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# Exploring Informal Caregivers' Roles in Medical Tourism through Qualitative Data Triangulation

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## Exploring Informal Caregivers' Roles in Medical Tourism through Qualitative Data Triangulation

### Abstract

When Canadian medical tourists go abroad, they are often accompanied by friends and family, referred to as caregiver-companions, who provide informal care. These individuals play a role in patient decision-making and are stakeholders in medical tourism, yet little is known about their participation in this consumer health practice. To examine the roles that Canadian caregiver-companions play while accompanying medical tourists abroad, and to identify how multi-perspective qualitative data can augment our understanding of these roles, primary and secondary analysis was undertaken on datasets generated from multiple qualitative studies: semi-structured interviews with medical tourists, caregiver-companions, and international patient coordinators, and a survey with medical tourism facilitators. The findings from the triangulated analysis of these qualitative datasets serve to better understand the multiple, overlapping perspectives of different stakeholders in medical tourism. Results show that medical tourism caregivers act as companions, providing physical and emotional care; navigators, providing logistical assistance; and knowledge brokers, participating in decision-making and information exchange between medical tourists and professionals. Using data triangulation to examine the narratives of multiple stakeholders confirmed, altered, and augmented our knowledge of caregiver-companion roles. The unique perspectives offered by each participant group augment our understanding of caregiver roles and the practice of medical tourism.

### Keywords

Caregivers/Caregiving; Family Caregiving, Medical Tourism, Semi-Structured Interviews, Qualitative Analysis, Triangulation

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## Exploring Informal Caregivers' Roles in Medical Tourism through Qualitative Data Triangulation

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*When Canadian medical tourists go abroad, they are often accompanied by friends and family, referred to as caregiver-companions, who provide informal care. These individuals play a role in patient decision-making and are stakeholders in medical tourism, yet little is known about their participation in this consumer health practice. To examine the roles that Canadian caregiver-companions play while accompanying medical tourists abroad, and to identify how multi-perspective qualitative data can augment our understanding of these roles, primary and secondary analysis was undertaken on datasets generated from multiple qualitative studies: semi-structured interviews with medical tourists, caregiver-companions, and international patient coordinators, and a survey with medical tourism facilitators. The findings from the triangulated analysis of these qualitative datasets serve to better understand the multiple, overlapping perspectives of different stakeholders in medical tourism. Results show that medical tourism caregivers act as companions, providing physical and emotional care; navigators, providing logistical assistance; and knowledge brokers, participating in decision-making and information exchange between medical tourists and professionals. Using data triangulation to examine the narratives of multiple stakeholders confirmed, altered, and augmented our knowledge of caregiver-companion roles. The unique perspectives offered by each participant group augment our understanding of caregiver roles and the practice of medical tourism. Keywords: Caregivers/Caregiving; Family Caregiving, Medical Tourism, Semi-Structured Interviews, Qualitative Analysis, Triangulation*

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### Background

Medical tourism occurs when individuals travel abroad to obtain private medical care that is not arranged through their home health care systems (Hopkins, Labonté, Runnels, & Packer, 2010; Hanefeld, Horsfall, Lunt, & Smith, 2013). Reliable quantitative data on medical tourism are not available due to data collection challenges and because existing figures are based on unreliable reporting (Hopkins et al., 2010), but most industry and media accounts suggest that this practice is growing in popularity. With information from the internet readily available and increased familiarity with international travel, some patients are readily choosing healthcare in new contexts, such as the private, international clinics of medical tourism (Connell, 2013). Medical tourism thus provides an interesting lens for the study of public participation in health care and health policy, as it intersects with themes of patient participation in health care decisions, patient empowerment, and health care consumerism.

