

Examining the Practice of Informal Caregiving in Medical Tourism

FINAL RESEARCH REPORT

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An abstract graphic in the bottom right corner of the page, consisting of numerous thin, overlapping lines that curve and flow from the bottom left towards the top right. The lines are colored in a gradient, transitioning from warm tones like red, orange, and yellow to cooler tones like green and blue.

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Table of Contents

Executive Summary.....	3
Introduction.....	4
Research Design and Participant Overview.....	4
Key Findings.....	5
Common Themes Across the Findings	8
Recommendations.....	9
Concluding Summary.....	10
Acknowledgements.....	10
References Cited.....	11
Appendix 1 – List of Study Publications.....	12

Executive Summary

Medical tourism refers to the process whereby patients purchase health care abroad, outside of their home health care systems, and pay privately for care. Some reasons patients engage in this form of private health care include: real or perceived wait times, desire to obtain experimental procedures not available at home, and mistrust of the domestic health care system. While the literature provides accounts of the experiences of medical tourists and industry facilitators, the friends and family who accompany medical tourists abroad as informal caregivers are under-researched. In this study, funded by the Canadian Institutes of Health Research, we have uncovered these caregivers' experiences through four datasets collected from different stakeholder groups: i) 32 former Canadian medical tourists interviewed between July and November 2010; ii) 7 Canadian medical tourism facilitators surveyed in 2012; iii) 21 international patient coordinators in destination facilities interviewed in 2012; and iv) 20 Canadian caregivers interviewed between September 2013 and February 2014. Data triangulation enabled us to compare, contrast and augment the results from these separate datasets to arrive at the following findings and recommendations.

Key Findings:

- 1) *Roles of caregivers in medical tourism*: Informal caregivers take on different duties during the medical tourism journey, and their most prominent roles are as knowledge brokers, companions and navigators.
- 2) *The nature of the work performed by caregivers*: Friends and family offer emotional care, hands-on care and deal with logistics across different care settings while abroad with medical tourists.
- 3) *Challenges created by and facing caregivers*: Informal caregivers may take time, attention, and resources away from the medical tourist, disrupt the provision of quality care, and/or be exposed to health and safety risks.
- 4) *Ethical dimensions of informal caregiving in medical tourism*: Caregivers feel a responsibility to take care of the medical tourist, and share a mutual experience with them, but are made vulnerable by the unfamiliar settings and unknown outcomes of medical tourism.
- 5) *Experiences drawn on to cope with caregiving abroad*: Informal caregivers sometimes use previous experiences of international travel, previous experiences of informal caregiving, and their existing relationships with the medical tourist to aid in their caregiving tasks.
- 6) *Advice for informal caregivers*: It is recommended that caregivers become informed health care consumers, anticipate the medical tourists' care needs, familiarize themselves with the logistics of the trip, and protect the health and safety of both medical tourists and themselves.

Key Recommendations for Caregiver-Companions:

- 1) Collaborate with international patient coordinators in the destination hospital/clinic and share information with them in order to avoid misunderstanding the health needs of the medical tourist or the duties of different stakeholders.
- 2) Understand the care needs of the medical tourist, anticipate problems that may arise in an international context, and plan appropriate solutions.
- 3) Undertake significant research on the procedure, destination clinic and doctor abroad to become aware of potential threats to safety, including unscrupulous businesses and dangerous destinations.
- 4) Be well aware of travel plans and the step-by-step logistics of the medical tourists' procedure and recovery period abroad.
- 5) Look after your own health, which can be adversely affected by the stress of travel and having a friend or family member undergo surgery in another country.

Introduction

Medical tourists are individuals who travel abroad to access private health care outside of their home country's health care system [1, 2]. Patients engage in medical tourism for a number of reasons, including bypassing real or perceived wait times in their home countries, undergoing surgeries that are less expensive than those offered at home, or purchasing health care that is experimental or unavailable in their home countries [3-6]. Different types of medical tourism, such as fertility travel, dental tourism, and cosmetic tourism, have varying impacts on destination countries [7]. Some of these impacts may include: providing new sources of international investment; offering new types of health services for the local population; and diverting health care workers from the public health system to private medical tourism facilities, thus reducing the availability and quality of services provided for patients in the public system [8].

