Canadian Informal Caregivers in Medical Tourism

by

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Abstract

When Canadians travel abroad to obtain private, self-funded medical care, they are engaged in medical tourism. Canadians who travel abroad for surgery are often accompanied by friends or family members. These informal caregivers, who I refer to as caregiver-companions, provide essential physical and emotional support to Canadian medical tourists. Centered on interviews with caregiver-companions themselves, this thesis sheds light on their experiences of the emerging medical tourism industry. This thesis consists of three analyses: 1) a methodological analysis that describes how multi-dataset triangulation was used to learn about caregiver-companions, 2) an analysis of caregiver-companions' narratives using an ethics of care framework and the landscapes of care literature, and 3) an analysis examining the practical resources and supports that might benefit caregiver-companions. Taken together, these three strands of research provide insight into the experiences of Canadian informal caregivers in medical tourism, and the complex, transnational care that they provide.

Keywords: medical tourism; informal caregiving; health geography; qualitative research; ethics of care

Acknowledgements

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Chapter 1.

Introduction

Medical tourism is an emerging global health mobility: a practice in which individuals travel abroad for privately-purchased medical treatment at destination hospitals and clinics (Hopkins et al. 2010, Hanefeld et al. 2013). Medical tourism is inherently geographic, and it has received growing attention from researchers in recent years, along with other emerging global health care phenomena such as routine medical travel across borders (Bell et al. 2015), medical 'voluntourism' (Snyder, Dharamsi & Crooks 2011; Asgary & Junck 2013), health worker migration (Runnels, Labonte & Packer 2011, Pylypa 2013), international retirement migration (Legido-Quigley & McKee 2012, Casado-Diaz et al. 2014, Hayes 2015), and offshore medical schools (Babcock, Babcock & Schwartz 2013). Medical tourism, despite having some similarities and shared causes with these other mobilities, has a unique set of economic, health and social impacts. In this thesis I contribute to a gap in the medical tourism literature by examining the informal care that is provided by friends and family members to Canadians traveling abroad for surgery. Throughout this thesis, these individuals are referred to as caregiver-companions.

Health geographers have a long-standing interest in the spaces and places that shape informal care (Kearns & Moon 2002, Parr 2003, Milligan & Wiles 2010). Following the shift from 'medical geography' to 'health geography,' geographers have developed an interest in broad social examinations of wellbeing, health and health care (Kearns & Moon 2002). In this thesis, I contribute to the literature on informal care in health geography by offering insights into the unique form of transnational caregiving that is provided by friends and family in medical tourism. This chapter sets out the structure of my thesis and reviews the strands of research in health geography that inform this project. In the first section, I provide a brief introduction to health geography literatures on globalization in health care,

health mobilities, and landscapes of care. Following this, I provide a review of research on medical tourism and the knowledge gaps that led to the overall study on informal caregiving in medical tourism. Finally, I provide an outline of the three main chapters of my thesis. These three analyses, written as peer-reviewed journal papers, examine the data triangulation strategy used in this study, an ethics of care in medical tourism, and the experiential resources drawn on by caregiver-companions. My concluding chapter draws together the results of these three analyses to identify future research questions and to speak across the themes identified.

1.1. Situating My Research in Health Geography

Kearns and Moon (2002) describe two key contributions of early health geography: 1) studies grounded in people's experiences of health in particular localities, and 2) research that considers broad social, political and economic 'landscapes' that shape health. My thesis project engages in both these styles of research: first, by considering the roles, responsibilities, experiences and voices of caregiver-companions; and second, by describing how cultural and political factors interact with informal care and place in medical tourism. My work also contributes to the established body of research on care and changing landscapes of health in geography. Health geographers have made significant contributions to the study of how we receive and experience health care, documenting how it is changing due to technology, telemedicine, globalization, consumerism, deinstitutionalization and privatization (Kearns & Moon 2002, Parr 2003, Andrews & Evans 2008, Greenhough 2010, Connell & Walton-Roberts 2015, Greenhough et al. 2015). These changes are providing new care options for sale to 'consumers' in both clinical and non-clinical settings. Armed with knowledge from the internet and word of mouth facilitated by social media, individuals are engaged in health decision-making in new ways. These changed settings of health care provision, particularly in informal care, are key areas of research for health geographers (Andrews & Evans 2008, Greenhough 2010). My project engages with this research by examining the new settings for informal care that are created by Canadians' engagement in medical tourism. It does so at both a micro and macro scale, looking at the experiences of caregiver-companions and a broader examination of landscapes of care.

Medical tourism fits within the broad research turn towards 'mobilities' in human geography (Sheller & Urry 2006, Cresswell 2010), which has been mirrored in health geography (Gatrell 2011). Many empirical foci of mobilities research, including air travel, tourism, migration and policy (Temenos & McCann 2013), come together in medical tourism. Research on mobilities rejects simplistic spatial understandings and focuses on networks, the transit between places and the ability or inability of people to engage in this mobility (Sheller & Urry 2006, Temenos & McCann 2013). In health geography, such research has focused on those who move for health reasons, such as to access care in medical tourism or to work in a foreign health care system (Connell and Walton-Roberts 2015). A mobilities-focused examination of medical tourism unpacks the complex ways that individuals are accessing care across different social and spatial contexts. The increasing speed and diversity of the trade in global health services is aligned with the study of global care chains, which are defined by links between people based on paid or unpaid care (Connell and Walton-Roberts 2015). My thesis considers the relationship between global care chains and informal care in medical tourism by describing how Canadian caregiver-companions and medical tourists engage with the medical tourism industry and how caregiver-companions enable such trade at a low cost by performing unpaid 'shadow' work in this multi-billion dollar industry.

Within health geography, Milligan and Wiles (2010) describe a growing interest in 'landscapes of care'; how "care and care relationships are located in, shaped by, and shape particular spaces and places that stretch from the local to the global" (p.736). They encourage geographers not to use the term loosely as a "spatial metaphor," but to use it as a framework to gain insight into the people who provide care and places where care is provided (Milligan and Wiles 2010). In this thesis, I use 'landscapes of care' to describe the ways that care is shaped by individuals as well as the forces that drive medical tourism. In addition, I describe a 'mobile' type of informal care that occurs in transit between countries and across transnational networks. Parr (2003) described a shortage of research on the practice and experiences of both caring and being cared for. She suggests that we should "ask more about who gives care, where and with what training, and about the experiences of being cared for" (p.217). In medical tourism, caregiver-companions and health care workers provide care, with varying degrees of training in community and clinical settings. My thesis seeks to describe caregiver-companions' experiences in and

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across these settings and to examine broader societal perspectives on care and caregivers.

Care has long been a subject of interest for researchers in the social sciences. Geographers have a history of studying informal care and the 'private' spaces in which it takes place. More recently, there has been a call for geographers to engage in an 'ethics of care' (Lawson 2007). Theorists working within an ethics of care framework define care as multidirectional and reciprocal; in other words, it does not occur in a simple linear fashion from 'carer' to 'cared for' (Tronto 1993, Kittay 2001, Noddings 2003, Milligan & Wiles 2010, Wiles 2011). Interdependence is foundational to caring relationships, and everyone is vulnerable to needing care to varying degrees (Kittay 2001, Held 2006, Milligan & Wiles 2010, Wiles 2011). An ethics of care suggests that ethical behaviour is rooted in responding to the specific context of a situation and needs of an individual. In this thesis, care is both relationship and action, as Canadians traveling abroad respond to the needs of their friends and family members. With these foundational tenets in mind, it is possible to examine how ethics play out in health care and specifically, in medical tourism. The power relations constructed in health care can be explicated through examinations of the microgeographies of care (e.g., in the home, the hospital, or the destination clinic), the day-to-day practice of care, and the experiences of those cared for (Parr 2003, Milligan & Wiles 2010). For example, due to the (often) private spaces in which it takes place, informal care work goes unaccounted for (Tronto 1993, Lawson 2007). This appears to be true in a domestic setting as well as in medical tourism. An ethics of care framework therefore provides a useful lens through which to examine medical tourism. My thesis uses this framework to highlight the elision of informal care in the industry, as well as to consider the ethics that inform the actual care provided by caregiver-companions.

My thesis draws together several strands of thought in the geographical literature: health geography research on globalization and changing trends in health care, 'mobilities'-focused geography, and landscapes of care. This research falls within these domains as it seeks to describe the provision of informal care by Canadians engaged in medical tourism, the mobilization of care at a global level, and how these changes fit into broader landscapes of care.

1.2. An Overview of Medical Tourism

When individuals travel abroad in order to access private health care outside of their home health care systems, they are engaging in what is sometimes termed medical tourism (Hopkins et al. 2010, Hanefeld et al. 2013). Media depictions of medical tourism often focus on a narrative of wealthy patients from the United States, Canada and Western Europe traveling to the Global South for procedures, yet it is unlikely that this type of care is the most common form of medical travel (Lunt et al. 2014). Many researchers argue that the majority of movement for medical care is between countries in the Global South, within specific regions, and/or by citizens of the destination countries' diaspora (Connell 2013, Ormond & Sulianti 2014, Bochaton 2015). Regardless of what types of medical travel are most common, more research is needed into the different flows of patients around the world and what impacts their mobility has on health care systems. While medical tourism may not be the most common form of international medical travel, it still has significant impacts on both medical tourists' home and destination countries. My thesis research shows one such impact: medical tourism affects many people beyond the patient, drawing in the support and resources of friends and family at home in order to enable engagement in this global health services practice.

Connell (2008) suggests that the increased quality of medical care in the Global South, combined with increasing ease of travel and research on the internet, have contributed to medical tourism. Countries such as Thailand, Costa Rica, India, Cuba and Malaysia are seeking to attract medical tourists. Medical tourists may use 'facilitators' or brokers that arrange their travel for a fee (Turner 2007). Hanefeld et al. (2014) argue that 'medical tourism' encompasses multiple types of travel driven by different patient motivations (e.g. fertility travel, dental tourism, cosmetic tourism) and that these phenomena and their impacts ought to be considered separately. Hopkins et al. (2010) state that medical tourists from places such as Canada, the United States and Western Europe share common drivers: high costs for uninsured procedures in their home countries, long wait times, and/or the desire to obtain procedures not available in their domestic health care system. Patients may also travel in order to access procedures that are illegal in their home countries (Cohen 2012a) or for experimental procedures that are driven by hope and/or desperation (Snyder et al. 2014).

Many medical tourists believe that framing their travel as 'tourism' is problematic. From their perspective, they are not tourists but are traveling due to their experiences of pain/disability or desire to access essential procedures which are not available in their home country (Kangas 2007, 2010). Most have consulted many sources of information (particularly on the internet), including testimonials of others who have traveled for the same procedure, before deciding to travel for medical tourism (Johnston et al. 2012). Despite the possibility of challenges associated with communication with care providers abroad and language/cultural barriers, research has shown that former medical tourists often express positive feelings about their engagement in medical tourism and the care they received abroad (Eissler & Casken 2013, Johnston et al. 2013).

In Canada, participation in medical tourism is thought to be growing and increasingly attracting lower and middle income individuals who previously would have relied on the domestic public system for care (Johnston et al. 2012). Due to the availability of publicly-funded health care in Canada, patients' decision to travel abroad for care is likely motivated by different factors than would occur in a private system such as the United States, where cost may be a more common driver of medical tourism. Canadians' increased involvement in medical tourism may have been precipitated by greater comfort with international travel, higher quality medical care in destination countries that is easily communicated over the internet, and an increasing familiarity with the 'patient as consumer' model (Connell 2008). Canadians' involvement in medical tourism also has impacts on the domestic health care system. For example, Johnston et al. (2010) suggest that patients leaving their home health system may benefit other wait-listed patients by removing themselves from the queue, or by obtaining preventative care that will ultimately lower the burden they place on the health care system.

Ethical and equity concerns have been raised with relation to medical tourism. Medical tourism facilities may draw health care workers away from public sectors already suffering shortages in destination countries (Hopkins et al. 2010, Johnston et al. 2010). Patients' health and safety may be at risk for a variety of reasons including possible complications, the transmission of antibiotic-resistant organisms, discontinuity of medical records, and uninformed decision-making (Crooks et al. 2013). Limited regulation and legal liability, along with the lack of involvement of medical tourists' home physicians, may

contribute to negative outcomes that can impact their home health care systems (Turner 2007, Johnston et al. 2010). Given that many medical tourists travel with friends and family members (Crooks et al. 2011), these risks are shared with their informal caregivers.

1.3. Informal Caregiving in Medical Tourism

Medical tourists are often accompanied by friends and family, who I refer to as caregiver-companions. This under-studied group has received some attention in industry reports and scholarly publications (Kangas 2007, NaRanong & NaRanong, 2011; Yu & Ko, 2012; Yeoh, Othman, & Ahmad, 2013; Margolis, Ludi, Pao, & Wiener, 2013, Ormond 2015a, Whittaker 2015). Two earlier autobiographical books written by caregiver-companions—*State of the Heart* (Grace 2007) and *Larry's Kidney* (recently optioned for a film, Rose 2009)—provide early accounts of informal care in medical tourism. Kingsbury et al. (2012) examined the emotional geographies described within these two books, describing the emotional 'amplification' and 'extensivity' caused by traveling to foreign locations for medical care. They argue that the anxiety felt by caregiver-companions relates to the unsupported decision-making they engage in, the blurred boundaries they experience, and their close proximity to 'Otherness' while in destination countries. This early consideration of caregiver-companions highlighted many interesting aspects of the medical tourism experience.