Patients may choose to travel abroad as medical tourists for several reasons: high out-of-pocket costs for procedures at home, inability to access desired procedures, and/or wait times (Hopkins et al., 2010; Snyder, Crooks, & Turner, 2011). Much of the qualitative research that has been conducted about medical tourism is focused on specific aspects of this phenomenon, such as medical tourism facilitators and websites (Maguire et al., 2016; Turner,

2012; Viladrich & Baron-Faust, 2014) or the experiences of individuals engaging in specific types of medical tourism. These include travel for fertility or reproductive procedures (Crozier & Martin, 2012; Deonandan, Green, & van Beinum, 2012; Hudson et al., 2016), stem cell interventions (Einsiedel & Adamson, 2012; Ogbogu, Rachul, & Caulfield, 2013), bariatric surgery (Kim, Sheppard, de Gara, Karmali, & Birch, 2016), procedures that are illegal in their home countries (Cohen, 2012; 2015) and plastic or cosmetic surgery (Adabi et al., 2017; Iorio, Verma, Ashktorab, & Davison, 2014). Researchers have identified specific areas of safety concern in medical tourism, such as the quality of care, patient safety, public health threats, legal liability, and health equity impacts on destination country health systems (Chen & Flood, 2013; Hohm & Snyder, 2015; Meghani, 2011; Neri, Turillazzi, Pascale, Reizzo, & Pomara, 2016; Turner, 2013).

Industry reports and recent studies show that when medical tourists travel abroad, they are often accompanied by friends and family (e.g., Crooks, Whitmore, Snyder, & Turner, 2017; Margolis, Ludi, Pao, & Wiener, 2013; Yu & Ko, 2012). These individuals, who we refer to as caregiver-companions, provide informal care that spans from providing emotional support to managing medications. The transnational nature of informal caregiving in medical tourism provides important context for this form of care. Margolis et al. (2013) found that informal caregivers traveling across borders face challenges related to language barriers, financial and emotional strain, and that they draw on the support of hospital staff and other family members to manage these challenges. Contextual factors have a significant impact on the levels of burden and distress that informal caregivers experience (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Tramonti, Bongioanni, Leotta, Puppi, & Rossi, 2015), which means that the transnational care context could impact outcomes for caregivers, as well as their access to useful supports. Although these individuals seemingly play an important role in medical tourism, little is known about the actual scope and breadth of their activities and experiences.

In this article, we present the findings of a triangulated analysis of four qualitative datasets to understand the main roles that Canadian caregiver-companions play while accompanying medical tourists abroad. Triangulation refers to the use of multiple data sources or approaches to analysis in order to enhance the credibility and dependability of a study or an analysis, and to generate new knowledge by synthesizing different methods or the voices of different participant groups (Moran-Ellis et al., 2006; Vikström, 2010). In this article we examine the perspectives of former Canadian medical tourists, former caregiver-companions, medical tourism facilitators, and international patient coordinators at medical tourism facilities. Informal caregivers are central to the provision of care throughout the medical tourism journey, in domestic and international settings. They often play a role in making the decision to engage in medical tourism, and they are significant stakeholders in this practice. Triangulation of these data sources is used to learn more about the roles they play in order to enable safer, better-informed decision-making about medical tourism and to inform health practitioners of some of the broader impacts of medical tourism. This analysis builds on our interdisciplinary team's qualitative research exploring the equity and ethical dimensions of medical tourism that has spanned the last decade. Though our team of social science and humanities scholars is based in Canada, our research has explored how medical tourism operates in a diverse range of destination nations, and it was through our first-hand international fieldwork that we first became aware of the significance of caregiver-companions to the practice of medical tourism.

## Methods

This analysis contributes to a multi-qualitative method study that aims to understand the roles taken on by the caregiver-companions who accompany Canadian medical tourists abroad. This study was spurred by previous interviews with Canadian medical tourists

examining their decision-making processes around seeking care abroad that first revealed the importance of informal caregiving in medical tourism (Crooks, Snyder, Johnston, & Kingsbury, 2011). The current study has involved data collection with multiple groups: an online survey of Canadian medical tourism facilitators (i.e., private agents who arrange travel and care plans for medical tourists); interviews with international patient coordinators at medical tourism facilities; and interviews with Canadian caregiver-companions. A summary of the four participant groups and datasets from the current and previous studies is provided in Table 1. A previous thematic analysis of the international patient coordinator interview dataset alone first introduced three key roles played by caregiver-companions: companion, navigator, and knowledge broker (Casey, Crooks, Snyder, & Turner, 2013a). We expand on these roles below via data triangulation. Here we undertake a single triangulated analysis of all four datasets summarized in Table 1 in order to directly compare the different perspectives each group brings to understanding the roles that caregiver-companions play in supporting and caring for medical tourists.