Previous research has identified several key groups of medical tourism stakeholders, such as: international patients, health care providers and administrators in destination countries, health care providers and administrators in patients' home countries, brokers/facilitators, and insurance agents [9]. Though important, these existing studies have largely ignored capturing or considering the important experiences of the friends and family members who travel abroad with medical tourists. Our research, funded by the Canadian Institutes of Health Research, aims to address this knowledge gap. In this report, we focus on our own qualitative research findings with the following stakeholders: medical tourists, caregiver-companions (i.e., the friends and family members who travel abroad with medical tourists), international patient coordinators (IPCs) (i.e., the persons working in destination hospitals/clinics who coordinate care and travel logistics) and medical tourism facilitators (i.e., agents who make booking arrangements for patients looking to travel abroad). Our overall study goals have been: i) to understand the roles of caregiver-companions from the perspectives of all four stakeholder groups; ii) to examine caregiver-companions' responsibilities using an ethics of care framework; and iii) to explore the challenges posed by and facing caregiver-companions from the perspective of IPCs. Appendix 1 contains a listing of all publications emerging from the study.

Research design and participant overview

The research findings presented in this report come from four datasets collected at different times that collectively contribute to meeting our study goals. The findings shared here are drawn across these datasets in order to identify cross-cutting conclusions [12].

Medical tourists: In 2010, we conducted 32 semi-structured telephone interviews with 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.

Medical tourism facilitators: In 2012, we recruited seven Canadian medical tourism facilitators who had been in contact with hundreds of prospective and actual medical tourists. The participants completed an online survey, with questions that asked about how often the facilitators recommended traveling abroad with a friend or family member, the relationship between medical tourists and these caregivers, and the roles played by these individuals.

International patient coordinators: In 2012, 21 semi-structured interviews were conducted with international patient coordinators (IPCs) working at medical tourism hospitals across a number of countries and clinical practice environments. We recruited IPCs 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.

Caregiver-companions: In late 2013 through early 2014, we recruited 20 Canadians who had previously accompanied a medical tourist abroad for semi-structured interviews through the following strategies: inviting past and new research participants to pass on study information to individuals that they thought might be interested, posting online advertisements on Craigslist across Canada, and reviewing media and newspaper articles for mention of medical tourists, locating contact information and contacting them when possible.

Key Findings

Roles of caregiver-companions in medical tourism

Friends and family of medical tourists take on a number of roles while caregiving abroad. These roles happen both inside and outside of the health care facility and when the caregiver is with the patient or interacting with other stakeholders (e.g., doctors and nurses). The three main roles identified by our research are: knowledge broker, companion and navigator.

- Knowledge brokers: As knowledge brokers, informal caregivers assist with the transfer of news, requests and information between the medical tourist and health care workers and staff members at the facility in the destination country.
- Companions: As companions, caregivers provide medical tourists with physical support in destination hospitals or clinics, in transit, and in the hotel room abroad. They also provide emotional care to the patient, especially post-surgery.
- Navigators: As navigators, caregiver-companions coordinate the documentation and logistics of the journey for the medical tourist. The tasks associated with navigating the decision-making and planning processes are often shared between the medical tourists and the caregivers. The navigator role is most evident while the medical tourist is in the destination country and the pre-trip planning done by the caregiver is less visible to other stakeholders.

The nature of work performed by caregiver-companions

The care provided by friends and family in medical tourism is often invisible to other stakeholders, and sometimes even to the medical tourists being cared for. Our research revealed the nuances of the work that caregiver-companions perform while abroad.

- Particular types of caregiving responsibilities: Caregivers have three main types of care responsibilities towards medical tourists, namely emotional care, hands-on care and care logistics. Caregiver-companions tend to take on the roles and responsibilities they have in the ongoing relationship with the medical tourist under normal circumstances.

- Types of care: Emotional care involves providing moral support and maintaining an extended support network and offering a feeling of safety. Hands-on care includes clinical tasks such as monitoring and administering medications and non-clinical tasks such as finding certain types of food for the patient. Care logistics describe how caregivers attempt to arrange for a smooth and hassle-free journey.
- Providing care in a variety of spaces: Caregiver-companions provide care in different care spaces, including travel spaces (e.g., airplane, taxi), the hospital room, the hotel room, and tourist sites in the destination country.
- Negotiating relationships in caregiving while abroad: Some factors to consider when choosing a caregiver-companion include: the extent to which one enjoys the company of the other person, the invasiveness of the procedure, and the types and duration of care needed.

