

**SICK WITH SUGAR: THE SOCIOCULTURAL DIMENSIONS OF MANAGING
DIABETES IN A SEMI-URBAN INDIAN TRINIDADIAN COMMUNITY**

by

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Abstract

This dissertation comprises ethnographies and narratives of the ways in which Indian Trinidadians in Debe, Trinidad negotiated their life-worlds, life-course expectations, and ethnic identities around Type 2 diabetes mellitus with family, food, and religion as central themes. In overview, this research explores how Type 2 diabetes mellitus, popularly known as “sugar”, is constructed and responded to, as well as the impact of inequities in access to healthcare on people’s ability to manage this disease. Diabetes is the second most common cause of death in Trinidad and Tobago, and has highest estimated prevalence among Indian Trinidadians. Much of the discourse in Trinidad blames high local rates of Type 2 diabetes mellitus-associated mortality and morbidity on unhealthy patient practices and lifestyles. Through participant observation, interviews, and archival research, I explored normative biomedical notions of disease and untangled who is affected by a diabetes diagnosis, how they are affected, and what they do when their lives change, or to change their lives in this context. This research revealed some ways in which overly simplistic notions of patient autonomy projected upon complex, enmeshed societies and polities can be translated as ineffective recommendations for disease management, producing unintended and detrimental changes to people’s life-worlds. Understanding diabetes and its management in Debe required not only understanding the pathological or biological disease process, but more crucially, the explanatory models of people with this diagnosis, how they coped with associated illness, and the crucial communities of care that facilitated therapeutic efforts. Particularly important were narratives of persons with diagnosis of diabetes, and their caregivers. The case narratives produced are grounded in the ethnography of an economically heterogeneous community that has undergone many transitions in the recent past, including the rise in the rates of diabetes and resultant transformations of everyday socialities. These stories are therefore also inherently concerned with temporality on different scales: the progression of a disease over time, the changes in an individual life course over time, and the temporal shifts in a community as it moves from a shared, agricultural past to an uncertain and multitudinous future.

Lay Summary

This dissertation explores the experiences of Indian Trinidadian people in Debe, Trinidad with Type 2 diabetes mellitus through narratives, family histories and case studies of its effects on them and their families. Type 2 diabetes is the second most common cause of death in Trinidad and is particularly common amongst Indian Trinidadians above 50 years of age. Diabetes is a chronic disease that challenged people's formed identities by requiring changes to their patterns of consumption, commensality and social interaction in their everyday lives, either through the development of illness, or through their attempts to meet management recommendations. This research showed that limitations to the accessibility of healthcare and its provision by the public health care sector in Trinidad also negatively impacted people's ability to manage their disease.

Preface

This dissertation represents original work by Vishala Parmasad, who is the sole author and designed, performed, and analysed all research herein. Any errors are the responsibility of Vishala Parmasad alone.

This research was approved by the UBC Behavioural Research Ethics Board under the title “Is better man belly buss than good food waste”: The sociocultural dimensions of Type 2 diabetes in Penal, Trinidad,” Certificate Number H12-03077 with Dr. William H. McKellin as Principal Investigator.

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List of Abbreviations

CDAP	Chronic Disease Assistance Programme
CDC	Chronic Disease Clinic
CHRC	Caribbean Health Research Council
PAHO	Pan American Health Organization
PNM	People's National Movement
SWRHA	South West Regional Health Authority
UNC	United National Congress
WHO	World Health Organization

Glossary

<i>Aarti</i>	Veneration of deities and respected elders involving use of flowers and a miniature lighted deya
<i>Agouti</i>	Also called “gouti”, rodent species of the genus <i>Dasyprocta</i> that looks like a large guinea pig whose meat is considered a delicacy in Trinidad
<i>Aloo pies</i>	Deep-fried pies stuffed with spicy mashed potatoes
<i>Baigan</i>	Eggplant
<i>Baigane</i>	Battered and deep fried eggplant fritter
<i>Bara</i>	Deep-fried flatbread
<i>Barahee</i>	Hindu celebration on the 12 th day of the birth of a child when, inter alia, mother and child are given ritual bath.
<i>Barfi</i>	Milk and sugar based sweet
<i>Bhaat</i>	Rice
<i>Bhaji</i>	Preparation of cooked green leaves such as spinach
<i>Bird peppers</i>	Flavourful, hot pepper
<i>Bodi</i>	String beans
<i>Carailie</i>	Bitter gourd
<i>Cascadoo</i>	Cascadura fish
<i>Channa</i>	Chickpea
<i>Chataigne</i>	Local chestnut
<i>Chokha</i>	Vegetable side dish made by roasting whole vegetables and mashing with spice infused hot oil
<i>Choonky</i>	Very small
<i>Chutney</i>	A condiment, sometimes sweet, sometimes hot and tangy
<i>Coolie</i>	A derogatory racial epithet used to describe Indians
<i>Cutters</i>	Appetizers
<i>Dabla</i>	Spatula
<i>Dal</i>	A legume dish of soupy consistency
<i>Dalpuri</i>	Type of roti or flatbread stuffed with ground dal
<i>Dasheen</i>	Root of taro plant, edible when cooked
<i>Dasheen bush</i>	Leaves of a taro plant that can be cooked in a variety of ways

<i>Deyas</i>	Oil lamps
<i>Eddoes</i>	Taro root varietal (a cultivated plant with large dark green rounded arrowhead-shaped leaves the edible tubers of which are widely eaten)
<i>Giddy</i>	Dizzy
<i>Godna</i>	Tattoos depicting Hindu religious motifs or the name of God in Hindi script
<i>Gulab jamoon</i>	Deep fried condensed-milk-based dough in a sugar glaze
<i>Hawan</i>	Offering of foodstuff to a sacred fire
<i>Iguana</i>	A type of herbivorous tropical lizard
<i>Jalebi</i>	Sweet fried sugar syrup
<i>Jharay</i>	Cleansing or healing ritual performed while prayers are recited
<i>Junjunie</i>	Pins and needles
<i>Kachourie</i>	Fried ground lentil patties
<i>Kaloungie</i>	Stuffed and fried bitter gourd
<i>Kurma</i>	Deep-fried milk-dough sticks in a sugar glaze
<i>Lappe</i>	Lowland paca, the largest rodent in Trinidad hunted for its meat
<i>Latrine</i>	Outdoor pit toilet
<i>Lime</i>	To hang out with company
<i>Maljo</i>	Evil Eye
<i>Malkadie</i>	A type of seizure
<i>Mandir</i>	Temple
<i>Manicou</i>	Opossum, wild meat delicacy in Trinidad
<i>Meethai</i>	Indian sweets
<i>Murtis</i>	Icons of the gods in either pictorial or statue form
<i>Obeah</i>	A folk system of magic and using supernatural forces to bring about effects ranging from success in life to changes in health
<i>Ochro</i>	Okra or ladies' fingers
<i>Paratha</i>	Layered roti, beaten to flakiness until it resembles a torn shirt hence the name "buss-up shut" (burst shirt)
<i>Parsaad or mohanbhog</i>	Ritual sweet food that has been offered to Hindu deities, afterwards shared among devotees
<i>Pera</i>	Sweet rice flour and sugar squares
<i>Phulourie</i>	Balls of deep-fried lentil dough
<i>Pimento</i>	A mild-flavoured sweet pepper varietal

<i>Puja</i>	Ritual Hindu religious prayer to the gods
<i>Pundit</i>	An officiant who performs Hindu religious services and ceremonies
<i>Ramayana yagya</i>	In Trinidad, a Hindu religious event over the course of one or more nights focusing on discourses on the Ramayan and Hindu scriptures
<i>Roti</i>	Stovetop baked flatbread
<i>Sada roti</i>	A plain, flat, thick round bread, cooked without oil, usually over an open flame
<i>Saheena</i>	Battered and deep fried spinach roll
<i>Samosas</i>	Ground vegetables or meats in a crisp pastry envelope
<i>Satsangh</i>	A Hindu religious gathering, including prayers, chanting and discourse
<i>Scotch bonnet peppers</i>	Also known colloquially as “congo peppers”, these <i>Capsicum chinense</i> red peppers are endemic to the Caribbean and Central America are similar to habaneros but much hotter.
<i>Seva</i>	A Hindu concept of selfless service performed for the community
<i>Sohari leaf</i>	A large, waxy, banana-like leaf used as a disposable plate for food especially at Indian events
<i>Talkari</i>	A side dish usually of vegetables made with sauce or gravy to go with rice or roti
<i>Tanty</i>	Aunt, used to refer to and address women elders in the community even if unrelated
<i>Tattoo</i>	Armadillo
<i>Wild meat</i>	Game
<i>Yagya</i>	A type of Hindu puja lasting seven or nine nights, usually held to achieve a specific aim

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Dedication

This dissertation is dedicated to my daughter, Ameya. You are the light of my heart.

Chapter 1: Introduction: The field and what is at stake

The puja (ritual Hindu religious prayer) was over, and knots of people from the congregation were strolling over to the kitchen-annex, to eat the traditional post-puja communal meal. Tanty¹ Dularie, a neighbour from Shambho Trace, however, was quietly heading the opposite way, leaving through the back of the temple. When I went to wish her a good night she furtively told me she hoped nobody else had noticed her slipping out. She had to leave, she explained, because she couldn't eat the prayers food, it sent her blood glucose "too, too high". Even if she ate just a little bit, the next morning her sugar would be over 200 mg/dL. She was tired of asking for less – she could eat no less without it being nothing at all. But it was rude to come to a puja and leave without eating, and sacrilegious to refuse the parsaad. Upset by this, Tanty Dularie was quietly slipping out.

1.1 Overview and purpose

This dissertation explores how the diagnosis, illness, and efforts at managing Type 2 diabetes mellitus transforms the lives of Indian Trinidadians living in Debe, Trinidad, from their own perspectives. It explores what is at stake for people in their illness experiences, and the social and cultural resources that enable or impede their efforts at living with “sugar”, as Type 2 diabetes mellitus is commonly known locally. It also outlines inequities in healthcare provision

¹ Tanty is derived from the French “tante” meaning aunt. It is used in Debe as a form of respectful address and to refer to all older women to whom one is not related.

subsequent to uneven healthcare access despite the presence of a purportedly free, nationalized healthcare system. Finally, it explores whether Indian Trinidadian ethnic identity is pathologized by the biomedical discourse around diabetes in Trinidad and Tobago, and the roots of this perception. In this chapter I introduce Trinidad and Tobago and the field site, Debe. I situate Debe in historical context to highlight the origins of structural inequalities in healthcare provision, as well as the genesis of deep-seated lifeways and life-course expectations that people in Debe share. In the last section of this chapter, I focus particularly on the domain of Indian Trinidadian ethnic identity, within which I identify three fields that were particularly affected by “sugar”: family, religion, and food.

Type 2 diabetes mellitus, called diabetes in the text after this, has very high prevalence in Trinidad and Tobago, and has consistently been estimated to have highest prevalence among the Indian Trinidadian population, especially women of over fifty years of age (Nayak et al. 2016; Chadee et al. 2013; Poon-King, Henry and Rampersad 1968). Diabetes has also been one of the five most common causes of death in Trinidad from 1997 to 2016 (Pan American Health Organization 2012; Ministry of Health Statistical Report 2016; Global Burden of Disease Collaborative Network 2017), and through its synergistic interactions with other common metabolic conditions in Trinidad, is a key contributor to the other non-communicable diseases that comprise the other four most common causes of death (Global Burden of Disease Collaborative Network 2017). It imposes a significant burden on the nationalised healthcare system from research conducted by and among healthcare providers (Roopnarinesingh et al. 2015; Gulliford et al. 1995a; Gulliford et al. 1995b). Medically, diabetes may be present for years as abnormal elevations of blood glucose, which epidemiological research has shown produces microvascular damage, without people experiencing any symptoms (Engelgau et al.

