



Tourism and autism: Journeys of mixed emotions



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ABSTRACT

There is an evolving tourism literature around psychological wellbeing, social exclusion and disability. This paper advances tourism knowledge into the terrain of psychological health and developmental complexities, and psychological distress. It draws on a phenomenological position to understand the lived experiences of mothers of children with developmental difficulties, in this case diagnosed with autism spectrum disorder (ASD). It discusses the emotional and everyday challenges of caring for a child diagnosed with ASD on holiday, discusses the perceived benefits holidays offer and outlines care-giving strategies adopted by mothers to manage their children's tourism experiences. The paper discusses the uniqueness of the context of autism and problematizes popular discourses, which predominantly frame tourism as pleasurable settings of escape, stimulation, novelty and relaxation.

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Introduction

Wellbeing is a multidimensional concept, which has recently been considered in tourism contexts (McCabe & Johnson, 2013; Petrick & Huether, 2013), where scholars have particularly examined later-life wellbeing (e.g. Morgan, Pritchard, & Sedgley, 2015) and quality of life (e.g. Dolnicar, Yanamandram, & Cliff, 2012). The past decade has seen an increase in tourism research adopting concepts from the physical and psychological sciences; indeed, positive psychology has been so well received that its advocates advise tourism educators, practitioners and researchers "...that holidays make people happy" (Filep, 2012, p.38). This focus on the positivity of tourism has also seen research engaged with marginalisation, deprivation and social exclusion highlight how tourism benefits socially marginalised groups by elevating self-worth and extending social worlds and social interaction (McCabe, 2009). Whilst we recognise the value of such research, positive psychology has been criticised for overlooking the embodied, relational and complex manifestation of emotions and offering a simplified, individualised understanding of subjectivity (Greco & Stenner, 2013). Therefore, we seek to explore the ways in which tourism experiences, specifically those involving children with disabilities, are a messy, conflicting constellation of emotions, embracing stress and guilt as well as pleasure and excitement (Backer & Schänzel, 2012). Tourism studies has rarely considered negative emotions and then largely in service settings (Liu, 2016). Instead its overwhelming focus has been on positive emotional stimulation, perhaps because it has traditionally been framed as a hedonic experience (Hosany, 2011; Picard & Robinson, 2012).

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A growing cadre of tourism scholars address physical (e.g. [Buhalis & Darcy, 2011](#)) and sensory impairment (e.g. [Pritchard & Morgan, 2010](#); [Yau, McKercher, & Packer, 2004](#)) whilst a number focus on social exclusion (e.g. [Minnaert, 2014](#)). Our paper extends tourism's reach into psychological distress and psychological health and developmental complexities, connecting with established work in leisure studies and community psychology (e.g. [Walker, Hart, & Hanna, 2017](#)). It draws on a phenomenological position to explore the emotional care-giving experiences of mothers holidaying with a child diagnosed with autism spectrum disorder (ASD), a neglected area of research in both disability and tourism studies ([Mactavish, MacKay, Iwasaki, & Betteridge, 2007](#)). The paper is grounded in mental health and psychology research approaches ([Gilbert, Rose, & Slade, 2008](#)), which value highly personalised testimonies of the affective, embodied, experiential, individual and intersubjective experiences of those living with, and caring for, individuals with mental health issues and developmental difficulties ([Aumann & Hart, 2009](#)).

Literature review

There is a growing corpus of tourism research exploring the experiences of people with disabilities, extensively reviewed elsewhere (e.g. [Buhalis & Darcy, 2011](#)) in the book-length format that such an undertaking requires. There is less focusing on children with disabilities ([Kim & Lehto, 2013](#)) and almost none on family care-givers for individuals with intellectual, cognitive and learning disabilities and mental health conditions ([Nind & Seale, 2009](#)); an exception being the [Mactavish et al. \(2007\)](#) study. In contrast, there is a body of leisure studies scholarship examining both the experiences of individuals with psychological disabilities and their carers (e.g. [Dodd, Zabriskie, Widmer, & Eggett, 2009](#)). Research has explored the impacts of community arts projects and support centres ([Aumann & Hart, 2009](#)) and activities such as fishing, cycling and singing on the wellbeing of individuals diagnosed with a range of learning and behavioural difficulties and mental health conditions ([Walker et al., 2017](#)). Some of these studies have focused on individuals diagnosed with ASD to examine the links between leisure participation, stress and quality of life (e.g. [García-Villamisar & Dattilo, 2010](#)) and to determine how these people process sensory information during leisure activities ([Hochhauser & Engel-Yeger, 2010](#)). Further studies have investigated the barriers to leisure for children diagnosed with ASD/attention deficit hyperactivity disorder (e.g. [Emira & Thompson, 2011](#)) and the challenges faced by parents seeking to engage them in leisure (e.g. [McGinnis, Fullerton, & Rake, 2014](#)).