Challenges created by and facing caregiver-companions

Informal caregivers accompanying medical tourists can make the international journey less stressful and benefit the accompanied patient. However, interviews with IPCs showed that caregiver-companions can also pose unexpected challenges to the medical tourist, health care workers and other staff. In addition, caregivers themselves might be subject to risks affecting their safety and health.

- Caregiver-companions require time, attention and resources: It takes financial resources to bring a caregiver to a foreign country with the medical tourist. Sometimes, IPCs need to attend to the needs of the caregivers, which redirects time and attention away from the medical tourist. The redundancy of roles between caregiver-companions and medical staff can cause discontinuity in symptom monitoring and record keeping.
- Caregiver-companions can disrupt the provision of quality care: Informal caregivers may not always respect facility norms and thus can create challenges and more work for the medical staff. Some caregivers may encourage the medical tourist to go against the advice given by health care workers.
- Caregiver-companions can be exposed to risks: Caregivers are commonly exposed to stress focused on the unknown outcome of the surgery or possible complications, and the uncertainty of their role as a companion. A lack of trust in the destination country, facility and the IPCs can also contribute to stress. These stresses usually fade when caregiver-companions gain more understanding of the local and medical environments. Beyond stress, caregiver-companions can also face travel safety risks such as being a target for theft, getting lost in an unfamiliar city, or consuming contaminated food or water.

Ethical dimensions of informal caregiving in medical tourism

Informal caregivers have a responsibility to tend to the needs of the medical tourists they care for. To do so, they need to feel a sense of mutual experience with the medical tourist. This mutuality, however, may subject them to physical and mental vulnerability such as experiencing caregiver burden [13, 14]. From our interviews with caregiver-companions, we found that ethical dimensions of responsibility, vulnerability, and mutuality are evident in medical tourism.

- Responsibility: Caregivers feel a personal responsibility to provide physical and emotional support to the medical tourist while abroad and en route to the destination country. Some

caregivers, however, have difficulty articulating these responsibilities because of the implied nature of the ongoing care they provide.

- **Vulnerability:** Being in unfamiliar environments, coupled with the uncertainty of a medical procedure, creates stress for caregiver-companions, which might render them vulnerable. Two specific scenarios that create vulnerability include the medical tourist experiencing complications post-surgery, and/or unexpected financial obligations incurred while abroad.
- **Mutuality:** Many caregiver-companions have a positive experience with the medical tourist because of a good surgical outcome, while others share the negativity brought on by a lack of health improvement. The effects of medical tourism are shared, and are not only felt by the medical tourists.

Experiences drawn on by caregiver-companions

To navigate an unfamiliar environment in a foreign country, provide physical and emotional supports to the accompanied medical tourist, and avoid caregiver burden, caregiver-companions rely on their experiential resources (i.e., previous lived experiences) across formal and informal care sites.

- **Previous experiences of international travel:** Informal caregivers who have prior travel experience, especially with the medical tourist, are better equipped to deal with problems that might arise and to respond promptly.
- **Previous experiences of informal caregiving:** Many caregiver-companions use experiences of providing care for the medical tourist at home and in previous trips to anticipate the challenges that might arise while abroad. These experiences also enable them to know when and how to care for their family and friends.
- **Existing relationship with the care recipient:** Many friends and family members of medical tourists believe that to be an effective caregiver, it is necessary to have a close bond with the care recipient. Even for those who do not have much care-giving experience, knowing the health status and care needs of the medical tourist aids in the provision of care in a foreign country.

Advice for informal caregivers

Reflecting on their own experiences of medical tourism, informal caregivers we have spoken with have offered several key pieces of advice to people who are considering traveling abroad with a friend or family member obtaining surgery. Although caregiver-companions have diverse experiences, this advice to prospective caregivers features several common themes.

- **Become an informed health care consumer:** Informal caregivers should conduct extensive research focused on the procedure and its risks as well as into the destination clinics and doctors abroad.
- **Assess and avoid threats to safety:** It is advised that prospective caregivers do research to help them avoid threats such as unsafe destination clinics or countries, and/or industry members with unethical business practices.
- **Anticipate the medical tourist's care needs:** In order to provide good care, it is suggested that caregivers become knowledgeable about the medical tourist's health condition and consider what physical and emotional care they might need while abroad.

- Familiarize yourself with important logistics: Caregiver-companions should be familiar with travel plans and the specific steps involved in the procedure and recovery, as they may need to manage logistics while abroad.
- Protect your health: There can be physical and mental health impacts of taking on the responsibility of providing informal care in the context of medical tourism and so these caregivers need to take measures to protect their own health and also to visit a travel medicine provider before departure.

