The ‘other’ within: Striving for health equity in the Maldives

Eva-Maria Knoll
Institute for Social Anthropology, Austrian Academy of Sciences, Vienna, Austria
eva-maria.knoll@oeaw.ac.at

Abstract: Relations within are quintessential in anthropological fieldwork — and in archipelagos in particular. The domestic sea is incorporated in the national consciousness connecting an archipelagic nation but distinguishing individual islands with a strong emphasis on the centre. The Maldivian archipelago displays this spatial organization of a socio-political and economic centre and a dependent island periphery. In the national consciousness, the capital island, Male', contrasts with “the islands” — a distinction which is particularly evident in the public health sphere, where striving for health equity encounters geographical and socio-political obstacles. Using the topic of the inherited blood disorder thalassaemia as a magnifying lens, this paper asks how different actors are making sense of health inequities between central and outer islands in the Maldivian archipelago. Intra-archipelagic and international mobilities add to the complexities of topological relations, experiences, and representations within this multi-island assemblage. Yet, my study of archipelagic health relations is not confined to a mere outside look at the construction of the ‘island other’ within the archipelagic community. It is a situated investigative gaze on disjunctures, connections, and entanglements, reflecting my methodological-theoretical attempt to unravel my own involvement in island–island relations and representations — my being entangled while investigating entanglements.

Keywords: archipelago, mobility, relationality, blood disorder, Maldives, thalassaemia

https://doi.org/10.24043/isj.177 • Received February 2021, Early Access November 2021

© Island Studies Journal, 2021

Introduction: Health mobilities

Three women came together to drink tea in a northern atoll of the Maldives: a slender woman in her early twenties for whom I use the pseudonym Zeena, a senior doctor specializing in blood disorders, and me, the medical anthropologist. Zeena is our host in the island where she was born. Since she was a very small girl, she had been inviting the doctor from the capital, Male', to visit her “beautiful island.” Every two weeks or so, Zeena had repeated the invitation when consulting the doctor in a specialist clinic in Male', some 300 kilometers further south. Zeena was constrained by health reasons to live in the capital island, yet, for as long as she could
remember, she had longed for her birth island, as she emphasized in our three lengthy meetings; one in the capital, and in her home island on two later occasions.

A small-scale island setting in the developing Global South, mutated genes and inter-island connectivity had determined Zeena’s undesired residence arrangement in the Maldives' capital of Male'. At the age of six months, she became critically ill and was diagnosed with beta-thalassaemia major, she explained. This most severe form of an autosomal recessive inherited single-gene disorder affects hemoglobin synthesis. Hemoglobin is an iron-containing protein in the red blood cells caring oxygen throughout the body. Suffering from severe anaemia, Zeena’s well-being and survival depended on blood transfusions at regular intervals. Yet, she was born into an island of a few hundred people occupied with fishing and subsistence farming. Since the island lacked a facility for processing and transferring donor blood, Zeena’s parents would have to take the little girl to a health facility on another island — every two weeks, in any weather. Ferry connections between smaller islands were scarce or non-existent, a privately hired boat would be very costly, and sea travel was particularly challenging during the stormy south-west monsoon. As a result, Zeena was entrusted to the care of her mother’s sister, who lived in Male'. The capital island is the geographical and socio-political centre of the sprawling Maldivian archipelago and the location of the country’s only specialist haemoglobinopathy clinic (see Figure 1). Over the last two decades, however, health and travel infrastructures have gradually improved throughout the archipelago. In fact, with the Seventh National Development Plan (Ministry of Planning and National Development, 2007), Zeena’s home island was transformed into a designated regional growth centre and a catchment area providing enhanced healthcare, education, and other relevant facilities for the inhabitants of the smaller islands in the vicinity. The prospect of transfusion services on the spot, and of a job, allowed Zeena to resettle to her birth island some twenty years after she had been forced to leave. Maldivian efforts towards health equity brought the doctor from the clinic in the capital to this island as part of an outreach team and allowed for Zeena, finally, to serve tea on “her beautiful island” to the doctor from Male’ she had been inviting for so long.

I take this ethnographic vignette as a starting point and base my reflections on local and academic productions of islandness and island relationality in parts on a recently published article (Knoll, in press). What is relevant for this contribution is the fact that all three women of this tea party are islanders, as well as insiders and outsiders to some extent, and that their get-together was triggered by health issues and inter-island relations. Using the topic of the inherited blood disorder thalassaemia as a magnifying lens, I scrutinize in the following how different actors are addressing and making sense of spatial disparities and health inequities between central and outer islands in the Maldivian archipelago. Weaving in a reflexive component, I ask for the everyday experiences with othering and belonging.
Malarial pasts and health inequity on a global scale

My scholarly interest as a medical anthropologist in the entanglements and interdependencies of geographical and biosocial challenges — and fieldwork as the key data gathering method of my academic discipline — has brought me to Zeena’s tea ceremony on the northern fringe of the Maldives. This small island country is particularly burdened by an inherited blood disorder with deep historical roots (Knoll, 2020). Once, the Dhivehin (Maldive islanders) were vulnerable to endemic malaria emanating from three species of malarial parasites: *Plasmodium falciparum*, *P. vivax*, and *P. malariae*. Long before the causative Malaria parasite became known, reports of the legendary “Maldive fever” ravaging the islands and lagoons of the archipelago and killing almost every European visitor span some 600 years. Only the successful eradication of *falciparum* malaria in 1975 and the less deadly malarial parasites by 1984 paved the way for the advent of a million-dollar tourism industry, which became the economic backbone of this small island developing state (SIDS). What remained of the former pronounced and now almost forgotten Malaria burden, however, is an island population struggling with a risky genetic legacy.

