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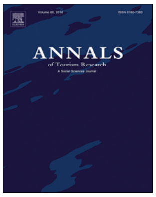

Full Length Article

Intellectual disability and care during travel

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ABSTRACT

This phenomenological study unveils the lived experiences of care during travel of carers and the adults with intellectual disabilities they care for. In-depth interviews unveiled the unique nuances and complexities of giving care to those who are otherwise unable to travel independently. Their care experiences were characterised by emotional entanglements of 'giving', 'attunement', and 'performance', which span personal, relational, and social caring spheres. The findings shine a light on intellectual disability as a complex and marginalised identity, and one that disrupts the generalised notion of travel as an independent activity. Our conclusions validate care as both a practice and an ethic that is amplified, negotiated, and mediated within a tourism context, and offer new directions for accessible tourism research.

Introduction

Extant tourism research fails to adequately challenge the common assumption of independence in travel. Despite burgeoning attention to accessible tourism (Darcy, McKercher, & Schweinsberg, 2020), and the marginalising nature of tourism for some groups of people (Richards, Pritchard, & Morgan, 2010), there remains a dearth of understanding of the experiences of people who are unable to travel independently, such as people with intellectual disabilities. The cognitive and social functioning needs associated with intellectual disability can create dependency on a carer, which is potentially heightened when navigating a complex tourism world and affects the giving and receiving of care within it. Indeed, previous accessible tourism studies have commonly noted the need for people with disabilities to travel with companions for support, such as a family member, friend, or support worker (McKercher, Packer, Yau, & Lam, 2003; Ray & Ryder, 2003). Yet, these studies remain generally remiss, not only in their consideration of the nature of intellectual disability and its impact on travel, but also of the essential care dynamics, which involve (inter)dependency and the support to travel, whether informal or formal, required by people with intellectual disabilities (Gillovic, McIntosh, Cockburn-Wootten, & Darcy, 2021). This is despite recent calls that have noted the comprehensive consideration of the experiences of carers in tourism, as well as the emotional and relational entanglements of such care (McIntosh, 2020; Sedgley, Pritchard, Morgan, & Hanna, 2017).

To move beyond the extant gaps in knowledge, this paper makes an original contribution to the burgeoning accessible tourism scholarship by unveiling the lived experiences of care during travel between carers and the adults with intellectual disabilities

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they care for. In our research, theories of the ethics of care and the phenomenology of lived experience intersect to shed light on the following research question: what are the lived experiences of care during travel like for carers and adults with intellectual disabilities? An interpretive phenomenological approach was undertaken, which is appropriately concerned with the lived experience of human beings, and with revealing their reflexive and subjective accounts (van Manen, 1990) of what it is like to give care to someone while away from home, and within the context of that individual who is being cared for, and is not otherwise able to partake in travel. We do not seek to define, conceptualise, or theorise the phenomena of care but rather to offer an in-depth and exploratory insight into it (van Manen, 1990), from the perspective of the ethics of care as an empathic concern for and respect of another, and an orientation toward relationship (Gilligan, 1982).

While not always expressly linked, the theory of phenomenology and that of the ethics of care appear complementary (Elley-Brown & Pringle, 2021). Martin Heidegger saw care as the very being of life, something preeminent in our existence and something that could provide meaning through our 'being-with' others in the world (Heidegger, 1926/1962). “The world is always the one that I share with Others. … The world of Dasein is a with-world” (Heidegger, 1926/1962, pp. 155, 118). *Sorge*, translated as 'care for' or 'concern for', is positively enacted when an individual directs their attention toward and nurtures others and the world in enabling ways (Elley-Brown & Pringle, 2021). We proffer the view that these theoretical intersections can reveal and contribute rich and nuanced understandings of the care experience during travel; that is, its manifestation, negotiation, and transformation at the personal, relational, and social levels. Ultimately, we put forward the idea that the ethics of care can contribute new analytic opportunities and directions to inform our wider thinking about accessible tourism. Notably, it can provide a more meaningful way to develop new understandings of the experiences of those who may not otherwise travel independently and thus remain marginalised within tourism knowledge, such as people with intellectual disabilities and the essential carers who enable their travel.

Literature review

This paper is situated within the growing field of accessible tourism scholarship that seeks to understand how people with access requirements – whether that be physical, sensory, cognitive, or otherwise – can engage in tourism independently and with equity and dignity (Darcy et al., 2020; Darcy & Dickson, 2009). Developments within this field of scholarship have provided increasing insight into the travel experiences of people with disabilities, primarily physical (Ray & Ryder, 2003), and sensory (Richards et al., 2010), noting the barriers and (dis)embodied nature of much travel for these groups of people. Less focus has extended to people with different disabilities (Innes, Page, & Cutler, 2016), for instance, those that are invisible (McIntosh, 2020), and those with intellectual disabilities (Gillovic et al., 2021). As such, our knowledge remains scant about how groups of people with potentially greater support needs and levels of functioning engage with travel. Equally, a review of the literature reveals that, despite it being well known that people with disabilities, such as those who require care or support needs, often do not travel alone (Lehto, Luo, Miao, & Ghiselli, 2018), it remains that, within the existing body of knowledge, there are limited representations of the caring relationships and activity that may enable travel.