Previously, the SFU Medical Tourism Group published two papers on caregiver-companions, based on interviews with international patient coordinators who work at destination facilities. In these interviews, it was found that caregiver-companions play a variety of roles in medical tourism: as companions, navigators, and knowledge brokers (Casey et al. 2013a). As companions, they provide physical and emotional care. As navigators, they assist with cultural and travel negotiation, as well as managing documents and finances. As knowledge brokers, caregiver-companions interact with staff at destination facilities and at home, sharing information for and about the medical tourist. Caregiving in medical tourism involves negotiating unfamiliar spaces, cultures, and medical treatments while providing care in each of these roles. Casey et al. (2013b) highlighted how caregiver-companions may create challenges for destination facility staff through disrupting care provision, being exposed to risks themselves, and drawing on the

attention and resources of staff. For example, if a caregiver-companion has a significant stress reaction to traveling or provides poor quality care, they may have a negative impact on the health of the medical tourist and/or require assistance from staff. These two studies were the first to use data from interviews specifically focused on informal caregivers in medical tourism.

Despite the fact that medical tourists travel with informal caregivers, to date few studies have focused on them. Ormond (2015) followed the caregivers of individuals traveling to Malaysia for health care on their journeys by bus and airplane. In fitting with a mobilities approach, she advocates for researchers to study how care is provided between home and destination, while these individuals are in transit. Margolis et al. (2013) found that informal caregivers traveling to the United States faced challenges associated with language and communication, finances, and emotional strain. Her participants required the support of hospital staff and family members to address these issues. Despite the challenges evident, it is also clear that many caregivers find helping a friend or family member gain access to treatment abroad rewarding (Petersen, Seear & Munsie 2013). My study is the first that interviews Canadian caregiver-companions directly about their experiences of medical tourism, and as such addresses a gap in the literature.

1.4. Study Overview

My thesis contributes to a larger multi-qualitative method Canadian Institutes of Health Research (CIHR)-funded study. This study's overall purpose is to understand the roles and responsibilities of caregiver-companions who accompany Canadian medical tourists abroad. The research objectives of the overall study are to learn: 1) how caregiver-companions identify and address health risks to medical tourists and themselves, 2) which of their roles and responsibilities they perceive as most important, 3) what they see as the practical and ethical impacts of their care. My thesis addresses these objectives from several different angles. Chapter Two describes how we can answer these questions by using multiple sources of data (interviews and surveys with different stakeholder groups) to find out what roles and risks caregiver-companions take on. Chapter Three uses an ethics of care framework to explore caregiver-companions' own views of the ethical aspects of their care. Chapter Four provides insight into how caregiver-companions

address the challenges they face in medical tourism, and identifies key points for supportive intervention. Taken as a whole, these three chapters address all the study objectives described above, albeit from very different perspectives.

The genesis of the CIHR-funded study to which my thesis contributes lies in earlier interviews with Canadian medical tourists that sought to learn about their decision-making processes; their accounts revealed the important role played by informal caregivers in medical tourism (Crooks et al. 2011). As a result of these findings, a larger study on informal caregiving was undertaken. This study has involved three sets of data collection: 1) an online survey of Canadian medical tourism facilitators (individuals who broker travel and medical plans for medical tourists), 2) interviews with international patient coordinators employed at overseas clinics and hospitals, and 3) interviews with Canadian caregiver-companions themselves. The online survey and interviews with international patient coordinators were completed in 2012-2013, prior to the caregiver-companion interviews that form the basis of my thesis. Thematic analysis of the international patient coordinator dataset identified three key roles played by caregiver-companions: companions, navigators, and knowledge brokers (Casey et al. 2013a); and revealed the sometimes conflicting opinions of international patient coordinators and caregiver-companions (Casey et al. 2013b). Following the interviews with international patient coordinators, the next step was to interview caregiver-companions directly. These interviews form the foundation of my thesis research.

In 2013-2014, I conducted 20 interviews with caregiver-companions following ethics approval from Simon Fraser University's Research Ethics Board. Participants were recruited through contact information retrieved from previous studies, through Craigslist postings, through personal networks, and through media searches. The interviews varied in length from 40 minutes to 80 minutes, and were conducted over the telephone or Skype. The interview guide is included in Appendix 1. Following the interviews, an honorarium of $40 was provided to each participant to acknowledge their important contribution to this research. The analytic methods and conceptual frameworks for each of my three thesis papers are distinct and described in detail in each chapter.

Reflexivity is a key consideration in qualitative research. I define reflexivity as an epistemological stance that acknowledges the positionality of the researcher, the interplay between researcher and participants, and how it may affect research outcomes (Pillow 2010, Berger 2013, Probst & Berenson 2014). As the sole interviewer for caregiver-companions in our larger CIHR study and as first author on three papers associated with this study, my personal characteristics and my social positioning impact the way that interviews were conducted and the meaning that I ascribe to our findings. Throughout this project, my goal was to provide a forum for participants to "tell their stories," and in each Chapter of this thesis I have used quotes in an attempt to have the voices of participants speak. That said, I recognize that my own interpretation of their accounts is shaped by my positionality. I am a young, highly-educated white woman who is comfortable advocating for my own health and has no chronic illnesses or disability. I am a researcher who had no previous experience of qualitative research prior to this study, and as a result I felt nervous and deferent to many of my early interviewees. Prior to beginning this study, I had an interest in informal caregiving stemming from my own experience as sister and caregiver to a person with disabilities. However, I did not find that the experiences of caregiver-companions were that easy to relate to, because they had taken place in the unfamiliar environments of medical tourism, and because of the significant age gap between myself and a majority of our interviewees. Most of our participants were older than me, and all were providing care related to surgery abroad, which I have never experienced. Being an 'outsider' to the study participants allowed me to act as a 'naive' researcher, and I have tried to frame them as the experts on this phenomenon throughout this research. However, there are also significant disadvantages to being an outsider researching this group. Researchers studying phenomena with which they have no direct experience may have a hard time recruiting participants, may not know what questions to ask, may not be able to identify subtle points, and their lack of context may influence their overall perspective on the phenomenon (Berger 2013). Periodic de-briefing with other graduate students in my research group as well as with my supervisor assisted my interpretation of our findings, as most of my fellow researchers have a more broad experience of researching medical tourism than I do.

1.5. Thesis Outline

Chapters 2, 3, and 4 are structured as peer-reviewed journal articles that have been submitted to academic journals for review. My second chapter outlines the data triangulation strategy used in the overall study and how it enabled learning about the roles of caregiver-companions from multiple perspectives. I used four datasets—interviews with medical tourists, caregiver-companions, and international patient coordinators, and a survey with medical tourism facilitators—to understand where their perspectives overlapped, differed, and confirmed the roles identified in Casey et al.'s previous analysis. This triangulated analysis confirmed the three roles (companion, navigator and knowledge broker) and added nuance to existing ideas about the actual tasks completed within each role.

The third chapter makes use of the ethics of care framework to explore the experiences of informal caregivers. I conducted a thematic analysis based on the ethics of care literature, and found three themes evident in the experiences of participants: responsibility, vulnerability and mutuality. Further, an ethics of care reveals how the under-valuation of informal care in medical tourism contributes to a long history of informal care being unaccounted for due to its relegation to private spaces. The positioning of care at geographic distance from the home countries of medical tourists, largely in the Global South, reproduces this narrative in a new care landscape.

The fourth chapter deals with the experiential resources (i.e., former life experiences that enable caregiver-companions to cope with caring in a transnational context) that caregiver-companions draw upon to manage stress and burden in the medical tourism process. The cross-border geography of medical tourism is a novel space in which to provide care, and as a result few supports are in place for informal caregivers. Participants had developed strategies based on their own experiential knowledge to manage their medical tourism trip. These strategies were focused on three domains: first, they drew on prior experience of travel; second, they drew on their skill as informal caregivers; and third, they drew on their intimate knowledge of the friend or family member they accompanied. This analysis brings literature on care transitions, caregiver burden,

and medical tourism together to identify key points of intervention to support caregiver-companions.

The final chapter of this thesis brings together the themes of Chapters 2, 3 and 4 and identifies the key knowledge gaps that my thesis informs. In this chapter, I revisit the overall study objectives to describe how they have been met and identify some general imitations to this study. I close by suggesting future research areas in informal care and medical tourism.

1.6. Importance

What's the value in studying informal caregiving in medical tourism? Without the perspectives of caregiver-companions, key information about the lived experience of medical tourism would be lacking. These individuals have a close vantage point to medical tourism: they accompany someone undergoing a surgery throughout the process, but they also have the distance of not having themselves undergone a procedure. Informal caregiving in medical tourism is also worthy of study due to its role in sustaining the industry. Given the importance industry representatives and caregivers attributed to traveling abroad with a companion, it is likely that many cannot undergo surgery abroad without these supportive individuals. The care provided by friends and family members also makes an important contribution to the wellbeing and recovery of medical tourists. Finally, informal caregiving in medical tourism provides an empirical lens through to examine the new types of informal care that are shaped by globalization, privatization of health care, and the international trade in health services. The impacts of these broad trends at the individual level are exemplified in the experiences of caregiver-companions.

Chapter 2.

Exploring Informal Caregivers' Roles in Medical Tourism through Qualitative Data Triangulation[1]

2.1. Abstract

Using data triangulation to examine the narratives of multiple stakeholders engaged in a complex phenomenon can help researchers better understand the multiple, overlapping perspectives of participants. When Canadian medical tourists go abroad they are often accompanied by friends and family who provide informal care, who we refer to as caregiver-companions. This article presents the findings of a triangulated analysis of four qualitative datasets—interviews with medical tourists, caregiver-companions, international patient coordinators, and a survey with medical tourism facilitators--in order to understand the roles that Canadian caregiver-companions play while accompanying medical tourists abroad. We ask if and how the datasets confirm, alter, or augment three caregiver-companion roles identified by a prior analysis: companion, navigator and knowledge broker. Our triangulated analysis of all four datasets confirms these roles and the unique perspectives offered by each group augment our understanding of the scope and scale of each role. Specifically, the use of multiple datasets adds nuance to our existing comprehension of the tasks completed within each role.

2.2. Introduction

Medical tourism occurs when individuals travel abroad intending to obtain private medical care that is not arranged through their home health care systems (Hopkins et al. 2010, Hanefeld et al. 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

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[1] Co-authored with Crooks, V. A. and Snyder, J. Currently under review at *The International Journal of Social Research Methodology.*

practice is growing in popularity. Meanwhile, Connell (2013) cautions that the majority of medical tourism is regional and diasporic, in contrast with sensational media accounts of 'Western' medical tourists traveling long distances for relatively invasive procedures.

Much of the qualitative research that has been conducted about medical tourism is focused on specific aspects, such as medical tourism facilitators and websites (Sobo, Herlihy & Bicker 2011, Turner 2012a, Viladrich & Baron-Faust 2014) or the experiences of individuals engaging in specific types of medical tourism such as travel for fertility or reproductive procedures (e.g. Culley et al. 2011, Crozier & Martin 2012, Deonandan, Green, & van Beinum 2012), stem cell interventions (e.g. Einsidel & Adamson 2012, Ogbogu, Rachul, & Caulfield 2013), bariatric surgery (e.g. Turner 2012b), procedures that are illegal in their home countries (Cohen 2012a) and plastic or cosmetic surgery (e.g. Ackerman 2010, Iorio et al. 2014). These and other qualitative studies about medical tourism have adopted a variety of methods and methodologies, including ethnographic observations, interviews, media reviews, content analyses, and focus groups. Specific areas of concern, including ethical problems, health and safety issues related to quality of care, patient safety, public health threats, legal liability, and health equity impacts on destination country health systems, have been identified by researchers as knowledge gaps for future qualitative exploration (Chen & Flood 2013, Turner 2013, Meghani 2013). Here we present the findings of a qualitative study that addresses one such gap.

Industry reports and recent studies show that when medical tourists go abroad they are often accompanied by friends and family, referred to herein as caregiver-companions (NaRanong & NaRanong 2011, Yu & Ko 2012, Yeoh, Othman, & Ahmad 2013, Margolis et al. 2013). They provide informal care that spans from holding hands to managing medications, as noted in two autobiographical accounts written by caregiver-companions: *State of the Heart* (Grace 2007) and *Larry's Kidney* (Rose 2009). Informal caregiving takes place under a variety of circumstances, whether in a long-term context or briefly, and generally occurs in a range of settings, including the home and hospital (Milligan & Wiles 2010). The transnational nature of informal caregiving in medical tourism thus 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 et al. 2014, Tramonti et al. 2014), which means that the transnational care context could impact outcomes for medical tourists' caregiver-companions 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 in order 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, Vikstrom 2010). Triangulation entails examining multiple sources of information or using multiple points of analysis to examine the same phenomenon. Triangulation offers "in-depth understanding, the use of multiple validities, not a single validity" (Denzin 2006, 271). Warin et al. (2010) highlight how the triangulation of multiple perspectives from individual family members produces a complex, rich narrative and acknowledge their own role as researchers in the production of this narrative. In this article we undertake data triangulation in order to explore how four different medical tourism stakeholder groups understand the roles played by Canadian caregiver-companions, seeking to confirm, alter, or augment an existing published interpretation of these roles through the use of multiple datasets. We examine the perspectives of former Canadian medical tourists, former caregiver-companions, medical tourism facilitators, and international patient coordinators at medical tourism facilities.