One in six Maldivians is a carrier of the genetic thalassaemia trait (Firdous et al., 2011, p. 176), challenging Asia’s smallest state (both in terms of demography and solid ground) with the world’s highest prevalence of beta-thalassaemia. The prevalence of this and related genetic mutations affecting haemoglobin synthesis and structure, such as alpha thalassaemia and sickle-cell disease, runs as the so-called ‘thalassaemia belt’ through tropical and subtropical regions of the world and results from an evolutionary adaption to the Malaria parasite. Islands in general are pronounced spaces as healthcare settings, in well-being as much as in disease formation, exchange, confinement, and extinction (Cliff et al., 2000; Kearns & Coleman, 2018; Knoll & Campbell, 2020; Sindico et al., 2020). Within the (sub)tropical zones where Malaria parasites, and *Anopheles* mosquitoes as their vectors, could thrive, it is also islands (such as Cyprus, Sardinia, Sri Lanka, and Madagascar, to name just a few) next to littorals and wetlands that have a distinct malarial history and, thus, often display a corresponding pronounced prevalence of haemoglobinopathies. It goes
without saying that historic and contemporary migratory movements contributed to the global dispersion of haemoglobinopathies — also to landlocked countries and cold-water islands without any malarial history (Angastiniotis et al., 2021). Yet, the highest prevalence of these inherited blood disorders still is confined to countries and islands within the ‘thalassaemia belt’. People with thalassaemia minor, the carriers of the thalassaemia trait, are otherwise healthy human beings, yet they might pass on the genetic mutation to the next generation — often without knowledge of their carrier status. For a carrier couple, each carrying one thalassaemia gene (heterozygous), the Mendelian laws of inheritance imply a 25% chance of conceiving offspring with not just one, but two affected genes (homozygous); one inherited from each parent. Burdened with the most severe manifestation, called thalassaemia major, such a homozygous, thalassaemic child like Zeena depends on donor blood throughout her life.

The first Maldivian beta-thalassaemia-major patients were diagnosed abroad in the 1970s. The Maldives’ population just had passed the 100,000 mark (National Bureau of Statistics, 2019) and the island nation ranked among the poorest countries in the world. Biomedical healthcare was rudimentary and only available in the capital, and the fight against Malaria was not completely over. In 1978, the World Health Organization noted the prevalence of thalassaemia in the Maldivian population, but it took another ten years until a management strategy was developed (Firdous, 2005, p. 132). Some fifteen years earlier, the world’s first thalassaemia prevention programme had already been introduced in the also heavily affected Mediterranean island of Cyprus (Angastiniotis & Hadjiminas, 1981). Eventually, in 1990, a Lancet article put the Maldives on the global map of blood disorders (Modell et al., 1990). In the mid-1990s, a national thalassaemia program was introduced there, a specialist clinic opened, prenatal diagnosis and selective abortion were legalized, and a genetic carrier screening program was introduced. Since then, thalassaemia has remained “a priority national disease” (World Health Organization South-East Asia Advisory Committee on Health Research, 2003, p. 2) in the Maldives. To this day, the twofold aim of all these measures is to provide thalassaemics with quality care of global standard and to reduce physical and social suffering by limiting the number of affected newborns. The latter is pursued by identifying heterozygous carriers, raising awareness, and by offering what is called ‘informed choice’ for islanders’ reproductive behavior (cf. Waheed et al., 2016, p. 251).

Where insider/outsider distinctions do not work

In 2011, I became the first social scientist documenting the biosocial burdens of Maldivian thalassaemics and of an island population at risk. My research into health concerns in archipelagic island life lines up with scholarly endeavors looking beyond the omnipresent image of the Maldives as an archetypical Robinsonian island destination. Within the last two decades, the glossy tourism brochure image has been challenged by discussions of political instability, corruption, domestic violence, tendencies towards religious radicalization, and the exposure to climate-change (e.g., Kelman et al., 2017; Fulu, 2014; Robinson, 2015). Yet, what brought me to the Maldives in the first place, and why is it of relevance to ask this question here? Countless islands have comprehensive, often woebegone colonial histories (Nadarajah & Grydehøj, 2016).
A description of islands on their own terms is thus a legitimate concern and an enduring debate within Island Studies. Yet, as a landlubber sticking my investigative nose into island affairs, I was sometimes met with skepticism (cf. Baldacchino, 2008). Moreover, I tend to see colonial pasts not merely as a question of island history, but simultaneously also as relevant in a researcher’s biographical positionality. The decolonial project in Island Studies (Nadarajah & Grydehøj, 2016) thus might be carried on by being sensitive to the global entanglements of colonial footprints. This should also include the historical past of scholars. I am, however, neither related to the colonizers nor to the formerly colonized island under investigation. So, from which positions do I investigate biosocial thalassaemia challenges in the Maldives, and how does this reflect my research design and island representations for my scholarly work?