Previous considerations of care in relation to travel have predominantly viewed it as a health aid (for example, Hunter-Jones, Sudbury-Riley, Chan, & Al-Abdin, 2023; Whitmore, Crooks, & Snyder, 2015), rather than a socially motivated leisure activity. A small albeit growing number of tourism scholars have touched on aspects of care within the travel experience itself, but the travel rather than the care experience has tended to be the predominant focus (for example, Gladwell & Bedini, 2004; Hunter-Jones, 2006, 2010). With this extant knowledge, we are, for the most part, limited in our understanding of care as a practical and functional requirement of travel and how care is personally and relationally enacted throughout the travel experience. Studies by Kim and Lehto (2013), Lehto et al. (2018), and Sedgley et al. (2017) have opened dialogue about the care dynamic between family members, including those with intellectual disabilities. In most cases, these existing studies adopt the perspective of either the 'one caring' or 'one cared for' (Noddings, 1984), rather than dynamics and (inter)dependency between the two or the shared experience, thus rendering one an active actor and another passive (Forbat & Henderson, 2003). Important for understanding care in the context of intellectual disability is consideration of the cognitive and social functioning needs that can create dependency and influence the care dynamic.

There is a noted complexity of disability that is magnified when providing care away from home. For people with disabilities, everything is heightened during travel, most notably stress and anxiety, as well as the need for extensive planning, structure, routine, and familiarity (Lehto et al., 2018; McIntosh, 2020; Richards et al., 2010; Sedgley et al., 2017). Carers can minimise stress and encourage a sense of autonomy and confidence among people with disabilities as they work to navigate common constraints and barriers found in travel (McKercher et al., 2003; Yau, McKercher, & Packer, 2004). That said, the burden of care on a carer, who may feel concerned about the individual they give care to, and the stress, fatigue, and burnout associated with that burden, is well-documented in disability and caregiving studies (Henderson & Forbat, 2002; Hubert, 2011), but the same attention has not been given to such matters in tourism scholarship. This is important from a relational perspective because it can indicate how a carer might give care to another, and how they might see themselves in relation to them. We also know that the daily demands and responsibilities of giving care are both time consuming and intensive in terms of the tasks involved (Pinquart & Sörensen, 2006), and can contribute a sense of resentment over compromised or foregone leisure opportunities (Gladwell & Bedini, 2004), despite an opportunity, such as travel, being acknowledged as contributing to quality of life and wellbeing (Mactavish, McKay, Iwasaki, & Betteridge, 2007). From the carer's perspective, therefore, what remains to be heard is why a carer would choose to enable such an opportunity, given its sometimes-challenging realities, and how care manifests and is lived within this context. While the context of daily life is largely the same for carers and people with disabilities, travel offers a new social context that is out of the ordinary and, at its best, transformational for them both.

Care has long been understood from the perspective of morality and moral reasoning (Kohlberg, 1981), and its theoretical development has increasingly demanded a more feminine dialogue to overcome oppressive gender norms (Gilligan, 1982). In her classic, influential text, *In a Different Voice,* developmental psychologist Carol Gilligan (1982) argued that the ethics of care necessitates empathic concern for, and respect of, another, and an orientation toward relationship. The ethics of care considers the impact of one on another, identifying and responding to their needs, and seeking to alleviate suffering (Gilligan, 1982). 'Care' is therefore considered a positive ethical disposition that morally guides our thinking, feeling, and behaviour, and sustains connection, intimacy, and relational wellbeing (Noddings, 2002). Care is also a practice that is cognitive, affective, and indexical, and emphasises values of attentiveness, commitment, openness, dialogue, reciprocity, and respect (Held, 2006; Henderson & Forbat, 2002). That said, considerations of care have been aligned with wider political and social discourses that have tended to exclude and devalue the work of caring in society (Noddings, 1984; Tronto, 1993). The scholarly discussion of care for people with disabilities has had a similar orientation, rendering care as a passive, disempowering and interdependent relationship (Oliver, 2004).

The ethics of care has been influential in understanding the psychology behind caring professions, such as education, nursing, and social work, which are established on notions of care and commitment to the needs of others and make sense of and approach moral issues in practice (Noddings, 1984, 2002). The ethics of care seeks to humanise relationships between self, other, and all others, giving cognisance to the giving and receiving of care, as well as comprehending the social undercurrents and embedded interconnected and interdependent nature of our individual lives (Kittay, 2011). The ethics of care reflects a certain way of being in the world with others, and especially of seeing self in relation to other (Gilligan, 1982). Given its applicability to such caring professions, the ethics of care applies to both informal and formal caring relationships in the private and public spheres (Held, 2006; Tronto, 1993). Because of this, the ethics of care can materialise beyond the personal and intimate in wider societal and global contexts (Kittay, 2011; Noddings, 2002). From a social and political perspective, the ethics of care can also help reframe our understanding of disability, rendering the value and indispensability of care work visible and a central good (Kittay, 2011; Tronto, 1993). Within tourism scholarship, the ethics of care and its relational ontology have been considered in wider discussions to reframe tourism toward more sustainable and just futures (for example, Carnicelli & Boluk, 2021), although these studies have not contributed specifically to the growing focus on disability and accessibility in tourism scholarship.

Ultimately, the ethics of care recognises the vulnerability of the human condition and, therefore, our dependence on, and responsibility to, each other, as relational beings (Gilligan, 1982; Noddings, 1984). As such, we proffer the view that the ethics of care has relevance for theoretically framing understandings of the personal and relational nature of lived experiences of care and disability during travel, beyond the mere functional and devalued elements of providing care support, thus opening up new analytic opportunities and directions for our understanding of accessible tourism. Indeed, we seek to dispel the idea of care as an oppressive activity and a "significant barrier to the emancipation and independence of disabled people" (Hughes, McKie, Hopkins, & Watson, 2005, p. 260). Instead, we proffer a more hopeful approach to view care as "commitment, trust, responsibility, respect, knowledge and a vision of human possibilities" (Pritchard, Morgan, & Ateljevic, 2011, p. 953), reinforcing the need for accessible tourism scholars to give greater critical consideration to the means by which we live in the world with others and are dependent upon them (Noddings, 1984).