1997; McCane et al. 1994; Finch, Zimmet and Alberti 1990). During this asymptomatic period it can nevertheless be diagnosed by the use of techno-scientific measures of the body, such as the screening of small amounts of blood obtained by pinprick using glucometers, or more complex biochemical assays of vials of blood (WHO 1999). Long term changes to diet and exercise patterns are standard recommendations for diabetes management, as well as medication regimens that vary with disease severity (WHO 1999; CHRC and PAHO 2006). Based on my experience as a physician and communication with medical colleagues, however, a popular perception persists within the medical establishment in Trinidad that blames persons with diabetes for being particularly “non-compliant” with medical recommendations for dietary changes and medication self-administration.

Debe is a semi-urban town settled primarily by Indian Trinidadians, located in what was once the heart of the rural, sugarcane belt of South Trinidad. It is currently a commercial and service-oriented hub and transit point within the region. Debe falls within the Penal/Debe municipality, and was chosen as a field-site in part because the Trinidad and Tobago 2011 Population and Housing Census showed it to have the highest percentage prevalence of diabetes of all the fifteen municipalities of Trinidad and Tobago at 7.51% (CSO 2012). One of the local health centres located within its confines was also estimated to have the greatest number of patients with diabetes registered to its Chronic Disease Clinic, the main means by which most people in this area of Debe received regular and continuous care.² Debe itself had started as a coalescence of agricultural villages strung along the San Fernando – Siparia Erin Road during the British colonial period (Richardson 1975; Bissessarsingh 2014). These villages were tight

² Private communication with local epidemiologist.

knit communities, often formed from extended families that settled together, within which people shared religious and ethnic identities. The yearly, seasonal cycles were demarcated by common agricultural production and religious festivities, historically rooted in shared life-course schema. These deep agricultural roots linger in the lifeways for many of the older population, the group mainly affected by diabetes.

This dissertation comprises ethnographic data, narratives, family histories, and archival research findings that are interwoven to explicate the ways in which people in Debe negotiated their life-worlds, life-course expectations, and ethnic identities around diabetes. Over the course of participant observation, interviews, and archival research carried out from 2013 to 2016, I immersed myself in the lives of people in the region to untangle normative biomedical notions of disease from patient explanatory models, and to reveal who is affected by a diabetes diagnosis, how they are affected, and what they do when their lives change, or to change their lives. How do people engage standardised diabetes recommendations, part of an international ecumene of biomedicine, which project simplistic notions of patient autonomy upon a complex, enmeshed, and postcolonial polity? Can such blanket recommendations be effective to the specificities of context, and what do they fail to account for?

People's ability to "manage" their disease was also delimited by an increasingly fragmented healthcare system, with widening disparities in healthcare provision between the public and private healthcare sectors. The general, widespread social disorganisation in the public sector is characteristic of postcolonial contexts and small states in which forces of neoliberalism and globalisation are active. As the majority of people engaged in this research were of a lower socioeconomic class, they mainly utilized the free, nationalized system of public healthcare through which diabetes care is provided in Trinidad. Understanding diabetes and its

management in Debe, therefore, required not only understanding the pathological or biological disease process, but also how people with the diagnosis coped with associated illness, and the communities of care that facilitated their therapeutic efforts. The findings of the upcoming chapters are thus rooted in the ethnography of an economically heterogeneous community that has undergone many transitions in the recent past, wherein the rise in the rates of diabetes and resultant transformations of everyday socialities were just one manifestation.

1.2 Trinidad and Tobago today

Trinidad and Tobago is located on the southern end of the Caribbean chain of islands, about seven miles from Venezuela. This dissertation focuses on Trinidad, the larger and more developed of the two islands. Trinidad and Tobago was granted independence from Britain in 1962, and is multi-ethnic and English-speaking, with a landmass of 5,127 km² and a population of approximately 1.3 million people. Ethnic identity, or as it is commonly referred to in Trinidad, “race”, is a key element of popular discourse locally. The Central Statistical Office of Trinidad and Tobago defines the major ethnic groups of Trinidad as “East Indian” (the descendants of Indian indentured labourers) and “African/Black” (the descendants of African slaves) in roughly equal proportions (~35%), along with a “mixed” population (consisting of both “mixed East Indian and African” and “mixed others”) of 22.8% (Central Statistical Office 2012). The other ethnic groups identified by the Central Statistical Office in Trinidad are found in much smaller percentages, including “Caucasians” (0.59%); “Chinese” (0.30%); “Indigenous” (0.11%);

“Syrian/Lebanese” (0.08%); “Portuguese” (0.06%); and “Other Ethnic Group” (0.17%) (Central Statistical Office 2012).³

The economy of Trinidad and Tobago is predominantly industrial and heavily reliant on resource extraction, based on its oil, gas and downstream industries. It has one of the highest per capita incomes in the Caribbean and since 2011 has been ranked by the World Bank as a “High Income Country”. While oil and gas account for approximately 40% of the gross domestic product (GDP) and 80% of the exports, they account for less than 5% of employment (Central Statistical Office 2018). Downstream industries including the production of methanol, ammonia, urea, steel, cement and more accounted for 48.8% of the GDP in 2017. Services account for 50%, while agriculture accounted for only 0.4% of the GDP (Central Statistical Office 2018; Central Intelligence Agency 2018).

³ The statistics and ethnic terminology used here are drawn from the national demographic report of the Central Statistical Office (CSO) of the Government of the Republic of Trinidad and Tobago conducted in 2011. This document defines the term “ethnic groups” as follows: “Broadly defined, ethnicity pertains to people of the same race sharing a common history and distinctive cultural characteristics,” and further states that “Indigenous refers to people of Amerindian descent, commonly known as Caribs and Arawaks” (Central Statistical Office 2012, xxvii). The CSO also qualifies the “mixed” category it uses as being “disaggregated into the ‘African/East Indian’ 7.7% and ‘Mixed Other’ 15.1%” (Central Statistical Office 2012, 15).



Figure 1.2: Road map of Trinidad with Debe's location highlighted. Map produced by the Digital Map Production Facility, copyright Lands and Surveys Division, Trinidad and Tobago.

1.3 Debe in historical context

The historical-anthropological work of Sidney Mintz and other Caribbeanist scholars informs much of the approach taken to the history of Debe, and Trinidad and Tobago on the whole.

Trinidad and Tobago owes its early development to the colonial sugarcane industry (Brereton 1981). An understanding of the history of Trinidad explains patterns of settlement, and daily and yearly agricultural rhythms of life that persist in parts of the country like Debe. Trinidad's history also undergirds persistent structural constraints, including disorganised social service provision and infrastructure, the politicisation of racial and ethnic differences, unequal wealth

distribution, income precarity, and inequitable access to healthcare, which manifest in people's illness narratives and experiences in Debe.

Trinidad was colonised by the Spanish in 1498 but remained a “backwater of the Spanish empire” (Higman 1978, 163) until productive sugar estates were established in 1787 by Francophone planters.⁴ The British succeeded the Spanish as colonisers in 1797, expanding the immature plantation-system into a full-blown sugar colony by 1820 (Brereton 1981). A labour shortage arose when slaves fled the plantations for the urban areas of Trinidad with the passage of the Slavery Abolition Act in 1833 (Brereton 1981). The British met this labour need by importing over 140,000 labourers from India from 1845 to 1917 under a system of indentured labour. Indians who came to Trinidad were in the majority from a Bhojpuri-speaking linguistic swathe across Northern India that today would include Bihar, Jharkhand, and Uttar Pradesh (Brereton 1981). Trinidad then followed the more typical path of an established sugar colony, shaped by the power relations inherent to colonialism, with the early agri-industrial production on sugar plantations charting its prosperity, and its multi-ethnic migrant population negotiating a collective identity and production as a “modern” people, much in accordance with Sidney Mintz's (1986) classic, *Sweetness and Power*.⁵

A characteristic pattern of land usage and settlement arose in Trinidad that persists to the present. A “sugarcane belt” extended along Central and South Trinidad, consisting of many plantations owned by Francophone and British planters. Interspersed within this were rural

⁴ See Bridget Brereton (1981) for a more detailed explanation of Spanish efforts to encourage settlement in Trinidad via the passage of the Cedula of Population that encouraged Roman Catholic Francophone immigration.

⁵ See David Scott (2004a) for a discussion of the Mintz's framing of the Caribbean as particularly modern, and Scott (2004b) for a discussion of how postcolonial re-imaginings of colonial pasts as tragedies may more produce productive politics leading to decolonized futures.

villages formed by ex-indentured Indian labourers and their descendants, the majority population of rural areas and agricultural labour in Trinidad from the 1880s onwards (Horowitz 1960; Brereton 1981; Richardson 1975). The urban areas, meanwhile, were dominated by emancipated African slaves and their descendants, especially along a corridor extending East to West along North Trinidad, leading to the capital city of Port of Spain (Horowitz 1960; Brereton 1981). The second largest city in the country, San Fernando, located in South Trinidad, retained a veneer of rurality in popular discourse⁶ when compared to the capital, Port of Spain, in North Trinidad.

Oil was discovered in South Trinidad in the early 1900s, however Port of Spain continued to dominate as the seat of government and primary commercial hub of the country (Brereton 1981). North Trinidad became increasingly densely populated along an urban East-to-West corridor. By the 1920s, oil had replaced sugar as Trinidad's most profitable export, and with the discovery of natural gas and offshore reserves, oil and gas have remained the mainstay of the economy.

Agricultural practices and patterns of life however continued and dominated the rural areas in Trinidad like Debe. Bonham Richardson (1975) has pointed out in *Livelihood in Rural Trinidad in 1900* that villages like Debe were integral parts of the colonial plantation system. On the outskirts of the Waterloo sugarcane estate in South Trinidad, Debe started in the 1870s, when time-expired, ex-indentured Indians settled and began to farm rice, root crops, and vegetables in

⁶ I engage Foucault's definition of discourse to refer to "ways of constituting knowledge, together with the social practices, forms of subjectivity and power relations which inhere to such knowledges and relations between them. Discourses are more than ways of thinking and producing meaning. They constitute the 'nature' of the body, unconscious and conscious mind and emotional life of the subjects they seek to govern" (Weedon 1997, 108). Discourse is also acknowledged to be "...a form of power that circulates in the social field and can attach to strategies of domination as well as those of resistance" (Diamond and Quinby 1988, 185). This approach is also informed by the postcolonial position that discourse includes utterances and symbols manifest in a variety of forms and contexts, both textual and non-textual, popular or subaltern forms of knowledge production, which may be revelatory of cultural constructions (Pels 1997).

the swampy soil (Richardson 1975). British colonials and planters incentivised this settlement by granting Indians access to these marginal lands skirting the plantations, to maintain the proximate and stable labour-force they required for profitable sugarcane production. Villagers acted as seasonal labour reserves for the estates during the cane-harvesting period and grew food-crops that the estates came to rely on to feed their indentured labour force cheaply. Soon villagers were also allowed to produce cane as a cash crop on a small scale, becoming cane farmers. Since only sugarcane estates owned sugar-processing facilities capable of converting raw cane to sugar, cane farmers remained tied to them and to colonial agricultural industry.