I live in the capital of a small, landlocked, mountainous country in central Europe. Although Austria has a deep history of global significance, colonial encounters with islands overseas rank as rather marginal foreign policy episodes (Sauer, 2012). In 1778, ships of the Ostindische Handelskompanie, the East Indian trading company founded by Empress Maria Theresa in Trieste, bought five of the twenty-two Nicobar Islands from the locals: Nancowry, Camorta, Trinket, Katchal, and Teressa (named after Maria Theresa). Six Austrians stayed as colonial officials, but some four years later the Danube monarchy had withdrawn due to the lack of a strong navy to secure these colonial territories. About eighty years later, in a period when the long planning of the Suez Canal moved to practical implementation, the young naval officer Wilhelm von Tegetthoff failed in a second attempt to secure an island colony for the Austrian crown. Attracted by its strategic location in the Indian Ocean at the entrance to the Red Sea, Tegetthoff secretly and rather awkwardly tried to buy the Yemeni island of Socotra for the Habsburg Empire. In 1895, attracted by the Solomon Islands’ nickel deposits, a military expedition aimed to put this Pacific archipelago under Austro-Hungarian authority. This venture failed due to courageous local resistance (Sauer, 2012). So, I am the subject of what remained, after the 1918 collapse of the Habsburg Monarchy and its rather ridiculous marginal historical colonial encounter with overseas islands, as a post-imperial successor state and small landlocked country. Yet, nevertheless, I am a resident islander.

For almost three decades, I have been living on the Mazzesinsel in Vienna. This nickname, composed of Mazzes (Yiddish-German for ‘matzo’, the unleavened flatbread of Jewish cuisine) and Insel (German for ‘island’), “provides something of a metaphor for the relations that the capital’s poorer Jewish immigrants (as well as many of its other working-call citizens) had with the city’s traditional brokers of power” (Kessler, 2015, p. 403). Mazzesinsel refers to an urban area surrounded by the river Danube and the smaller Danube Canal. Historically, this floodplain “was the only area in which Jews could live legally” (Kessler, 2015, pp. 402–403). Until the horrors of the Holocaust and World War II, it had remained the Viennese neighborhood with the highest density of Jewish inhabitants. So, I am the subject of a country with a rather failed overseas colonial island history, living on a piece of land surrounded by water, that is of ethnic-religious and political historic depth and significance but hardly considered any longer a segregated island space. Indeed, the insider/outsider distinction does not work all that well when it comes to islands (Baldacchino, 2008). Or, in anthropological terms, the distinction of emic/etic
perspectives does not always work. Between viewpoints from within the social group associated
to an island space and perspectives by an observing outsider, the interrelation is often dynamic
and blurred.

In the Maldives, I clearly started out with the etic perspective of an outsider. Inspired by
Austrian diving pioneer Hans Hass, the first scuba diver in Maldivian waters in 1958 (Knoll,
2018), my initial encounter with the Maldives was in 2004 as a tourist thrilled by the underwater
life. I was dwelling on an iconographic circular tropical island (Baldacchino, 2005, p. 247) where
a ten-minute circuit along the resort’s shore conveyed the experience of isolation, physical
limitation, and smallness. An organized island-hopping activity brought me, en groupe, to my first
local island. We visited the school and the mosque, the single diesel generator that runs for just
two hours every night, and the telephone booth that we learned was the only line to the outside
world. The island’s health centre comprised one consultation room, one bedroom with two beds,
and a delivery room. An information board in the sandy little front yard educated the islanders
about the basics in traffic behavior: be aware of fast motorbikes and even cars on the paved roads
of Male’, use sidewalks, and look right and left before crossing the street. It dawned on me that
such a small island community of some two-hundred living on confined lands had to be prepared
for the busy, unfamiliar traffic in the densely populated capital. The illustrating graphic showed
a man and a boy in the narrow, bustling streets of the capital, both just wearing loin cloths, the
mundu (sarong), and the man caring a kalhubilamas (bonito, skipjack tuna); the Maldives’
formidable fishing and transoceanic trading history is based on this pelagic fish of the Scombridae
family (Knoll, 2018). Over the next years, I would acquire additional cultural understanding,
slowly shifting from the etic perspective of a tourist-outsider to a partially emic understanding of
a dedicated social anthropologist. I would, for example, learn to read the mundu and the
kalhubilamas as unambiguously insignia representing islandness, remoteness, and ‘backwardness’
within the archipelago. Beforehand, however, on my fourth day on the tiny Maldivian resort
island, the 2004 Indian Ocean tsunami washed over the archipelago and lastingly shifted my
attention from marine life below to questions of survival, socio-spatial health organization, and
inter-island entanglements above the water line.

Spatial-temporal obstacles in a transformation

I started work on thalassaemia as a biosocial and geographical health challenge in the Maldives at
a time when shortcomings in the management of this debilitating blood disorder were mainly
ascribed to scarcity. The general shortage in infrastructure, health professionals, equipment,
medical supplies, and donor blood (Knoll, 2017a) was palpable. Limitations and scarcity were
impeding a transformation of thalassaemia from a fatal pediatric diagnosis to a care-intensive and
preventable chronic disorder in these islands, while affected societies and islands in the Global
North were some twenty years ahead in this transformation. Cyprus or Greece hardly see any
thalassaemic newborns, and their patients have an almost regular life expectancy. Zeena, by
contrast, belongs to the very first cohorts of transfusion-dependent Maldivian thalassaemia
patients to have survived childhood. Scrutinizing interdependencies between genetic risk
management and an island habitat, I started out investigating, reflecting, and representing the inhabited islands of the Maldives as located in the Global South. Accordingly, the Maldives were at a disadvantage regarding biomedical and genetic developments due to limited health and other infrastructure (Aboobakuru, 2014).