Methodology

This interpretive phenomenological study aims to reveal lived experiences of care during travel for carers and adults with intellectual disabilities. Phenomenology privileges the rich and complex diversity of human experience and prioritises a need to delve deeper into that which is ordinary or taken for granted (McManus Holroyd, 2007). At the start and end points of interpretive phenomenological research is lived experience, as it can only be reflected upon, and its meaning, intricacies, and subjectivities intuited, once it has been lived through (van Manen, 1990). Importantly for this study, it maintains that our experiential reality is mediated relationally, in that we find ourselves both living, and living with others, in the world (van Manen, 1990). We recognise that this coming together of lifeworlds also extends to us, as researchers, and those involved in the study (McManus Holroyd, 2007). Positionality was indeed an important aspect of the research as it determined our epistemological intersubjectivity with the participants, especially in terms of our role in (re)interpreting the ontological perspectives of their lived experiences (McConnell-Henry, Chapman, & Francis, 2009). Given the confines of this article and to ensure that the focus remains on the care experience between the 'one caring' and 'one cared for' (Noddings, 1984), we intend to deal with our positionality and reflexivity elsewhere, as a specific focus, to critically consider the varying ways in which each of our own histories informed the research.

This study explores experiences of 'care' during travel. As experiences of care are shared and relational, it was necessary to understand the lived experiences of, and relationship between, the individual giving care and the individual receiving care, both being important as significant people in each another's lives. In this article, the term 'carers' includes those who provide care in an informal/unpaid capacity, such as parents, siblings, other family members, or friends, and support workers who are employed in a formal/paid capacity by an organisation in the health and disability sector. As identified by the carers, those they care for were adults with disabilities for whom the primary nature of their impairment was intellectual. This group comprised adults with varying types of intellectual disabilities, including attention deficit hyperactivity disorder, brain injury, cerebral palsy, Down syndrome, fetal alcohol spectrum disorder, and Fragile X syndrome. In some instances, these adults also had additional disabilities, including epilepsy, mobility impairment, and polyarthritis nodosa. Within the context of their care relationship, participants in this study had travelled domestically and/or internationally together within the year prior to their interview.

Carers and adults with intellectual disabilities were recruited through purposeful and professional criterion sampling in New Zealand (Lincoln & Guba, 1985; Patton, 2002). We developed relationships with national and regional disability service and support organisations over several months, who then distributed the call for participants through their networks. The time taken to build these relationships enabled the researchers' learning and familiarity with the local context, and allowed a level of rapport and trust to be established. In total, 15 carers and nine adults with intellectual disabilities were recruited to participate in the research: an appropriate sample size, typical of the qualitative nature of an interpretive phenomenological study (Szarcyz, 2009). A profile of participants is provided in Table 1. Whilst there was a total of 24 participants in the research, Table 1 identifies a further seven adults with intellectual disabilities who did not directly participate in the research but who were cared for by, and travelled with, some of the carers. The degree of their disabilities and level of support needs was considered high to very high, which precluded them from participation.

Ethical approval was granted for the research by the university's ethics committee. Ethical considerations are particularly important in studies that seek the lived experiences of adults with intellectual disabilities, as their comprehension and expressive-receptive communication abilities may be limited (Nind, 2008). To ensure their capacity to give consent and participate (Boxall & Ralph, 2010), and to meet the demands for rich narrative in interpretive phenomenological research (Kafle, 2011), the study, therefore, drew on sampling criteria used in previous intellectual disability studies to include a final sample of adults with low to medium levels of support needs as opposed to high or very high (for example, Corby, Taggart, & Cousins, 2015). This determination of ability to participate was made by the carer in terms of their understanding of the individual. We recognise the limitation of our research in not including the voices of adults with high or very high levels of support needs. Augmentative or alternative communication measures (AAC) could have been drawn upon to supplement communication, or carers could have facilitated the interview process as a ‘proxy’ (Nind, 2008). Creative and visual research methods, like photo elicitation or photovoice, could have also been utilised to promote participation (Schleien, Brake, Miller, & Watson, 2013; Sigstad & Garrels, 2021). Scholars such as Coons and Watson (2013) and Nind (2008) have highlighted the very real challenges of engaging people with more profound intellectual disabilities in research, irrespective of the availability of alternative communication tools and visual research methods.

In keeping with an interpretive phenomenological approach, and essential to meeting the aim of this study, was the ability of participants to comprehend and narrate their experiences. Given the different communicative abilities of some of the participants with intellectual disabilities, we are aware this may be perpetuating the power yielded by the interview format, which may also

