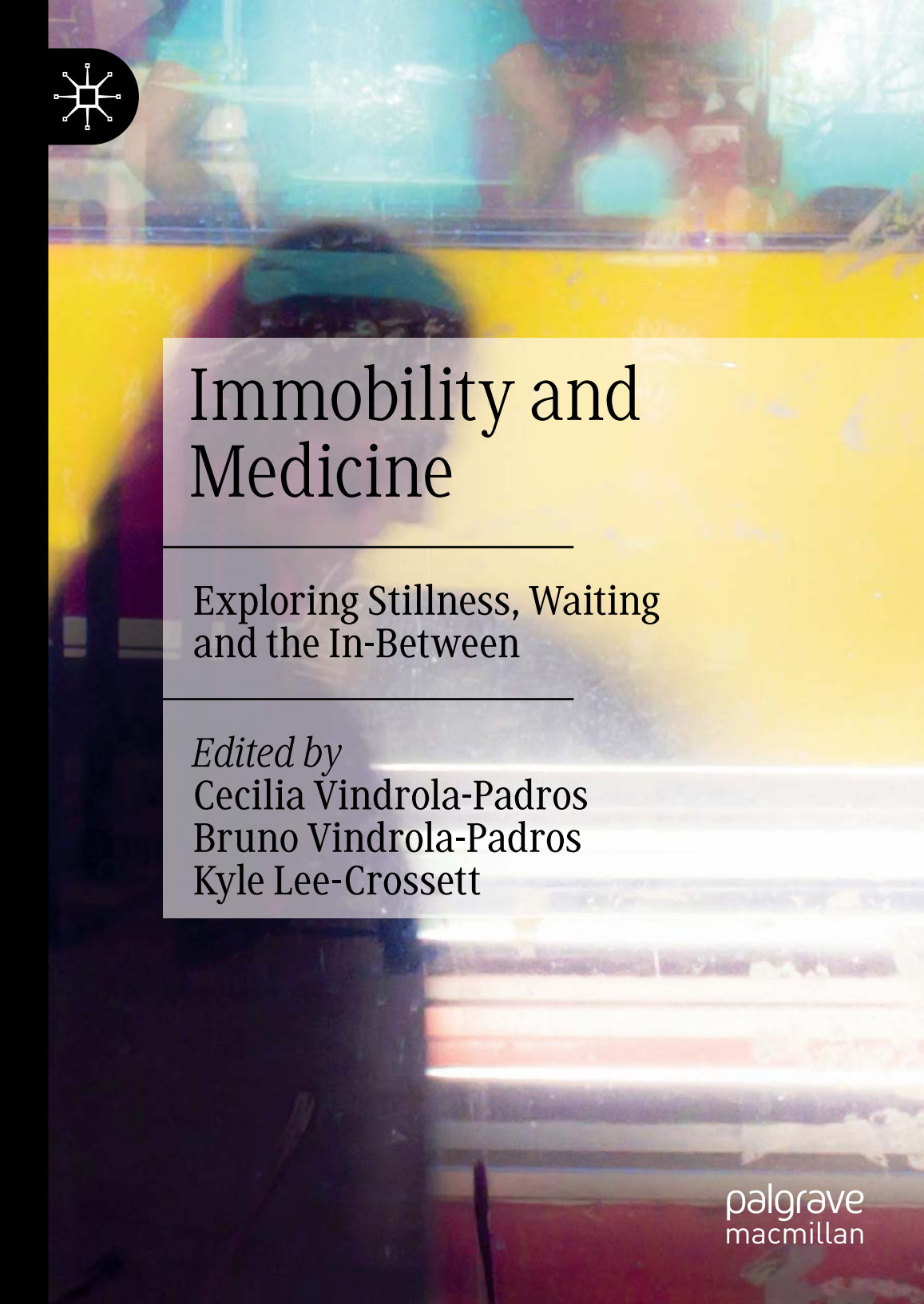

Immobility and Medicine

Exploring Stillness, Waiting and the In-Between

Edited by
Cecilia Vindrola-Padros
Bruno Vindrola-Padros
Kyle Lee-Crossett

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Malika Bouhenia is an epidemiologist with thirteen years' experience in international health. She began her career as a Program Coordinator with Médecins sans Frontières in Ivory Coast, Chad, and Yemen. Over the past seven years, she has worked in a diverse range of epidemiologist positions with Epicentre and conducted several surveys in refugee camps, South Sudan, Chad, France, and Greece. Her areas of expertise include epidemiology of infectious diseases, surveillance, and management of outbreaks.

