broader social contexts including the role of tourism in promoting social justice and equity through human rights provisions (e.g. Khatri et al., 2012). Scholars argue that tourism is a space for self-recovery, renewal, and social and family capital building for disabled individuals (Hunter-Jones, 2003; Hyde & Olesen, 2011; Minnaert, Maitland, & Miller, 2009). In this context, scholars treat tourism as a site of resistance strategies for travelers with a disability, advocating pro-social justice in an inclusive environment (Eichho, Miller & Tribe, 2013).

Investigating the relationship between tourism and resistance is particularly important for individuals with disabilities. Tourism serves as a resistance site which enables individuals to break away from daily constraints and gain greater autonomy (Pritchard et al., 2011). Fundamental to this concept is an accepted and assumed knowledge for the meaning of 'resistance'. Two main perspectives of resistance have been identified in the tourism context. The first approach recognizes resistance from a collective perspective. Joseph and Kavoori (2001) argued that from the perspective of host communities, exclusionary, political, and religious rhetoric serve as 'mediated resistance' against threats to tradition and religion brought by tourism into the community. The second approach embraced an individual perspective. Crouch (2007) highlighted tourism as a context for resistance. It provides individuals with the opportunities to act for themselves and attain a greater understanding of the world. Additionally, resistance can protect individuals from oppression and lead to self-discovery (Eichho, Miller & Tribe, 2013). In this sense, resistance can be seen as a counter-mechanism to overcome unequal power structures affecting minorities, such as women, the economically deprived, or individuals with disabilities (Tribe, 2007).

Eichhorn, Miller, and Tribe (2013) investigated strategies against social exclusion employed by people with mobility or vision disabilities both at home and while traveling. They showcased that individuals with disabilities relied on a collective approach to resistance in their daily lives while a tourism experience triggered an intrinsic desire to highlight the self. On the other hand, as a counter force to resistance strategy, reproduction can hinder their travel experiences. Reproduction can take on various forms, including: (a) reproduction through sensitivity towards other individuals, and (b) reproduction through resignation. Here, individuals with disabilities experience a reproduction of the marginalized identity positions ascribed to them. Additionally, this reproduction was strongly related to restrictions imposed by social norms (Chenoweth & Stehlik, 2004; Holt, 2007). This perspective allows researchers greater insights into the meaning-making of travel experiences of individuals with disabilities and their travel companions.

### 2.2 Caregivers and leisure

Caregivers are defined as 'anyone who provides assistance to someone else who is, to some degree, incapacitated and needs help'. Informal caregivers refer to those who perform activities involved in providing assistance to relatives or friends who are unable to provide for themselves (Pearlin, Mullan, Semple, & Skaff, 1990). The role of informal caregivers has become an important issue at political, sociological and economic levels (Van Durme, Macq, Jeanmart, & Gobert, 2012). The stress placed upon caregivers and the challenges attributed to informal caregiving have led to increasing research attention dedicated to this population. Caregiving stress and fatigue adversely

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