Table 1
Profile of participants.*

Carers				Adults with intellectual disabilities						
Pseudonym	Gender	Age	Travel frequency	Pseudonym	Gender	Age	Travel frequency	Travel nature	Care relationship	Length known
Alyssa	Female	45–54 years	Active	Sadie	Female	25–44 years	Active	Domestic and international	Mother and daughter	N/A
Aroha	Female	45–54 years	Active	Maggie	Female	25–44 years	First-time	Domestic	Support worker and client	Three to five years
Ashleigh	Female	45–54 years	Active	Brooklyn	Female	18–24 years	Active	Domestic and international	Mother and daughter	N/A
Ava	Female	64–75 years	Active	Francesca*	Female	25–44 years	Active	Domestic and international	Mother and daughter	N/A
Cassie	Female	45–54 years	Active	Mason	Male	18–24 years	Active	Domestic and international	Mother and son	N/A
Georgia	Female	45–54 years	Active	William*	Male	18–24 years	Active	Domestic and international	Mother and son	N/A
Gemma	Female	25–44 years	Active	Chloe	Female	25–44 years	First-time	Domestic and international	Friends	Less than one year
Harriet	Female	64–75 years	Active	Ethan*	Male	25–44 years	Active	Domestic	Mother and son	N/A
Jade	Female	45–54 years	Active	Liam	Male	45–54 years	Active	Domestic and international	Sister and brother	N/A
Lily	Female	55–64 years	Active	Noah*	Male	25–44 years	Active	Domestic and international	Mother and son	N/A
Mia	Female	45–54 years	Active	Anastasia	Female	18–24 years	Active	Domestic and international	Mother and daughter	N/A
Nathan	Male	25–44 years	Active	Jacob	Male	45–54 years	First-time	Domestic	Support worker and clients	Three to five years
				Oliver	Male	45–54 years	First-time	International		Three to five years
Phoebe	Female	25–44 years	Active	Gracie*	Female	25–44 years	First-time	Domestic	Support worker and client	Less than one year
Shelby	Female	55–64 years	Active	James* Emma*	Male Female	25–44 years 25–44 years	Active	Domestic and international	Mother and son and daughter	N/A N/A
Sophia	Female	55–64 years	Active				Active		Aunty and niece and nephew	N/A

* This individual with intellectual disability did not directly participate in the research, although they are presented in the article in respect to their relationship with their carer.

be complicit in the silencing or disempowering of some participants (Boxall & Ralph, 2010). All our participants wanted and were able to converse via an interview, although they seemed to find it easier to narrate their travel rather than care experiences, which meant that, inevitably, the thick descriptions of the care experience came mostly from the carers. This is not unexpected given that care is a complex, abstract concept; both a disposition and a practice (Tronto, 1993). Even so, we were touched deeply by what all participants had to say, whether that was fragmented and minimal or coherent and comprehensive.

The data was collected using semi-structured interviews as an appropriate method for adults with intellectual disabilities to be included (Corby et al., 2015) and to reveal lived experiences using an interpretive phenomenological approach (Kafle, 2011). Interview questions covered the dynamics of the care relationship, the travel experience, the care experience, and emotions. Interviews were conducted separately to capture each participant's uncompromised voice and subjective lived experience, although both the carer and adult with intellectual disability were present in some instances. The interviews conducted with the adults with intellectual disabilities drew on a person-centred, strengths- and abilities-based approach. As put forward in Gillovic, McIntosh, Cockburn-Wootten, and Darcy (2018) and Gillovic et al. (2021), this study made accommodations to personalise the content and the process of the interview for the individual, discerned from prior information relayed by the carer, and used when communication was difficult and needed further facilitation. For example, visual prompts, like holiday scrapbooks and souvenirs, were used to encourage conversation. The interviews were conducted in the homes or workplaces of the carers and adults with intellectual disabilities, lasted up to two hours, and were audio-recorded and then manually transcribed. To enhance the credibility and trustworthiness of the data, the carers were given the opportunity to validate their transcripts (Lincoln & Guba, 1985). It is noted, however, that there are practical challenges in member checking with adults with intellectual disabilities, and so care was taken to clarify responses and our interpretation of them (Nind, 2008).

The analytic process followed Braun and Clarke's (2006) ‘phases of thematic analysis.’ Thematic analysis allows for the elucidation of patterns of meaning from the data, emerging inductively, to elicit subjective lived experience (Patton, 2002). Through a manual, iterative and inductive process, units of meaning and key ideas were coded from the transcripts, and then further grouped into conceptual themes, which were given a descriptive label. We did not seek common or definitive findings, and we do not suggest that they are generalisable. Instead, the findings are exploratory and construct but one possible interpretation of the care experience during travel. Three key themes emerged from the thematic analysis, *‘giving’*, *‘attunement’*, and *‘performance’*. These themes are discussed below.

Findings

Giving

The first theme denotes *‘giving’* as a disposition in the care experience. Giving was revealed in this theme through the informal and formal carers' expressions of wanting to give the individuals they care for a *“good life”* through travel that might otherwise be unattainable. The giving of care in this instance involved the carers' mentality of ‘you before me’, knowing and prioritising the needs and wants of the individual they care for while potentially compromising their own, and encouraging autonomy and independence. Inherent in this theme was also the recognition that giving was not one-way but rather reciprocal; the carers equally felt positive from giving care.

The notion of giving arose in recognition of the limitations of an individual's intellectual disabilities which meant they required assistance or support for functioning. Jade [sister] explained this as *“a recognition that he [Liam] can't function in society as it is without some assistance.”* In giving care, the carers felt that they were able to provide positive opportunities for a *“full experience,”* or *“normal life”* and travel was seen as an important way in which to enable this. It has been well-reported that travel contributes positively to the quality of life and life satisfaction of people with disabilities; it provides a break from everyday life, as well as new and novel experiences (Domínguez, Fraiz, & Alén, 2013; Packer, Small, & Darcy, 2008). The findings here potentially exhibit the importance of enabling travel experiences for the adults with intellectual disabilities. The disposition of giving is illustrated aptly in the following quote from Shelby [mother] who travelled frequently, domestically and internationally, with her two adult children [James and Emma] with intellectual disabilities: *“Just because they have very significant disabilities, it's still really important that they get to see lots of things, making it a positive journey, and just having a good life.”* Furthermore, the disposition of giving was also felt positively by the carers. For example, Nathan [support worker] explained, *“You feel pretty privileged to be able to support someone to do all that stuff; stuff you normally wouldn't be able to do.”*