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Dr. Nolan Kline is Assistant Professor of Anthropology and Co-Coordinator of the Global Health program at Rollins College. His book, Pathogenic Policing: Immigration Enforcement and Health in the US South (Rutgers), traces the multiple health-related consequences of immigration legislation and police practices in Atlanta, Georgia. His work has been funded by the National Science Foundation, and he has published several peer-reviewed articles and book chapters on im/migrant and farmworker health and human papillomavirus interventions. As an applied, medical anthropologist who uses community-based methodologies to examine the social and political determinants of health, Kline's work intersects with policy and activism.

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Hannah Stott is a Chartered Psychologist and Research Fellow at University of the West of England, where she was awarded her Doctorate for her thesis exploring "Embodiment, Altered Perception and Comfort After Stroke." She has a special interest in qualitative, visual, and realist research methods and is currently working on a large realist evaluation of physiotherapy services within primary care. Prior to working in academia, she has worked supporting stroke survivors and others with long-term physical and psychological conditions and is passionate about supporting individuals to improve their well-being.

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Bruno Vindrola-Padros is based in the Institute of Archaeology, UCL. He specializes in material culture studies and is currently exploring manifestations of (im)mobilities in the Neolithic period. His interest lies in understanding how objects have unintended consequences on human social life when they (are) break(ing). Some of these consequences relate to social re-categorizations of space, modifications of social practices through the incorporation of broken objects, and/or the development of a social care or maintenance of certain objects. He has published articles in Antiquity and has recently expanded his work into the healthcare field by publishing in BMJ Quality and Safety.

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Immobility and Medicine: An Introduction

Cecilia Vindrola-Padros, Bruno Vindrola-Padros, and Kyle Lee-Crossett

The social sciences have experienced a "mobilities turn" in the last two decades, which critiqued fixed and sedentary notions of social life and drew attention to the constant flows of people, ideas and objects that permeate our daily lives. This emerging field of thought proposed to study mobilities "in their own singularity, centrality and contingent determination" (D'Andrea et al. 2011, 150), creating a new, dynamic, lens through which to (re)examine social thought and practice (Soderstrom et al. 2013, vi).

Mobility forms were considered as acting in dialectical relationship with the immobile, where flows of people, information or objects might

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be interrupted, fixed or suspended at specific time points (Hannam et al. 2006; Urry 2007). Recent work has highlighted the importance of thinking about the relation between mobility and immobility, where movement intersects with processes that might entail episodes of transition, waiting, emptiness, uncertainty and fixity (Adey 2006; Khan 2016; Leivestad 2016; Szakolczai 2009). These moments when motion seems to be frozen in time and space (Adey 2006), when things are stuck, incomplete or in a state of transition can point to new theoretical, methodological and practical dimensions in social studies of medicine.

Social studies of health, illness and medicine have drawn from the mobilities literature to explore the flows of people, patients, medical technologies and healthcare workers through concepts such as healthscapes (Llewellyn et al. 2017), biotech pilgrimage (Song 2010), medical travel (Inhorn 2015; Sobo 2009; Holliday et al. 2019) and mobilities of wellness (Masuda et al. 2017). Considerable work has been carried out on mobile technologies in healthcare delivery, mainly in the form of mhealth or virtual care, such as telemedicine (Lupton 2018). A significant amount of attention has been placed on the study of mobility, but not always in relation to immobility (Vindrola-Padros et al. 2018). This represents a significant gap in knowledge, as episodes of standing still or "doing nothing" are critical in shaping daily life routines. As Ehn and Lofgren (2010) have argued, these mundane activities allow us to explore how habits, thoughts and feelings are culturally shaped and might even provide insight into larger and existential social issues.

In this edited volume, we bring the concept of immobility to the forefront of social studies of medicine to answer the following questions:

- How does immobility shape processes of medical care?
- How does the medical context develop forms of movement and stasis?
- What are the theoretical and methodological challenges of studying immobility in medical contexts?
- How can we change the ways in which we conceptualise and study immobility to address these challenges?