Since 2011, however, when the Maldives left the ‘least-developed country’ status behind, the battleground against the potentially lethal blood disorder began to shift from global to archipelagic stratification. The urgency to catch up with international standards in terms of health infrastructure and personnel turned more and more into a struggle for equal access to quality treatment and prevention services throughout the 187 inhabited islands of the archipelago. More than twenty thalassaemic newborns were still being registered every year, and too many thalassaemia patients had passed away in their late teens and early twenties. It became painfully clear that preventive and curative measures showed better results in the capital island, Male'. According to internal statistics of the specialist thalassaemia clinic in Male', more than 80% of new thalassaemia cases were recorded between January 2012 and May 2015 in children from “the islands.” Island patients, furthermore, seem to be less compliant with treatment schedules compared to patients living in Male', thus showing in general poorer health outcomes. “The islands” crystallized as the stumbling block in the archipelago’s overall thalassaemia road of transition from a lethal childhood disease towards a manageable chronic disorder. This island factor on the bumpy transitional road had brought me and the haemoglobinopathy specialist to Zeena’s island in the north.

**Male' and the islands: Socio-spatial organization in an archipelago**

Scrutinizing archipelagos is thinking with and about relations. The more you do it, however, I have learned, the more distinctions between insider/outsider and emic/etic perspectives become blurred. At least since Bronislaw Malinowski’s (1922) description of ceremonial Kula exchange networks in the Kiriwina islands (today’s Milne Bay Province, Papua New Guinea), anthropology has been concerned with island/island interactions within archipelagos (e.g., Hannerz, 1974). An exaggerated sense of otherness perceived for islands, criticized Pamila Gupta (2010, pp. 275, 281) almost a century later, made islands typical places for early ethnographic studies. I am further drawing on the interdisciplinary field of Island Studies’ attempts to understand archipelagos by scrutinizing the interplay of topological relations, cultural geographies, representations, and experiences of such multi-island assemblages (Stratford et al., 2011; see also Baldacchino, 2012, 2015; Baldacchino & Duarte Ferreira, 2013; Bethel, 2000; Bremner, 2017; Hayward, 2012; Pugh, 2013, 2018; Xie et al., 2020). The anthropologist Alan G. LaFlamme (1983, p. 361) defines the archipelago state as a state society subtype and outlines major defining attributes, such as large numbers of constituent islands; since they are very small and “severely deficient in most economically essential commodities,” they depend on tourism and migration. The waters surrounding the component islands are seen as an integral part that “manifest[s] historically established intimacy of political and economic association” (LaFlamme, 1983, p. 361). This “internal sea” (LaFlamme, 1983, p. 361) is one of the “effects of geography on archipelagic
Eva-Maria Knoll

nations,” (Bethel, 2000, p. 10, p. 240) argues anthropologist Nicolette Bethel for the Bahamas. It plays a crucial role in the national consciousness, connecting a nation but distinguishing individual atolls and islands with a strong emphasis on the center.

Twenty-six natural atolls constitute the 860 km-long, garland-shaped Maldivian archipelago that separates the Lakshadweep Sea, bordering India and Sri Lanka, from the vast waters of the Indian Ocean. They comprise 1,192 low-lying coral islands and islets, scattered across a surface area that is 300 times more water than land. Taken together, solid island ground amounts to just 298 square kilometers. The spatial organization into a socio-political and economic centre and a dependent periphery of more or less remote islands pervades all aspects of Maldivian daily life, including thalassaemia clinical management and prevention. The National Thalassaemia Register started in 1993 and by 2014 listed 803 cases, 563 of them alive; the median age of the roughly 1.6 thalassaemia patients per 1000 of the total population was just 13 years (Angastiniotis, 2014, pp. 3, 6). About 50% of today’s more than 600 thalassaemia patients receive their regular treatment in the islands. In the Maldivian national consciousness, the capital island, Male’, contrasts with “the islands” — also referred to as “the outer islands” or “the atolls.” Time and again, urbanization and population growth have brought the lenticular capital island to its limits. Since 1986, the original just 1.05 square kilometers of Male’ island were extended, initially by the filling of the surrounding lagoons. In the meantime, urban extension covers six islands. With about one third of the total population of 344,000 (National Bureau of Statistics, 2015) inhabitants living on 5.8 square kilometers, however, the Greater Male’ Area conurbation still ranks among the most densely populated cities in the world (Knoll, 2018, pp. 396–398). By contrast, only five of the 187 inhabited islands have a population of over 5,000, and 27% of the islands have a population of less than 500 (National Bureau of Statistics, 2017, p. 7).

With the Maldives’ single specialist haemoglobinopathy clinic, thalassaemia expertise is also centered in Male’. Until the late 2010s, the capital also housed the only two genetic laboratories offering preventive carrier testing (at the time of my most recent fieldwork in 2018, however, two more genetic testing centers in the north and south of the archipelago were about to open). If not optimally treated, thalassemia can quickly develop into a multi-system disease that gradually affects the whole body — all organs and glands, and the skeletal structure. Optimal treatment permits an almost-normal life expectancy and a good quality of life, while zero treatment results in early childhood death. Yet, as the Thalassaemia International Federation (Eleftheriou & Angastiniotis, 2021, p. 12) emphasizes:

Only a minority of patient benefits from the truly huge medical and scientific advances achieved in the management of haemoglobin disorders in the last 2-3 decades and this is evident in the outcomes which are observed across all regions of the world.