The disposition of giving could also be found in sentiments of ‘you before me.’ Both informal and formal carers conveyed this through statements like *“it was completely for him,”* and *“this trip was all about her.”* To illustrate, Alyssa [mother] explained that *“we were very conscious that all the decisions, everything, was going to be what Sadie wanted and what was going to work for her best,”* while Jade [sister] expressed, *“I think that's probably the main thing about it; it was individualised for him [Liam], considering what he was needing, wanting, choosing.”* Carers holding a sense of responsibility to prioritise the needs of individuals with disabilities has been recognised by previous scholars examining travel experiences (Hunter-Jones, 2010; Kim & Lehto, 2013). By having their needs prioritised, the adults with intellectual disabilities benefitted from being supported to travel by the carers. Common comments included, *“I did love it and want to go on another trip; go to other places I haven't seen,”* and *“I love travelling a lot in the world, it's my big thing, I've realised I love going so much.”*

In prioritising the adults with intellectual disabilities, the carers often compromised their own travel wishes, or those of other family members, which other accessible tourism scholars have also found (Kim & Lehto, 2013; Mactavish et al., 2007; Sedgley et al., 2017). Jade [sister] explained that her husband did not go on a particular trip to Rarotonga because of *“some inter-*

dynamics about it all," in relation to the giving of care that her Liam [brother] required while away. Similarly, Cassie [mother] described how she abandoned family plans to go to Fiji because it was *"not going to work"* for Mason [son]. This finding was nuanced by the situation of formal carers, for whom travel was not a pre-requisite of their work, but they felt was a priority to enable the travel wishes of the individual they cared for. For instance, Phoebe [support worker] travelled with Gracie [client] on her first ever trip away, and relayed, *"If I didn't volunteer, she wouldn't have gone. I just thought, 'what's a few days', that could make her happy for a whole lifetime."*

An additional element of giving care was around *"providing a platform for their own independence," "supporting them in their decisions," "encouraging self-determination,"* and *"fostering self-reliance,"* in *"whatever shape that takes"* or *"whatever form that may be."* This disposition extended to involving the adults with intellectual disabilities in the holiday preparation where possible. Packing was one example of this, empowering them with a sense of ownership over the process. Ava [mother] commented:

> She [Francesca] can decide what to pack in her bag and take as far as activities go. Often, we'll go shopping and she'll choose something that she wants to take on the plane with her to do, and usually she chooses one of her soft toys.

Carers also described how they involved them in the holiday planning to facilitate autonomy. For example, together they prepared a *"daily schedule," "holiday spreadsheet,"* or *"holiday diary,"* to *"keep them involved," "prepare a sense of interest,"* and afford the *"feeling of having some control over what was happening."* Some carers recognised that the adults with intellectual disabilities required time to mentally process and prepare themselves for travel, due to *"a need to know in advance what was going to be happening."* Alyssa [mother] explained, *"You can't just spring something on her [Sadie]; you've got to sow the seed and give her time to process a holiday."* Other carers interpreted that communicating holiday planning too far in advance could heighten anxiety among the adults with intellectual disabilities. Georgia [mother] explained, *"I actually won't tell him [William] pretty much until it's about to happen, because otherwise it's a sense of him getting all anxious in the buildup of it."* Determining the nature and right time to communicate travel plans depended on the carer's understanding of the individual. Facilitating autonomy in the giving of care during travel thus came from an important understanding of their unique needs, and communication was an important example of this.

Attunement

The second theme revealed emotional *'attunement'.* This was characterised by the carers' ability to perceive and respond to the emotions of the adults with intellectual disabilities. Attunement was demonstrated through comments such as, being *"intuitive"* and *"perceptive," "trying to pick up on their emotion; staying in tune with how they're feeling."* Based on the carers' experience and knowledge of the individuals, they described themselves as being able to *"read"* them and, as a result, could tell what they were thinking, feeling, or likely to say or do. This was illustrated in comments like *"I can usually read him and sense if there's something wrong,"* and *"I generally know what he wants before he wants it, and I've already delivered it to him."*

Carers described noticing changes in their body language, general demeanour, and mood, including for example, *"retreating into silence"* or *"getting a little bit watery-eyed."* Alyssa [mother] explained, *"She [Sadie] usually has all these signals for when she's not happy about something; so, we are just attuned to, 'this is what's going to happen,' she'll go quiet and then she'll start."* It was important for the carers to use simple strategies like *"keeping an eye out"* or *"checking in without being overbearing,"* because they *"can't say, 'I'm upset. I'm going to leave the room and go and have quiet time,' and just lashes out."* As previous scholars have noted, intellectual disability and associated expressive-receptive communication can bring unique challenges, requiring a distinctive thoughtfulness (Ruddick, 1989; Tronto, 1993).