To facilitate the transportation of cane, a Trinidad Government Railway stop was established in Debe in 1912, and by 1920 Debe was a popular transit point between more rural areas and the major Southern Trinidad city of San Fernando, especially after the busy San Fernando - Siparia Erin Road (S.S. Erin Road) was built, connecting Southern oil and natural gas industries to the rest of Trinidad. Debe was also a market town where farmers from the region sold what they grew. Debe hosted public amenities such as the post-office, police station, and a cinema. By the mid-twentieth century it had also already become well known for the vendors selling doubles (chickpeas and fried dough sandwiches) and other “Indian delicacies” (Bissessarsingh 2014; Homer 1999). The railway was closed in 1968 with the arrival of automobiles, however it enabled Debe to become a focal point in the region and villages around it to expand linearly along the roadways and coalesce. Adjacent villages like as “Coolie Wood,” (now Gandhi Village) effectively became part of Debe.⁷

⁷ “Coolie” was initially a term for manual labourers in India, but in Trinidad became a generic degrading racial epithet for all Indians. “Cooliewood” was a derogatory racist reference to both the wooded rurality of the village, which connoted backwardness, as well as its exclusive settlement by Indians. This name was changed in 1958 to

The numerous sugar plantations across Trinidad were progressively bought, centralised and consolidated under the control of the British multinational corporation Tate and Lyle by the 1950s (Wilson and Parmasad 2014). Trinidad and Tobago was granted independence by the British in 1962, the first government being formed by the People's National Movement (PNM), with the major opposition being the Democratic Labour Party (DLP). These parties were respectively (and putatively) the African Trinidadian party and the Indian Trinidadian party, and reinforced a dynamic of contestation and inter-ethnic rivalry established during the colonial period (Brereton 1974; Brereton 2002).

Tate and Lyle sold its holdings to the Government of Trinidad and Tobago after independence and the nationalised agricultural company Caroni (1975) Limited was formed from these holdings by the early 1900s. This company assumed great significance in the lives of rural Indian Trinidadians, in the majority still tied to the estates and to sugarcane cultivation. It was responsible for the management of the largest dedicated area of agricultural land in the country (over 700,000 acres) (Wilson and Parmasad 2014). Caroni (1975) Ltd became the largest agricultural employer in Trinidad for the next thirty years.⁸ It also performed roles inherited from colonial-era plantations: providing basic healthcare for employees through estate doctors and health centres, performing infrastructural tasks such as road development and land management in rural communities, and providing some economic support for its seasonal employees (e.g.

erase the derogatory associations of the name. Gandhi Village and Debe merged over the years with continuous settlement into the continuous entity of today (see Bissessarsingh 2014; Homer 1999).

⁸ The organization of sugarcane cultivation under Caroni (1975) Ltd mirrored the pre-existing arrangements between estate holders and the sugar mills. While Caroni (1975) Ltd, and therefore, the State, owned the vast majority of the established sugarcane lands, the company only cultivated an estimated 40% of the land directly, rented out the other 60% to private cane farmers, who then supplied its factories with set quotas based on the number of acres cultivated (Wilson and Parmasad 2014).

extending “sugar loans” to cane farmers develop their own agricultural lands or construct houses). In effect, Caroni (1975) Ltd buttressed inadequate local and municipal government service provision in Debe and other rural areas, in some places replacing it entirely (Wilson and Parmasad 2014).

Despite the low international profitability of sugar, the Trinidad sugar industry (via Caroni [1975] Ltd) still employed 25% of the total labour of the country by the 1990s (Palmer and Pemberton 2007). The sugar industry also existed in a dynamic relationship with “private agricultural holders”, i.e. individuals, households and sole proprietors who performed the majority of the agricultural production, such as cane farming (Central Statistical Office 2004). For most of its existence, however, Caroni (1975) Ltd had been considered a loss making venture (Mitchell 2005), and efforts to diversify from sugarcane to increase its profitability (Spence 1978) were intermixed with threats of the company’s divestment as a national holding. In July 2003 the Government of the Republic of Trinidad and Tobago, then formed by the political party of the People’s National Movement (PNM), “restructured” and effectively closed Caroni (1975) Ltd, retrenching 9,000 workers, 6,000 cane farmers directly, and an estimated 35,000 more dependent on the industry throughout Trinidad, including within Debe (Mitchell 2005; Wilson and Parmasad 2014; Divestment Secretariat 2003).

Caroni (1975) Limited was the primary employer, and sugarcane farming a naturalised facet of everyday life for most participants in this research for at least part of their lives, many of whom were at most one generation removed from involvement in the sugarcane industry. This was consistent with the findings of a report prepared by a European Union delegation to Trinidad in 2010, which estimated that of those affected by the closure of Caroni within Sugar Related Areas of Central and South Trinidad, 70% were Indian Trinidadian (Fernández Trillo and

Benjamin 2010). People's loss of income in Debe caused by the closure of Caroni (1975) Ltd was buffered somewhat by lump sum "Voluntary Separation Package" severance payments the retrenched workers had received and promises of lands (Fernández Trillo and Benjamin 2010; Wilson and Parmasad 2014). However many of the ex-Caroni workers engaged and encountered in this research had been left destitute due to poor money management, poor skills transference, and an inability to obtain other jobs due to their advanced ages.⁹ This resulted in widespread income precarity in Debe. Employment in the agricultural sector had additionally shrunk dramatically after Caroni (1975) Ltd closed, and large-scale agriculture in Trinidad and Tobago has never recovered (Wilson and Parmasad 2014). Agricultural employment today accounts for only 1.5% of the population of both sexes, and produces only 0.4% of the GDP along with forestry, hunting and fishing (Central Statistical Office 2018). Despite these figures, many people in Debe continued to "make garden" (cultivate kitchen gardens) to supplement their diets and for local sale.

The loss of Caroni (1975) Ltd was still reflected in the narratives of many research participants as a moment of disjuncture between one life and the next, and the loss of temporal rhythms attuned to the yearly agricultural cycle of planting, growing, and crop-time, which had given predictability to the year. This was reflected in the landscape as well, the waving seas of green sugarcane that once dominated the landscape of South Trinidad having been replaced by patchy overgrowth and scrub, with occasional outcroppings of cane-stalks in the abandoned fields of former cane-lands. Though the closure of Caroni (1975) Ltd had been lauded in the

⁹ I refer here not only to the individual money management of ex-Caroni workers, but the collapse in 2008 of the Hindu Credit Union, which was not bailed out by the Government, resulting in the loss of life-savings and investments of the many ex-Caroni workers and farmers who formed its primary membership. This is outlined more in Wilson and Parmasad 2014.

press by the People's National Movement (PNM) government as both an economic necessity due to the company's massive losses, and an act that finally freed Indian Trinidadians from the chains of colonialism which brought them to Trinidad, it was widely perceived as a politicised and racist act to undermine the rural, Indian, voter support base of the major opposition party, the United National Congress (UNC) (Bagoo 2013; Ramsaran 2013, 130). Threats about the closure of Caroni (1975) Ltd had long been seen as a continuing source of inter-ethnic strife in an on-going contest between rural Indians and urban blacks, as noted scholar John La Guerre (1989, 37) stated, "For a government to pursue a national policy in one area only [i.e. oil and gas] and to abandon it in others is to compromise the neutrality of the state." Racial tensions in Trinidad and Tobago between the majority populations of Indian- and African-descent are a popular theme of discourse in Trinidad, and are implicit in many local debates about inequities in rural-urban services, infrastructure, development, and division of resources (Reddock 2010).

For much of this research, the People's Partnership coalition formed the Government of Trinidad and Tobago (2010 to 2015), only being voted out of power after a recession in 2015 by the opposition PNM. The People's Partnership coalition had huge support in Debe, as a significant branch of the coalition comprised the UNC lead by Prime Minister Kamla Persad-Bissessar. People in Debe were very proud of her for having come from Siparia, a town south of Debe, for being the first female Prime Minister of Trinidad and Tobago, and for being the second Indian Trinidadian Prime Minister. The UNC was founded by Basdeo Panday, who had long represented the labour interests of people working in sugarcane, predominantly Indian Trinidadian. Basdeo Panday was also a source of pride in Debe for having become in 1995 the "first Indian Prime Minister" of Trinidad and Tobago since its Independence in 1962, and because he also came from South Trinidad.

It was not uncommon to hear simultaneous praise of Kamla Persad-Bissessar and condemnation of the government for general inefficiency, corruption and lack of transparency. This was part of a generalised discourse amongst “South people” that successive governments had prioritised the needs of the more urbanised Northern half of Trinidad through the provision of basic amenities, economic investments, and infrastructural development. People in Debe resented what they described as “an unequal flow” from South to North Trinidad: of agricultural produce from Southern farms that sold for higher prices up North; skilled professionals from South who moved their practices to the North where they could command higher fees; oil and gas revenues earned from extractions in South Trinidad that supported the development of the North; more hospitals and better infrastructure in the North built with South tax dollars; and “make-work” programs employing mainly the urban poor of the North. The rural peripheries of the country and the rural poor were seen as neglected and ignored, which a doubles vendor in Debe explained to me as, “Massa day not done.” Plantations owners were called “Massa” (Master) by their subordinates, and this statement implies that one colonial master had been exchanged for another; that is, the elites in government were continuing a colonial legacy.

This was also attributed to anti-Indian racist policies of the PNM, that formed the first Government of the Republic of Trinidad and Tobago post-Independence, and had governed the country continuously for 30 years after. For example, older people in Debe referred to the PNM’s history of racism by quoting its first leader, Dr Eric Williams, who famously described the Indian community in a speech from the 1950s as a “hostile and recalcitrant minority” and was also known to have derogatorily referred to early Hindu schools as “cowsheds”. Williams further attacked the “Indian illiterates of the country areas who were threatening to submerge the masses whom Williams had enlightened” (MacDonald 1986, 120).

Kamla Persad-Bissessar however, was particularly praised for making good on her campaign promises over the tenure of the People's Partnership, when two major infrastructural projects were completed. The first of these was the extension and expansion of the Sir Solomon Hochoy Highway from Debe to Mon Desir in 2014, despite the objections of environmentalists.¹⁰ The Sir Solomon Hochoy Highway is the major artery that connects North Trinidad to South Trinidad, and its extension decreased the transit time between Debe and Central Trinidad from an hour to ten minutes. The effects of this transformation were felt as an immediate increase in the volume and speed of traffic on the Debe Main Road, increased commercialisation along the Main Road, and a slow influx of new residents and renters to the village. The effects of this increase in accessibility are still manifesting in what were once relatively inaccessible villages to the interior of the countryside.

The second major infrastructural work undertaken under the People's Partnership was the expansion and addition of a Teaching Hospital to the San Fernando General Hospital, the only tertiary hospital in South Trinidad. This effectively doubled the size of some wards, a much-needed expansion given the estimated 600,000 people within the hospital's catchment area. Plans were also floated for the expansion of the University of the West Indies to a location within Debe, and a new Children's Hospital was also built with the intention of serving the South and Central Trinidad. These projects were all halted in 2015, however, with a change in government

¹⁰ The environmentalists were protesting both the environmental impact of the highway extension and its potential displacement of hundreds of established rural families. This became a highly political and charged rhetorical battle, mainly played out in the media. Supporters of the People's Partnership government condemned the protests as manipulations of the opposition-PNM, and characterized the protestors as from "up North". Most people I spoke with in Debe saw this as a political ploy to keep "the South" rural, and were either indifferent or strongly in support of the highway expansion.

and subsequent recession, and the completed Children's Hospital currently stands unstaffed and empty.