*Table 1. Overview of participant groups*

Participant Group	Number of Participants	Method of Data Collection
Former Canadian medical tourists	21 (a subsample who travelled with caregiver-companions from a dataset with 32 participants)	Semi-structured telephone interviews
Canadian medical tourism facilitators	7 from 7 different facilitation companies	Online survey
International patient coordinators	21 from 16 different medical tourism hospitals in 10 countries	Semi-structured telephone or Skype interviews
Former caregiver-companions to Canadian medical tourists	20	Semi-structured telephone or Skype interviews

In the companion role, caregiver-companions provide physical and emotional care to their friends and family members while abroad, en route, and at home. As navigators, caregiver-companions help the medical tourist deal with unfamiliar cultures, the stresses of travel, and documents and finances. Finally, as knowledge brokers, caregiver-companions interact with staff and health care professionals at the destination facility, sharing information with and on behalf of the medical tourist (Casey et al., 2013a). These three roles were identified based upon experiences reported by 21 international patient coordinators working at 16 different medical tourism facilities in 10 countries. Although the identification of these roles provided important new insights about caregiver-companions, an obvious limitation of the initial analysis is that caregiver-companions themselves were not consulted. We overcome this limitation in the current analysis, while also adding rigour to the analytic process through triangulating four datasets.

In the section that follows we set out the recruitment and data collection methods for the four datasets used in this analysis and describe how the initial interviews and inductive analysis published by Casey et al. (2013a) provided a framework for the deductive analysis of all four datasets reported on here. We then present the findings of the triangulated thematic analysis, elaborating on how the unique perspectives offered by each participant group inform

our understanding of the various roles played by caregiver-companions. We generally find they confirm and add nuance to the previously identified roles. Different stakeholder groups place different degrees of emphasis on the importance of different tasks, which provides a robust picture of the scope and scale of each role.

## **Recruitment and Data Collection**

Recruitment and data collection methods from the medical tourist and international patient coordinator datasets have been reported on elsewhere (Casey et al., 2013a; Casey, Crooks, Snyder, & Turner, 2013b; Johnston, Crooks, & Snyder, 2012). This section will briefly overview the methods for those studies and introduce in full the methods used for the medical tourism facilitator survey and retrospective semi-structured caregiver-companion interviews. All portions of the studies received ethics approval from the Research Ethics Board at Simon Fraser University prior to their start. To be clear, and acting in accordance with O'Reilly and Parker's (2013) article highlighting issues around the notion of "saturation," we do not claim to have saturated sample sizes in any of the datasets. Rather than seeking saturation, which would not have been practical or possible given the participant groups consulted, for all four datasets we sought instead to capture maximum diversity and sufficient depth of information within the allotted recruitment time period.

### **Former Canadian medical tourist interviews**

Between July and November 2010, we conducted semi-structured phone interviews with 32 Canadians who had previously obtained surgical treatment abroad. Participants were recruited through five concurrent strategies: media scans, advertising in print newspapers, online postings, snowball sampling, and by providing study information to medical tourism facilitators. Upon contact with our team, detailed study information was provided to potential participants. Once potential participants were found eligible, interview times were scheduled, and interviews were conducted over the telephone. Data collection ended when all the recruitment methods had been exhausted and no new participants were identified for a one-month period. Interviews were recorded and typically lasted 1-1.5 hours, covering a range of topics that included elements of planning prior to the trip, experiences during the trip, and post-trip access to follow-up care. All interviews were transcribed verbatim for analysis.