The carers reported that they also needed to be attuned to their own emotions, and to how they might impact upon the care experience. The carers described how the adults with intellectual disabilities could pick up on their emotions, and common comments relayed included: *"If I'm getting cross, impatient and frustrated, if I show it, straight away he will pick up on it,"* and *"we had to be quite deliberate about not getting stressed; if I get stressed too, she will get even more stressed."* The carers expressed their intention to be both self-aware and positive. To illustrate, Nathan [support worker] who travelled with Jacob and Oliver [clients] on each of their first trips explained, *"I think a lot of it is just positivity, positive experiences, positive reinforcement, positive encouragement. Just to not seem too worried and keep the vibe positive on the trip."*

Maintaining presence and positivity was nuanced since carers did not always find it easy to attune to their own emotions and the effect of them. In these instances, it required the carers to draw on emotional coping strategies, particularly as the care experience during travel was described as *"intense."* Tourism scholars have similarly recognised the intensity of travel when caring activity is involved (Lehto, Soojin, Yi-Chin, & MacDermid, 2009; Sedgley et al., 2017). Carers reported that they called on support from home as *"an avenue for decompression,"* or attempted to create *"a bit of space," "downtime,"* or *"timeout."* Whilst providing care for Chloe [friend] on her first trip overseas, Gemma [friend] relayed:

> I just needed time to reground myself, and that's how I really eased myself back into being happy and relaxed again. I think about halfway through I was kind of burning out a little bit, just emotionally going a bit crazy.

Chloe recognised Gemma's need for space, and commented:

> Gemma became dependent in about the middle of our trip, in the sense that she needed me to take on more responsibility so she could rest. I think she felt a bit of burnout after the first leg, so we needed to moderate that.

Indeed, there was an interpretation by some carers that the adults with intellectual disabilities also showed them emotional attunement in the care experience. Ashleigh [mother] commented, *"She's [Brooklyn] pretty good at noticing if I'm not happy and at making me happy."* Aroha [support worker] reflected on a situation where she felt as though there was a role reversal in the care relationship, as Maggie [client] seemed to be attuned to her fear of flying. She recalled:

> I realised it was me, she was actually the calm one, and I was going on and on, talking the whole way. She wasn't freaking out or anything – which I wouldn't have known how it would have affected me – but it was almost like she was looking after me on the plane.

As some carers also travelled with another person, such as their partner or child, there were other relational dynamics that helped them manage their emotions. Their comments included, *"we were able to play tag-team,"* and *"we are pretty good at managing between us; if one gets stressed, the other can usually stay calm."* That said, travelling with others was also found to create additional emotion work for the carer, as they needed to be attuned to everyone's needs, while also trying to manage the relational dynamic. To illustrate, Georgia [mother] explained:

> I don't find it necessarily less stressful because my husband is not so patient with William [son]. He will get even more cross. They end up having a confrontation, so that doesn't really help me because I'm stuck playing piggy in the middle.

For formal carers, there was noticeably less emotional support available while travelling than there was at home. Phoebe [support worker] explained, *"In the home that she [Gracie] stays in, we are double staffed. It was overwhelming, I was extremely exhausted; we usually have two people to help with her cares and supporting her, and I was doing it on my own."* The ability to attune was further nuanced by the temporary and intense nature of the travel context. This was expressed by both informal and formal carers through comments like *"he was just pushing all the buttons, I was getting really agitated so walked out for some fresh air,"* and *"just take a little break and get back to it and know that it wasn't going to be forever."*

Performance

The third theme represents the nuances of the ways in which care was performed and negotiated during travel. This *'performance'* was predominantly determined by the perceived or actual discernment of disability and/or care relationship by others, and the visibility of this. Due to the invisibility of intellectual disability, *"because these disabilities aren't always obvious"* or *"immediately apparent,"* the carers described how they made efforts to render the individual's need for care visible to others; *"to be made known to a degree."* This need for disclosure has also been referred to by other tourism scholars to minimise the potential for misunderstanding or stigmatising (Innes et al., 2016; McIntosh, 2020; Packer et al., 2008). The carers did this, for example, by prompting the individual to speak to make their disability, and therefore need for care, visible. The carers would say something to make this known too: *"You might jump in and say something that sort of makes it known you are there; you might just help smooth it out somehow."* The carers would also make this known through performed actions, such as taking the individual's arm.

Where the disability was visible, the carers noted that there was less of a need to make the care relationship known, as they felt others perceived and interacted with them more positively. Gemma [friend] described how Chloe's [friend] power chair presented a tangible visibility of her cerebral palsy to others, making her *"personally approachable and accessible."* She reflected on the *"warmness"* she felt, where *"people talked to her a lot more, smiled at her a lot more."* This was often viewed as affirming dependency and paternalism. Chloe, for example, explained:

> People offer to help you, people want to help you – very nobly – but it doesn't give you a sense of self-competency, confidence, or coping; because you're not expected to cope, and when you travel, all you do is cope. It's becoming a bit of a spectacle, so you're not just the fellow traveller, you're the awkward one that gets carried everywhere, and it's not a particularly pleasant experience.

The carers, in these instances where the adults with intellectual disabilities they cared for were also wheelchair users, were affirmed as 'heroes', suggesting a noble image. To illustrate, the following statement was made to Lily [mother] while she was travelling with Noah [son], *"You people are marvelous at what you do,"* assuming she was a support worker and not his mother. This was also true for Gemma [friend], who was praised, *"what a good person,"* assumed to be *"there in a professional not a personal sense."* She depicted this as *"the whole 'hero' mentality."*

In contrast, where the intellectual disability was less visible, because, for example, they were not a wheelchair user, the carers felt that others perceived and interacted with them less positively, denoting othering and stigma. The carers conveyed these attitudes and behaviours as *"ignorant," "intolerant," "looking away," "moving away," "giving funny looks," "staring,"* and *"pointing."* The adults with intellectual disabilities similarly described *"being shoved out of the way"* and *"pushed around,"* feeling *"annoyance," "frustration," "anger,"* and *"upset."* It has been acknowledged that people with disabilities, and the care they receive, are exposed to the discernment of others (Hughes & Paterson, 1997; Thomas, 2007) when travelling. A consequence of this discernment was heightened anxiety, stress, and behavioural problems among the adults with intellectual disabilities, requiring the carers to manage such behaviour due to their visibility in the public space of the travel context, which is also exposed to the judgment of others. Harriet [mother] explained how Ethan [son] who has Fragile X syndrome could exhibit behaviour challenges:

> He starts to get anxious, calls and lashes out, bites himself and sort of bangs the window. I used to get the feeling that people would look at me and think, "Look at that undisciplined child, why isn't the mother dealing with it?" Because

> he looked normal, people didn't understand that there was actually a problem, and that it wasn't simply a discipline problem.