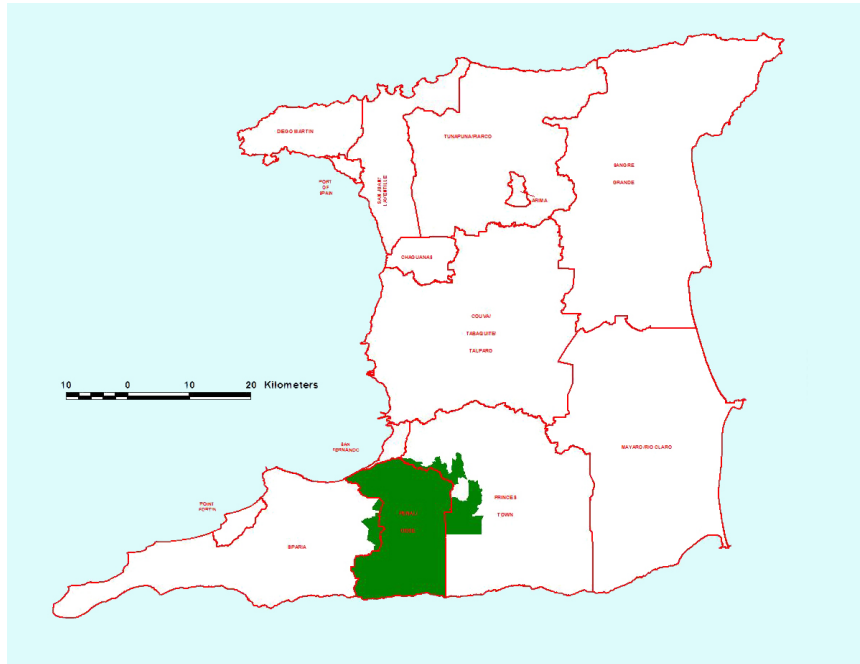


Figure 1.3: Map showing location of Regional Corporation of Penal/Debe in Trinidad. Copyright 2005, Ministry of Planning, Housing and Environment, Central Statistical Office, Geographical Information Section, Trinidad and Tobago.

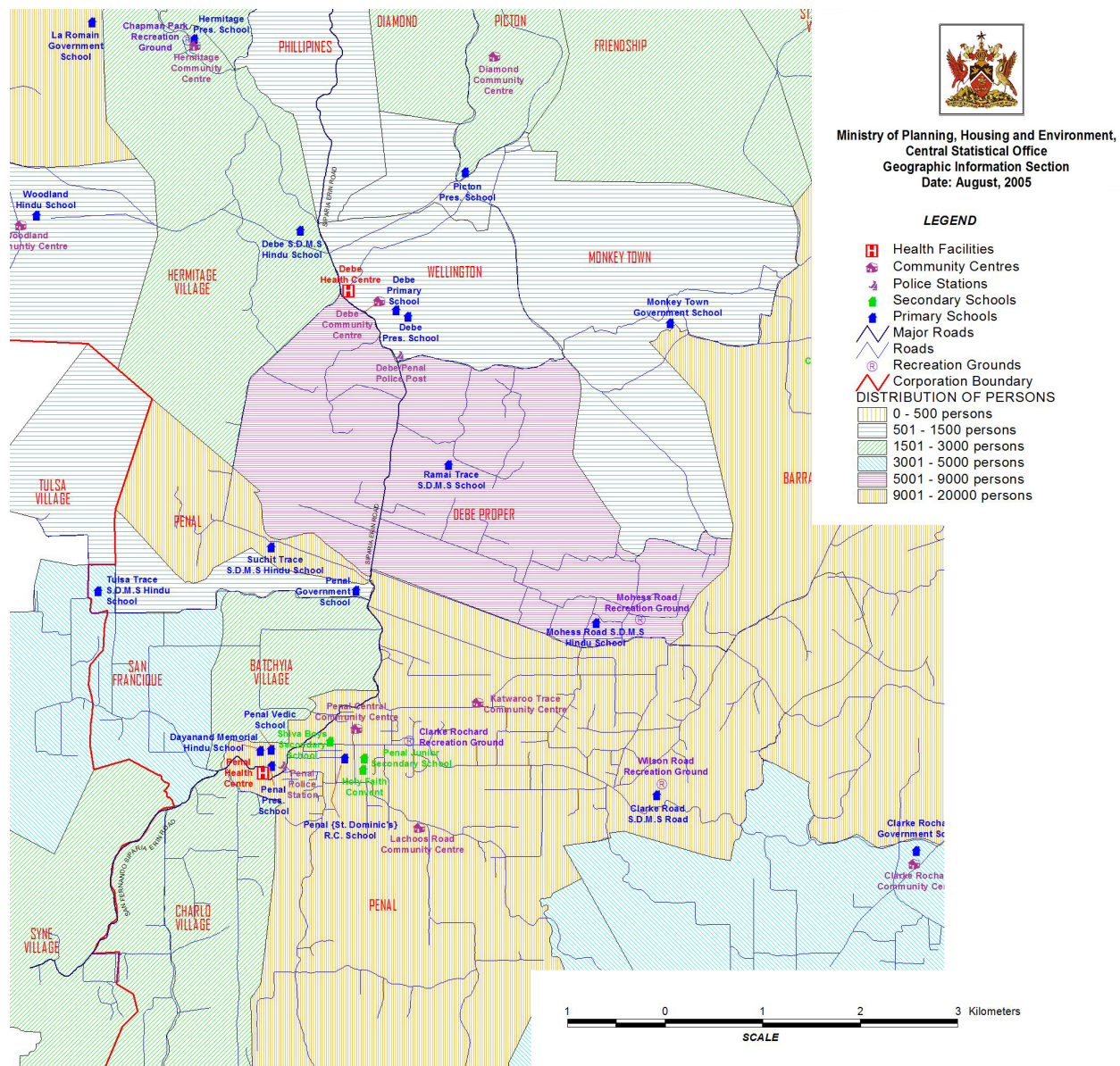


Figure 1.4: Population distribution of Debe Proper and adjacent communities for the Regional Corporation of Penal/Debe showing social infrastructure. Copyright 2005, Ministry of Planning, Housing and Environment, Central Statistical Office, Geographical Information Section, Trinidad and Tobago.

1.4 The field: Local geography, administration and health care provision in Debe

1.4.1 Local geography and administration

On political maps such as Figure 1.4, Debe “proper” is about 5.5 km at its largest diameter, and has a densely nucleated settlement pattern around the central hub formed by the Debe Junction, at the intersection of the San Fernando - Siparia (S. S.) Erin Road and Wellington Road. I refer to the S. S. Erin Road after this as it was called locally: the Debe Main Road, or the Main Road. My primary field site constituted a roughly four-kilometre length of the Debe Main Road extending between recreation grounds,¹¹ along with the minor roads (or traces), that branched off at irregular intervals. The primary settlement pattern in the area is linear, with both residences and businesses extending along the roads that radiate at right angles off the Main Road into the sparsely populated, formerly agricultural countryside.

A local government system once provided municipal services in Trinidad along colonial-era geographic demarcations, assisted by Caroni (1975) Ltd in the more rural agricultural areas. The municipal system was replaced in 1991 by a Regional Corporation System with different geographic boundaries, and with the closure of Caroni (1975) Ltd, people in Debe bemoaned the gradual deterioration of the rural roads, drains, and verges. The two major urban centres the region, Penal and Debe, were grouped under the administration of the Penal/Debe Regional Corporation, which manages an area of 246.91 km² with a population of 83,609 persons. The region’s population density of 340/km² makes it amongst the most sparsely populated in the

¹¹ A recreation ground is an area of public land designated for sports, usually large enough to allow football play, with a cricket pitch, a running track along its outside and spectator stands.

country, especially in comparison to the northern towns with a longer history of urbanisation (Central Statistical Office 2006).

A slow drive along the Debe Main Road revealed a wide variety of commercial services including hardwares; Chinese fast-food restaurants; auto parts and supplies shops; pharmacies; supermarkets; tire shops; roti-shops (Indian Trinidadian food shops); American fast food chains including KFC, Pizza Boys and Subway; gas stations; Indian delicacy fast-food stalls (Debe Doubles); groceries large and small; produce stands; restaurants; office buildings; a primary and secondary school; bars and rum shops; a casino; lawyers' offices; Indian Expo Trade Fair tents; and small shopping complexes with miscellaneous businesses. The Debe Main Road was also under continuous transformation over my time in the field, with two new Chinese restaurants being established, a new office building being constructed, and three residences undergoing renovations to make them commercial spaces.

The busiest businesses along the Main Road were inevitably those that sold food, especially the Debe Doubles¹² stands. This cluster of local Indian fast-food sheds located at the Debe Junction had started when Debe was far more rural, and by the 1950s had already established Debe's reputation as a centre for "authentic" Indian delicacies: ubiquitous doubles, sweets, snacks and meals cooked on the spot, the rurality of the location adding to perceptions of authenticity. Many people from Central and South Trinidad continued to stop in on a Sunday morning to get snacks, meals and sweets, causing an inevitable traffic-jam along the road.

¹² Doubles" is a fast food comprising curried channa (chickpeas) sandwiched between two deep-fried bara (dough patties), served to go with a profusion of sauces. Vendors set up mobile doubles stands in multiple locations across the country, though certain locations, like Debe in South Trinidad and Curepe in North Trinidad, have permanent roadside installations.

The Debe Junction was also where people went to catch taxis (privately owned, publicly-licensed car-shares with fixed fares along fixed routes) and maxi-taxis (privately owned, publicly-licensed small vans with fixed fares along fixed routes) to many destinations. Other major public services were also located along this stretch, including the post office, banks, the high school, gas station, and health centre.

1.4.2 Health care in Debe

Healthcare in Debe was provided through a combination of free public healthcare and private health care, as in the rest of Trinidad (healthcare in Trinidad is discussed in more depth in chapter three). Public health was provided for the entirety of the Debe/Penal Region by the South West Regional Health Authority (SWRHA). The SWRHA also administered the Debe Health Centre, one of fourteen health centres within that region, which was estimated to have one of the highest numbers of persons with diabetes registered to its Chronic Disease Clinic (CDC).¹³

Given Debe's development, the improvement in its road networks, and the spread of urbanisation along the roadways in the region, the distinctions between villages are eroding due to new commercial constructions and residential settlement. The catchment areas of the different health centres therefore often do not reflect the residence patterns of patients, who may be registered at one health centre while living closer to another. Most local health centres, including the Debe Health Centre, open for 8 hours – from 8 am to 4 pm – which is shorter than the usual working day for many people. The clinics additionally may run only for morning or afternoon sessions.

¹³ Personal conversation with public health administrator.

People with diabetes receiving on-going medical care within the public health sector primarily access the CDC at the Debe Health Centre, which was held all day on Thursdays, with a break for lunch. However, their phlebotomist was scheduled only in the morning, and the health centre pharmacy closed at 4 pm, so patients all tried to be seen earlier rather than later, to have all their investigations done and collect their medications on the same day. Like all CDCs in Trinidad, discussed later in this chapter, the Debe Health Centre was overburdened, with over a hundred patients having appointments to be seen on a single clinic day, with only a few doctors in attendance.