### **Canadian medical tourism facilitator survey**

Our online survey was completed in 2012 by seven Canadian medical tourism facilitators who collectively had contact with hundreds of prospective and actual medical tourists. The seven surveys completed represented well over half of the medical tourism facilitation companies in operation in Canada at the time. The purpose of the survey was to gain an initial sense as to caregiver-companions' roles and responsibilities towards medical tourists before speaking with international patient coordinators or former caregiver-companions. Questions were exploratory and open-ended, with the exception of some closed demographic questions. The secure online survey was distributed via email to Canadian medical tourism facilitation companies identified through an exhaustive online review, inviting the companies to have an employee participate. The survey itself consisted of 32 questions, asked on a single page, about how often the facilitators recommend traveling abroad with a companion, the relationship between medical tourists and companions, and the roles played by companions. It took approximately 15-30 minutes to complete. Prior to completing the survey, participants were provided with information about their rights as a participant.

### International patient coordinator interviews

In 2012, we conducted 21 semi-structured interviews with international patient coordinators working at medical tourism hospitals. Recruitment of international patient coordinators occurred through three concurrent methods: emailing invitations to hospitals with websites that mentioned international patient coordinators, those identified on online directories, and those who had posted on online forums; snowball sampling; and by disseminating advertisements for participants through the team's networks and online medical tourism forums and magazines. Once their eligibility was confirmed, interested potential participants were provided with information about the study by email and then Skype or phone interviews were scheduled. Interviews typically lasted 45-60 minutes and asked about the characteristics, roles, responsibilities, and risks associated with informal caregiving in medical tourism. All interviews were transcribed verbatim for analysis.

### Former Canadian caregiver-companion interviews

Our recruitment of, and interviews with, caregiver-companions spanned from September 2013 to February 2014. Recruitment was conducted through four concurrent strategies. First, past medical tourist study participants were emailed to ask if they had been accompanied and, if so, whether their companion would be interested in participating. Second, past and new participants passed on study information to individuals that they thought might be interested. Third, we disseminated study information through online postings on Craigslist across Canada. Finally, media and newspaper articles were reviewed for mention of medical tourists, locating contact information and contacting them when possible. Recruitment emails included general study information and follow-up emails to interested study participants confirmed their eligibility. Once someone had been deemed eligible to participate, we sent them more detailed study information, including information about ethics approval and participant rights. We stopped actively recruiting participants when we reached our target sample of 20 individuals.

Twenty interviews with caregiver-companions were conducted over telephone or Skype, lasting between 40-80 minutes. Verbal consent was obtained before each interview and a semi-structured interview guide was used to frame questions about topics such as planning prior to travelling abroad, experiences while in the destination country and in the foreign medical facility, experiences of interactions with health care workers, impacts on their own health, relationships with the medical tourist, and advice they would give to other caregiver-companions or to policy makers (see Table 2 for selected questions). Interviews were recorded digitally and transcribed verbatim, save one interview that was not recorded due to technical difficulties. For the unrecorded interview, detailed interviewer notes were kept.

*Table 2. Selected questions from semi-structured interview guide*

<b>Question</b>	<b>Sub-probes</b>
Describe the nature of your relationship with (the medical tourist)	<ul style="list-style-type: none"> <li>• How long have you known each other?</li> <li>• How familiar are you with his or her health issues?</li> <li>• Had you traveled together prior to the medical tourism trip?</li> <li>• How have your previous travel experiences been?</li> </ul>
How did you plan for this?	<ul style="list-style-type: none"> <li>• Did you help the medical tourist find and review information (e.g., about the country, the hospital, the surgeon, the surgery, the recovery location, potential risks, other types of information)?</li> </ul>

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<p>What assistance did you provide the medical tourist while abroad but outside of the hospital or clinic?</p>	<ul style="list-style-type: none"> <li>• Did you consult a doctor before going abroad (e.g., own family doctor, travel clinic)? If so: What kind of information did they give you? Did they mention potential risks? Were they helpful?</li> </ul>
<p>What assistance did you provide the medical tourist while abroad but outside of the hospital or clinic?</p>	<ul style="list-style-type: none"> <li>• How would you characterize that support (e.g., organisational, coordination, logistical, first aid, everyday activities, mobility, moral, spiritual, emotional, encouragement, familiarity, communication)? Why?</li> <li>• What was it like (e.g., equipped, (un)comfortable)?</li> </ul>