The carers felt others judged the behaviour as *"not congruent with social norms"* and lacking in understanding about intellectual disabilities. They often drew comparisons between adults with intellectual disabilities and young children but argued that the behaviour would be treated more sympathetically if it was a young child. To demonstrate, Ava [mother] articulated, *"People with young children are moved through, and sometimes I feel like one of those as well – because it's like having a young child – but I don't get the advantages of having a young child."* Cassie [mother] gave the example of how Mason [son] has a propensity to *"completely phase out and stare,"* a characteristic common of people with Fragile X syndrome. She recalled an incident where his staring was ill-received by a restaurant patron: *"This woman stood up and shouted in his face: 'What are you staring at? What's the matter with you? Will you stop him staring?'"* She reported that she challenged the woman by saying, *"He's got a disability, what's your excuse?"*

These instances drew responses of *"disappointment," "embarrassment,"* and *"vulnerability"* among the carers. They expressed frustration with the way other people reacted to them, commenting, *"I just want to put him in a t-shirt that says something like, 'stop staring, I am this…'," "There are times where you want a badge or a card or something where you can say, 'well actually, this is…',"* and *"This is what a disabled person looks like; she's not causing you any harm, so just put up with it, people."* The carers did feel these frustrations lessened as they acquired an aptness and developed a *"resilience"* in negotiating such experiences with others.

Discussion

This phenomenological study was driven by the research question: what are the lived experiences of care during travel like for carers and adults with intellectual disabilities? Care during travel was found to be a disposition of *'giving'*, a quality of emotional *'attunement'*, and a socially constructed *'performance'*, nuanced through the intricacies of each care relationship. This research revealed that care is an ethical disposition and an affective, reciprocal practice (Tronto, 1993); it is a way of being in the tourism world and not merely a functional activity. Together, these expressions of care are representative of the ethics of care (Gilligan, 1982), emotion work (Hochschild, 1983) and, indeed, are a labour of love (Finch & Groves, 1983), and they serve to counter claims of care as disempowering (Oliver, 2004). Equally, they confront and problematise notions of independence, pleasure, and visibility, which tend to dominate conceptualisations of the travel experience. As such, our inquiry, in which the theories of the ethics of care and the phenomenology of lived experience intersect, highlights three points of wider significance for accessible tourism scholarship.

First, *'giving'* highlighted the personal caring sphere, "where day-to-day care is carried out relationally" (Rogers, 2016, p. 2). For the carers, care is emotion work at home as it is during travel, but care was never seen as a burden or painted in a negative light – rather the opposite. As in Lehto et al. (2018), none of the carers "articulated sentiments of unchosen obligations or burdens" (p. 182). Rather, care was selflessly given by both the informal and formal carers in our study, with the prioritising of someone else's needs over their own and positive meaning derived in doing so. Care ethicists have recognised this sensitivity to, and emphasis on, the needs and wants of others, as a feminine selflessness (Gilligan, 1982; Tronto, 1993). This is particularly demonstrated in this research because of the altruistic way in which carers facilitated meaningful travel experiences for the individuals they cared for. In line with previous tourism studies (for example, Kim & Lehto, 2013; Lehto et al., 2018), we found that there was a sense of pride and gratitude among the carers from giving care to enable travel, even when, at times, it necessitated some compromise to their own wishes. However, previous tourism studies have not primarily focused on intellectual disability or the entanglements of care around that such as, for example, knowing how and when to communicate and organise travel plans to allow time for mental processing and to minimise anxiety. Our study has shown that a disposition of giving, beyond the daily care already provided, is what enabled travel for these adult individuals who might otherwise not have such an opportunity because of their unique cognitive and social functioning abilities. This disposition was found among both the informal and formal carers, although further investigation is needed to confirm this finding.

Secondly, *'attunement'* highlighted the emotional caring sphere, "where love and care are psycho-socially questioned" (Rogers, 2016, p. 2). Here, the carers were attuned to self, to self in relation to other, and to others, which the ethics of care and emotion work both denote (Gilligan, 1982; Noddings, 2002; Tronto, 1993). 'Emotion work [or] labour' (Hochschild, 1983) has frequently been discussed in relation to disability and care (Ruddick, 1989; Steinberg & Figart, 1999). It is the "act of trying to change in degree or quality an emotion or feeling … to 'work' on an emotion" (Hochschild, 1979, p. 561). Care ethicists have emphasised attunement as feminine capacities to intuit, attend, sense, and feel the emotions, and emotional cues of another, and to meet them with compassion (Kittay, 2011; Noddings, 2002). Previous studies have determined the often-unfamiliar travel context as emotionally over-stimulating (Richards et al., 2010; Small, 2015). Indeed, our study found that the adults with intellectual disabilities' stress and anxiety, vulnerability, and dependency were heightened and nuanced during travel. Consequently, the carers' emotion work was amplified. Not only did it require the carers to moderate these heightened feelings, but to also moderate their own feelings and responses, recognising how these may potentially further impact the care relationship in being away from their usual environment. Furthermore, there was some evidence of the adults with intellectual disabilities demonstrating attunement toward their carers, which potentially acknowledges a certain mutuality and reciprocity in the emotional attunement of the care experience, despite differences in cognitive and social functioning (Henderson & Forbat, 2002; Hubert, 2011; Noddings, 2002). These findings contribute new insights into accessible tourism scholarship by highlighting the quality of attunement and the emotion work that is involved in giving care to enable travel for adults with intellectual disabilities.