Inadequate clinical management and insufficient socio-psychological support result in poor quality of life and premature death.

Maldivian patients’ report books document debilitatingly high iron levels, irregular transfusion intervals, and missed check-ups. Insufficient clinical management can literally also be
‘seen’ in patients’ bodies and faces. In optimally treated patients, by contrast, one can no longer ‘see’ the disease; these patients can expect an almost regular life expectancy and are fit and strong — one UK thalassaemia major patient even runs marathons. The majority of Maldivian patients are somewhere on the way; they have left the former poor, underdeveloped conditions but have not yet arrived at the optimal treatment level. A study from 2013 revealed high levels of ferritin in adolescents, indicating toxic iron deposits in various organs, which are associated with severe complications such as diabetes mellitus, thyroid disorders, and hypogonadism and a reduced quality of life (Mansoor et al., 2018). Patients from the islands tend to lag even further behind (Angastiniotis, 2014, p. 4). “I just need one glance,” explained the senior doctor who has worked in Male’ s specialist clinic for almost all of her professional life. “They knock at my door [of the consultation room], open the door a crack and peek in. I can tell immediately whether this is an island patient.” In island patients, the doctor sees prominent facial bones resulting from overactive bone marrow (erythroid hyperplasia) caused by chronic anemia resulting from an irregular and inadequate blood transfusion scheme; dark, colorless skin resulting from unjustifiably high iron levels; and whitish lips signifying severe anaemia. Often, the insufficient medical care has taken its toll on the endocrine glands, resulting in growth retardation and keeping adult patients — again predominantly island patients — effectively trapped in the body of 12-year-olds.

This doctor had come from Pakistan to work in the Maldives, married one of the first Maldivian biomedical doctors and, after completing additional training in the UK, had significantly built up the thalassemia program in the archipelago. She spoke Dhivehi (Maldivian) fluently but, due to her attire, she differed from the average Maldivian women in the streets of Male’. Just a few years after we had tea on Zeena’s island, the doctor passed away. I met her late in life; she was already a widow, and her children lived abroad. I felt sorry for her when she spoke about sometimes being treated badly as a foreigner and feeling increasingly insecure in the busy streets of Male’. I learned a lot from her about thalassaemia and health organization in the Maldives. She and many other working migrants in the Maldivian health sector whom I had the privilege of meeting made me think; what makes an islander? What makes an island a true and cozy home, both from a short- and long-term perspective? Accordingly, what is a legitimate representation of an island? How is islandness connected to birthright, residence, labor migration, work performance, marrying in, and so forth?

Failed numbers in thalassaemia prevention were also interpreted as representing islandness. The genetic identity produced in the two genetic testing laboratories in Male’ is manifest in laminated thalassaemia cards in the size of a credit card. They come in seven colors, signifying the six most prevalent haemoglobin gene mutations in the country, all captured by the generic term, ‘thalassaemia’. A chart helps to translate and communicate this individual carrier-identity color in genetic counselling sessions into what Barbara Prainsack and Gil Siegal (2006) have analyzed as “at-risk genetic couplehood.” A red and red, red and blue, or blue and green card-carrier couple, for example, are at a statistical 25% risk of conceiving thalassaemic offspring, while a red and purple card couple is not at risk, nor are any combination from a carrier with a white card, indicating a non-carrier (see Figure 2). For Male’ resident couples, it is mandatory to present their thalassaemia cards when they register for marriage. Island couples, by contrast, either travel
to Male’ for carrier testing, or their island is catered for by an outreach team taking blood samples on the spot to be tested in the laboratories in Male’ (see Figure 3) — or, unavoidably, island couples marry without knowledge of their carrier status due to the lack of testing services in the islands. It was not until late 2018 that the numbers of transfusion-dependent newborns began to decline in the Maldives, most probably due to intensified thalassaemia-prevention efforts — especially via outreach services addressing “the islands.”

**Figure 2:** Receiving results from thalassaemia carrier testing. *Source:* E.-M. Knoll, 2015.

**Figure 3:** Outreach service to a northern atoll; packing blood samples in a cool box to be carried to the testing laboratories in Male’. *Source:* E.-M. Knoll, 2015.

Until the mid 2010s, survival rates and the health status of Maldivian thalassaemics signified the lagging behind in global health equity. The improvement of health equity is on the United Nations 2030 Agenda for Sustainable Development (see United Nations, 2015). Since the 2000s, therefore, health inequalities, defined as “differences in health across population subgroups” (Hosseinpoor et al., 2018, p. 654) increasingly had been of concern to ensure that nobody would be left behind. This includes “disadvantaged or hard-to-reach populations,” and dimensions of inequality thereby “can reflect social, economic, demographic, geographical and other
characteristics by which health is unevenly distributed in a population” (Hosseinpoor et al., 2018, pp. 654–655).