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### Triangulated Analysis

The triangulated thematic analysis of all four datasets outlined in Table 1 involved several steps. First, transcripts and notes from the international patient coordinator and caregiver-companion interviews were hand-reviewed for theme identification. Coded NVivo extracts from the original medical tourist interviews that dealt with companions and the raw findings of the facilitator survey were hand-reviewed next. Second, the first and second authors determined that the datasets displayed enough consistency in the scope and scale of caregiver-companion roles that it would be possible to meaningfully triangulate them in a single analysis. Third, using a deductive approach, the first author coded the caregiver-companion and international patient coordinator datasets in NVivo using a scheme based on the three roles of companion, navigator and knowledge broker. As explained above, these three roles were determined inductively through a previous analysis (Casey et al., 2013a). The coding scheme for this study was created by using general codes for each of the three roles, and iteratively breaking each role down into further components as they emerged from the data. For example, the navigator role had two components: pre-trip planning and interactions with healthcare professionals at the destination facility. The second author provided confirmation on the interpretation and application of the codes. Fourth, the first and second authors identified points of agreement and divergence related to caregiver-companions' roles within the codes and between the datasets. Fifth, the identified points were confirmed by all authors, with coding excerpts circulated to confirm coding and the triangulated interpretation of caregiver-companions' roles. Excerpts shared in the results section were selected to provide context to the roles described, and to provide examples of both agreement and disagreement between participant groups.

### Results

The different datasets collectively make clear the important roles played by caregiver-companions as stakeholders in medical tourism. Of 32 medical tourists interviewed, 21 were accompanied by friends or family members, and most recommended that those considering medical tourism take someone abroad as a companion. Caregiver-companions themselves also unanimously said that it would be beneficial to bring a companion on a medical tourism trip. International patient coordinators and facilitators typically recommend or require that medical tourists bring a friend or family member on their trip. These various stakeholders and participants in medical tourism confirm the need for, if not the industry's dependence on, informal care. As we show here, examining their perspectives also provides insight into the different tasks performed by caregiver-companions, how the groups perceive the relative importance of the roles, and how their situatedness in relation to the practice of medical tourism informs these perceptions.



In this section we highlight how nuance was added to our understanding of the roles played by caregiver-companions. For example, simultaneously working with data from four participant groups helped to identify how the roles played by caregiver-companions change *throughout* the medical tourism experience, both pre- and post-procedure as well as pre-departure and post-arrival abroad. This also enabled an understanding of how the care provided by caregiver-companions takes place across care settings, and that different roles are taken on in different care contexts (e.g., pre-trip planning support at home vs. providing hands-on care in the hospital abroad). Second, we examine which caregiver-companion roles were emphasized by the different participant groups. Third, the triangulated findings illustrate how participants' understandings of the roles taken on by caregiver-companions are shaped by their own roles in relation to the global health services practice of medical tourism.

### Confirming roles across datasets

Triangulating findings across four datasets added nuance to our understanding of caregiver-companions and their roles. The findings shared in this sub-section therefore greatly advance our understanding of the practice of informal caregiving in medical tourism, confirming the tasks taken on by friends and family and highlighting their contributions to the medical tourist's experience. Our interviews and surveys with multiple stakeholders add to the knowledge of how informal care varies across different contexts, providing insight into the scope and breadth of roles associated with informal caregiving in medical tourism.

Caregiver-companions highlighted their own involvement in completing tasks for medical tourists and providing emotional support and someone to talk with while recuperating in the companion role. They often played a part in getting food and water for medical tourists, fetching items, providing mobility assistance, assisting with aftercare, and occasionally in bathing and assisting with toileting depending on the medical tourist's mobility. One caregiver-explained that the companion role was necessary, "I guess mostly for the physical support if somebody had mobility issues... But also, on the emotional side for support too just keeping the person calm and not get anxiety over being there for the procedure." Former caregiver-companions linked the need for companionship in the sense of both moral support and physical support, with no clear separation between the different types of care that they provided. A medical tourist further explained the need for both: "Cause there are times when you're not able to do little things for yourself like recuperation and stuff like that" and "for companionship too...you've got someone you can talk to, right?"