1.5 The field: As is the building plan, so is the cosmic plan¹⁴ - an ethnographic preamble to the village contexts of Debe

The political and administrative demarcations of the Penal/Debe region outlined above, or on maps of the area, are a different view of the field than that observed while traversing it as someone from Debe, or an ethnographer like myself. In this section, I locate the field ethnographically, as a context with overlapping and enmeshed networks of people and places, connected by history, kinship, religion, class, and custom. This section serves as a preamble to the upcoming ethnographic narratives, grounding them in the spatial and social relations I encountered while in the field.

In 2012, after phone calls, meetings, and conversations with people whom I knew second- and third-hand who had a “connection” in South Trinidad, I was able to rent a room in a

¹⁴ This quotation is extracted from the Sthapatyaveda Upanishad of the Vedic scriptures. It refers to the concept of the “macrocosm in the microcosm” in the relationship between the dweller, dwelling and cosmos.

house on Shambho Trace,¹⁵ a minor road not very far from a local health centre. This was in keeping with how things work in Trinidad, and in the Caribbean more generally, as Horst and Miller (2005) have discussed – it is often through “link-ups” (or “connections”) and “contacts” (people known in common) that personal networks are extended, favours claimed, and things made to happen. In my case, the link-up was to the household of a longstanding Debe family consisting of Tanty Indra Ramgoolam, a widow of 71, and her elder son and his wife, Arjun and Meena Ramgoolam respectively.¹⁶

Indian Trinidadian ethnicity, what it meant and how it was lived, arose early on in the field, as both a point of distinction and commonality: the commonplace, tacit, ground state of everyday life for most people in Debe. Tanty Indra, her family, and almost everyone I interacted with in Debe self-identified as variously “Indian”, “East Indian”, “Indian Trinidadian” or “Indo-Trinidadian.” The particular historical processes of Indian Trinidadian ethnic identity construction, grounded in larger discourses of othering and alterity in a colonial context, are discussed in the following section. In this section I instead describe markers of ethnicity as they arose in the everyday of fieldwork, drawing upon the constructivist approach embodied in Fredrik Barth’s (1969) classic *Ethnic Groups and Boundaries*. Barth’s framing suggests that the focus of ethnicity should be on identifying the boundaries by which the group defines non-self. As Barth states, ethnicity has “no simple one-to-one relationship between ethnic units”, with ethnic groups as the “categories of ascription and identification by the actors themselves” that are responsible for organising “interaction between people” (Barth 1969, 10).

¹⁵ The names of this and all other minor roads in this study have been changed to preserve anonymity.

¹⁶ Names, identifying characteristics, and details of this family have been changed to protect their privacy.

In this section I describe in broad outline three domains that people considered crucial to their ethnic identities, and how these manifest in their everyday lives, through an ethnographic focus on of Shambho Trace. These domains were also dimensions of their life-worlds which diabetes, associated illness, and its management disrupted and challenged, on which I focus more in ethnographic case studies of chapters four to eight. Shambho Trace, in its settlement, bonds of community, and everyday practices of food production and commensality, was very similar to the other villages strung together by the Debe Main Road to make Debe Proper. Through this ethnographic lens, the networks of relationships, social situations, and material conditions of everyday life in wider Debe were magnified.¹⁷

1.5.1 Kinship, family and community

In village Debe, kinship was described as foundation of the community. This was reflected in patterns of settlement within villages, such Shambho Trace, and in the ascription to neighbours of categories of kinship, whether consanguineal, affinal, or fictive.

For example, the house I lived in had been the familial home of Tanty Indra's husband, Balo Ramgoolam, which she had moved to after marrying at sixteen. Balo had died fifteen years before, leaving the property to Tanty Indra and his older son Arjun, and to their younger son, Naveen, a plot of land further along Shambho Trace from its junction with the Debe Main Road. Naveen, his wife and their two children now lived in walking distance to his parental home, and there was regular, almost daily back-and-forth, between the two households.

¹⁷ The names of these roads have been changed to preserve anonymity.

Kinship has consistently been considered a crucial institution that distinguished and defined Indian communities in Trinidad in the academic literature. Indentured Indians came to Trinidad not as families but as individuals, from different geographic locations in India. They left behind established and highly variable Indian kinship structures and patterns, dependent upon geography, wealth, caste, occupation, and time (Mandelbaum 1970, 45). Given their diverse geographic, caste and social origins, lineage took generations to reconstruct in Trinidad since the genealogical criteria for social clusters were difficult to identify (Kuper 1960, 32 quoted in Vertovec 1992). Early social science research in Trinidad emphasised the kin-focal nature of Indian cultural expressions in Trinidad, initially focusing on identifying kinship forms as cultural “retentions” and later, on a more general “reconstitution” of kinship within this community.¹⁸

More recently, Aisha Khan (2004) has described Indian culture in Trinidad as characteristically kin-focal. Historically, the extended Indian familial form was widely mobilised post-indenture to decrease Indians’ social and economic marginalisation in Trinidad, through the creation of tight-knit and enmeshed families, fostered by a corporate attitude towards familial resources. The pooling of economic and symbolic capital resulted in the entire family “rising” in socioeconomic status together: families could own larger properties by pooling their resources; could claim higher caste status (“up-casting”) as their economic class status rose; could gain prestige through larger houses, bigger weddings and social events, or en masse through the

¹⁸ Classic works by Morton Klass (1961), the Niehoffs (1960), and Morris Frielich (1960) emphasized “retention” in kinship units to be corporate, with permanent affinal ties by marriage, and Indian families being a distinct type compared to other ethnic groups. Barton Schwartz (1965, 1967) and later, Joseph Nevadomsky (1980, 1982, 1983) found that while there was a kin-focal quality to Indian culture and the traditional joint-family type of India constituted the “general cultural model”, the nuclear family household was overwhelmingly frequent in comparison to the joint or extended family household.

educational attainments of but one of their members (Khan 2004).¹⁹ This was what Balo Ramgoolam's grandfather Munnu and had done, pooling money with siblings and cousins for a 15-acre purchase to become cane farmers. Balo had inherited much of his father's lands, as had a few of his cousins, who also built houses along Shambho Trace and raised their families there. Arjun and Naveen had therefore grown up with cousins as neighbours, playmates, and friends, their parents residing along Shambho Trace in proximity to the Debe Main Road roughly according to birth order. Some family members had since moved out of the village, and the closeness of some relationships had decreased in adulthood, however awareness of the family persisted: these were the houses to which I was first introduced when I moved to Debe, they occasionally dropped excess seasonal fruit off at each others' houses, there were family get-togethers for Diwali and Christmas, and everyone "helped out" each other when needed.

Tanty Indra also highlighted two households along Shambho Trace as being "jahajhi bhais" of Munnu's. The term "jahajhi bhai" refers to the "brotherhood of the boat" that formed between unrelated individuals on the harrowing three-month journey from India to Trinidad, before the start of indentureship (Brereton 1985; Reddock 2010). For some people, like Munnu's jahajhi bhai neighbours, this bond had outlasted indentureship, and continued into succeeding generations as well. They had settled near to each other on the basis of this bond, and this connection of fictive kinship was still invoked by Tanty Indra.

¹⁹ Caste has ceased to be a significant determinant of new marital linkages except amongst those who claim Brahmin (priestly) antecedents. See Khan (2004), Munasinghe (2000), Vertovec (1992) for further discussion of the loss of caste as a significant domain of social identification amongst Indians in Trinidad, and the equivalence often drawn in Trinidad between "higher" caste and "higher" socioeconomic class.

Similarly, Tanty Indra sometimes identified other neighbours as “pumpkin vine,”²⁰ tracing tortuous linkages through questionable affinal bonds sometimes four generations distant. Whether related by “blood,” by complex affinal ties, by “pumpkin vine”, “jahajhi bhais”, or simply because of co-residence, it was understood that most villagers strove to “live good” with each other, consistent with what Khan (2004) has described. Part of living good with each other was not making too much of a nuisance of oneself by imposing on one’s neighbours. Part of living good was also cooperating to pull off communal celebrations, particularly religious prayers that were performed at home or in a temple, to which other family members in the community were invited (described more in chapter 4).

Janet Carsten (1995, 1997) has explored how Malays constructed their relatedness in reference to their native categories of the sharing of blood (i.e. through direct descent) or through the eating of food or milk (breastfeeding), which were understood to eventually result in the production of blood. Birth was simply the beginning of the process of becoming a person, and the acts of living and consuming together (sharing a hearth) enabled people to become both complete persons and kin: the shared substance and emotive connection of the house produced personhood, feeling and kinship. The bodily substance forming the grounds for relatedness was therefore not only “biogenetic” and limited to birth, but also shared food. In her later work *Substance and relationality*, Carsten (2011) later identified multiple ethnographic contexts in which shared bodily substance that flowed between peoples constituted the ground state for relatedness, including from research in India, which tied the unity of bodily substance with codes of conduct. Carsten (2011) highlighted that relationality is understood to derive from flows of

²⁰ This is a Trinidadian colloquialism that refers to extended kin.

substance are heightened by the polyvalent properties of bodily substance in particular, which allows greater emotional resonance through its investment with ideas about relatedness.

Carsten's social constructivist approach to kinship is useful in Debe in relation to the role of food in establishing and maintaining communal bonds, not only through commensality, but through the necessarily cooperative tasks of preparing the large meals required to feed the community or large number of guests invited for a particular events. While these were primarily Hindu religious prayers in Debe, weddings, Muslim prayers and parties were also sites in which communal food preparation was performed, in accordance with the normative injunction of "living good together" that Tanty Indra and others in the community expressed. This produced within the villages of Shambho Trace and adjacent traces a strengthening of community ties, especially amongst the older generations, who once shared more coordinated leisure times along with agricultural rhythms than the younger generations currently do.

In contrast to Carsten's more broadly constructivist approach, Schweitzer (2000, 16) argued in the *Dividends of Kinship* that "while it has become evident that biology alone is insufficient for a comprehensive understanding of what kinship *is* and *does*, it is equally hard to maintain that kinship has nothing to do with biology and procreation." Schweitzer advocates what he calls an "instrumentalist" approach to kinship, arguing that people instrumentally claim kinship in the effort to reap particular dividends, but that the dividends reaped go beyond economic interests and the assumptions of "rational choice" theory. Rather, people claim more or less kin in relation to complex notions of relatedness that also draw upon the resources available to them. He identifies situations of economic and political scarcity and abundance as being particularly crucial: when abundant, people collect kin, when scarce, people limit their families.

Living on Shambho Trace therefore suggested that the community was underlain by bonds of kinship that were both based on biogenetic kinship, and socially constructed kinship, that was instrumentally invoked in accordance with the needs of the moment. The ground state for settlement, community formation, and a characteristic in which people believed, however, was that they shared a belief in and perpetuation of family bonds that was uniquely Indian Trinidadian.

“Indians have strong family values” and “Indian people does take care of they family” and “blood come first” were common sentiments, that these patterns of settlement, ascriptions of kinship, and regular everyday interactions in Shambho Trace supported. It is useful to consider, however, that these statements might also constitute iterations of the condition of alterity underlying ethnic identity in Trinidad; they are perpetuations of colonial-era discourses contrasted (and arguably constructed) ethnic stereotypes of a single parent African nuclear family and the two-parent Indian nuclear family against each other. This is discussed briefly in the upcoming section of this chapter on ethnic identity formation in Trinidad.