Common Themes Across the Findings

Through our analyses we have uncovered the roles, responsibilities, experiences, and challenges facing the friends and family who accompany medical tourists abroad. We have found that three common themes run across our findings and here we integrate the perspectives from all four stakeholder groups in characterizing them: former Canadian medical tourists, caregiver-companions, medical tourism facilitators and IPCs. Data triangulation ensures that these themes apply across each group and that the different perspectives complement each other.

First, caregiver-companions take on very important roles and hold significant responsibilities, but there are very few formal resources (e.g., websites, brochures, information sheets) available to them. Our findings indicate that there is the potential to offer supports that can assist this group, such as providing pre-departure information about what to expect while abroad and what they should take with them, as well as reminders to visit a travel medicine clinic before departure and to obtain travel health insurance. Being as prepared as possible for the journey abroad lessens the stress and the possibility of experiencing the types of caregiver burden that has been documented by informal caregiving researchers.

Second, the care work provided by caregiver-companions is important and it is clear that the medical tourism industry is dependent on their unpaid labour in order to provide quality care for medical tourists. However, this work is sometimes invisible to other stakeholders and even to the medical tourists because it happens behind-the-scenes and is taken for granted, and is therefore not considered as 'labour' or 'work'. Our study has revealed that caregiver-companions provide physical and emotional supports to medical tourists that cannot be replaced by other health care staff at home or abroad.

Third, despite the challenges they encountered abroad and at home, most of the caregiver-companions we have consulted with throughout our research emphasize the positive nature of their caregiving experience. They indicate that the prospect of helping their friend/family member through surgery abroad is more rewarding than any of the possible negative outcomes they could experience throughout the course of caregiving. The negative aspects and outcomes identified in this study included the stress of international travel, the unknown outcomes of the medical treatment, and the unfamiliar health care and social environments that must be navigated while abroad. Despite these downsides, we found that caregiver-companions can find ways to overcome these challenges or avoid experiencing them all together and have a satisfactory experience.

Recommendations

Here we offer five recommendations that emerge directly from our findings that get at ways to better support friends and family members who take on the responsibility of providing informal care to medical tourists while abroad. First, health care providers and administrators and medical tourism facilitators alike can offer supports to caregiver-companions by providing formal pre-departure information, such as what kind of insurance to get and what to expect as a caregiver while abroad. The supports could take the form of pamphlets or information sheets that can be distributed online, in travel medicine clinics, by doctors, and by facilitators. Currently, these resources are lacking – at least in the Canadian context – and caregiver-companions are often left on their own to figure out the logistics of the experience.

Second, caregiver-companions are encouraged to be open to collaboration with IPCs and other workers in the destination facility, particularly in the form of information sharing, to allow for a safe and less stressful experience. Our interviews with IPCs and with caregiver-companions point to some misunderstandings about the roles and responsibilities of informal caregivers. Openly sharing information with the IPCs, such as the health needs of the medical tourists and what parts of the process caregiver-companions hope to be involved in, will result in less duplication of duties and a clearer delineation of roles. We believe such transparency will ultimately aid medical tourists in coping with transitions across care settings.

Third, it is important that caregiver-companions have experience caring for and understand the care needs of their friends and family in an international context. Often, informal caregivers already have experience tending to the needs of the medical tourists in different contexts while at home. However, unexpected care needs from the medical tourists may arise while abroad. These could include accessibility concerns on the airplane due to limited mobility and language barriers with health care professionals in the destination country, among others. Caregiver-companions are encouraged to draw on past experiences of caring for the medical tourists to anticipate what problems they may encounter while abroad and how to address them in order to be as prepared as possible for providing care in a transnational context.

Fourth, prior to committing to go abroad as an informal caregiver, caregiver-companions should undertake significant research on the procedure, destination clinic and doctor abroad. This will help them become aware of potential threats to their own and the medical tourist's health and safety, including the risks of the procedure, unscrupulous businesses, and dangerous destinations, ultimately engaging in more informed decision-making. Caregiver-companions should also become aware of travel plans and the step-by-step logistics of the procedure and recovery period abroad. These responsibilities often fall to informal caregivers, as the medical tourist may be incapacitated following their surgery or medical procedure. We believe that the types of informational interventions referred to in our first recommendation can usefully prompt potential caregiver-companions of such considerations.