International patient coordinators supplemented these accounts, noting that caregiver-companions also play an important role in monitoring symptoms and providing aftercare and companionship following surgery. They suggested that caregiver-companions provide many types of care in their roles as companions depending on what is needed:

Well, you know, making sure they [medical tourists]...have a bandage, they have the medicine, they double-check they have the right medicine, or how to give the medicine to their companion when they get back to the hotel or recovery whatever... Somebody they can talk to or not talk to. Sometimes they don't want to be talked to, they want to sleep. Initially, all they want to do is rest and sleep and not talk too much, like any surgery. And then afterwards, then just be there for them. Enjoy each other. Go see the view, or go, you know, go walk with them. I noticed that, that they [caregiver-companions], some of them walk with them [medical tourists] and help them.

Medical tourism facilitators also spoke to the need for caregiver-companions to accompany their clients abroad in order to provide daily physical care and emotional support.

Comparing across the four datasets provided new insights into the “navigator” and “knowledge broker” roles identified by Casey et al. (2013a). The interviews with caregiver-companions confirmed previous findings that identified a role for them in logistical matters such as geographic and cultural navigation, tracking paperwork, and interacting with destination facility staff and health care workers. For many of the caregiver-companions we spoke with, these roles were tied to the need for medical tourists to be free from such concerns so as to focus on their procedure and the recovery process. This perspective was shared by some participants from other groups. According to an international patient coordinator, caregiver-companions are “the type of people” who want to be “responsible so that the patient can concentrate on getting better and leaving and going home.” Medical tourists reported that the logistical assistance provided by caregiver-companions in their capacity as navigators was essential, particularly given the vulnerable state in which they found themselves. For them, caregiver-companions were able to keep track of information and files, locate necessary items, and to do “stuff I just couldn’t do.” Descriptions of these tasks from all participant groups linked emotional and physical-logistical support by characterizing how caregiver-companions’ assistance provides reassurance to medical tourists. Interviews with caregiver-companions revealed that the tasks associated with navigating decision-making and planning processes were often shared between them and the medical tourists, which might not have been evident from interviews with one group alone.

As evidenced above, all four participant groups described a variety of types of care provided by caregiver-companions in their roles as companions, navigators, and knowledge broker. Participants used different terminology to describe their companions, ranging from “gopher” to “cheerleader” to “care partner.” Each group offered new insight into different tasks (e.g., caregiver-companions described their direct interactions with medical tourists, international patient coordinators described how the caregivers interacted with facility staff). A clear strength of our triangulation strategy derives from this type of complementary information and the added nuance that can only be gained by considering the perspectives of multiple stakeholder groups.

### **Comparatively emphasizing roles across datasets**

An unexpected strength of the triangulated analysis is that different participant groups placed differing degrees of emphasis on the relative importance of caregiver roles and the particular tasks attributed to them. For example, while the international patient coordinators and facilitators emphasized the importance of caregiver-companions as navigators during their time in the destination country, caregiver-companions themselves were more focused on the importance of their involvement in the planning process. As noted by one caregiver-companion:

We both really looked at all of the pros and cons and it was amazing, the amount of work we did pre-planning this was more than like buying a house or other life shattering experiences because we knew it wasn’t something we were going to take lightly...it was amazing that with the internet how much information you can get, how much you can learn about something you know something like a weight loss surgery to actually know the, the nitty gritty details of what’s involved, the risks and potential dangers perhaps.

Medical tourism facilitators confirmed that they typically communicate with caregiver-companions prior to the trip to describe itineraries and make travel plans in addition to medical tourists, thereby enabling their roles as navigators. However, most caregiver-companions interviewed did not make use of facilitators, instead making primary use of the internet to plan trip details. Despite the importance attributed to planning prior to the trip by caregiver-companions themselves, medical tourists and international patient coordinators overall did not emphasize this aspect of the navigator role. This may be due to the invisibility of such work, which occurs “out of sight” and in the private space of the home (see Ansello & Rosenthal, 2007).