With increasing economic prosperity in the Maldives, many of the former inadequacies — then typical for a low-income country — gradually became a thing of the past. Since the numbers of newborn thalassaemia cases, nevertheless, remained constant, as did premature deaths in patients in their early twenties, attention shifted from global relations to relations within the archipelago; from reading affected bodies as poor ‘have-nots’ in a global perspective to “healthcare not evenly distributed” on the archipelagic scale (cf. Angastiniotis, 2014). Consulting for Maldivian and international thalassaemia institutions and engaging with the field for a decade, and sharing my research results in the form of reports, publications, and personal encounters, I am, to some extent, entangled and engaged in these developments. Since 2011, I have been conducting qualitative social research based on consecutive ethnographic fieldwork periods with island communities in ten of the twenty Maldivian atolls. Collecting data in local language (Dhivehi) and English is focused not only on what people say or report that they do, but also on what they do in practice. As an observer, becoming part of the observed to gain a deep and broad understanding of the ‘natives’ point of view is the aim of ethnographic fieldwork; participant observation and taking fieldnotes are the primary data-collection strategies (cf. Musante-Dewalt, 2018). For a total of 22 months, I had the privilege to immerse myself in health-centered and other daily activities, practices, events, and relationships of Maldivian islanders. I collected empirical data in clinical settings via participating in patient consultations, outreach services, and risk awareness events and through consulting with patients, care givers, and medical experts in clinical and private settings. I accompanied patients on ferries and in ambulance cars to clinical appointments, I accompanied people to carrier testing and blood donation appointments, I visited patients in their home islands, had shorter conversations in waiting rooms and lengthy open-ended and structured interviews and informal chats, also during the long hours of blood transfusion treatment.

The increased attention to inner-archipelagic relations which I have observed since around 2015 is not limited to thalassemia but deeply entangled with broader changes in the relations between islands within the Maldivian archipelago.

The dialectical perspectives of a mental map

The thalassaemia health landscape corresponds to the dichotomous mental map of “Male' and the islands” many Dhivehin share with regard to their archipelago. This mental map, or inner-island representation, is dialectical — a geographical foundation, loaded with ambivalent desires and projections and interacting with socio-political realities (cf. Baldacchino, 2005). In contrast to the capital island, “the islands” on the one hand fall short when it comes to jobs, education, community services, infrastructure, and shopping facilities. Accordingly, geographic exile on remote islands was and is a popular punishment for legal offenders and political opponents (Maloney, 1980, pp. 192–198). On the other hand, island life is considered to be traditional, simple, slow, and rather backward, though more authentic and healthier than the busy life in the
densely populated, noisy, and polluted capital. The islands are associated with handicraft skills and living cultural traditions — and they are valued as holiday destinations, especially for Islamic Eid holidays, resulting in densely packed ferries — a phenomenon highlighted in a 2015 comic shared online with the caption, “Typical ferries! It’s time for the holidays […]” (see http://www.facebook.com/TypicalDhivehin/photos/a.813775125332512/99761663028169). Under the title of Typical Dhivehin, two female, most probably Male'-based, Maldivians use well-crafted cartoons as a medium to reflect typical behavior of their fellow islanders. The Dhivehin’s longing for island holidays demonstrates that the stereotypical tropical holiday island idyll no longer is the privilege of a white, Western, affluent middle- and upper-class in the metropolitan centers of former and existing colonial powers. In an almost orientalizing grammar of identity/alterity (Baumann & Gingrich, 2004), the islands are seen both as inferior and as desired places of retreat. Zeena’s longing for her beautiful home island and her repeated invitation to the haemoglobinopathy doctor from Male' is embedded in this local cultural dialectical understanding of and dealing with islandness. The local Maldivian perception and representation of remote islands and the longing for the remote island experience blur the insider/outsider distinction and obscures emic/etic perspectives within the archipelago.

**Raajjetherey: Otherness within a healthscape of islands**

Asked about the causes of the islanders’ shortcomings in thalassaemia treatment and prevention, my interlocutors referred to an unfavorable interplay between this topographical and socio-economic disadvantageous location and the islanders’ mentality. As Nicolette Bethel (2000, p. 244) has pointed out, in an archipelago, “the sea […] is a source of division in more ways than the purely geographical.” In Dhivehi, the official language of the Republic of Maldives (also spoken in the neighboring and culturally and historically related island of Maliku: Minicoy, India), a person born in raajje-tere — in “the other islands apart from Male island” (Reynolds, 2003, p. 312) — is often labeled with the pejorative Dhivehi term raajjetherey meehaa. This idiom literally refers to a person belonging to the kingdom but is used in the snarky sense of “country bumpkin.” From a Male' resident’s perspective, raajjetherey meehun (plural) are considered to be uneducated, stubbornly traditional, generally backward, and utterly careless when it comes to genetic responsibility. The islanders therefore often served as a subject for educational purposes — in schoolbooks or in posters conveying traffic regulations or information for thalassemia prevention.

This othering within, resulting from a strong emphasis on the archipelago’s centre and its distinction from the rest of the islands, has a long history. Since pre-Islamic times, the later Sultan’s island of Male' served as the ruler’s residence and as the country’s urban centre. This “hub of the Maldivian universe” (Bell, 1921, p. 10) is probably not coincidentally located in the geographical centre of the archipelago, as the anthropologist Elizabeth Overton Colton (1995, pp. 71–72, 98–99) observed, emphasizing the lasting political power and influence of the Male' resident elite over the entire archipelago. In Colton’s (1995, p. 71) representation of the islands in the late 1970s/early 1980s modernizing period, the Maldives’ traditional class system interlocked with this dichotomy: it distinguishes between urban Male' elites and “the ‘islands’
and ‘atolls’, as all the rest of the country is referred to by all Maldivians [...] the rural region where most of the country’s so-called ‘ordinary people’ (miilihun, the lowest class, the country’s fishermen) live.”