Finally, caregiver-companions must always look after their own health, which can be adversely affected by the stress of travel and having friends or family members undergo surgery in another country. The international literature on informal caregiving consistently points to the fact that caregivers' and care recipients' health are intertwined, and so by maintaining their own health and wellbeing caregiver-companions are better able to aid in doing the same for the medical tourists.

Standard travel medicine precautions (e.g., obtaining vaccinations, bringing a first aid kit) should also be observed.

Concluding Summary

The current literature on medical tourism centres mostly on the experiences of the medical tourists themselves, health care workers and administrators at home, and health care staff at the destination clinic/hospital. Friends and family members of medical tourists who accompany them abroad, whom we have termed caregiver-companions, are an important stakeholder group in the practice of medical tourism that has largely been overlooked. In our qualitative research, we have uncovered the roles and responsibilities they undertake, the challenges they create and face, the nuanced nature of the work they perform, considerations of ethics in what they do, and the previous experiences they rely on in caring for medical tourists.

Our research has shown that many friends and family members will take on the duties of an informal caregiver without explicitly being asked to or “assigned” because of the existing relationship they share with the medical tourists. The care work they do happens before, during and after the trip, in a variety of spaces such as on an airplane, in the hospital or in the hotel, and includes both physical tasks, such as monitoring medication intake, and emotional tasks, such as comforting the medical tourist post-surgery. Their labour is also typically taken for granted and invisible to other stakeholders such as medical tourism facilitators, international patient coordinators, and potentially even to the medical tourists they care for. We are confident that this research has revealed the importance of their unpaid labour within the medical tourism industry and encourage their work to be properly recognized through the development of informational interventions that can aid future caregiver-companions in protecting their health and safety as well as that of the medical tourist.

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11. Casey V, Crooks VA, Snyder J, Turner L. 2013b. "You're dealing with an emotionally charged individual ...": an industry perspective on the challenges posed by medical tourists' informal caregiver-companions. *Globalization and Health* 9:31.
12. Whitmore R, Crooks VA, Snyder J. 2015. (in progress). Exploring informal caregivers' roles in medical tourism through qualitative data triangulation.
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14. Macdonald M, Lang A. 2014. Applying risk society theory to findings of a scoping review on caregiver safety. *Health and Social Care in the Community* 22(2): 124–133.

Appendix 1 – List of Study Publications

Book Chapters

1. Crooks VA, Casey V, Whitmore R. (2015) (in press). Informal caregiving on the move: Examining the experiences of Canadian medical tourists' caregiver-companions from patients' perspectives. In: NE Fenton & J Baxter (Eds). *Practicing Qualitative Methods in Health Geographies*. Burlington, USA: Ashgate Publishing Company.

Syntheses

1. Casey V, Crooks VA. (2013). Friends and family roles and responsibilities abroad. *Medical Tourism Magazine* 29: 49-50. <http://medicaltourismmag.com/friends-and-family-roles-and-responsibilities-abroad/>
2. SFU Medical Tourism Research Group (2014). *Roles and responsibilities of informal caregivers in medical tourism*. Burnaby, BC, Canada: Simon Fraser University.
3. SFU Medical Tourism Research Group (2013). *Industry perspectives on informal caregiving in medical tourism*. Burnaby, BC, Canada: Simon Fraser University.

Journal Articles

1. Crooks VA, Whitmore R, Snyder J, Turner L. (in progress) Five elements for ensuring 'best practice' of informal caregiving in medical tourism: A public health approach.
2. Whitmore R, Crooks VA, Snyder J. (in progress). Exploring informal caregivers' roles in medical tourism through qualitative data triangulation.
3. Whitmore R, Crooks VA, Snyder J. (2015a). A qualitative exploration of how Canadian informal caregivers in medical tourism use experiential resources to cope with providing transnational care. *Health and Social Care in the Community* pp.1-9.
4. Whitmore R, Crooks VA, Snyder J. (2015b). Ethics of care in medical tourism: Informal caregivers' narratives of responsibility, vulnerability and mutuality. *Health & Place* 35: 113-118.
5. Casey V, Crooks VA, Snyder J, Turner L. (2013a). Knowledge brokers, companions, and navigators: a qualitative examination of informal caregivers' roles in medical tourism. *International Journal for Equity in Health* 12:94.
6. Casey V, Crooks VA, Snyder J, Turner L. (2013b). "You're dealing with an emotionally charged individual ...": an industry perspective on the challenges posed by medical tourists' informal caregiver-companions. *Globalization and Health* 9:31.