Notwithstanding such research, little enquiry examines the experiences of parents holidaying with children diagnosed with learning and behavioural difficulties; this despite the importance of the family in determining the tourism and leisure opportunities of children with disabilities ([Brewster & Coleyshaw, 2010](#)). Indeed, the predominance of children in the practice of tourism contrasts with their neglect in its study ([Poria & Timothy, 2014](#); [Schänzel, Yeoman, & Backer, 2012](#)). Research that has focused on holidays for children diagnosed with ASD and their families has examined local government provision and identified its role in reducing stress and maintaining family cohesion ([Chan & Sigafos, 2001](#); [Gray, 1994](#); [Olsson & Hwang, 2001](#); [Tarleton & Macaulay, 2003](#)). Similar studies in the third sector demonstrate how holidays create spaces for children with disabilities and their families to enhance their relationships, wellbeing and resilience ([Holidays Matter, 2017](#)). This echoes research, which regards family holidays as opportunities to escape, relax, and enjoy shared experiences ([Prentice, 2004](#); [Yoo, McIntosh, & Cockburn-Wooten, 2016](#); [Zabriskie & McCormick, 2003](#)). Indeed [Dodd et al. \(2009, p.262\)](#) observe that researchers have consistently found “positive relationships between family leisure involvement and family functioning.”

This is a nascent area of tourism research with pioneering studies recognising tourism's role in enhancing physical and mental health and quality of life and reinvigorating relationships for families with a child with a disability ([Kim & Lehto, 2013](#)). Whilst some researchers maintain that families with and without a child with a disability participate in leisure in the same way ([Ferguson, 2002](#)), others emphasize its value for families with a child with a disability ([Scholl, McAvoy, Rynders, & Smith, 2003](#)). However, evidence from developmental disability research also suggests that holidays can have a negative impact on family functioning for families with a member diagnosed with ASD ([Abbeduto et al., 2004](#); [Ghaziuddin & Greden, 1998](#)). Parents in these families often experience higher levels of tension and anxiety than those of children with other disabling conditions ([Gray, 1994](#); [Williams & Aaker, 2002](#)), because of coping with difficult behaviours and providing high levels of emotional support and supervision.

Advancing from this research bridgehead, we turn attention to the emotional and commonplace tourism experiences of mothers holidaying with a child diagnosed with ASD. To do this however, we need to contextualise recent understandings of ASD and its diagnosis within contemporary mental health research. This cannot be a comprehensive conceptualisation of ASD; rather we aim to offer a sense of the lived experiences of mothers holidaying with children diagnosed with ASD and the subsequent complexities this presents in the tourism context. ASDs have largely been characterised by a range of difficulties in social interaction, communication, restricted interests/fluctuating attention span, and a propensity for repetitive behaviours ([American Psychiatric Association, 2000](#)). These characteristics were previously understood as a range of diagnoses (Asperger's Disorder, Autism etc.) under the umbrella term of 'Pervasive Developmental Disorders.' However, the most recent iteration of the Diagnostic and Statistical Manual of Mental Disorders (DSM) ([American Psychiatric Association, 2013](#)) now categorises all such mental health issues, including conditions such as Asperger's Disorder, in the broader diagnosis of ASD (with Rett Disorder the only diagnosis remaining an independent diagnosis). It should be noted that whilst there are distinct differences in approaches towards mental health and disability between the UK and USA, the DSM has long been the standard diagnostic manual used by UK health professionals for mental disorder diagnoses.

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