Thirdly, *'performance'* highlighted the socio-political caring sphere, "where social intolerance and aversion to difficult differences … played out" (Rogers, 2016, p. 2). Within a travel context, disability and care are at the mercy of social construction and stigma (McIntosh, 2020). Tourism does not take place in a 'social vacuum' (Small, 2005); everyday social identities, restrictions, and stigma associated with disability are still felt, imposed upon, and even internalised while travelling (Eichhorn, Miller, & Tribe, 2013; Sedgley et al., 2017). Because of the cognitive and social functioning complexities of intellectual disability, and the often-invisible nature of intellectual disability and care, giving care can become performative. Our study found that the carers' emotion work not only necessitated that they were attuned to the emotions and behaviour of the adults with intellectual disabilities, but also to the actual and potential reactions of others. Thus, in any given situation, the direction and intensity of emotion work is somewhat demarcated to meet social norms, practices, and expectations (Goffman, 1959; Hochschild, 1979; Steinberg & Figart, 1999). Sedgley et al. (2017) relayed how, for mothers of children with autism, a significant challenge faced in giving care during travel was being subjected to the judgment of others, their public censure and condemnation. However, our study provides new insights into the performative way in which these social restrictions were actively resisted and negotiated by the carers. For example, by making intellectual disability and/or the care relationship visible, they attempted to mediate the social gaze and judgment of others in an effort to make their perceptions and interactions more positive. Given carers become active agents seeking to challenge and disrupt the social gaze during travel, previous considerations of accessible tourism have therefore been remiss in their lack of consideration of the importance of care work as empowering in this regard. Our study highlights the importance of this in the distinctive context of intellectual disability, where disability may be invisible and associated behaviours misinterpreted and stigmatised, particularly for adults.

Conclusion

Our phenomenological inquiry reveals the lived experiences of care during travel between carers and adults with intellectual disabilities. Care was experienced, not merely as a functional activity, but as dispositions of *giving* and emotional *attunement*, and the nuances of the ways in which care was *performed* and negotiated during the travel experience to mediate the actual and potential judgment of others. Our study confirms that tourism appears to perpetuate the dependency, marginality, and invisibility of both intellectual disability and care (Gladwell & Bedini, 2004; Lehto et al., 2018; Sedgley et al., 2017). Our participants with intellectual disabilities would remain marginalised from travel without support from their carers, or the financial means to facilitate it. At the discernment of others, care for an adult with intellectual disability could play into ableist and heroic discourses of care, and further emphasise the dependency surrounding intellectual disability (Higgins & O'Leary, 2022). That said, their carers prioritised their needs to enable travel challenges disempowering notions of care work (Oliver, 2004). Whilst disability scholars have tended to resist the notion of 'care', our study tends to confirm a feminist critique of the concept, its emotional aspects, and the mutually beneficial ethics of care. Furthermore, the findings of this study highlight the care experience during travel as entailing strategies of performance and resistance (Eichhorn et al., 2013; Gillovic et al., 2021). That the adults with intellectual disabilities were less able to articulate their experiences of the care they received during travel compared to their carers only serves to highlight the more complex nature of intellectual disability. As such, we call on accessible tourism scholars to further understand the heterogeneity of disability (Gladwell & Bedini, 2004; Innes et al., 2016; Richards et al., 2010; Small, 2015) and its complexities in 'meeting one another morally' through the ethics of care in tourism (Noddings, 1984).

We posit that the ethics of care can provide a new analytic opportunity and direction to inform our understanding of accessible tourism, specifically, the dispositions, (inter)dependency, and emotional and relational entanglements of the care experience that enables travel for people with disabilities. As international travel involves the crossing of different geographic and cultural spheres, future accessible tourism research could examine demographic, cultural, social, economic, and political dimensions of the care experience during travel. These broader dimensions merit critical consideration in the context of the informal and formal care and welfare systems, social and health policies, wider discourses, ideologies, and constructions of care, as well as gendered and embodied distinctions that may impact upon the ability of carers to enable travel for people with intellectual disabilities, the skills required, and effective strategies for resistance and empowerment. We also invite future researchers to reflect on contexts and processes where 'words may fail' to fully convey the lived experiences of people with intellectual disabilities; the embodied and affective atmospheres of caregiving may offer analytic routes that supplement the understanding of providing care during travel that may not be discerned from limiting talk-based methods alone. To conclude, we have much yet to discern about our empathic concern for others and the relational and care dynamics of travel. We make a plea to accessible tourism scholars to make common cause in recognising a need for the ethics of care to enable people with cognitive and social functioning needs to engage in travel 'independently' and with equity and dignity (Darcy & Dickson, 2009).

CRediT authorship contribution statement

Brielle Gillovic: Conceptualization, Methodology, Investigation, Writing – original draft, Writing – review & editing. **Alison McIntosh:** Conceptualization, Methodology, Writing – original draft, Writing – review & editing, Supervision. **Cheryl Cockburn-Wootten:** Writing – review & editing, Supervision. **Simon Darcy:** Writing – review & editing, Supervision.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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