In comparison to the other two roles, some international patient coordinators emphasized the value of the navigator role, and specifically those aspects of this role that are enacted while abroad, such as handling paperwork or dealing with transportation. One international patient coordinator explained that: “Basically that they’re usually more concerned with you know the accommodations and the hotels and the tours and things like that, and they usually leave the medical procedures and things like that to the actual patient.” Perhaps this emphasis is due to the fact that these caregiving tasks occur in public areas and involve interactions with industry employees, including international patient coordinators. In contrast, caregiver-companions themselves spoke less about the tasks associated with the navigator role. Caregiver-companions were far more likely to discuss the hands-on physical care or emotional support that they provided and to recount their interactions with health care workers in the knowledge broker role. These types of care may be perceived as a “duty” and go unaccounted for by the industry. The tendency of caregiver-companions to discuss relationship-focused tasks—interacting and talking with the medical tourist or health care provider—highlights the emotional nature of care undertaken by caregiver-companions. However, it appears that this care continues to be less visible to other stakeholders in medical tourism.

### **Different interpretations across datasets**

An additional benefit of triangulating four datasets arose from the different situatedness of participants within the practice of medical tourism. For example, all participant groups were in agreement about the role played by caregiver-companions in managing interactions between medical tourists and health care workers—the “knowledge broker” role identified by Casey et al. (2013a). At the same time, they had different interpretations of what this role entailed based on their position in the interactions. This was evident in caregiver-companions’ views of their role as “advocates,” which occasionally came into conflict with facility practices.

Participants emphasized the knowledge broker role as a means both to share the experience with and to minimize the burdens on the medical tourist, while international patient coordinators viewed it differently. One caregiver noted that medical tourists need the “extra set of ears and that support mechanism there to help you through it and if anything ever does go wrong you’ve got somebody there who can be your voice for you.” Some medical tourists described the role of the caregiver-companion as an advocate to counterbalance the views and opinions of health care workers in the destination facilities. A medical tourist described her companion’s role in medical treatment overseas, stating that: “If I was not happy with what somebody was doing he would go and he would talk to them or try and talk to them to get across to them that something was wrong or whatever.” These interactions were perceived quite differently by international patient coordinators, who noted that caregiver-companions can require time, attention and resources and can disrupt the provision of quality care by being “over-protective” or ignoring facility norms (see also Casey et al., 2013b). Interactions between health care workers in destination facilities and caregiver-companions in their capacities as knowledge brokers are sometimes challenging. Caregiver-companions reported that

destination facilities may have different cultural practices and/or languages that collectively make interactions with health care workers in their capacities as knowledge brokers difficult. One caregiver described the experience of having their partner wheeled in to surgery by a nurse with limited English language abilities: “She just grabbed my wife and took her away and I just sat there for about twenty minutes and then she came and grabbed me and I’m like ‘what the hell’s going on’ (chuckle).” The situatedness of participants clearly impacted their understanding of these situations.

Some participant groups differed in their perceptions of whether a medical tourist needs a caregiver-companion to accompany them at all. While facilitators and international patient coordinators almost unanimously encourage medical tourists to travel with companions, some medical tourists and caregiver-companions said that the presence of a companion might not be necessary depending on the type of surgery medical tourists are having abroad and the affordability of bringing an additional person on the trip. Medical tourists noted that the facilities abroad are typically set up to provide care and so friends and family may not be needed: “I know lots of people take, take somebody with them but you don’t really have to; ‘cause if you do need help those guys will help you.” Meanwhile, a caregiver-companion noted that while medical tourists might “maybe not actually really need someone,” it would be better for the medical tourist’s recovery to “have someone to just help you out and then you kind of just focus on resting.” Although overall, international patient coordinators were very supportive of caregiver-companions accompanying medical tourists, those who worked with patients obtaining bariatric or cosmetic surgeries also noted that caregiver-companions could be more challenging than helpful in their companion role if they become distressed by observing swelling and surgical wounds following a procedure (see Casey et al., 2013b).