As Farmer et al. (2006) note, although triangulation is common in qualitative health research, the literature offers only a small amount of practical advice for how triangulation should take place. Moran-Ellis et al. (2006) further advocate for researchers to be clear and purposeful in articulating the triangulation processes by which data are integrated, and what the resulting impact on insights into phenomena might be. Addressing such calls, here we describe the process of multi-dataset triangulation in our own analysis. As a result, our consideration of Canadian medical tourists' caregiver-companions contributes not only

to the nascent medical tourism literature but also to the qualitative methods literature more generally.

2.3. Methods

Data Triangulation Context

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 et al. 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 2.1. A previous thematic analysis of the international patient coordinator interview dataset alone identified the three key roles played by caregiver-companions: companion, navigator, and knowledge broker (Casey et al. 2013a). We expand on these roles below. Here we undertake a single triangulated analysis of all four datasets summarized in Table 2.1 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 2.1.   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

A paper we published previously first introduced the companion, navigator, and knowledge broker roles that we seek to examine here via data triangulation (Casey et al. 2013a). 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. 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. Using four datasets of stakeholders who are differently-situated in relation to the practice being examined gives us the opportunity to uncover what common understandings are shared by all and what differs in their conceptions of informal caregiving in medical tourism.

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, with different stakeholder groups placing different degrees of emphasis on the importance of different tasks which, when taken together, provides a very robust picture of the full scope and scale of each role. We subsequently reflect on the benefits of using data triangulation, concluding that as a result of data triangulation we have reduced the bias inherent in interviewing only one stakeholder group while enabling exploration of both agreement and divergence in participant responses.

Recruitment and Data Collection

Recruitment and data collection methods from the medical tourist and international patient coordinator datasets have been reported on elsewhere (Johnston et al. 2012, Casey et al. 2013a, 2013b). This section will briefly overview the methods for those studies as well as introduce in full the methods used for the medical tourism facilitator survey and the 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 within the allotted time period and sufficient depth of information.

Recruitment and Data Collection – Former Canadian Medical Tourists

Between July and November 2010, semi-structured telephone interviews were conducted 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 researchers, detailed study information was provided to participants. Once participants were found eligible, interview times were

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scheduled and interviews were conducted over the telephone. Data collection ended when all of 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.

Recruitment and Data Collection – Canadian Medical Tourism Facilitator Survey

The facilitator online survey was completed in 2012 by seven Canadian medical tourism facilitators who had 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.

Recruitment and Data Collection – International Patient Coordinators

In 2012, 21 semi-structured interviews were conducted 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.

Recruitment and Data Collection – Former Canadian Caregiver-Companions

The recruitment of and interviews with caregiver-companions took place in 2013 and 2014. Recruitment was conducted through four concurrent strategies. First, we emailed past medical tourist study participants to ask if they had been accompanied and, if so, whether their companion would be interested in participating. Second, we had past and new participants pass on study information to individuals that they thought might be interested. Third, we disseminated study information through online postings on Craigslist across Canada. Finally, we reviewed media and newspaper articles 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 and 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 2.2 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 2.2.   Selected Questions from Semi-Structured Interview Guide

Question	Sub-probes
Describe the nature of your relationship with (the medical tourist).	How long have you known each other? How familiar are you with his or her health issues? Had you traveled together prior to the medical tourism trip? How have your previous travel experiences been?
How did you plan for this?	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)? 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?
What assistance did you provide the medical tourist while abroad but outside of the hospital or clinic?	How would you characterize that support (e.g., organisational, coordination, logistical, first aid, everyday activities, mobility, moral, spiritual, emotional, encouragement, familiarity, communication)? Why? What was it like (e.g., equipped, (un)comfortable)?

Triangulated Analysis

The triangulated thematic analysis of all four datasets outlined in Table 2.1 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 were discussed that it would be possible to meaningfully triangulate them for purposes of confirmation in a single triangulated analysis. Third, using a deductive approach, the first author coded the caregiver-companion and international patient coordinator datasets in NVivo using a scheme developed specifically for this analysis 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. Once coding of the

international patient coordinator and caregiver-companion datasets was completed, data from the original medical tourist dataset and the facilitator dataset were then compared and contrasted using the same scheme. 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 the full team, with coding excerpts circulated to confirm coding and the triangulated interpretation of the full scope and scale 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.

2.4. Findings

Comparing Participant Roles across Datasets Using a Triangulation Strategy

This section is focused on determining if and how the triangulated datasets outlined above and in Table 2.1 confirm, alter, or augment the caregiver-companion roles identified in our prior analysis: companion, navigator, and knowledge broker. 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 would recommend taking someone abroad to those considering medical tourism. 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 in travel abroad for private health 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. We view this to be an important 'value added' outcome of the triangulated analysis.

In this section we highlight three strengths that emerged through the triangulated analysis of the four datasets. First, we discuss the ways in which the findings of the original

analysis were not only confirmed in the current analysis but that also nuance was added to our understanding of their scope and scale. 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 degree of nuance 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 how the different participant groups place differing degrees of emphasis on the importance of the three caregiver-companion roles. 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. In Table 2.3 we synthesize the full scope of the each of these three strengths and the specific insights they yielded, contrasting them against the findings reported by the initial analysis published by Author et al., 2013. In the remainder of this section we examine these strengths, providing specific examples to complement the synthesis presented in Table 2.3.

Table 2.3.   Synthesis of the Strengths of our Triangulated Analysis

	Original insights identified by Author's (2011) analysis	New insights identified by current multi-qualitative dataset triangulation		
	Roles identified and defined	*Strength 1: Roles confirmed in importance*	*Strength 2: Roles comparatively emphasized*	*Strength 3: Roles augmented in scope*
Companion	Caregiver-companions provide physical and emotional care to their friends and family members while abroad, en route, and at home.	All participant groups agreed this role was important, offering new examples of tasks. For example, an international patient coordinator highlighted medication management, while many caregiver-companions mentioned fetching necessary items for the medical tourist.	Companionship was the primary focus of caregiver-companions, who emphasized that they were best situated to take on this role relative to others that medical tourists will come into contact with.	Participant groups were mostly in agreement about the need for companionship, although some medical tourists said that it would not always be necessary for someone to take on the companion role. International patient coordinators noted that companions can sometimes require attention and resources in a way that can detract from the attention given to the medical tourist.
Navigator	Caregiver-companions help the medical tourist deal with unfamiliar cultures, the stresses of travel, and documents and finances.	All participant groups agreed that this role was important. An interesting new insight was that this role was perceived to enable the medical tourist to focus on their procedure.	This role was particularly emphasized by the international patient coordinators, who valued the ways in which caregiver-companions aided medical tourists with navigation-related tasks while abroad. Caregiver-companions most commonly emphasized the importance of the planning (pre-trip) aspect of this role.	Participants provided insight into the different locations and times at which caregiver-companions take on the navigator role due to their involvement in different stages of the medical tourism process (e.g., medical tourism facilitators had more familiarity with pre-trip navigation tasks while international patient coordinators primarily observed these tasks first-hand while care was being provided abroad).
Knowledge broker	Caregiver-companions interact with staff and health care professionals at the destination facility, sharing information with and on behalf of the medical tourist.	All participant groups attested to the importance of this role. Caregiver-companions offered specific insight into how they act as 'advocate' or 'voice' for the medical tourist, sharing these responsibilities.	While the knowledge broker role was discussed by all four participant groups, it was of particular importance to medical tourists and thereby emphasized during their interviews, possibly due to feelings of vulnerability while undergoing their procedure.	Individuals working in the industry, namely the medical tourism facilitators and international patient coordinators, and those involved in receiving care, namely medical tourists and caregiver-companions, had different views on an expectations of this role. The former viewed the knowledge broker role as having an 'extra set of ears' for information exchange while the latter viewed it as a form of advocacy.

2.4.1. Confirming Roles across Datasets

Adding Nuance to our Understanding of the Tasks Completed by Caregiver-Companions

Triangulating findings across four datasets allowed us to confirm the results of the initial role-focused analysis published previously, and to add 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-companion said that their role as companions 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 the accounts of medical tourists and caregivers themselves, 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 Author et al. (2013a). The interviews with caregiver-companions confirmed previous findings from medical tourists, international patient coordinators, and facilitators that identified a role for them in logistical matters such as geographic and cultural navigation and tracking paperwork, and in interacting with destination facility staff and health care workers. For many of the caregiver-companions we spoke with, these roles were tied to the perceived need for medical tourists to be free from such concerns in order 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 them, 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, etc.). A clear strength of our triangulation strategy derives from this type of complementary information and the added nuance gained only by considering the perspectives of multiple stakeholder groups.

2.4.2.   Comparatively Emphasizing Roles across Datasets

How Participants Placed Differing Degrees of Emphasis on the Importance of Different Roles

An unexpected strength of the triangulated analysis is that although all three roles (caregiver, navigator, and knowledge broker) were confirmed, different participant groups placed differing degrees of emphasis on the relative importance of these 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 and 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.

2.4.3. Augmenting the Scope of Roles across Datasets

Different Understandings and Interpretations by Participant Groups

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 significant 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). Meanwhile, they also 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 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 his wife 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 international patient coordinators were overall 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).

2.5. Strengths and Limitations

The data triangulation strategy employed in this analysis has significant strengths that can be applied to other studies seeking to better understand the roles taken on by various players in health interactions. Most simply, our description of this strategy and how it was enacted responds in part to the need for more detailed, practical accounts of triangulation (see Farmer et al. 2006). One strength not shared earlier was the ability of each subsequent dataset to guide other interviews or surveys, while leaving room for participants to raise new topics and to discuss aspects of the experience important to them. An additional strength drawn from triangulating the four datasets comes from the ability to supplement information from one group with the observations of others, a point made repeatedly throughout the findings shared previously. At times caregiver-

companions found it difficult to articulate their roles, while other participants were able to observe what they do and to supplement their experiential account with further information. For example, many caregiver-companions found it challenging to delineate the tasks that they completed while caring for their friend or family member, while medical tourists were particularly able to speak to this. One reason for this is that the caregiver-companions we spoke with may not have considered tasks that they normally assist with to be caregiving labour. The multiple perspectives brought by the four participant groups increased the rigor of our analysis, serving as a considerable strength; participants' perspectives do not prove or disprove each other, but balance each other out and provide greater nuance to our understanding of what caregiver-companions do in medical tourism.

The first limitation of this analysis is that because reliable quantitative information about medical tourists themselves 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 those involved in this global health services practice. In addition, we recognize the potential limitations of using deductive analysis to determine the roles played by caregiver-companions. However, because the deductive analysis was a means to check the roles that had been determined inductively in a prior analysis, our current deductive strategy was needed to assess the actual experiences and roles of caregiver-companions as well as the full scope of these roles. On the whole, we have employed both inductive and deductive approaches to data coding and analysis, which we consider to be a strength.

Due to the voluntary nature of participation there may have been be a recruitment bias in participants from all four datasets, and because of the limited time frame in which interviews were conducted, some individuals may not have been able to participate due to scheduling conflicts. Beyond the limitations of our recruitment strategy, there are also known limitations to telephone interviewing, which was the data collection method most commonly used in our datasets: tendency of participants to provide less detailed responses than in face-to-face interviews, lack of visual cues or rapport, challenges scheduling in different time zones, difficulty communicating with individuals who tire easily or have communication challenges, 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, and we also offered to conduct interviews in French but no participants requested this.

2.6. Conclusion

Triangulation is discussed in the qualitative literature, but its practicalities and potential benefits are less often described in detail. This paper used data triangulation for the purpose of confirming, altering, or augmenting an earlier analysis, considering the accounts of different groups involved in the practice of medical tourism. In doing so we sought to make clear the benefits of using multiple datasets. 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 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.

All four participant groups considered in this analysis underscored the great importance of caregiver-companions in the global practice of medical tourism, clearly illustrating the need for supports to be put in place to ensure their wellbeing while abroad. 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 different emphases and viewpoints offered by these diverse groups reduced any bias inherent in interviewing one group, which assists greatly in enhancing the rigour of our qualitative analysis. Most broadly, we show how multi-qualitative dataset triangulation can serve as a tool for researchers to learn deeply about complex phenomena by speaking with multiple groups involved in order to gain the fullest sense of how such phenomena are undertaken, experienced, and perceived.

The multi-qualitative dataset triangulated approach employed in this analysis offers important insights for other researchers. Perhaps most important, researchers seeking to use a similar approach will face choices about the selection of stakeholder groups for multi-dataset triangulation, which will ultimately shape the findings. How these

stakeholder groups are best selected, and the extent to which they can offer complementary and conflicting perspectives are considerations specific to each research project. As Moran-Ellis et al. (2006) suggest, there must be a clear rationale for the inclusion of each group and transparency around the integration of the datasets gathered from each in the analytic process. We echo this sentiment and, based on our experiences of undertaking the current analysis, we advocate not only for a clear rationale but for explicit consideration to be given to the ways in which the situatedness of each stakeholder group contributes to the triangulated findings as a whole and explains, at least in part, factors they place emphasis upon in their interviews.

Chapter 3.

Ethics of Care in Medical Tourism: Informal Caregivers' Narratives of Responsibility, Vulnerability, and Mutuality[2]

3.1. Abstract

This study examines the experiences of informal caregivers in medical tourism through an ethics of care lens. We conducted semi-structured interviews with 20 Canadians who had accompanied their friends or family members abroad for surgery, asking questions that dealt with their experiences prior to, during and after travel. Thematic analysis revealed three themes central to an ethics of care: responsibility, vulnerability and mutuality. Ethics of care theorists have highlighted how care has been historically devalued. We posit that medical tourism reproduces dominant narratives about care in a novel care landscape. Informal care goes unaccounted for by the industry, as it occurs in largely private spaces at a geographic distance from the home countries of medical tourists.

