Health & Place 35 (2015) 113–118

Contents lists available at ScienceDirect

Health & Place

journal homepage: www.elsevier.com/locate/healthplace

Ethics of care in medical tourism: Informal caregivers' narratives of responsibility, vulnerability and mutuality

Rebecca Whitmore [a,*], Valorie A. Crooks [a], Jeremy Snyder [b]

[a] Department of Geography, Simon Fraser University, 8888 University Drive, Burnaby, British Columbia, Canada V58 1S6
[b] Faculty of Health Sciences, Simon Fraser University, 8888 University Drive, Burnaby, British Columbia, Canada V58 1S6

ARTICLE INFO

Article history:
Received 25 March 2015
Received in revised form
22 July 2015
Accepted 12 August 2015

Keywords:
Caregiving
Ethics of care
International healthcare
Landscapes of care
Medical tourism

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.

1. 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, 2015; 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 and Sulianti, 2014; Crush and Chikanda, 2015; Bochaton, 2015). Glinos et al. (2010) offer a typology of patient mobility that describes some key examples, wherein medical tourism is but a single type of global health care mobility, including the travel of un- or under-insured patients for privately-initiated low-cost dental and medical care and the movement of subsidized patients across national borders through formal cross-border care arrangements. These authors emphasize two factors in their typology: the patient motivations and types of funding that drive patient mobility. Hanefeld et al. (2014) highlighted 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 and NaRanong, 2011; Yu and 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.

* Corresponding author.
E-mail addresses: rwa13@sfu.ca (R. Whitmore), crooks@sfu.ca (V.A. Crooks), jeremycsnyder@sfu.ca (J. Snyder).

http://dx.doi.org/10.1016/j.healthplace.2015.08.004
1353-8292/

Care is a relational, reciprocal, interdependent and multidirectional practice (Tronto, 1993; Kittay, 2001; Noddings, 2003; Milligan and 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 labor 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). Critics of this theory have commented on its exclusive adoption of care—traditionally gendered as a woman's task—as its central concern; however, care theorists argue that making the (previously unacknowledged) value of care visible gives voice to a subjugated group (Kittay, 2011). 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 and 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" (Noddings, 2003, p.16). Many care theorists highlight the centrality of emotion to care work (Kittay, 2001; Held, 2006; Milligan and Wiles, 2010; Wiles, 2011). This affective and physical labor renders caregivers vulnerable to negative mental and physical outcomes – sometimes referred to as caregiver burden (Lilly et al., 2012; Macdonald and 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. Here we explore how features of an ethics of care—responsibility, vulnerability, and mutuality—are enacted across landscapes of care. 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 labor of caregiver-companions in both private and formal spaces complements the labor 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 labor 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 to 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 labor 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).

2. 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.

2.1. Data collection

Following ethics approval, the lead author completed all semi-structured telephone interviews with caregiver-companions between September 2013 and February 2014. 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