The location within the archipelago remains the “first—and most influential—driving factor” (Ministry of Finance and Treasury & United Nations Development Programme in the Maldives [MoFT & UNDP], 2014, p. 49) in existing inequalities and vulnerabilities, emphasizes the Maldives Human Development Report, determining: “opportunities and choices available to a person. Remote islands with small populations have limited access to services, including schooling, healthcare, social services and job opportunities and face overall isolation” (MoFT & UNDP, 2014, p. 49). A person living in Male' is likely to complete three more years of schooling and to receive an average income almost twice as high as an “islander”, who is likely to pay more for food and convenience goods due to high transportation costs and local traders’ small-scale operations (MoFT & UNDP, 2014, pp. 6, 25). Furthermore, an islander is more likely to need to travel for health issues (Knoll, 2017b, p. 156).

**Consolidation and decentralization: Movement in response to spatial disparity and health inequity**

Movement is the islanders’ response to the challenges of spatial disparity and constraints associated with remote location and small-scale settings (see Connell, 2013, pp. 127–132). Male' is addressed for all kinds of tertiary medical services, and the capital serves as the major medical hub for the booming and publicly funded cross-border medical travel (Knoll, 2017b). In the fight against thalassaemia-related health inequity, people, equipment, and blood samples have been set in motion. Whole families have moved to Male' to ensure optimal care for a thalassaemic family member, or a sick child was cared for by relatives in the capital, as in Zeena’s case. Patients and caregivers accept long ferry journeys to obtain the recurrent blood transfusions in the thalassaemia clinic in Male', and patients from across the archipelago are expected to visit this clinic for crucial check-ups at least once or twice a year. Working closely with this clinic, I had the chance to talk to patients from all over the country. Health providers, in turn, are on the move to bring thalassaemia services from the capital to the islands. Since 1997, outreach services have been catering for the islands, initially operated by a local NGO (Society for Health Education, 2016) and publicly funded since 2015. One of these outreach campaigns brought thalassaemia awareness lectures, carrier screening, patient consultations, and staff training to a northern atoll — and it brought me and the haemoglobinopathy doctor from Male' to Zeena’s island and tea table. Yet, Zeena’s tea party cannot be traced back to developments in the health sector alone. These developments are interlinked with wider political visions and with a reassessment of island identities and inter-island relations.

Political visions and policies striving to ease disparities in the archipelago, including health inequity, had been oscillating within the contradictory strategies of population consolidation and service decentralization. The requirement for 40 adult males for Friday congregational prayers in each of the small island communities had always been of concern. In 1968, a law was passed that
led to the depopulation of islands with less than 50 male adults, but many communities returned to their original islands when the law was repealed in 1975 (Maniku, 1990, pp. 47–48). The resumed relocation and incorporation of smaller island communities into larger ones should improve access and allow for more cost-efficient provision of services (Ministry of Planning and National Development, 2007). The introduction of six regional hospitals into the Maldives’ healthcare referral system should bring advanced health services to within a maximum two-hour boat ride for every islander (Ministry of Health, 2014, pp. 17–18; Aboobakuru, 2014, p. 25). The Decentralization Act under Mohamed Nasheed’s presidency (2008–2012) received a counterweight under Abdulla Yameen’s presidency (2013–2018), who envisioned a better future for the archipelago with 75% of the population living in Hulhumale’, an artificial island reclaimed as the major urban expansion area for congested Male’ island (President’s Office, 2015). With Ibrahim Mohamed Solih (President since November 2018), a party friend of Nasheed’s, a reinvigoration of decentralization policies can be expected. Nevertheless, a governmental Population Projections Report foresees a rapidly growing and urbanizing island population; it predicts the Maldivian resident population will have almost tripled by 2054, to 974,359, and 64% will be living in the Greater Male’ Area (National Bureau of Statistics & United Nations Populations Fund, 2018, p. 89).

The proud other within: Island–island relations on the move

Population projections foresee the archipelago’s future as a reversal of the contemporary socio-spatial arrangement — with just one third of the Maldivian population remaining living in the islands. The division in the Maldivian mental “Male’ and the islands” map, on the one hand, decouples the capital — freed and relieved from its island status (while other archipelagoes, remarkably, address their central or largest island as “the mainland” [Baldacchino, 2008, p. 47]). On the other hand, it produces a remoteness full of islands. In his seminal article, the anthropologist Edwin Ardener (1987/2012) laid the ground for capturing remoteness as relational: as both imaginary and real. Building on that, Saxer and Andersson (2019, p. 143) capture the pronounced re-emergence of remoteness everywhere on this planet as a “dynamic historical and geographic process.” Remoteness has a geographical foundation but is not a given, timeless, geographically fixed condition — it also is a social and political process. A social movement is striving to highlight and counter human-made remoteness in the Maldives, denouncing the systematic governmental discrimination against the Maldivian islanders. The movement has its roots in a Facebook page started by an islander from a southern atoll in 2013. By 2015, the islanders, organized by social media, had appropriated and reinterpreted the previously derogatory raajjetherey meehun identity in positive ways (Muna Mohamed, personal communication, 4 October 2016). The islands were fighting back by reclaiming island identity (cf. Baldacchino, 2008, p. 48) and by criticizing the population-consolidation program that has been pursued so far. According to these critical islanders’ voices, a balanced development of the archipelago as a whole has been sacrificed to ever-increasing investment in the further development of the capital area. The unbalanced spending, in turn, produces ever-more
migrating internal ‘others’, leading to bigger and bigger problems linked to rural shortcomings (Mohamed, 2016). This results in the kind of pervasive, rapid, and problematic urbanization that had been recognized in island countries (e.g., Keen & Connell, 2019). In turn, these problems in the urban conurbation call for and justify additional and further investments. The Greater Male’ Area has devoured multi-billion-dollar land reclamation projects, such as the embankment of the largely artificial island of Hulhumale’ (Bremner, 2017, pp. 24–25), and other developmental mega-projects, such as the $200m Sinamale Bridge (previously called the China-Maldives Friendship Bridge) linking Male’ island with the neighboring airport island of Hulhule’ and the adjacent urban expansion area of Hullmale’. At the time of writing, in this ongoing geopolitical rivalry for influence in the island nation and the Indian Ocean at large, India has countered by announcing the financing of the next $500m landmark project. The Greater Male' Connectivity Project is to link Male' island to the other three islands to the west, Villingili, Thilafushi (the garbage island), and Gulgificialhu (currently another land-reclamation project) (Ganapathy, 2020). Nadarajah and Grydehøj (2016) emphasize Island Studies as a decolonial project, sensitive to the processes and tensions in this transformative postcolonial and postmodern era between locally accentuated multiple modernities (Eisenstadt, 2000) and novel geopolitical power plays of global significance (Lintner, 2019; Xie et al., 2020).