1.5.2 Hinduism and Indian Trinidadian ethnic identity in Debe

Debe was mainly settled and populated by Indian Trinidadians, and was also the only administrative district in Trinidad and Tobago in which Hindus were a clear majority.²¹ Tanty Indra and her children were all Hindu, as were all the other residents of Shambho Trace.

Participation in Hindu religious activities, communally or in the privacy of one’s home,

²¹ Christian denominations comprise the majority group in most administrative districts. Hindus in Debe comprise 50.5% of the population while the other major religions represented in Debe include Roman Catholics (9.5%), Muslims (7.5%), Pentecostals (6.9), Presbyterians (6.7%), Baptists (3.2%), Anglicans (2.9%), and Jehovah’s Witnesses (0.9%) (Central Statistical Office 2006).

constituted a marker of Hindu piety that for many people in Debe formed a backdrop to their notions of ethnic identity (Vertovec 1992). Similar to the national prevalences of these different Hindu sects, people most commonly described themselves as Sanatan Dharma (or Sanatanists), followed by affiliation with Arya Pratinidhi Sabha, and Kabirth Panth, though none of the participants identified themselves as Shivanarinepanths.

Moving through Shambho Trace and Debe on the whole was an experience of immersion in an Indian Trinidadian, Hindu spatial vernacular. Hinduism marked the space through material culture physical signifiers, like the colourful jhandis (triangular prayer flags atop bamboo poles) fluttering alongside people's houses; Shiva lingams (icon of the god Shiva) in the front or back yards; or the square-domed, private mandirs (temples) sitting on the Eastern edges of people's properties, decorated with Om (symbol of Hinduism) signs.²² More subtle markers were the patches of tulsi (holy basil) found in most people's gardens, along alongside mango trees and perpetually flowering plants (all of which were needed for Hindu ritual worship); murtis of Sri Hanuman, Rama and Sita, Krishna or Ganesha hung above front doorways; and the Om symbol on cars or businesses in the area. Gaudily decorated doorways along the Debe Main Road welcomed shoppers into the many stores selling murtis and puja materials, along with shalwars, gararas and saris (Indian clothes). Local advertisements above businesses in the area sometimes included the image of a Hindu god, such the trucking company that had a picture of Hanuman above the logo "Moonan Moves Mountains."

²² While some of these mandirs were separate structures in the yard, other Hindu homes incorporated a prayer space into the houses themselves, as dedicated room, a wall, or the corner of a room. Private shrines held murtis (pictorial and statue icons of the gods), sacred texts, and the ritual apparatus of worship such as deyas (oil lamps), lotas (brass vases) and tarias (brass trays). The form and expressions manifest in these "home temple" is explored in more depth by Carolyn Prorock (2015).

Along almost every minor road in Debe, additionally, mandirs (temples) were found, their white or coloured ball-domes intermittently dotting the landscape.²³ Hindus from a single village were likely to attend the nearest temple, located along their minor road, though people would also attend events at larger temples and ashrams beyond their immediate environs, such as the well-known celebrations of Hanuman Jayanti (birth of Hanuman) at an ashram in Penal, the once-yearly Diwali Nagar held in Chaguanas, or learned discourses from visiting Indian Swamis at other temples across the country. Village mandir congregations tended to be mainly female, with more people being over the age of fifty, and men attending most frequently with their families. People gathered for communal celebrations within the mandir's shared congregational spaces, facing an altar upon which were installed constellations of the Hindu gods and goddesses in statue and iconographic pictorial form. As part of her longstanding research into Hindu and ethnic identity in Trinidad, Carolyn Prorok describes the materiality of temples in Trinidad as "expressions of religiosity in the landscape, imbued with issues of collective intention regarding identity and community cohesion" (Prorok 2015, 252). The temples in Debe that I attended as a part of this fieldwork differed structurally and functionally from temples in India, in having a congregational space facing a single altar, in contrast to temples in India that are intended more for individual worship and perambulation (Prorok 1991). This, along with a series of other transformations, Prorok (1987) seminally identified as part of the evolution of the Trinidadian form of the mandir that was reflective of the Indian Trinidadian history of migration to Trinidad, the development of communal cohesion, changes in economic status, and its transformation as a

²³ Specific and identifying details of the temples attended in the area have been withheld to preserve anonymity of the research participants.

minority, Oriental, religious group in the space of a dominant, Western Christian, plural society.²⁴

While all these signs, signifiers, and symbols could be found throughout other parts of Trinidad, their concentration in the region indicated the saturation of the space with a Trinidadian Hindu presence. Yet everyone in Debe, Hindu and Christian alike, celebrated Christmas as one of the biggest festivals of the year, in close competition with Diwali, the Hindu festival of lights. The local bakery near to Shambho Trace on the Main Road sold hot-cross buns for Easter (the resurrection of Christ). Temples in the region often had pictures of Jesus on their altars, alongside the iconography of Hindu gods and goddesses.

Part of the background hum of Hinduism was the tacit expectation that everyone in a village would participate in or attend the communal religious observances and ceremonies held at village temples that occupied many successive nights, multiple times a year. While private homes had pujas and prayers in accordance with what they could afford, and therefore might have more limited guest lists, temple events were open to the entire village, and all who were willing to attend. Walking down the road every night to the temple, or to a neighbour's house for satsangh, sitting, listening, singing, and eating, constituted a major form of everyday sociality at the most active and auspicious periods of the Hindu calendrical year, for example, Navratri and Makr Sankranti. For most festival celebrations, the entire village would be invited, and a

²⁴ Prorok (1991, 77) categorizes temples built in Trinidad from the 1820s to the end of indentureship into as "traditional," and reflective of the form and structure of temples in India at the time, having a central altar with iconographic images and statues of the gods that could be perambulated. The second form of temples built from 1921 to 1944 she termed "the Koutia" (Prorok 1991, 80), in which an addition was added to the traditional temples that took on the function of an assembly hall where meetings were not only social but political. The final form and most popular resulting form Prorok terms the "Trinidadian temple" (Prorok 1991, 83) in which domes and religiously adorned facades overlie a koutia, in which there is both an altar area and the housing of all deities under one dome, space for perambulation as a part of religious rituals, and an adjoining congregational or assemblage space.

communal meal was also shared. Some temples would stagger their celebrations so that people could attend as many as possible, though the simple village temples in the area mainly catered to the immediate populations of the Traces they were found on.

Temples in the area had formal or informal Mandir or Temple Groups that were responsible for their maintenance, provisioning, and for supporting the pundits in their activities. My introduction to the community was largely through three of these groups. I helped with their common tasks of preparing and cooking communal meals, readying spaces for pujas (ritual prayers), grocery-shopping, transportation, and cleaning up after community events. Temple Groups were mainly comprised of women from the community, many of whom were older and no longer worked outside of the home, or women who worked jobs that allowed them to devote a lot of time to the temple. The women of the Temple Group were also regularly asked by families in the wider community to assist with Hindu religious rituals held at home, such as pujas, weddings, birth rituals, prayers for the deceased and so forth, to which I was also invited.

The pundits in the area were exclusively male. Pundits were affiliated with the largest and oldest Hindu organisation in the country, the Sanatan Dharma Maha Sabha (SDMS), which had also built the Hindu denominational Parvati Girls' secondary school near the Debe Junction, the only secondary school located in Debe. While residents in Debe tended to patronise their nearest village Temple, they often attended events at other Temples both within Debe and outside, and some pundits were more popular than others.

Perhaps the most significant and continuing boundary between Hindus and non-Hindus, however, are religious proscriptions around food practices. Indeed, no matter how unobservant

they were in other ways, most Hindus in Trinidad continue to follow the proscription against the eating of beef, or foods containing beef or beef extracts (Debysingh 1986).²⁵ This proscription results from both a Hindu tenet of non-violence or compassion to all things, and from the concept of pollution, famously explored by Harris (Harris 1966; Pal 1996). Some Hindus were entirely vegetarian, while others fasted from all meats (including eggs, egg products and fish) on certain days of the week, or for periods ranging from a few days to a month prior to performing ritual prayers. Purifying periodic fasting also included the avoidance of specific foods such as onions, garlic and salt, prior to the performance of ritual prayers.

Caste-based rules about who could cook for whom, and who could eat from whom without pollution were eroded as the instability of caste categories based on geographic and genealogical specificities in India proved difficult to translate in the transition to Trinidad, and the caste system itself largely eroded through the forced residential proximity of the ship voyage, estate life and shared conditions of labour (Khan 1994; Jayaram 2006; Munasinghe 2001). Indeed, it was only the neighbours on Shambho Trace who claimed priestly Brahmin ancestry who continued to observe loosely caste-affiliated dietary practices, such as complete vegetarianism, however they were vastly outnumbered in the village. That these dietary proscriptions have changed over time is evident in the presence of godnas (tattoos) depicting religious motifs inscribed on elderly Hindu women in Debe, all above the age of seventy. Without these markers of purity, they explained, “Your father-in-law, pundits, and India people [ex-indentureds from India] wouldn’t even *take water* from your hand.”

²⁵ The number of Hindus in Trinidad and their consumer power has been suggested as one reason that the American fast food chain McDonalds experienced such low sales after it opened in 1997 that it was forced to withdraw from Trinidad in 2003, after six failing years, before reopening in 2011 with a uniquely chicken-centric menu and far fewer beef products.

The preparation of foods for religious Hindu religious food habits unite those Hindus who adhere to them into a single “moral community”, in which the sacred and profane constitute a system of classification (Douglas 1966). Drawing upon Mary Douglas’ classic constructivist and symbolic lens, Hindu food taboos in Debe categorised the natural world into the pure and the impure, a classificatory drive toward order “like the signs which at every turn inspired meditation on the oneness, purity, and completeness of God” (Douglas 1966, 57). Hindu religious proscriptions around food can therefore also be understood as boundary-making categories through which people in Debe and Trinidad on the whole consolidated group identity.

1.5.3 Food, tradition, and Indian Trinidadian ethnic identity

As was previously noted, Indians who came to Trinidad were in the majority from a wide region across Northern India with many local variations in food practices. In Trinidad today, however, there are homogenised expectations within the community of what constitutes Indian Trinidadian food.²⁶ These descriptions are also intended as background for later chapters in which foods and food practices are referred to.²⁷

The link between ethnic identity and food is also entangled with notions of memory, nostalgia, diaspora, love, embodiment, and temporality, as numerous anthropologists have described before. In this research, I draw particularly on Carole Counihan’s (1988, 2013) work in considering how people in Debe spoke through food and how that changed (or did not change)

²⁶ It must be noted that these recipes and foods are themselves the historical and social products of diverse dietary practices Indians brought to Trinidad in the 1800s, the effects on these diets of food availability to indentured labourers in depots in India, on the ships to Trinidad, from the commissaries of plantations, and in villages in Trinidad subsequently (Perry 1969, Bissessarsingh 2012).

²⁷ The historical and social processes through which community and ethnic identity consolidation have taken place are elaborated on in the next section of this chapter.

with diabetes. That is, how their engagement with dietary practices, foodways, and notions of meals in their everyday lives were affected by the dietary recommendations or demands of diabetes, especially in relation to its gendered domain (Counihan and Kaplan 2005). David Sutton's (2001) approach in *Remembrance of Repasts* was also useful in framing people's memories and experiences of dietary behaviours as both a gustatory embodiment of identity and identity through which construction social relations were constructed.