3.2. Introduction

Medical tourists are individuals who travel abroad with the intention of accessing private medical outside the context of referral from their home health care system (Hopkins et al. 2010, Hanefeld et al. 2013). To date, reliable quantitative data about medical tourism are limited (Connell 2013). Researchers suggest that factors such as price, convenience, hope, necessity, and desperation drive patients to consider engaging in medical tourism (Ormond 2015a, Snyder et al. 2014). The majority of movement across borders for private care is regional, diasporic, and often between countries in the Global South (Ormond & Sulianti 2014, Crush & Chikanda 2015, Bochaton 2015). This counters the often-reported notion that patients from the Global North are flocking to Global South countries for such

[2] Co-authored with Crooks, V. A. and Snyder, J. Currently under review at *Health & Place.*

care (Lunt et al. 2014). Hanefeld et al. (2014) highlight how medical tourism is not just a single phenomenon, nothing that different types of travel (e.g., fertility travel, diaspora travel, dental tourism, cosmetic tourism) are guided by different patient motivations and have different impacts on destination countries. In this paper we are not focused on the impacts of medical tourism on a particular destination country or patient group but, instead, we shed light onto a relatively silent and invisible stakeholder group: the friends and family members who accompany medical tourists abroad.

An emerging area of research in medical tourism has to do with the informal care provided by friends and family who accompany medical tourists abroad, whom we refer to as caregiver-companions. Industry reports and recent studies show that these individuals are often active participants in the practice of medical tourism, although the scope and scale of their care work has only been partially documented (see NaRanong & NaRanong 2011, Yu & Ko 2012, Yeoh et al. 2013, Margolis et al. 2013, Casey et al. 2013a, 2013b). These reports and studies document caregiver-companions taking on roles such as providing hands-on care, liaising with health workers, booking accommodations, coordinating travel, monitoring symptoms, and maintaining communication with friends and family at home. Two autobiographical accounts written by caregiver-companions, *State of the Heart* (Grace 2007) and *Larry's Kidney* (Rose 2009), further highlight the broad range of care provided by friends and family in medical tourism. These accounts also demonstrate that caregiver-companions provide informal care not only between countries but across community sites such as the home, hotel, and airplane in addition to the hospital or clinic.

Care is a relational, reciprocal, interdependent and multidirectional practice (Tronto 1993, Kittay 2001, Noddings 2003, Milligan & Wiles 2010, Wiles 2011). In this article we draw on an ethics of care framework to argue that medical tourists' caregiver-companions are a significant part of the labour drawn on by the medical tourism industry, and to articulate the ethical implications of such care work. Lawson (2007) advocates for the use of care ethics to inform questions in social research, arguing for the centrality of emotions and social relations in understanding what is happening in the world. Here we employ an ethics of care framework to examine the experiences of Canadian medical tourists' caregiver-companions, how they perceive their relationship to the medical tourists

they cared for, and what the effects of the care they provided are. The unique geography of informal caregiving in medical tourism, whereby care provision crosses national boundaries and multiple formal and informal (or community-based) care sites, offers a novel context for applying an ethics of care framework.

An ethics of care, as defined by Noddings (2003), differs from "contract" theories of ethics due to its focus on reciprocity. The defining feature of care is that it requires a focus on taking the needs of another as the basis of action (Tronto 1993). Caregivers perceive that they have a responsibility to look after the needs of the person they are caring for, and many argue that to do so effectively they must feel some sense of mutuality. This is particularly true for informal caregivers who typically have no formal health care training and are not providing care as a form of paid work (Donovan & Williams 2015). For Noddings, "apprehending the other's reality, feeling what he feels as nearly as possible, is the essential part of caring from the view of the one-caring" (2003, 16). Many care theorists highlight the centrality of emotion to care work (Kittay 2001, Held 2006, Milligan & Wiles 2010, Wiles 2011). This affective and physical labour renders caregivers vulnerable to negative mental and physical outcomes – sometimes referred to as caregiver burden (Lilly et al. 2012, Macdonald & Lang 2014). The affective nature of caregiving relationships is often highlighted, but little research has been done on how care changes across contexts, such as in medical tourism, and how this reinforces existing geographies of power.

Milligan and Wiles (2010) describe 'landscapes of care' as the complex spatiality of care, as it is enacted, embodied and organized. This concept acknowledges that the places shaping care, including private spaces (e.g., the home, the community center), institutions (e.g., the hospital, the clinic), and the transitions between them, play a role in how care is delivered and received. We posit that the landscapes of care central to medical tourism are at once similar to those experienced in domestic informal caregiving and specific to this transnational phenomenon. This is because many of the activities associated with the care provided, as identified by Casey et al. (2013a), are in keeping with most informal care work (e.g., monitoring symptoms, providing emotional support, liaising with formal care providers), while aspects of the geographical context and the types of care transitions encountered (e.g., from hospital to hotel, from airport to home)

are particular to this global health services practice. Further to this, the care work produced by medical tourists' caregiver-companions necessitates that both parties have the financial, emotional, and social means to travel abroad (Kingsbury et al. 2012), and so a very limited number of people will ever encounter this care landscape. The value attributed to informal caregiving varies across landscapes of care. The often invisible labour of caregiver-companions in both private and formal spaces complements the labour of health care workers and others employed in the medical tourism industry in destination countries (Casey et al. 2013a, 2013b). Ethics of care theorists point to the tendency for informal care work to be devalued, in part because it often occurs outside the institution, while privileging formal care work in institutional settings (Tronto 1993, Lawson 2007). We contend that medical tourism reproduces this positioning of care: first, by devaluing the labour of caregiver-companions (see Kingsbury et al. 2012, Casey et al. 2013a, 2013b), and second, by hiding care from view in foreign places and private spaces, such as the hotel room.

In this article we present the findings of interviews with Canadian caregiver-companions examined through an ethics of care lens in order understand how ethical issues emerge in everyday caring relationships in the specific landscapes of care associated with medical tourism. Using inductive coding, we gain unique insight into the lived experiences of these informal care workers whose unpaid labour propels a multi-billion dollar trade in health services. In the section that follows we set out the recruitment and data collection methods used, and describe our thematic analysis. We then present our findings, elaborating on the ethics of care-focused themes of responsibility, vulnerability and mutuality. We subsequently reflect on how these elements of care exist in medical tourism, and how they are framed more broadly. We conclude that an analysis focused on the ethics of care in medical tourism provides clear examples of the tensions between responsibility and vulnerability. This analysis also makes clear the mutuality of care, and the landscapes of care that are created by a transnational medical tourism industry that requires informal care work to cross a number of formal and informal settings. For ease of description, throughout we use terms such as 'caregiver-companion' and 'care recipient,' but we acknowledge the mutuality of the caregiving relationship and the ways in which we are all continually giving and receiving care (see Kittay 2001, Wiles 2011).

3.3. Methods

This thematic qualitative analysis contributes to a multi-method study that aims to learn about the experiences of Canadian caregiver-companions who accompany medical tourists abroad through understanding the roles and responsibilities they take on. The multi-method study emerged from an earlier set of interviews conducted with Canadian medical tourists that revealed the important participation of friends and family in informal caregiving in medical tourism (Crooks et al., 2011). In this analysis we present the findings of subsequent interviews conducted exclusively with caregiver-companions who had accompanied Canadian medical tourists abroad for surgical care.

Data Collection

Following ethics approval, the lead author completed all semi-structured telephone interviews with caregiver-companions. We recruited participants by emailing past study participants to ask if they knew any caregiver-companions, snowball sampling through new participants, placing online postings on Craigslist, and reviewing media and newspaper articles that mentioned medical tourists and contacting them when possible. Once a potential participant expressed interest in the study via e-mail or by contacting our toll-free phone line, we emailed them general study information. Follow-up emails confirmed eligibility to participate (i.e., that they resided in Canada, were over the age of 18, and had previously accompanied at least one adult abroad for the purpose of privately obtaining surgical care), and provided more detailed study information, which included information about our ethics approval and participant rights. The recruitment phase ended when our target sample of 20 participants was met.

The 20 semi-structured interviews were completed over telephone or Skype telephone, and ranged in length between 40 and 80 minutes. Verbal consent was obtained prior to each interview. Our semi-structured interview guide was developed in an iterative and collaborative process following extensive review of the ethics of care, medical tourism, and transnational informal caregiving literatures. Semi-structured interviewing was selected as a method due to its appropriateness for exploring the experiences of participants (Tong et al. 2007) and the meanings they attribute to the care they provided. We determined that telephone/skype interviews were the most viable for this study due to

recruitment considerations, and refer to research showing that telephone interviews are an effective method for qualitative research (e.g. Sturges & Hanrahan 2004). Questions in the guide were about topics such as: how caregiver-companions planned their trip, the risks they experienced in relation to providing care, what their experiences were in the destination country and at home, the preparatory activities they undertook, and their relationship to the medical tourist. All interviews except for one were recorded and transcribed verbatim. The single interview that was not recorded due to technical difficulties was documented through detailed interviewer notes.

Data Analysis

Verbatim transcripts were prepared and reviewed by the team prior to analysis to identify emerging themes. Our thematic analysis was managed with NVivo software, and the transcripts were loaded into NVivo in preparation for coding. Three themes central to the ethics of care framework were identified in the initial transcript review: responsibility, vulnerability and mutuality. A coding scheme was developed collaboratively in order to capture the nuances of these themes, after which we came to agreement on how to interpret the scope and scale of each in relation to the coding process. Following this, the first author coded the transcripts and notes using the scheme that was developed, adding sub-codes as they emerged from the data. The excerpts were then circulated to the full team in order to achieve agreement regarding the coding of the transcripts, and data extracts for each of the three themes in this analysis were shared in order to achieve consensus on the interpretation of the scope and scale of each.

3.4. Findings

Of the 20 caregiver-companions we spoke with, ten had traveled abroad with their spouse, while others had traveled with their brother, sister, mother, father, friend or child. Participants ranged in age from 23 to 67 and consisted of 13 men and seven women who had collectively accompanied friends and family to Mexico, the United States, India, Germany, Poland, Egypt, Turkey, Costa Rica, Spain, Philippines, Venezuela and Aruba. Many indicated that they had played a role in assisting the medical tourist with decision-making about the destination. The surgical procedures sought were: hip/knee

replacement, bariatric surgery, cataract surgery, colorectal surgery, hernia repair surgery, and the "liberation procedure" for Multiple Sclerosis. Some participants had made multiple trips to the same or different countries with friends and family members for repeat treatments or for different procedures. Many stayed in hotels with the medical tourist following surgery, and spent a significant amount of time in the destination hospital or clinic, providing care in both sites and while travelling. The trips ranged between a few days to several weeks in length. Participants provided physical and emotional support, while assisting with record-keeping and communication with health care staff, as well as dealing with travel and transportation arrangements. Most found the experience to be rewarding, although they faced challenges related to language, finances and emotional strain.

As we explore in this section, participants overall saw their caregiver-companion roles as a personal responsibility, but thought that taking on this role exposed them to vulnerabilities, both physically and emotionally. At the same time, their overall involvement in this practice created a sense of mutuality with the medical tourists they accompanied abroad. In the context of this analysis, responsibility refers to caregivers' sense that they had a duty to look after the needs of the medical tourist, and that this duty should be their primary focus during the trip. Vulnerability refers to their susceptibility to physical and emotional stresses resulting from their care activities in particular places. Mutuality refers to the shared nature of the experience, which they undertook with a medical tourist with whom they shared the vicissitudes of the trip.

3.4.1. Responsibility

Caregiver-companions, by their own account, felt that they had a personal responsibility to provide care while abroad and en route to and from the medical tourism destination. When asked if they had volunteered or were asked to accompany the medical tourist, most participants reported that it was understood that they would go: "*I don't really think we, we just knew I was going* (chuckle). *It was just like 'okay you tell me when and we're going'*." One caregiver-companion described how "*there just wasn't any question, if he was going to do this I was going to be there. So there was no sort of, no question of that one, it was always planning for both of us to go.*"

For several participants, family responsibility meant an implied agreement to provide care, which sometimes meant that no explicit decision was made:

Well I guess what I can say is support…and you do…the best you can because you're trying to save and help a person and you're helping your daughter and she means the world to you…this for us was part of the nature of us as a family… My husband's parents were very ill, we were used of supporting them. My mother went downhill very quickly, we were used to supporting her. My husband and I are really trained caregivers, we've been supporting people, our parents and everything for years. For us, you just do what you do, you have to.

For most caregiver-companions, the purpose of the trip was clearly caregiving, versus sightseeing or tourism. Although some accounts of caregiver-companions did involve significant engagements in tourism activities like shopping or visiting sites of interest, most stayed in the hospital with the medical tourist for the majority of their trips. This further illustrates the sense of responsibility they felt towards the medical tourists.

During the actual procedure, most caregiver-companions described a similar experience: sitting in a facility waiting room, often watching television or reading. Their responsibility was to provide care and support to the medical tourist, and for some that meant staying nearby at all times, particularly while the patient was undergoing the procedure. A participant described waiting for his spouse:

I sat in the room 'cause the other spouses or brothers or family members that were there for the other people we just kind of sat together and everybody hung around together and we had our own little group cause you were with each other the whole time. So everybody pretty much stayed at the hospital and just entertained each other that way right.