We believe that the study of immobility can make contributions to our understanding of health, illness and medicine by highlighting previously invisible processes concerning movement and inaction in health and medicine, particularly in relation to the nature of immobility, that is, how inaction can lead to the (re)constitution of people, places and things (Khan 2016). It can illustrate the unequal distribution of mobility as a resource, mainly when movement is required to maintain health (Vindrola-Padros et al. 2018), shedding light on how immobility imaginaries enable or limit certain kinds of movement and action (Salazar and Smart 2011). Finally, a study of immobility can foster methodological innovation by experimenting with new ways to capture movement and stasis, but also by using stillness or remaining in a fixed place as a method in itself (Coates 2017). All of these contributions have implications not only for our current understanding of health, illness and medicine, but also for the analysis of mobility and immobility in other areas.

"Thinking with" Immobility

The tension between mobility and immobility is made explicit in several scenarios or cases throughout the book. As we were developing the content, we encouraged contributors to think about some concepts that might help frame different manifestations of immobility such as: (1) liminality, (2) stillness, (3) emptiness, and (4) motility. The chapters are organised in relation to these different manifestations, alluding to material culture and materialities, practices, imaginaries and emotions.

Liminality has been widely used in anthropology and other disciplines to explore conditions and practices of uncertainty, in-betweenness, never-ending transition and waiting (Szakolczai 2009) and how these are (re)produced. As Horvath et al. (2015) have argued, liminality captures situations where established structures might be dislocated and hierarchies reversed, where outcomes are uncertain. These spaces of ambivalence are, nonetheless, central to sustaining social reality (Horvath et al. 2015). In medicine, the concept of liminality has been used to explore topics such as clinical staff and parents' experiences of dealing with uncertain new-born screening results (Timmermans and Buchbinder

2010), liminality and breastfeeding (Mahon-Daly and Andrews 2002), or waiting for care (Day 2015). The concept of liminality represents a useful heuristic tool to move beyond binary oppositions (as the liminal often relates to states of in-betweenness) and focus on incompleteness and processes of becoming.

The concept of stillness considers physical and imagined restrictions of movement and a sense of "stuckedness", fixity or "going nowhere" (Hage 2009). In medicine, stillness is often understood as the state of remaining motionless or stuck, which can be desired or undesired. For instance, Gask et al. (2011) have explored the relationship between depression, isolation and feeling "stuck", while the gradual loss of motion and slow succumbing into a "fixed" state has been studied in patients' experiences of disrupted motor coordination (McMillan, this volume). An interesting dimension of the concept of stillness is its potential for uncovering different mobility empowerments (or capacities for movement), where not all who desire to move will be able to do so.

Emptiness has been associated with processes where markers of certainty are eroded, leading to a sense of vacuum, where everything seems to melt into a void. According to Khan (2016), the concept of emptiness sheds light on the affective dimension of immobility, by pointing to states or emotions that might be unavailable (Deleuze and Guattari 2004). Political anthropologists have theorised emptiness in relation to empty places of power, instances of "authority vacuum, where the place of power is empty and can only be appropriated temporarily" (Wydra 2015). In medicine, feelings of emptiness have been analysed in the context of women's experiences of miscarriage (Adolfsson et al. 2004) and couple's experiences with infertility (Phipps 1993).

Motility refers to the potential for movement, aspirations for movement that are never materialised, movement imaginaries, ideas of incompleteness and never-arriving (Leivestad 2016). It allows us to explore more symbolic dimensions of immobility in the sense that movement might only rest in the imaginaries of individuals and never enacted in practice. In medicine, dimensions of motility are present in the concept of disnarration proposed by Vindrola-Padros and Brage (2017) to analyse parents' stories of their child's illness, where parents reflect on past and future scenarios that did not occur, yet are deemed important enough

to be included in the story. The authors reflect on the power of these hypothetical scenarios for uncovering instances of anxiety and regret in parents' stories (Vindrola-Padros and Brage 2017).