Within the Debe community, the terms "traditional Indian food" and "East Indian food" were used interchangeably, as fixed categories with shared understandings about their typical methods of preparation, and established expectations as to their composition and taste. "Indian Trinidadian food" included many different dishes, which I group into meals, snacks, sweets, and condiments, à la Mary Douglas (1972). A meal generally comprised a main carbohydrate that was eaten with one or more side-dishes. The carbohydrate component was usually white rice or white wheat flour rotis (grilled stove-top flatbreads) of different kinds, while the range of potential side-dishes included talkaris or chokhas (vegetable side dishes), dals (legume-based soups), or curried meats. The most common roti in everyday contexts was the sada (plain) roti, made by rolling white-flour and water dough into a circle and baking it stove-top on a tawa (flat round griddle) until it swelled. The most common festive rotis, meanwhile, were paratha (or "buss up shut") and dalpuri (flatbread stuffed with ground lentils).

Talkaris were made by frying or currying chopped vegetables with various spices and seasonings, while chokhas were made by roasting whole vegetables, mashing them with diced onions, then seasoning them with garlic- and spice-infused hot oil. Curried meats were also an extremely common side-dish, to be eaten with roti or rice. Chicken and fish were the most common, everyday meats, with duck, goat, and lamb more expensive and festive. In Debe,

especially amongst men, the truly prized meat was wild meat (game), indigenous and unique Trinidadian fauna.²⁸

Snacks, meanwhile, were mostly made of seasoned dough or batters (of either white flour, chick-pea flour, or lentil flour) which were deep-fried with various vegetables, to be eaten with a wide variety of condiment-sauces. The most popular snacks consisted of a crisp crust of golden-brown batter in which a vegetable had been deep-fried, and included baigane (battered eggplant), saheena (battered spinach rolls), kachourie (seasoned ground lentil balls), aloo pies (white-flour casings stuffed with spicy mashed potatoes) and phulourie (lentil dough balls). Condiments were either basted inside the cooked snacks, or accompanied them in little plastic bags for dipping. Sauces were crucial to the tastiness of the snacks, as is attested to by the title and chorus of the classic Indian Trinidadian song by the early chutney artist, Sundar Popo: *Phulourie bina chutney kaise bane*²⁹ (Ramnarine 1996). Some sauces were freshly made every day, including tambran (tamarind) chutney, or the cucumber-and-bandhania (wild coriander) sauce. Other sauces were made from preserved elements, such as the ubiquitous “pepper sauce”, made of chopped scotch-bonnet peppers and other spices, cured in salt and vinegar in the sun. Sour, sweet and hot were the predominant flavours, and most people would select more than one sauce as an accompaniment to their snack or their meal.

The last category of foods, the sweets, were various combinations of wheat flour, rice flour, ground lentils, milk, sugar, and aromatic spices like cardamom, clove, and cinnamon.

²⁸ These included tattoo (armadillo), lappe (lowland paca), iguana, agouti (large guinea-pig like rodent), manico (black-eared opossum), deer, and wild hogs. Skill was needed to clean these meats to decrease their gamy scents, and they had to be cooked for long times to make the meat tender.

²⁹ Loosely translated, this phrase means: “How can you make phulourie without chutney?” It refers to the necessity of flavour in life.

Popular Indian sweets included kurma (deep-fried milk-dough sticks in a sugar glaze), gulab jamoon (deep fried condensed-milk-based dough in a sugar glaze), barfi (milk and sugar based wafers), pera (rice flour and sugar wafers), jalebi (sweet fried sugar syrup) and more. If wheat flour was used, in the typical iterations of these foods it was most highly refined white flour available, which was usually the cheapest as well.

The major component of most meals for people in Debe was the carbohydrate component, which was often refined (for e.g. white roti or white rice). Indian Trinidadian foods are also popularly considered to be “greasy”, “oily”, “spicy”, “heavy”, and fattening, as numerous references in popular culture attest. For example, a chutney song by the name, “Dal Belly Indian”, specifically links a protruding gut with abdominal fat to the Indian Trinidadian food, dal, making an identity claim for both. There is also a complex relationship in the discourse around doubles, the pre-eminently popular combination of fast food and snack, praises of which are often closely followed by concerns about its caloric content.³⁰ The associations of unhealthiness with Indian food hold despite the wide range of preparation styles described above, and the many possibilities for substitution.

It is important to note that many of these foods are part of a national lexicon of Trinidadian food, and are made and eaten by Trinidadians of all ethnicities.³¹ There is also a popular discourse in wider Trinidad around these foods as “creolized”³² and “uniquely Trinidadian” syncretic products, rather than being of “purely” Indian origin. In depth exploration

³⁰ For example, journalist Debbie Jacob comes down on the side of doubles in comparing local fast-food breakfasts (Jacob 2011).

³¹ It is, however, considered verboten for Indian Trinidadians to *purchase* these foods from non-Indian Trinidadians.

³² See following section on ethnic identity formation for an outline of creolization.

of the critique of purity and authenticity in Trinidad is outside of scope of this dissertation. I present the terms as people in Debe used them.

1.6 Ethnic identity formation and maintenance

As feminist scholar Rhoda Reddock writes, “A discourse of race, ethnicity, and color has been central to all conceptualizations of the Caribbean...This discourse on and the reality of race of contributed to great social and economic disparity within societies as well as to the cultural creativity that is so evident within this complex and diverse region” (Reddock 2010, 571). This perspective outlines my approach to ethnicity as it was articulated within Debe in the larger discourses of identity in Trinidad, and as constituted by and constitutive of the domains I have previously discussed: the domains of kinship, religion, and food.

While anthropological scholars have highlighted the analytic limitations of concepts like “ethnic groups,” that divide the world into autonomous, culturally distinct units, with group-specific properties (Basch, Schiller and Blanc 1994), these continue to be categories with which people in Trinidad identify and construct the world around them (Brereton 2007; Reddock 2010). This is especially so since Trinidad’s history of colonisation and both forced and unforced migratory settlement has resulted in its habitation by different ethnic groups, with the legacy of a racially-defined colonial experience. Negotiating this diversity as a nation, as in many other postcolonial contexts, has produced longstanding attempts to resolve competing discourses and narratives about race and ethnicity within the hegemonic medium established by the colonial powers (Braithwaite 1953; Brereton 2007; Avtar 1996; Bhabha 1994).

One popular national narrative is encapsulated in the tourism rhetoric, which proclaims Trinidad a multi-racial and multi-ethnic “rainbow nation,” often referencing a line from the national anthem to validate the claim of harmonious diversity: “Here every creed and race finds an equal place.” Another competing narrative, lingering in the discourse since attaining independence, presents Trinidad as a space of universal hybridity or “creolisation,”³³ wherein identification with ancestral origins can be no more than a pretension, if not actively anti-nationalist.³⁴

Claims to ethnic identity within the Indian Trinidadian community have historically been perceived as primordialist sentiments that emphasise linkages to Indian ancestral origin and reject national identification (Lewis 2004). As Bhabha (1994, 90) notes, the hybrid identities of postcolonies embody the tensions of the colonial encounter between modern, rational modes of subjectivity and selves, and “traditional” modes, this duality closely entwined with colonial memories of power and humiliation. Bhabha also states, “The objective of colonial discourse is to construe the colonised as a population of degenerate types on the basis of racial origin, in order to justify conquest and to establish systems of administration and instruction” (1990, 75).

³³ Creolization refers to a process of reciprocal acculturation and admixture that occurred amongst the phenotypically, religiously and culturally heterogeneous people juxtaposed in the New World by colonial expansion, inflected by the power relations within these young societies. Creolization was described, embraced and valorised by the nationalist movement of pre-Independence in Trinidad and Tobago as producing homogeneity from diversity, considered crucial to the incipient formation of the new nation. It was simultaneously considered the antithesis of colonial efforts at harkening back to an authenticity enshrined in the “Motherland”. Further discussions of this concept are beyond the scope of this dissertation, though the following works provide a useful introduction: Palmié 2006; Trouillot 1998; Mintz 1996; Price 2001; Khan 2001; Stewart 2007; Hannerz 1996; and Hintzen 1997.

³⁴ See statements such as “Trinidad East Indians who believe that their total culture is distinct from that of other West Indians are espousing a myth best dispelled by visiting India” and further that “...their racial nationalism is a part of the death throes of the attenuated culture brought by the indentureds” (Crowley and Crowley 1963, 158; Crowley 1957). Similarly, Smith (1996, 21) argued that any original culture being retained in such a diverse context promoted an “incoherence of the national and societal image.”

The focus on ethnicity in post-colonial Trinidad that lingers to the present may originate in colonial preoccupations.

From a Barthian perspective, the underlying ideology to the everyday discourse on racial and ethnic identity in Trinidad is the attempt to categorise similarities and differences in a heterogeneous context (Munasinghe 2001; Khan 2004; Birth 1997). For example, the population demographics census form of the Central Statistical Office of Trinidad and Tobago lists the following choices, which it categorises as “ethnic groups”: “African/Black”, “Indian”, “Chinese”, “Syrian/Lebanese”, “Caucasian”, “Portuguese”, “Mixed – African and East Indian” and “Mixed – Other” (Central Statistical Office 2012). The Central Statistical Office’s categorisation of “ethnicity” presents race as a biological entity, and conflates ethnicity and culture with ancestral origin, flattening into a single category racial, ethnic and ancestral ascriptions. Yet the Census form is accurate, in so far as the terms and implications of race and ethnicity are used interchangeably in Trinidad in both popular and academic discourse. These categories are used interchangeably by individuals as self-ascriptions as well. Not listed on the census form are additional categories that people use to describe themselves: “Dougla”, for people of mixed African and East Indian ancestry; “Brown”, to describe people of mixed African, European and other ancestry who appear physically closer to their African heritage; “Red” to refer to people of mixed African, European and other ancestry who appear physically closer to their European heritage, and “Spanish”, to refer to people who are and/or who physically appear to be from Latin and South America.

In everyday life in Trinidad, there is the naturalising of race as a biologically self-evident category that produces seemingly common-sense groupings of difference and similarity through which people categorise and understand the wider society, which result as well in generalisations

about shared ethnic commonalities. As Kevin Birth (1997, 586) points out, racial categories in Trinidad have “assumed the authority of biologically grounded facts.” The pervasive discourse on ethnicity in Trinidad is both a reflection of the heterogeneity of the society (Munasinghe 2001), and perpetuated by groups in an effort to conserve “boundaries and essences” (Khan 2004, 12). It is also rooted in Trinidad’s colonial past, and colonial preoccupations with the hierarchy of races that justified the violence of the system in the name of capital (Dirks 2004). This is particularly significant in the context of diabetes in Trinidad, where family histories of diabetes amongst Indian Trinidadians have lead some people to ascribe a degree of genetic determinism to the inevitability of their eventually contracting the disease. It is also important in a consideration of the validity of epidemiological research in Trinidad that qualifies Indian Trinidadians as having higher rates of Type 2 diabetes: is potential “ethnic” admixture factored in to probabilistic calculations or risk, and if not, should it be?