Some caregiver-companions reported having stayed in the hospital for almost the entire time they spent in the destination country:

When he was at the hospital I stayed the time that he, while he was going through the procedure. The only time that I left the room is when we both went out together to get some fresh air or just go for a walk…we didn't really do too much except stay mostly in the room.

Participants' foci on providing care and attending to the needs of the medical tourist is demonstrated by their desire to stay in close proximity while in the destination country.

In many interviews, when asked to elaborate on the tasks they had completed in their role, caregiver-companions had difficulty articulating caregiving tasks because they felt it was their duty to do whatever was needed. In many ways these tasks were a seamless part of the ongoing relationships they held with the medical tourists and were not explicitly associated with their roles as caregiver-companions, even if they had never performed such tasks before:

> *You know it's hard to say it's just [I did] this, that and the other thing. Since "M" has mobility challenges I would certainly be there to help her move, you know sleep, in pain or things that are, you try to help with in terms of massage and a little prayer and some laughter. But I wouldn't, I wouldn't go to a point and say 'whoa, I had to do so many different things', it's just part and parcel of two individuals who've been together for a good chunk of their lives.*

Participants who were long-term caregivers were accustomed to the type of tasks they undertook while engaging in medical tourism, which further underscores the implied nature of their responsibilities as carers. For example, a participant described the care tasks that he undertook in the medical tourism context as "*just normal, my normal caregiving support. Just what I always do.*" This description of caregiving tasks as "*just normal*" indicates the general sense that many participants had: the care they provided was a responsibility and not outside the bounds of that typically provided in close relationships.

3.4.2. Vulnerability

Heightened vulnerability for caregiver-companions in medical tourism exists because patients undergo medical treatment in what is often an unfamiliar environment. Participants described how this creates a need for physical and emotional care, most obviously for the medical tourist. All participants said that it would be necessary for medical tourists to travel abroad with a caregiver-companion:

> *Like to be in a strange place having an unfamiliar medical procedure, I think that for most people…that would just be a stressful and frightening situation, no matter how, how minor the procedure or how confident you are about how, how it was going to turn out. And you know part of the time you're [the medical tourist] entirely helpless too, like you don't speak the*

language, you're on the operating table or you're bound up or whatever.
And I think to face that alone that would be quite nerve-wracking.

This quote highlights the two factors that participants commonly described as creating their own vulnerability: being in an unfamiliar environment and having a friend/family member undergo a surgery.

Participants reflected on how the factors that promoted their own vulnerability could be stress-inducing and may contribute to experiencing caregiver burden. For example, participants reported feeling anxiety due to travel and feeling isolated or unsure in foreign environments: "*I'm a creature of habit and…it was a little bit stressful of course going into the unknown and trying to figure out how you're going to do things… So yeah there was quite, there was a fear of the unknown for sure.*" The diverse care environments experienced by caregiver-companions, in addition to the sheer stress of being in an unfamiliar country, made providing care in medical tourism challenging and ultimately stressful at certain times and in certain places. Caregiver-companions found it particularly stressful to provide care in airports and on airplanes for medical tourists with mobility limitations or impairments.

Two areas of particular concern to participants were the risk of the medical tourist experiencing complications and the need to address financial challenges incurred abroad. In both cases caregiver-companions felt responsible for ensuring that medical tourists, who they perceived to be vulnerable, did not have to deal with negative health or financial outcomes:

> *…that was my biggest fear, that I'm in the hotel room at midnight and something [a complication] happens. Because we had to watch over them, every two hours we had to wake them up…and…what happens if something, if the wound opens up kind of thing? Then I'm going to panic…*

As shown in this example, the medical tourist's vulnerability led his caregiver-companion to experience fear. Another participant similarly described feeling emotionally scared and physically drained to the point of exhaustion: "*I was passed out on a couch, I remember this cause it was, you know I was at the point of, I was a bit scared and I was like just hoping everything would be fine… At that moment I just sort of gave out 'cause I was exhausted with the whole process.*" Caregiver-companions' desires to care for

medical tourists throughout a vulnerable process in turn left them vulnerable to experiencing various forms of stress and burnout.

3.4.3.   Mutuality

Many caregiver-companions had positive experiences of medical tourism and felt that they had personally benefited from the experience due to the improved health status of the medical tourist. As one participant explained, "*you know, the good stress is hard work and then you get something out of it and then it's over so that was fine…so it was a good stress, it was hard work but for a particular purpose and it turned out well and then it was done, it was great.*" In this quote the participant relates 'good stress' to worrying about the medical tourists' positive health outcome, in which case both parties had a mutually positive experience.

Caregiver-companions noted the downside of mutuality, wherein there was the potential for sharing in the negative experiences of medical tourists. One participant, who traveled with his brother for an experimental surgery, noted the disappointment they shared in the lack of follow-up care received: "*it's like once the six months was up or the four months was up there's been no contact at all, so it's kind of like take the money and run.*" The participant and his brother shared feelings of frustration at the lack of health improvements following the surgery and what they perceived as the poor quality of care provided by the surgeon abroad upon their return to Canada.

Medical tourists and caregiver companions shared the vulnerability created by medical tourism. Recognizing such mutuality, many participants considered the impacts on both caregiver-companions and care recipients when deciding to engage in medical tourism:

> *I guess my role is one of a…care partner, as opposed to caregiver. So the effects of "M's" MS [Multiple Sclerosis] has plenty of impact upon myself [already], so when we were sitting down and considering these [medical tourism] options it isn't without a view of the person who is standing next to that individual. The days of stresses and the days of angst and the days of pain affect both of us in different ways.*

Caregiver-companions identified strongly with those they accompanied and are therefore impacted by the practice of caregiving. As such, the effects of medical tourism are shared, rather than borne solely by the medical tourist.

3.5. Discussion

An ethics of care takes as its starting point the notion that caring for another involves understanding their needs and acting to try and meet those needs (Tronto 1993). Caregivers therefore often feel a sense of mutuality; they share the experience with the care recipients and they can feel what the other person feels (Noddings 2003). The labour of caring is highly affective, and this plays out in the transnational care landscape of medical tourism as clearly as it does in other settings, such as informal caregiving in the home. For example, participants reported how medical tourists' vulnerability to negative health outcomes exacerbated their own vulnerability to experiencing stress as a result of having to navigate an unfamiliar care landscape. Meanwhile, caregiver-companions perceived that the potential *benefits* of enacting their ongoing responsibilities to the medical tourists far outweighed the potential for such vulnerability. This meant they were unlikely to decline the opportunity to provide care in the first place. Further to this, there was also a recognition that the caregiver-companion and medical tourist both shared in the risks and rewards of medical tourism, which may have helped to mitigate the concerns they had about this role. Given the nature of the ongoing relationships caregiver-companions had with the medical tourists (and their attendant obligations and responsibilities), would the risks to their wellbeing outweigh the need of the medical tourist and the potential rewards of taking on this experience? The interview findings suggest that the answer to this question is no. Perhaps the strongest indication of this is that many participants did not even conceive of themselves as having a choice in taking up this role and some were reluctant to even conceptualize themselves as caregivers.

The findings highlight the ways in which caregiver-companions feel responsible to care, are made vulnerable by care, and feel that care is a mutual experience. Milligan and Wiles (2010) offer examples of the "micro-landscapes of care" that are formed in the hospital room, the home and other spaces where formal and informal care takes place. These landscapes are a product of the social and working conventions present in

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destination facilities. The interviews show that caregiver-companions have to interweave care across a number of micro-landscapes, playing a key role in enacting the landscapes of care in destination facilities and across other care settings (e.g., the hotel), and mediating interactions between medical tourists and health care professionals abroad (see also Casey et al. 2013a, 2013b). These micro-landscapes were nested within the larger context of enabling the provision of care across countries, cultures, care contexts, and sometimes also languages. The findings also point to the fact that some caregiver-companions found or created micro-landscapes of coping throughout their transnational journeys as caregivers. For example, it was commonly reported, as noted in the findings, that caregiver-companions would group together in hospital lounges and waiting rooms to talk, eat, and watch television together. While a medical tourist's hospital room or hotel bed may have been a space anxiety at times, such micro-landscapes could be drawn upon to enact the mutuality of experience they shared with other caregiver-companions.

Ethics of care theorists advocate that ethical responsibility is not derived from abstract rules, but from relationships (Tronto 1993, Noddings 2003). Caregiver-companions felt a clear responsibility to care, which stemmed from their connections to and relationships with the patients. The informal caregiving literature emphasizes caregiver burdens (e.g., Adelman et al. 2014, Tramonti et al. 2014), but rarely recognizes mutuality in caregiving. Our findings reveal that while caregiver-companions experienced stress due to the complexity of having to provide care across multiple micro-landscapes of care, they also reported some benefits of providing care in the context of medical tourism. For example, they emphasized the importance of being able to aid their friends or family members in achieving improved health, which is a benefit that has been reported elsewhere in the caregiving literature (e.g., Petersen et al. 2013) – though not from a perspective that has emphasized this is an aspect of mutuality. Wiles (2011) examines the experiences of care recipients, suggesting that more attention should be given to those receiving care and that vulnerability should not be framed solely as weakness or susceptibility but also as openness or receptiveness. Our findings support this view, while also pointing to the fact that the medical tourist should not be constructed simply as a passive care recipient, but as an engaged actor in their experience of care abroad who also plays a role in outcomes for the caregiver-companion. Such a perspective also underscores the established notion that care is not provided in a linear fashion from

caregiver to care recipient in a static place. In reality, the need for care and practice of giving care is bidirectional and often unpredictable, occurring in settings that are informed by complex processes and practices (Milligan and Wiles 2010, Wiles 2011).

We contend that caregiving in medical tourism is part of the 'changing topography of care' that Milligan and Wiles (2010) describe. Medical tourism fits into larger trends brought to light by an ethics of care, such as privatization and marketization, and is enabled by processes such as globalization and trade liberalization. It is one of several global health care mobilities that have gained in scope and scale in the last decade (Bell et al. 2015). Thus, informal caregiving within this practice reflects not only a changing topography of care but also a changing topography of the commodification of health. In her 2007 Presidential Address to the Association of American Geographers, Victoria Lawson argued that care has been marginalized by two trends: the extension of market relations into the caring arena, and the reduced public provision of social care. The privatized, market-driven practice of medical tourism thrives on these trends (Bell et al. 2015). Lawson suggests that care ethics provide a useful lens for examining power relationships, interdependence and mutuality in research on social phenomena (2007). Given the pre-existing tendency for care work to be privatized and devalued (Tronto 1993, Lawson 2007), the omission of informal care from discussions of medical tourism provides a clear mandate for further research on this topic. In addition, medical tourism provides a key example of marketization in the provision of care, as destinations compete to attract consumers of medical services (Connell 2013, Hanefeld et al. 2013, Lunt et al. 2014). Research on the trade in global health services has highlighted the ethical and equity impacts of medical tourism in destination countries (Meghani 2010, Cohen 2012a, Chen & Flood 2013, Turner 2013). An ethic of care requires that we continue to examine the ethical ramifications of this industry at multiple scales, including the micro-landscapes of care, and examine the consequences for individuals in destination as well as source countries, including caregiver-companions.

3.6. Conclusion

This analysis contributes to the developing literature on medical tourism, linking the idea of an ethics of care to the unique landscapes of care in medical tourism. We found

that informal caregivers in medical tourism are driven to take up this role by a sense of responsibility to care, and that providing this care renders them vulnerable physically and emotionally while also bonding them to the medical tourist through mutuality. Given the important role that caregiver-companions play in the global medical tourism industry, we believe it is essential to continue to articulate the ethical and practical implications of their unpaid labour. We further contend that medical tourism provides an example of a unique landscape of care, where informal care provision crosses countries and takes place in novel care sites, including hotels and airports, and thus advocate for others to employ the landscape of care concept when researching this transnational practice.

Chapter 4.

A Qualitative Exploration of How Informal Caregivers in Medical Tourism Use Experiential Resources to Cope with Providing Transnational Care[3]

4.1. Abstract

Canadians travelling abroad for privately-arranged surgeries paid for out-of-pocket are engaging in what has come to be known as medical tourism. They are often accompanied by friends or family members, who we call caregiver-companions. Caregiver-companions provide care in and across a variety of formal and informal settings, such as in hotels, airplanes and at home. This qualitative study examines the experiences of informal caregivers in medical tourism to learn more about the 'experiential resources' they draw upon to cope with providing care and avoiding caregiver burden. The caregiving literature has demonstrated that such burden can negatively impact caregivers' wellbeing. The unique, transnational context of caregiving in medical tourism and recent growth in popularity of this practice means that there are few supports or resources currently in place to assist informal caregivers. We conducted semi-structured telephone interviews with 20 Canadians who had accompanied their friends or family members abroad for surgery. Interview questions dealt with the roles they played in supporting medical tourists before, during and after the trip abroad for surgery. Thematic analysis revealed the ways that participants had developed practical strategies to deal with the challenges they faced in medical tourism. Specifically, participants drew on previous lived experiences to help them in their trip, which we refer to here as 'experiential resources'. The interviews revealed three important experiential resources drawn upon: (1) previous experiences of international travel; (2) previous experiences of informal caregiving; and (3) dimensions of the existing relationship with the care recipient. Differences in access to and use of these experiential resources related to participants' perspectives on medical tourism and the

outcomes of the trip. By identifying the experiential resources drawn upon by informal caregivers in medical tourism, we can more effectively identify supportive interventions.