Throughout the book, these four concepts are not developed in isolation, but interlace to formulate complex instances of waiting, restraint and the negotiation of imagined scenarios. The contributors bring these concepts to life in their rich descriptions of clinical scenarios, individuals' search for services and their struggles with ill health. The book brings together contributors from a wide range of disciplines (anthropology, sociology, social work, medicine, psychology and public health) working in countries such as Argentina, Canada, Czech Republic, Germany, Greece, South Africa, Netherlands, Switzerland, the US and the UK. These contributions highlight the importance of integrating concepts of immobility to explore experiences of enforced waiting and their effect on mental and physical health, patients' search and access to medical services for cancer treatment and transplants, and embodied experiences of spinal cord injury, stroke, cancer and dementia.

Immobile Infrastructures and Enforced Waiting

The chapters in this section of the book highlight the need to consider the invisible infrastructures of immobility, the processes, structures and actors that both enable and hinder immobile states. In doing so, however, they move beyond representations of these immobile states as passive and, instead, underscore the dynamic role of actors in maintaining and transgressing them. Bjertrup and colleagues, in their chapter on the lived experiences of refugees in Greece, argue that the act of waiting has varying degrees of activity. The authors analyse the disciplining practices of refugee camps, exploring how these create different emotions and reactions in refugees, with some choosing to leave the indefinite waiting state and others deciding to "endure the wait".

The variability of waiting experiences is also explored in the chapter by Tiseyra and colleagues, documenting the experiences of transgender patients seeking care in Argentina. According to these authors, the stigma

associated with transgender in this country shapes the waiting experiences of patients who suffer continuous discrimination and humiliation. The waiting room embodies a history of exclusion and the power relations inherent to the medical gaze. Through the act of waiting, patients become disciplined into the ideal concept of the "good patient".

Processes of waiting are further unpacked in the chapter by Rehsman on patients' experiences of being on a transplant waiting list. Rehsman's analysis is granular as she considers the waiting list as "bureaucratic technology, marker of eligibility and symbol for patients' chances to receive life-saving treatment". She presents a detailed account of the material culture of waiting, the algorithm used to create the list or the telephone patients will not leave out of their sight, as this is how they will know if an organ is available for them. These tools and objects act as symbols of both mobility and immobility and are imbued with emotions such as fear and hope.

Brage centres her analysis on the concept of liminality, reflecting on the experiences of families who had to leave their place of origin to access cancer treatment. According to her, the geographic displacement as well as the uncertainty produced by the disease and treatment combine to generate a transitional state characterised by ambiguity, lack of belonging, loss of social ties, isolation and the feeling of "being out of time". The liminal states included in the narratives of the parents in her study demonstrate the central role of immobility in patient and family therapeutic itineraries.

Embodied Stillness and Fixity

This section focuses on the performative aspects of immobility, the different ways in which the body becomes still, stuck or fixed. The authors contributing to this section theorise the body in different ways, including the "object body" (Stott), the "denying body" (Řezáčová), the "undeserving body" (Kline, et al.) and the "damaged body" (Llewellyn and Higgs). These different depictions of bodily experience visualise embodiment as an active process reconfigured by the individual, which entails different stages of both movement and stasis.

When analysing the experiences of patients with spinal cord injury, McMillan asks if medicine reproduces feelings of "stuckedness". The SCI body is viewed as "problematic" in the sense that it questions the central purpose of medicine: cure a disease or fix an injury. The immobility of the injured body is a constant reminder to medicine of its failure to fulfil its main purpose, leading to negative configurations of this body that does not comply with its normative role. It signals the limitations of medical knowledge, as it fails to provide alternative ways of understanding the SCI body. In this sense, an interesting finding made by McMillan is the nuanced signs of resistance towards this dominant discourse, offering alternative conceptualisations of the SCI body where stuckedness and in-betweenness are recognised and made sense of.

The relationship between injury and disrupted mobility is further explored in the chapter by Stott on embodied perceptions of immobility after stroke. The unexpected and uncomfortable nature of the immobile body leads to, what the author has identified as, a psychological separation between body and self, which ultimately impacted on patients' identity. This separation creates intermediate bodily states that call into question dualistic notions of mind and body and, instead, represent a multi-modal definition of the body as "heavy", "unresponsive" or "untrustworthy".