## Discussion

This study demonstrates how informal caregivers share in and contribute to medical tourists’ health expectations. Our triangulated analysis demonstrates the important roles that caregiver-companions play in providing care, navigating unfamiliar environments, and interacting with medical and industry members. The different interpretations and emphases offered by different participant groups provide new insights into medical tourism. More broadly in the literature, concerns have been noted about the “patient-consumer” hybrid role (Gatrell, 2011) and the ability of medical tourists to provide informed consent. In our study, medical tourists and their caregivers emphasized that the decision to engage in medical tourism is shared. International patient coordinators and facilitators spoke to the decision-making support provided by caregivers during the trip. Thus, caregiver-companions will also be impacted by uninformed decision-making and issues surrounding continuity of care for their friend or family member. Other studies have noted that medical tourists may feel empowered by the choice to purchase care, or they may choose medical tourism based on feelings of desperation (Johnston et al., 2012; Snyder, Adams, Crooks, Whitehurst, & Vallee, 2014; Snyder, Crooks, Johnston, & Dharamsi, 2013). Their caregivers undoubtedly share in these feelings and in the outcomes of medical tourism, whether positive or negative.

More broadly, this paper demonstrates how multi-qualitative dataset triangulation can serve as a tool for researchers to learn about complex phenomena. By speaking with multiple groups involved, we gained a fuller sense of how medical tourism is undertaken, experienced, and perceived. Our research reveals how the unpaid labour of caregiver-companions is essential to the functioning of the medical tourism industry. Industry professionals, medical tourists and caregivers themselves perceived a duty to provide care on the part of friends and family members. The value of this unpaid caregiving work is a hidden cost within the medical tourism industry (Whitmore, Crooks, & Snyder, 2015, 2017). Given medical tourists’ need for care, it

is important that the informal care provided by caregiver-companions does not continue to go unnoticed.

### Limitations

The first limitation of this analysis is that because reliable quantitative information about medical tourists and medical tourism is lacking (Crooks et al., 2011), it is difficult to know how representative any and all of our participant groups are within the overall scope of medical tourism. In addition, due to the voluntary nature of participation, there may have been a recruitment bias in participants from all four datasets. Beyond the limitations of our recruitment strategy, there are also known limitations to telephone interviewing: participant responses that are less detailed than those from face-to-face interviews, the lack of visual cues or rapport, challenges scheduling in different time zones, and ensuring that participants are not distracted by their environment (Irvine, 2011). Also, because interviews were only conducted in English, individuals who do not speak English or would be more comfortable speaking a different language did not participate. An exception is that we conducted one international patient coordinator interview in Spanish.

### Conclusion

Through our analysis, we examined how caregiver-companions in medical tourism act as key supports and play three main roles: caregiver, knowledge broker and navigator. These three main roles were confirmed by four participant groups, medical tourists, caregiver-companions, international patient coordinators, and medical tourism facilitators alike, while thoughts about the relative importance of each role differed across these participant groups. Analyses of the interviews and surveys show that all four participant groups considered in this analysis underscored the great importance of caregiver-companions in the global practice of medical tourism. Specifically, caregiver-companions provide valuable hands-on and emotional care, logistical support, coordinate the sharing of information, and facilitate transitions between home and abroad, among other role-oriented tasks. These findings clearly illustrate the value in developing supports and interventions to ensure medical tourists' caregiver-companions' wellbeing while abroad given the significant scope of their unpaid labour. Elsewhere we have started to explore the potential of developing informational tools targeting caregiver-companions to serve as such an intervention (Crooks et al., 2017). The uniqueness of the perspective offered by each group added to the richness of our understanding of the scope and scale of these roles. In addition, the unique emphases and viewpoints offered by these diverse groups enhanced our qualitative analysis through, for example, providing opportunities for confirmation and complementarity across differently situated participant perspectives.

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