4.2. Introduction

Political changes and social trends in Global North countries such as Canada are increasingly shifting informal care (i.e., care that is unpaid) into spaces that have heretofore gone unconsidered (Dyck et al. 2005, Curtis et al. 2009, Skinner & Power 2011), such as in medical tourism. Medical tourism, where individuals travel abroad to obtain privately paid for medical care outside of their home countries (Hanefeld et al. 2014), is part of a larger trend towards the privatization and globalization of care (Greenhough et al. 2015). The care provided in the global practice of medical tourism occurs in formal spaces such as private hospitals and clinics in destination countries, but also in informal spaces such as airplanes, airports and hotels, as well as at home before and after the trip is taken (Casey et al. 2013a,b). In this article we examine particular dimensions of the provision of informal care in medical tourism from the perspectives of the friends and family members who previously accompanied Canadian medical tourists abroad, who we refer to as caregiver-companions. We specifically consider the ways in which participants' lived experiences are drawn upon as 'experiential resources' across formal and informal care sites. These experiential resources aid in coping with care provision in the context of medical tourism, lessening caregiver burden.

Medical tourists have many different motivations for seeking care elsewhere and go abroad for a vast array of procedures, including but not limited to: dental, cosmetic, orthopaedic, bariatric, fertility, and experimental treatments (Turner 2012, Hanefeld et al. 2014). Medical tourists from Global North countries such as Canada are driven to go abroad by some of the following motivations: cost, avoiding wait times in their domestic systems, and/or the ability to access treatments not available at home (Hopkins et al. 2010, Cohen 2012a, Hanefeld et al. 2015). Patients traveling across borders are often accompanied by caregiver-companions. Their experiences and the care that caregiver-companions provide have only recently begun to be documented in a limited number of studies, several of which only mention this group in passing (see NaRanong & NaRanong 2011, Yu & Ko 2012, Kingsbury et al. 2012,Yeoh et al. 2013, Margolis et al. 2013, Casey

et al. 2013a,b, Ormond 2015b, Whittaker 2015). Two lengthy autobiographical accounts written by caregiver-companions detail the complex range of care provided by caregiver-companions, from arranging travel logistics to dressing wounds, across a multitude of formal and informal settings, including the airport and taxi (Grace 2007, Rose 2009). Given such complexity, it is not surprising that Ormond (2015) encourages researchers not just to look at the most obvious sites where care is provided to medical tourists (e.g., the destination hospital), but also to closely examine *how* care is provided during transitions between home and abroad, hospital and hotel, airport and taxi and other transitions. In this article we build on this by considering *who* provides such care during these transitions, showing that the informal care provided by caregiver-companions is enabled by their experiential resources.

The informal caregiving literature has repeatedly established that caregivers' health is impacted by the nature of the care they provide. Caregiver burden is the term used to characterize the negative impact that caregiving has on individuals' emotional, physical and/or financial health and overall wellbeing (Adelman et al. 2014). The stress brought on by the simultaneous management of paid and unpaid work, the financial toll of purchasing supplies and equipment, the lack of supports and informational resources available, and the physical demands of providing hands-on care, among numerous other factors, all contribute to caregiver burden (Bruhn & Rebach 2014, Davis et al. 2014, Williams et al. 2014). Whether or not caregiver burden sets in, and the extent to which it impacts individual caregivers, varies based on access to formal resources (e.g., respite care, information from professionals), personal resources (e.g., social support, finances), personality characteristics, coping strategies, the needs of the care recipient, as well as the relationship between caregiver and care recipient (Bastawrous et al. 2014, Bruhn & Rebach 2014, Chappell et al. 2014, Davis et al. 2014, Williams et al. 2014). Much existing research has shown that there is an extreme lack of information and support available to medical tourists to assist with decision-making, accessing care abroad, enabling continuity of care, and ensuring follow-up care (Runnels & Carrera 2012, Eissler & Casken 2013, Turner 2013). It is thus logical to assume that informational supports and other types of formal resources for the caregiver-companions who accompany them abroad are similarly lacking, which may contribute to the burden experienced by this group. In addition, as noted above, the context in which care is provided plays a role in determining if and how

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caregivers manage burden (Adelman et al. 2014). Caregiver-companions provide care in a highly complex transnational context that involves navigating language, cultural, social, and health care differences (Casey et al. 2013a, 2013b, Ormond 2015b, Whittaker 2015); a context so complex that it may very well promote the onset of caregiver burden.

In this article we ask: how do caregiver-companions draw upon their previous lived experiences to cope with providing care in a transnational, unfamiliar context and to minimize or avoid the onset of caregiver burden? We analyzed 20 interviews conducted with Canadian caregiver-companions. Our analysis shows that these caregivers makes sense of providing care by drawing on their existing experiences of international travel, caregiving, and the relationship with the medical tourist. In the remainder of this article we explore these three experiential resources in order to: 1) understand how they shape the informal care work taken on by caregiver-companions, 2) explore the impact that providing care has on caregiver-companions, and 3) identify resources that can assist in helping them to avoid or manage burden.

4.3. Methods

This analysis contributes to a multi-method study seeking to learn about the informal care responsibilities taken on by friends and family members in medical tourism. The overall study has involved interviews with international patient coordinators in destination hospitals/clinics and an online survey with Canadian medical tourism facilitators. The study also involved conducting semi-structured interviews with caregiver-companions themselves, which we report on in this article. Semi-structured interviews were selected as the method for learning about the experiences of caregivers because other studies have shown that such interviews are effective for soliciting participants' own perspectives and accounts of care (Rothing et al. 2014).

Following ethics approval from Simon Fraser University, recruitment of former caregiver-companions began through four strategies: emailing past medical tourism study participants to see if they had been accompanied; snowball sampling with new participants; postings on Craigslist; and contacting medical tourists that had been named in media reports to see if they had been accompanied. We employed multiple strategies

in order to recruit a diverse participant group. Once participants had been identified and provided with general study information, their eligibility to participate (i.e., residence in Canada, age over 18, and having accompanied at least one adult abroad for medical tourism) was confirmed via email. They were also provided with study information, participant rights, and details of our ethics approval. We ended the recruitment period when our sample target of 20 participants was reached.

Semi-structured interviews were conducted by the lead author over the telephone or Skype, and varied from 40 to 80 minutes in length. The questions asked addressed trip planning and preparation, risks and challenges encountered in providing care, the relationship between caregiver and medical tourist, and the caregiver-companions' experiences in the destination country and at home. Interview recordings were transcribed verbatim, except one which was not recorded due to technical difficulties. The sole unrecorded interview was documented through notes.

Transcripts were independently reviewed by all investigators prior to analysis in order to identify themes related to the issue of experiential resources. Three themes that characterized the experiential resources drawn upon by caregiver-companions were identified in the initial transcript review. Once we reached consensus on the scope of each theme, the lead author coded the notes and transcripts in NVivo. Coded excerpts were next extracted and shared amongst the full team to discuss interpretation of the thematic findings relative to the existing literature (Saumure & Given 2008). Quotes shared in the findings section come from these coded excerpts, and come from a broad set of interviewees. We believe the perspectives of multiple researchers, incorporated throughout the analytic process, enhanced the richness and dependability of our interpretation of the data, thereby contributing to overall rigour of the analysis presented herein (Saumure & Given 2008).

4.4. Findings

Of the 20 participants, ten had traveled abroad with their spouse while others traveled with a sibling, parent, friend or adult child. They ranged in age from 23 to 67, and 13 identified as men and seven as women. They had collectively traveled to 12 countries

to accompany medical tourists (with some having traveled to multiple countries): Mexico, the United States, India, Germany, Poland, Egypt, Turkey, Costa Rica, Spain, Philippines, Venezuela and Aruba. The surgeries obtained abroad included: hip/knee replacement, bariatric surgery, cataract surgery, colorectal surgery, hernia repair surgery and the chronic cerebrospinal venous insufficiency (CCSVI) treatment for multiple sclerosis. Trips ranged in length from a few days to several weeks, and all participants provided care before, during and after the trip. Most participants reported that the trip was rewarding, but that they faced burdens related to language barriers, finances, and emotional strain that brought on stress and negatively affected their wellbeing (see also Margolis et al. 2013, Casey et al. 2013a,b, Ormond 2015b, Whittaker 2015). They described coping with these burdens through a variety of means, including drawing on previous experiences of travel, caregiving, and knowledge about the medical tourists they were accompanying. The remainder of this section examines how participants characterized these experiential resources.

4.4.1. Prior Travel Experience

For most participants this was their first experience of engaging in medical tourism, although they had varying experience with prior international travel. This prior travel experience was perceived to be necessary to deal with the stresses of travelling for surgery: "*Unless you're used to traveling internationally…I think it would be pretty worrisome.*" Many participants were also accustomed to providing some degree of care (but not post-surgical care) while traveling, because of prior travel with the care recipient. One participant said that she provided care "*the same way as if we go on a holiday or just [while] visiting some of our kids away from home.*" Providing care during the medical tourism trip involved some similar considerations (e.g., locating accessible hotel rooms, ensuring availability of preferred foods, booking appropriate seating options for transportation) as during past travel experiences. Those participants who had previous travel experience in general, and especially with the care recipient, were aware of the challenges they might encounter and were able to prepare for them, avoiding becoming overburdened during the trip.

Some participants had prior travel experience to the destination country where surgery was purchased (although previous trips had not been for medical tourism in any of the cases). When asked about whether he had any concerns about traveling to a foreign country for medical care, one participant said that he had traveled to the destination country a few years prior. As a result of this experiential knowledge of the destination, he was "*quite confident that it was a place where there would be North American standards of healthcare…and that it was a comfortable place*…[and not] *an exotic travel destination.*" Even some of those participants who had not previously traveled to the destination countries found them to be 'familiar,' because the destination hospitals had experience with a Canadian-type clientele. One participant remarked: "*I could tell that I wasn't the first Canadian to do this…or first you know tourist from outside that area to do, to go there for a procedure.*" As a result, he did not find it to be a particularly stressful place in which to provide care.

Many facilities abroad were designed specifically to cater to the tastes of medical tourists, and had an aesthetic that was comfortable for individuals coming from healthcare systems in the Global North. Participants reported that, despite the distances they had travelled, the hospitals/clinics in destination countries were familiar spaces. One participant said:

> *If I closed your eyes and then wiggled my nose and then you opened your eyes in that hospital, you would not know you were in India. The [hospital abroad] was all in English, the, they had all the latest equipment, I didn't see one iota difference between the [hospital abroad] and any of the hospitals that I've been to in [home city], none whatsoever.*

Participants also made sense of foreign clinics and hospitals by relating them to a more familiar setting: the resort. Several described hospitals abroad as "*pretty much like a four star hotel resort*" and "*like a resort, it was like a luxurious experience in a way.*" Even if they had not traveled for medical tourism before, many had traveled to resorts and drew on that experience to navigate the 'international' or 'resort' aesthetic of the destination hospital/clinic.

4.4.2. Prior Caregiving Experience

Many participants drew heavily on ongoing experiences of providing care at home while abroad, framing many core caregiving duties in medical tourism (e.g., symptom monitoring) as unexceptional. As a result, those who were long-term caregivers did not seem especially overburdened by the care they provided while abroad. One participant said that "*nothing was different than regularly*," it was "*just my ordinary* [care] *that I have to do at home*." When asked what it was like providing care while abroad, another participant reported that:

> *It would be no different than anywhere else…you just have to think ahead of time before you do anything only because…things you kind of take for granted…you can't do sometimes right. So you just have to be a little bit more creative. But overall like I said to me it was no, nothing more than you do at home.*

This participant acknowledged that it can be necessary to adapt to changing circumstances in medical tourism, but in general the care recipient's routine needs continued to be the same. Caregiver-companions' knowledge of how and when to care for their friend or family member, drawn from experience at home and during previous travels, helped them avoid unnecessary stressors.

Participants often used their knowledge of navigating other challenging care settings to manage caregiving during the trip. They had typically thought through the awkwardness of providing care in an unfamiliar setting prior to going abroad. One participant related that helping his partner toilet was difficult because "*when you're in a hotel it's not set up the way our house is, so she was unable to do any of that on her own*." As a long-term caregiver, he had experienced such situations before: "*You know because everybody's version of…a handicapped or a wheelchair friendly suite or a toilet…is completely different from what people actually require, even in Canada*." As a result of his and his partner's prior difficulties in finding accessible hotels and facilities, he anticipated the challenges of providing care while abroad and was able to plan ahead to avoid feeling stressed. Another participant related a similar set of concerns about flying: "*I knew it was going to be hard* [on the airplane] *since she has no, she can't lift herself, I had to do all the lifting… And airlines are very difficult to move a person that (chuckle) that is paralyzed*." Caregiver-companions with prior care experience, and especially long-term caregivers,

drew on such experiences to address the challenges of caregiving in the unique care contexts encountered in medical tourism, including the hotel, airport, and airplane.

Most participants had significant experience navigating the Canadian health care system as caregivers to their friend or family member. Commonly, they had spent years interacting with health care professionals on behalf of/with the care recipient, and they continued to play a significant role doing so while engaged in medical tourism. Many caregiver-companions framed themselves as 'advocates' on behalf of their loved ones, drawing on experiences of acting in this capacity at home to ensure adequate care was provided abroad. As one participant explained: "*We've been working together with this problem [daughter's health] for years, we would never let our child go on her own, my husband's retired, we were going to do this together and support her*." This participant had a long history of seeking treatment for her daughter, and the knowledge she had gained doing so was a valuable experiential resource as they undertook medical tourism. She drew on this knowledge to make decisions about engaging in medical tourism, to interact with medical professionals in Canada and abroad, and to provide the care her daughter needed as she recuperated.