The book explores immobility from the point of view of another body, one suffering from dementia. In their analysis of the lived experiences of patients with dementia, Collins and Vermeulen (in their respective chapters) argue that mobility and immobility shape the person's mental condition as well as the delivery of care. Two different states of movement interlace throughout care delivery: the immobile patient with dementia who must remain still or fixed and the mobile healthcare professional who must move to carry out their work. The movement of the person with dementia is always controlled and when this is not so, as in cases of wandering, the patient is labelled as risky or dangerous. Collins' chapter urges us to be sensitive to the different rhythms of movement, variable gradients of moving and staying still, that coincide in the same clinical environment. Vermeulen considers the benefits of focusing on instances of stillness her research participants highlighted as essential components of their lives, and visualises these as "phenomena that trigger creativity"

and are capable of helping others to make sense of vulnerable moments in life.

Motility and (Im)Mobile Possibilities

This section focuses on the ways in which imagined possibilities for the future shape current processes of movement and stillness and potential strategies for accessing care. The chapters in this section generate interesting discussions on the important role of imagination in (im)mobility studies, in the form of both anticipation and alternative scenarios (Stephan and Flaherty 2019). Kline and colleagues use the concept of motility to examine the efforts of migrant farmworkers to vaccinate their children against HPV that might never materialise. While the benefits of vaccination were acknowledged by the participants in Kline et al.'s study, the structural barriers preventing their (and their children's) access to medical services meant that vaccination remained only in the imaginary, as a distant possibility.

Llewellyn and Higgs also explore the power of the imagination, but the imagined state is one of the potential immobility that might affect patients with brain tumours. The patients in their study were "living suspended", waiting for the progressive mental and physical debility generated by their disease. The authors argue that these patients go through an anticipatory loss of self, that is, "a subjectivity and an interpretation of oneself—mind and brain—produced in the intersubjective encounters between people with a brain tumour, their families, clinicians, biomedical technologies and the physical sensations that emerge as tumours develop and patients undergo intensive monitoring, surgery and therapies". In other words, patients' projected image of themselves being mentally lost and deprived of any agency in turn immobilises patients' actual daily life. This powerful interpretation of oneself represents a useful lens through which to understand the experiences of those living with disease.

Conclusion: Moving the Field of Immobility and Medicine

The motivation behind the book was to show how mobility cannot be understood under its own gaze but requires its contraposition with immobility. The perpetual pull or tension that lies between these two dimensions frames the medical treatment/healthcare practices/experiences presented in this book. While we decided to understand this tension by unpacking immobility into four different domains in the first instance (i.e. liminality, stillness, emptiness and motility), the chapter contributors have gone to great lengths to move this emerging field of thought to different, unplanned, directions.

The evident "take home" messages from these chapters relate to the need to consider the invisible infrastructures of immobility, exemplified in the waiting list that dictates movement and access to medical treatment, the refugee camp that facilitates and constrains movement. Stasis and permanence bring their own sets of challenges and can shift social practices in any direction. Immobility might seem initially framed around ideas of impotence or constraint, but being unable to move does not need to be seen as a disempowering condition. Power can be used to move others around you, and being "chosen" might mean not having to move. The "highly-mobile" might also experience barriers to care.

While there are some outstanding contributions drawing from the concept of liminality (Turner 1992), we feel there is some caution required with this elusive concept. In many of the experiences described as liminal in healthcare studies, many social relations appear to be reinforced, rather than dissolved or mitigated as the term originally suggests. Similarly, previously existing conditions of inequality often pervade and are even accentuated in so-called "transitional" contexts. The concept does seem to work rather well with highlighting certain aspects of the experiences described, such as the transformation of social roles, moments of deep reflection and critique, helping to blur the line between fixed categories and move away from binary dualisms. Nonetheless, it certainly should not be regarded as an absolute, as it runs the risk of obscuring crucial elements of social practice, as well as power relations.

The ethnographic approaches used in many of the chapters of the volume also highlight the importance of taking into consideration the interaction of gradients of mobility and immobility in the same space/bodies. This requires examining the practices of immobility at a granular level and exploring their reconfiguration in everyday life. A key aspect of this exploration of practice will be its analysis in conjunction with the affective dimensions of mobility and immobility: subjective experiences and feelings of emptiness, fear, hope and stuckedness that shape the many lives described in this book. These emotional states underscore aspects of humanity in our study of health and illness and our understanding of the diseased body and the healthcare establishment, often shaped by our experiences of waiting, exclusion, agency and everything in-between.

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Part I

Immobile Infrastructures and Enforced Waiting