While land in the Male’ area is time and time again artificially reclaimed, extended, and connected under ecologically, financially, and politically questionable circumstances, as the raajjetherey movement is criticizing, large enough natural islands would be ready for use in other parts of the archipelago — for example, in the vicinity of Zeena’s island (Mohamed, 2016, p. 15; Mohamed & Shaira, 2016).

Moona Mohamed (2019), for instance, identifies the income gap with Male’ as the biggest obstacle to equitable development in the Maldives. The 2020 budget for the public sector investment program calculates 3,353m Rufiyaa (15,4 Rufiyaa are equivalent to $1) for Male’ and 2,514m Rufiyaa for the twenty administrative atolls together (Mohamed, 2019, p. 17). This disproportionate share of government expenditures benefiting Male’, she argues, results in pressures towards increasing domestic migration in search of jobs, education, and healthcare. In the capital, however, domestic migrant islanders become impoverished tenants due to exorbitant high rents, while the large houses they own on their homelands are gradually collapsing (Z. Rasheed, 2014). “We raajjetherey meehun have been uprooted and transplanted to a place where we do not thrive,” reads a popular Dhivehi blog entry (Raajjethere, n.d.). “We will never fully belong to the urban society of Male' but we have also long become strangers to the community of our home islands” (Raajjethere, n.d.). Primarily for inheritance reasons, domestic migrants remain registered in their home islands. Their absence indicates the enormous scope of the migration movements within the archipelago. Only 65% of registered islanders actually live in the northernmost atoll (Mohamed, 2016, p. 16): for more than twenty years, Zeena was among this atoll’s absentees. The raajjetherey meehun movement is therefore calling for alternative paradigms to population consolidation (R. Rasheed & Zakariyya, 2017) and for diversification strategies for income-generating sectors, especially tourism (Fathimath, 2015). In spring 2020, the raajjetherey movement sought to capitalize on an unexpected boost. While decentralization
had been on the political agenda for more than two decades, people nevertheless continued to converge on the Greater Male' area. The COVID-19 pandemic and the working experience in lockdown mode finally ought to convince political leaders that “they do not need to physically converge to a single location to manage the affairs of the state,” as argued by the economist Athif Shakoor (2020). He postulates that a relocation of state agencies to selected islands would create stable jobs throughout the archipelago and ease the population pressures of Greater Male'. Shakoor’s vision of a decentralized government working online and offline with ministries dispersed across the country marks a shift in the public envisioning and representation from the centuries old hierarchical centre–periphery model to a spatial organization form of de-centred archipelago (Xie et al., 2020, pp. 10–14).

People with intersecting thalassaemic and raajjetherey meehun identities, like Zeena, are also getting more attention. Thalassaemics from the islands were specifically invited to the first National Thalassaemia Conference, organized by the local patient and parent group the Maldives Thalassaemia Society (MTS) in Male’ on May 8, 2015. There, island patients reported on their own terms about genetic responsibility in peripheral contexts. They spoke about difficulties of organizing blood donors in small island settings and about treatment schedules often following the ferry timetable rather than their bodies’ haemoglobin requirements.

**Conclusion**

Scrutinizing the dynamics of the interface between island habitat, genes, and people, this article draws an arc of island health representations stretching from geographic determinism in the economic world system to a critical reflection of island–island interaction within the archipelago; from a correlation of its geographic position in the thalassaemia belt and in health development to a critical scrutiny of remoteness within the inner socio-economic relations. Through my own positioning and in my representation of health-entangled islandness, I hope to have captured some of the lively complexity and polyphony in intra-archipelagic relationality. The physical island spaces in central and remote locations, connected and distinguished by an inner sea, house a plethora of outsiders, insiders, and hybrids. Personalized positionalities and their connectivities are intrinsic to this archipelagic setting in a changing world. From various standpoints and experiences of both insularity and connectivity, they all represent islands and produce islandness and, thus, the Maldives as a dynamic archipelago of relations within and beyond.

**References**