4.4.3.   Prior Relationship Experience

Nearly all participants, even those who did not have much experience of caregiving, drew on their knowledge of their friend or family member to aid in caregiving abroad. One participant who did not have much prior experience caring for someone recovering from surgery described it as a: "*unique experience, I've never experienced anything like that, I don't have any caregiving experience. I was there because she's my wife and I care for her health and giving her the support that she needs*." Although this participant claimed not to have any caregiving experience, he had knowledge about what support his wife might need as well as her general preferences. Overall, participants felt that the caregiver-companion role necessitated a close existing bond with the care recipient. One participant said that she would travel abroad with a friend or family member obtaining surgery again, but that she "*wouldn't just do it for anybody I didn't know…because I wouldn't know their needs*."

Due to their existing relationship with the medical tourist, most participants had detailed knowledge of the patient's health status prior to traveling abroad for surgery. One participant reported monitoring his brother's diabetes while abroad: "*I know him very well so…I can kind of like pick up on his attitudes and stuff to, to know when his blood sugars are out of whack and whether he needs help or not.*" In terms of advice for other caregiver-companions, one participant suggested that it is essential that they understand and have experience with the health needs of the medical tourist: "*make sure you know the situation of the person and their needs cause that's so important that you have…someone that knows everything and that person's comfortable with this person.*" In other words, it is key that the caregiver-companion know the medical tourist's health needs, and that they are comfortable providing care in this context. This experiential knowledge, derived from the relationship between caregiver and care recipient, was perceived by many participants to be the most important experiential resource that enabled them to cope with caregiving abroad.

As a result of their existing relationship to the medical tourist, many participants drew on experiences of shared decision-making to navigate aspects of the trip. For example, the medical tourist and caregiver-companion often researched and planned the trip in tandem: "*we researched where you were treated and everything, we looked up the hospital and everything and…we felt that their care seemed to be the best before and after.*" In contrast, others reported that they did not explicitly help the medical tourist decide when or where to travel, but that they were accustomed as caregivers and friends or family members to participating in shared decision-making about health care. For example, when asked how he had decided to accompany his wife abroad, one participant said that: "*it was just, she's my wife so obviously I agreed, it was a mutual decision.*" Some participants had a more hands-off approach to research on destinations and ongoing considerations, but were involved in the final decision-making about engaging in medical tourism: "**when she started to sort of finalize what she wanted to do, then I, I got involved in all the pros and cons.*" These different contexts reflect the range of ways that caregiver-companions participated in decision-making, typically drawing on their experience in the relationship.

4.5. Discussion

The aim of this analysis is to examine how medical tourists' caregiver-companions draw on experiential resources to aid in coping with the complexities of providing transnational, informal care. The findings shared above reveal that their experiences shape the impact that caring has on them and how they manage this burden. Importantly, this analysis shows that providing informal care in medical tourism, for most participants, shares many similarities to care provision in other contexts (e.g., the provision of long-term care at home, providing care while on holiday, acting as an advocate in routine medical appointments). This overall finding is important because the medical tourism literature tends to place emphasis on how vastly different the experience of receiving care abroad is for medical tourists (e.g., Cohen 2012a, Eissler & Casken 2013, Whittaker 2015). Instead, what we found is that the range of settings that caregiver-companions encountered did not drastically change the informal care provided. Rather, it intensified certain aspects of the caregiving experience (e.g., needing to lift the medical tourist in a non-accessible hotel washroom, which they could manage independently at home). Experiential resources, such as previous travel and the ongoing relationship with the patient, were drawn upon by participants to make sense of these new care settings, anticipate medical tourists' needs in unfamiliar spaces, and navigate transitions between settings.

Transitions in informal care, both between settings and across countries, intensified responsibilities and thus may be stressful for caregiver-companions. Previous research has shown that care transitions—such as between the home and hospital—can be a time where poor management occurs and there is an increased risk of medical complications (Cadogan et al. 2014, Brock et al. 2013). All three types of experiential resources identified in this analysis aided participants with managing these transitions while minimizing burden, such as drawing on previous knowledge of air travel and opting to reserve particularly well placed seats in advance. The findings also point to the fact that experiential resources enabled several participants to anticipate the challenges experienced in these transitions and to plan ahead accordingly.

Our findings are in accordance with previous studies that demonstrate that caregivers' personal resources and experiences can help them avoid burden (Bastawrous et al. 2014, Bruhn & Rebach 2014, Chappell et al. 2014, Davis et al. 2014, Williams et al. 2014). This analysis highlights three domains of experience that help informal caregivers in medical tourism avoid burden. However, which factors are most important in mitigating burden is not clear, so continued study is necessary in order to assess their relative importance. That said, numerous participants did place particular importance on having first-hand knowledge of the medical tourists' health status as an essential experiential resource. This is not surprising given how central the relationship between patient and caregiver is to the overall experience of informal care provision (Bastawrous et al. 2014, Chappell et al. 2014).

This analysis points to some areas where meaningful interventions can be developed in order to enable caregiver-companions to minimize the onset of burden. First, participants' accounts highlighted the need to plan for mobility challenges in informal care settings such as airplanes and hotel bathrooms. For medical tourists who face physical difficulties in boarding and being on board planes, ensuring access to early information about flight schedules or gate changes, airplane layout, adequate seating space and on-board first aid supplies are key interventions (Poria et al. 2010). Poria et al. (2010) note that the specific needs of each individual vary, and that no single intervention will suffice. In terms of hotel rooms, a key intervention is for destination clinics or facilitators to ensure that hotel rooms are designed to accommodate the *actual* physical needs of the medical tourist, and not just a standard 'accessible' room (Kim & Lehto 2012). Second, the importance participants attributed to planning before the journey highlights the need for caregiver-companions to familiarize themselves with the needs of the medical tourist, as well as the logistics of the trip and the specifics of the medical procedure to be undertaken prior to departure. Research by Casey et al. (2013b) suggests that international patient coordinators in destination hospitals are well positioned to provide such information and offer informational resources to caregiver-companions that can prompt them to take on such familiarization. Third, other studies have noted that informal care burden is greatest immediately after a change in health status, and that some caregivers are unfamiliar with recovery processes which can then bring on stress (Nahm et al. 2010). This may be heightened in the medical tourism context given that participants reported additional stress

being brought on by transitions in care settings and not just changes in care recipients' health. Thus, providing educational resources about the medical aspects of providing informal caregiving in the context of medical tourism, such as what types of hands-on care may be needed and what a patient may look like following surgery, is a useful intervention.

This analysis has several limitations. First and foremost, it is impossible to know whether or not our participants are representative of Canadian caregiver-companions as a whole, given the lack of population-level data about medical tourism (Hopkins et al., 2010). Our recruitment may have biased the research towards those able to volunteer for an interview, and to commit to an interview within the timeframe of our study – a group who may not be reflective of caregiver-companions as a whole. However, this is not a genuine concern in the context of the current study given that the goal of qualitative research is transferability and not generalizability (Whittemore et al. 2001). Second, because our interviews were only conducted in English, potential participants with limited English-language skills were excluded. Third, our study used telephone and Skype interviewing, which lack visual cues for the interviewer and may have resulted in less detailed answers from participants and/or difficulty communicating. However, we refer to other research that has found that telephone and face-to-face interviewing yield similar results, as well as enabling access to difficult-to-reach or geographically-dispersed participants (Sturges & Hanrahan 2004, Novick 2008).

4.6. Conclusion

Our thematic analysis of 20 interviews with Canadian caregiver-companions revealed the experiential resources they use to deal with the challenges they face in medical tourism and to avoid the onset of caregiver burden. Specifically, participants drew on: (1) prior experience of international travel; (2) prior experience of informal caregiving; and (3) their existing relationship with the care recipient. They used these resources to effectively plan for situations in medical tourism where stresses and responsibilities were heightened, such as in unfamiliar contexts and during care transitions. Identifying these resource domains helps identify the best points of intervention to support caregiver-companions and thereby minimize onset of caregiver burden among this group of transnational informal caregivers.

Chapter 5.

Conclusion

The three previous chapters of my thesis address important knowledge gaps related to the provision of informal care in medical tourism. The first analysis (Chapter 2) presents methodological considerations while the second (Chapter 3) and third (Chapter 4) present the findings of interviews conducted with caregiver-companions. Taken together, these analyses contribute to answering two questions. First, what are the experiences of Canadian informal caregivers in medical tourism? Second, why should we care about informal care in medical tourism? In this concluding chapter, I revisit the objectives of the larger study on caregiver-companions to which my analyses contribute, synthesizing the findings of my three analyses (Chapters 2, 3 and 4). First, I will summarize the key findings of each analysis, and then revisit the study objectives with reference to all three analyses. Next, I will describe the remaining knowledge gaps and future research directions, before concluding with an overall reflection on the study.

5.1. Summary of Analyses & Knowledge Gaps Addressed

The three papers that are included in my thesis examine informal caregiving in medical tourism using three different lenses. Chapter 2 incorporates the perspectives of medical tourists, international patient coordinators, facilitators, and caregiver-companions. This analysis seeks to re-examine the roles revealed by previous analyses (Casey et al. 2013a,b), using a triangulated approach. Through inductive coding, this analysis demonstrates that the previously-identified roles held true for many of our participants. This chapter argues that multi-dataset triangulation is a powerful strategy for studying a small, difficult-to-access group, like informal caregivers in medical tourism. Although I interviewed only 20 caregiver-companions, this analysis incorporates the perspectives of medical tourists who had been cared for by friends/family members, international patient coordinators who interact with caregivers in destination hospitals or clinics, and facilitators who help caregivers plan their travel abroad. This strategy allows us to see the same phenomenon from the perspectives of different participant groups, and in doing so to

gather a fuller picture of the actual tasks completed by caregiver-companions. Chapter 2 provides an example of multi-dataset triangulation in the qualitative health literature, responding to calls for researchers to provide more detailed examples of triangulation (Farmer et al. 2006, Moran-Ellis et al. 2006). The findings also confirm the need for supports for caregiver-companions, while highlighting some settings in which their presence might be a challenge for industry employees and/or medical tourists (see also Casey et al. 2013b). Overall, the different emphases offered by the four participant groups helped gain a more nuanced understanding of the roles played by caregiver-companions in medical tourism.

Chapter 3 presents the results of a thematic analysis of interviews with caregiver-companions, focused on an ethics of care framework. This normative ethical framework suggests that we are all in need of care, and have a responsibility to care for those around us (Tronto 1993, Noddings 2003). The findings of this analysis speak to how Canadian medical tourists perceive the care that they provide, as well as their relationship to the medical tourist. First, caregiver-companions feel a strong sense of responsibility to provide care, even to the extent of staying at the destination hospital for the duration of this trip (versus undertaking 'tourist' activities). This responsibility is often implied or assumed as a familial duty, and is linked to a clear focus on caregiving as the purpose of the trip. Second, caregiver-companions and medical tourists share the physical and emotional vulnerability associated with traveling for medical care. Participants were stressed by being in an unfamiliar, foreign location and having a friend or family member undergo surgery in that environment. Third, caregiver-companions share in the positive and negative aspects of medical tourism, through the mutuality of their relationships. Overall, an ethics of care approach problematizes the binary of 'carer' and 'cared-for,' (Kittay 2001) highlighting how both individuals are in need of care and provide care, and that they share any stresses or successes associated with the trip. Further, an ethics of care requires that we examine the broader landscape in which care takes place in medical tourism (Tronto 1993). In the discussion section of Chapter 3, I highlight how caregiving in medical tourism is inextricably linked to the devaluation of care, broader processes of privatization and globalization, and a commodification of health. The closing of this chapter calls on researchers to continue the examination of the ethical and equity issues associated with medical tourism.

Chapter 4 provides insight into the experiential resources (i.e., existing lived experiences) drawn upon by caregiver-companions to cope with the burden of providing care while abroad. The findings indicate that while formal supports are lacking, these individuals draw on their experiences of providing care in other community settings, while traveling, and on their knowledge of the medical tourist. Caregiver-companions use these experiential resources to manage burdens, avoid burnout and anticipate what will arise in informal caregiving in the context of medical tourism. Chapter 4 emphasizes the novel spaces in which caregiving takes place in medical tourism--such as the airport, airplane, destination clinic, and hotel—as well as the transitions between these spaces. In general, caregiver-companions describe their experiences as being somewhat unexceptional; they are accustomed to supporting and caring for their friend or family member. Nonetheless, the unique environments--and particularly transitions--that take place in medical tourism can heighten stress for informal caregivers. Thus, Chapter 4 highlights key interventions and supportive policies that could help caregiver-companions manage these transitions and challenging environments.

My analyses, presented in Chapters 2, 3, and 4, inform several key knowledge gaps. First, this thesis offers an early engagement with caregiver-companions in the literature on medical tourism. The bulk of research on informal caregiving in medical tourism thus far has focused on regional flows (Ormond & Sulianti 2014, Ormond 2015), individuals traveling from less-developed to more-developed health systems (Kangas 2007, 2010), has dealt only peripherally with caregiver-companions (NaRanong & NaRanong 2011), or has not spoken directly to caregiver-companions themselves (Casey et al. 2013a, 2013b). This thesis reports on the first study that has interviewed Canadian caregiver-companions about their experiences of medical tourism. Second, this thesis fills a gap in the informal caregiving literature, which has not yet meaningfully engaged with medical tourism, despite having an interest in transnational care and global care chains (Dhar 2011). Third, this thesis makes a methodological contribution to the qualitative health literature, as it illustrates how a research project can emerge through secondary analysis (Crooks et al. forthcoming) and provides a detailed look at triangulation in qualitative research (as called for by Farmer et al. 2006, Moran-Ellis et al. 2006).

5.2. Revisiting Objectives

In this section, I will revisit the objectives of my thesis research with reference to the themes and issues raised across Chapters 2, 3 and 4. Each analysis contributes to answering the questions raised by my thesis objectives: What roles and responsibilities do caregiver-companions take on in medical tourism? How are risks to the medical tourist or the caregiver-companion addressed? What are the ethical and practical ramifications of this informal care? Although each analysis has its own focus, they all deal with these central questions and contribute to an increased understanding of informal care in medical tourism.

Roles and responsibilities taken on by caregiver-companions

The foundational objective of my thesis is to document the roles and responsibilities that are taken on by caregiver-companions. Chapters 2, 3, and 4 demonstrate that the myriad tasks and types of assistance provided by caregiver-companions are in accordance with previous research (Casey et al. 2013a,b, Ormond 2015). All three analyses document the types of care provided, including: hands-on physical care, emotional support, and assistance navigating transitions and unfamiliar environments, among other types of care. Chapter 3 adds information about *why* caregiver-companions take on these roles and how they internalize responsibility for the wellbeing of their friend or family member. Chapter 4 details some of the strategies caregiver-companions use to effectively complete these tasks, and to manage their own wellbeing in the process. Taken together, the three chapters provide insight into both the actual tasks and roles caregiver-companions take on, as well as their own sense of responsibility to care.

All three analyses highlight the importance of the labour undertaken by caregiver-companions, albeit from different perspectives. Chapter 2 makes clear, from the point of view of multiple participant groups, that the labour caregiver-companions provide is necessary to support the medical tourist. Participants were almost unanimous in their belief that the presence of friends or family members is essential to the wellbeing of an individual recovering from surgery while abroad. The care that they provide is therefore essential work, and facilitates the medical tourism industry's operation. Feminist

researchers have long noted how informal care ("the second shift") enables broader market relations to exist. This perspective has resulted in attempts to economically value caregiving, rather than leaving it unaccounted for by markets (e.g. Folbre 2006, Hoefman et al. 2013). However, such attempts have met with difficulty, due to the heterogeneous nature of caregiving. In medical tourism, while the *economic* value of labour provided by caregiver-companions remains unclear, its importance is nonetheless evident. Given the vulnerability of medical tourists and their heightened need for care, as described in Chapters 3 and 4, it is important that the care provided by caregiver-companions is regarded as an essential type of work. Together, my three analyses provide new insight into the labour of caregiver-companions, and thus the roles that they take on.

This thesis emphasizes the importance of geography and place to the roles and responsibilities taken on by caregiver-companions. While the care these individuals provide is similar other community settings, the unique geographies and contexts of medical tourism alter the roles taken on by caregivers. Due to the specific landscapes of care that exist in medical tourism, responsibilities are heightened and caregivers must take on roles related to managing these unfamiliar landscapes. Chapter 2 describes how the roles taken on by caregiver-companions change throughout the experience of medical tourism. International patient coordinators and facilitators speak to the roles taken on before departure and during the trip, while medical tourists and caregivers themselves can speak to the roles taken on before, during and after the trip. Chapter 3 delineates, in broad terms, the landscapes of care in which caregiver-companions will find themselves, such as privatized health care systems, international hospitals with a particular aesthetic, and online communities of past medical tourists. This analysis in particular describes how changing landscapes of care might shape the roles taken on by caregivers, as they deal with changed mobilities and take on a supportive role for 'patient-consumer' (Gatrell 2011, Greenhough et al. 2015). The roles and responsibilities taken on by caregivers are undoubtedly changed by these novel landscapes. Chapter 4 provides a finer-grained look at the airports, airplanes, hotels, hospitals and specific places where care is provided in medical tourism. Other geographers have explained how micro-landscapes clearly shape the nature of care (Milligan and Wiles 2010, Giesbrecht et al. 2014), and this analysis demonstrates how these spaces shape the roles of informal caregivers in medical tourism.

Across all three analyses, this focus on *where* care happens gives us new insight into what responsibilities are undertaken by these individuals.

The three analyses also highlight *why* responsibility for care falls to the caregiver-companion. In discussing the need for accompaniment, industry professionals, medical tourists and caregivers alike described a 'duty' to care (Chapter 2). Some caregiving labour even went largely unnoticed because it was expected by industry professionals or not considered 'work' by caregivers themselves. An ethics of care describes us as all having a responsibility to care for others based on their needs (Tronto 1993), and fits with the self-narratives described by caregiver-companions (Chapter 3). This responsibility is assumed by caregiver-companions and industry professionals, and provides important labour that facilitates the operation of the medical tourism industry. In Chapter 4, caregiver-companions described the most important experiential resource as being their pre-existing knowledge of the medical tourist and his or her needs. Thus, they clearly perceive that understanding and meeting those needs is their primary responsibility in medical tourism.

Risks to the caregiver-companion and medical tourist

The second objective set out for my thesis involves assessing how risks are addressed for and by this group. Prior research demonstrates that caregiver-companions are potentially at risk of experiencing negative health consequences (Johnston et al. 2013, Casey et al. 2013a,b), and raises concerns that companions could face personal safety risks in destinations, be susceptible to infections, and/or experience illness associated with travel and stress (Crooks et al. 2011). This thesis does not address all of these risks, as caregiver-companions did not describe them in the same terms as the literature. The three chapters do, however, shed new light on who might be able to mitigate these and other risks, and how this might be done.

In Chapter 2, several different stakeholder groups are identified who could play a role in mitigating risks to both caregiver and medical tourist. International patient coordinators and facilitators can play a role in educating both medical tourists and caregiver-companions prior to travel. Chapter 4 also suggests that one key intervention would be to ensure that they are well-informed before they travel abroad. Industry

professionals could provide clear descriptions of the medical procedure that will take place and tasks caregivers can expect to take on, as well as essential safety information. Given the need to pre-book trips and the growing use of the internet to facilitate medical tourism, there is a clear opportunity for the distribution of pre-travel advice via this medium. However, online resources lack centralized information and internet sources may not exert as much influence on behaviour as face-to-face advice (Graham 2013). This is of particular concern because both caregivers and medical tourists are at risk, as evidenced by this thesis. Chapter 3 highlights how risk is shared in medical tourism, through mutuality and vulnerability. Despite the fact that only the medical tourist is undergoing surgery, caregiver-companions are also exposed to stress and other potential negative impacts on their health. One key stressor, identified in Chapter 4, is navigating transitions and particular landscapes associated with medical tourism. An intervention that could help mitigate risks to caregiver-companions would be to more effectively manage these transitions at different scales. For example, industry professionals could be more involved in supporting the transitions between hospital and hotel, on airplanes, and/or between the domestic health care system and hospital abroad. Such an intervention would help medical tourists and caregivers alike to decrease the risks associated with medical tourism.

Ethical and practical implications of caregiver-companions' labour

My third thesis objective is to articulate some of the ethical and practical implications associated with the involvement of caregiver-companions in medical tourism. Most of the practical implications generated by the findings of the three analyses are detailed above, in the description of the first two objectives. This section focuses on the ethical implications of the findings of the three analyses. Most explicitly, Chapter 3 engages with an ethics framework and draws out themes about the responsibility to care for vulnerable individuals, and the mutuality of care in all settings. However, all three analytic chapters bring attention to a primary ethical issue: the ways in which informal care (in this case, in medical tourism) is not defined as work, but is unpaid, undervalued and unsupported in any formal sense. This lack of attention to informal care in medical tourism is not new, but merely a continuation of the trend towards devaluing care (Tronto 1993,

Lawson 2007). The value of unpaid caregiving labour is a hidden cost that nonetheless supports market interactions, in this case, engagement in medical tourism.

Currently, informal caregivers in medical tourism are not supported by any formal measures, despite the vulnerability of these individuals to stress and burden. The lack of formal supports is an ethical issue; due to the vulnerability of medical tourists and caregiver-companions, there is a corresponding responsibility for the industry and policy-makers to provide care. Chapter 4 describes how few supportive measures exist, and details the experiential resources that caregiver-companions draw upon in the absence of formal supports. In Chapter 2, different participant groups all agree that the labour provided by caregiver-companions is essential, despite the fact that it is unsupported. If this care is essential, then there is an ethical burden on the industry to acknowledge and provide support to caregiver-companions. All three of my analyses therefore work together to bring informal caregiving in medical tourism to the attention of the industry and policymakers.

My focus on an ethics of care also highlights the continued importance of considering ethical questions in the study of medical tourism. Examining informal care with an ethical lens contributes to the broader literature on health care ethics in medical tourism. Other areas of medical tourism that have been examined from an ethical perspective include the impacts on destination countries (Hopkins et al. 2010, Johnston et al. 2010), patient health and safety, including uninformed decision-making (Crooks et al. 2013), limited regulation and legal liability, as well as impacts on medical tourists' home health care systems (Turner 2007, Johnston et al. 2010). Examining ethics at the scale of individual caring relationships begs the question of what we ought to care about in a broader sense. From an ethics of care perspective, attention must be given to the broader landscapes in which medical tourism takes place: private hospitals and clinics abroad, which are inaccessible to most people. A broader ethical analysis would look at the impacts this industry has on local access to care in destinations, as well as the implications for medical tourists' domestic health care systems. Significant research has already been undertaken in this area (see Adams et al. 2013, Snyder et al. 2015), and an ethics of care simply reiterates the need to consider the impacts medical tourism has on those who are

most vulnerable, such as residents of destination countries, as well as more privileged recipients of care, such as medical tourists.

5.3. Remaining Knowledge Gaps and Future Research Directions

Significant knowledge gaps related to this thesis research remain. First, there is no reliable quantitative evidence about how many Canadians are traveling abroad, where they are traveling to, what surgeries they travel for, whether or how often they are accompanied, or about their health outcomes (Hopkins et al. 2010). Undoubtedly, this information will be useful to policy-makers in both destination and source countries. In source countries like Canada, this information can help create policy interventions and give policymakers a sense of the magnitude of this phenomenon. In destination countries, this can assist with planning and mitigating any negative impacts the industry might have on local health care systems.

In terms of the caregiver-companion interview participants, there were some groups that were not represented. First, of the twenty caregiver-companions I interviewed, none had accompanied a medical tourist that experienced a severe complication associated with their travel abroad. I am aware that such complications do arise (see Johnston et al. 2013), and it would be interesting to hear what responsibilities caregiver-companions take on in these cases. Second, my study focused on Canadian caregiver-companions, who represent only a small number of those traveling for care. Individuals providing care to those traveling for care in South-South and South-North medical tourism flows likely have very different experiences. Future studies examining the informal care provided by friends and family in medical tourism that occurs regionally and in flows other than between Canada and the Global South can provide a key addition to the informal care literature.

5.4. Overall Limitations

In Chapters 2, 3, and 4 I have identified limitations specific to each analysis. There are some overall limitations to the thesis that should also be acknowledged. First, it was very challenging to recruit participants for this study, and I may have missed key individuals due to the difficulty of identifying members of the target group: friends and family members who had accompanied Canadians abroad for surgery that they paid for privately, and which was the main purpose of their trip. Most of my participants did not necessarily identify themselves as 'caregivers,' but simply took for granted that they would accompany their friend or family member abroad, adding another layer of complexity to their recruitment. Second, this thesis can only speak to the experiences of those caregiver-companions who I interviewed, and is not likely to be representative of this group as a whole. As noted in the three main chapters, participants underwent particular procedures in specific destinations, and cannot necessarily speak to other types of medical tourism trips. That said, I did not seek representativeness or saturation in the recruitment strategy (Whittemore et al. 2001, O'Reilly and Parker 2013). While not therefore exhaustive, this analysis provides an exploratory look at the experiences of some Canadian caregiver-companions.

5.5. Conclusion

The interviews with caregiver-companions that are the foundation of this thesis highlight many important aspects of the medical tourism experience. As the friends and family members of Canadians seeking care abroad, these individuals share in the risks associated with the industry, and they are well-positioned to understand (and share) the motivations to travel abroad for surgery. Caregiver-companions are an essential stakeholder group for any Canadian policy intervention into medical tourism. A key contribution of my thesis research is that it presents informal caregivers' own perspectives on medical tourism for the first time in academic research. I strongly believe that interventions designed to support these informal caregivers must: 1) focus on the challenges they themselves have identified, and 2) empower them to address these challenges. Failing to support caregiver-companions is likely to result in both worse outcomes for medical tourists and potentially overburdened caregiver-companions.

The nature of care, as both action and relationship, is complex. This thesis attempts to see care through the experiences of Canadians who traveled abroad to look after their friends and family members. I have attempted to situate this care in the complex landscapes of medical tourism, global health mobilities, and the changing relationship between individuals and health services. Within the broader literature on modern landscapes of care, this represents a small group of individuals providing a highly specialized type of care. However, to these individuals, the experience can be profound. Caring across transnational borders, similar to caring at home, is an expression of mutuality that is shaped by the health systems in which it takes place.

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