The literature describes two main dialectically related pressures acting upon identity formation was, which I will briefly explicate. These include conditions of alterity under which Indians were first received in Trinidad, and the process of diasporic re-articulation.

Indian indentured labourers brought to Trinidad were in the majority from a Bhojpuri-speaking swath across Northern India, but came as unrelated individuals from different specific regions, castes, sub-castes, and religious streams within India (Dabydeen and Samaroo 1996). Arriving to Trinidad, they were placed into a British colonial, multi-racial context in which power, prestige and wealth were distributed along a Eurocentric white-to-black racial continuum, within a ground state of a shared, dominant Christianity (Khan 2004; Brereton 1979, 1981, 1985). The other groups in Trinidad at the time included greatly reduced numbers of indigenous peoples, African-descent ex-slaves, small numbers of Spanish settlers, immigrants from

Venezuela and South America, Chinese immigrants, Francophone planters,³⁵ and British planters and colonials. Entering the spaces the ex-slaves had vacated, Indians occupied the lowest social tier in Trinidad, and became one of the most oppressed groups under colonial authority (Brereton 1979; Mahase 2008).

Indians were differentiated from the already existing population in Trinidad by virtue of their non-Christian (Hindu and Muslim) religious and cultural practices, unfamiliarity with the dominant European languages spoken on the island (English and French), and the restrictive conditions of indenture that localised them to rural and isolated parts of the country (Brereton 1981, 2002). Discrimination resulted as well from the power relations that marked Indians as different, as “other”. This discrimination was institutionalised to persist until well into the 20th century through such practices as the denial of access to formal education;³⁶ the denial of the legality of marriages performed by non-Christian religious rites;³⁷ the refusal to expand state support for religious denominational schools to non-Christian schools; and the suppression and denial of cultural and religious freedoms.³⁸

Othering, discrimination, oppression, and exclusion were negative pressures exerted from the *outside* that fostered the formation of communal bonds amongst the disparate and unrelated indentured immigrants, and prompted their mobilisation into networks of exchange and

³⁵ Trinidad’s racial diversity was unusual since French planters in Trinidad were “both white and coloured”, and Trinidad possessed an “unusually large free coloured class, considerably outnumbering the whites” (Brereton 2002, 8).

³⁶ Presbyterian schools for the children of Indian indentured immigrants were only established in 1868 as a part of the proselytizing efforts of the Canadian Presbyterian Mission to “save” the Indians through conversion, however the numbers of functional schools and school attendance only rose after the 1920s.

³⁷ Muslim marriages were not deemed legal until 1936 and Hindu marriages until 1945.

³⁸ In 1884, Indians protested the colonial authorities banning of the public celebrations of Hosay (Muharrum), an annual commemoration of the martyrdom of the grandsons of the Prophet Mohammed. Twenty-one “rioters” (as protestors were called by the colonials), in the majority Hindu, were shot and killed (Parmasad 1980).

communication that created new Indian Trinidadian communal organisations (Vertovec 1997). A proletarian culture also developed under these conditions of marginalisation and oppression, through the collective labour struggles of Indians working in sugar for better living conditions, more pay, and more freedom to practice their religions from the 1860s until the 1990s (for more discussion see Campbell 2014; Haraksingh 1988). The claiming of religious identity also contributed to the burgeoning ethnic identity formation, as Hindu and Muslim religious bodies formed, including the Sanatan Dharma Maha Sabha (founded in 1932) and the Trinidad Muslim League (founded in 1947).

A related process of Indian Trinidadian ethnic identity formation, from the *inside*, was a collective attempt to iteratively constitute an “authentic” identity after the rupture of transplantation to Trinidad. The construction of this collective identity was consistent with the efforts of many diasporic communities in the modern era, from the perspectives of diaspora as a “social form” (Vertovec 1997), a type of “consciousness” (Clifford 1994), and an “ethnoscape” (Appadurai 1996, 48-65). Vertovec (1997, 278-279) identifies characteristics of diasporas that render them “social forms” including: maintenance of group social relationships-despite-dispersal cemented by common ties to history and geography; the conscious maintenance of a collective identity by sustenance of an “ethnic myth” of common origin, common historical experience and ties to a geographic place; and the creation in the new lands of communal organisations and networks of exchange and communication. Each of these characteristics is applicable to the Indian Trinidadian experience of identity formation.

James Clifford (1994), meanwhile, provides a more nuanced approach to diasporas as a form of “consciousness” which through decentred attachment “lives loss and hope as a defining tension” (312), an “empowering paradox ...that dwelling here assumes a solidarity and

connection there” (322). In Trinidad, this was manifest through the multi-vocal discourse expressions that reference both India and Trinidad as “mother-land”: articles and opinion pieces both in the popular press and community-specific publications, in popular cultural forms (e.g., Sundar Popo’s Indian folk songs, chutney folk songs, calypsoes such as Brother Marvin’s *The Ganges and the Nile*), in media advertisements, everyday conversations, and in religious discourse. Khan (2004) has also suggested that references to India and the striving for authenticity within the Indian community was born out of a desire to identify with a “pure” original culture, to erase the debasing and oppressive conditions of their indentured servitude. This striving for “purity” was manifest in the field as repeated efforts at doing things the “right” way, such as eating “traditional Indian food”, or living a particular notion of “the good life”.

Indian Trinidadian ethnic identity formation can therefore be framed as the result of protracted processes of group consolidation, both negative and external (such as experiences of oppression and exclusion) and positive, and internal (such as identification with an honoured heritage). These processes also occurred in a broader context of a nation formed by a colonial state, in which the specific apparatus of everyday life was structured by and reproduced the colonial condition. Three domains in which the boundaries of identity were primarily manifest included family, religion, and food. These domains prove both fluid and intractable to medical management, and complicate simplistic assumptions about lifestyles as choices that underlie medical therapeutic recommendations for diabetes management.

1.7 Chapter progression

There are nine chapters comprising this dissertation: this introductory chapter, a chapter outlining my conceptual approach and methodology, six chapters of findings, and a concluding chapter.

In chapter two, I present the conceptual approach and methods used in this research. Chapter three outlines the historical development of the current categorisation of diabetes with the rise of internationalised biomedicine, and briefly summarises the complex entanglement between diabetes and genetics in this discourse. I expand on the role played by the World Health Organization and its espousing of particular guidelines and standards in Trinidad and Tobago. I also condense the state of health science research into diabetes in Trinidad and Tobago, and its relationship with ethnic designations. In the final part of this chapter, I outline the structure of the healthcare sector in Trinidad and Tobago.

Chapters four and five present contrasting ethnographic narratives of people with a diagnosis of diabetes and no symptoms, the group that comprises the largest proportion of people I engaged in the field. In chapter four, I explore people's relationships with food as constitutive of ethnic identity, religious observance and forms of communal and familial sociality. Chapter five highlights the cases narratives of two successful efforts at managing diabetes while maintaining a "normal life."

Chapter six details the narratives of people whose lives have been drastically changed by diabetes associated illness and complications. Through their engagement with the local healthcare sector, people present a range of the explanatory models through which they understood their illness experience.

In chapter seven, I explore the narratives of caregivers, whose efforts I found crucial to the management of diabetes, and whose experiences challenge the notion of the patient as an atomistic individual. In chapter eight, I explore and summarise the gendered expectations of the life course I encountered in Debe, and the changes experienced with the onset of diabetic illness.

In chapter nine, the concluding chapter, I summarise my research findings, and present possible directions for future research.

Chapter 2: Research approach: Conceptual and methodological issues

In this chapter I focus on the methodological and conceptual framing of this research and its findings. The disease of Type 2 diabetes mellitus, from a clinical medical perspective, is largely dependent upon techno-scientific measures of the body for its diagnosis, definition, assessments of its progression, and recommendations for its management (Montoya 2007; Wehling 2011). These techno-scientific imaginings construct bodies suspended outside of people's own experiences of health and illness, the meanings they ascribe to them, the cultural specificities of local contexts, and the macrosocial and structural forces to which they are subject (Burri and Dumit 2007). This dissertation is an attempt to invert the biomedical gaze on diabetes for this community, and to ground it in people's lived realities and their particular historical, structural and systemic contexts. It is an attempt as well to present individuals and collectives affected by diabetes *within* their societal context, to move away from the rigid dichotomy of studying either/or.

Methodologically, this chapter outlines use of a meaning-centred, narrative approach (Good and Good 1982). I privileged people's own descriptions, explanations, and expressions of their disease diagnosis, illness experiences, and biographical disruptions or transformations. In Debe, diabetes affected both those with this diagnosis and the collectives (for e.g., relations and friends) within which they were enmeshed. Shared lifeways, rooted in a shared agricultural past mythologised as "long time days", Hindu concepts of the life-course, and the desire to live their best lives, also created normative notions of the expected progression of life that formed cultural life course expectations. This framing of diabetes as integrated in familial and communal

lifeways thus extends “management” beyond diagnosed individuals bodies into “the work of caregiving,” on which I elaborate more in chapter seven.

Conceptually, the ethnographies and narratives of this research are also framed by larger historical, social, and structural forces which impact upon individual and collective abilities to enact changes in their lives. This conceptual approach aims to highlight the tensions running through the ethnographic case narratives, and suggest a postcolonial conceptual approach for engaging them. This work is also a critique of a globalised biomedical discourse around Type 2 diabetes (the generation of which I explore in chapter three), and the problematics of biomedicine’s individually oriented management recommendations to an enmeshed social context. It also highlights epidemiological constructions that closely relate diabetes and ethnicity in Trinidad.

2.1 Illness narratives

Illness narratives and life course histories were the building blocks of this research, as I sought to identify what was at stake for people when their lives changed with diabetes, or when they sought to change their lives. Narratives are a crucial way by which people make meaning of the disruption in life-continuity that changes such as illness bring, within the larger contexts of shared cultural frameworks, historical meanings, and life-course expectations (Becker 1997; Charon 2006; Gardner 2002; Garro 2000a, 2000b; Good 1994; Kleinman 1988; Mattingly 1994, 1998a, 1998b, 2010; Mendenhall et al. 2010; Mattingly and Garro 2000).

I draw particularly upon Arthur Kleinman’s (1988, 3) classic and useful definition of illness as the “innately human experiences of symptoms and suffering” encompassing all the

ways the “sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability”. Kleinman differentiates this from “disease”, as the pathological abnormalities in the structure and function of organs and organ systems defined by the biomedical model, and illness, which is determined by a person’s perceptions and experiences of their disease state and other socially devalued states.³⁹ Kleinman’s definition is particularly apt because as the upcoming discussion of the category of Type 2 diabetes and the subsequent ethnographic case studies demonstrate, diabetes as a clinical disease entity may exist in the absence of illness, causing incongruence between medical recommendations and expectations and people’s continued experiences and practices within their cultural and social life-worlds.

Social scientists have also shown that illnesses may “act as sponges, soaking up meanings from the societies in which they occur; the embodiment and narration of sickness is socially embedded, and not separable from its political, economic and cultural context” (Gardner 2002, 169). From the perspective that narratives are themselves actively constructed social facts, the narratives of diabetes illness experience in Debe are themselves cultural artefacts revelatory of not only the individual experience, but the life-worlds within which they are constructed and enacted (Mattingly and Garro 2000).

Narratives are characterised as having defined plots (storylines); emplotment (an atemporal interpretive configuration of events rather than simple succession); a beginning, a middle and end; and subjunctivising elements if the end is not in sight (Becker 1997). Narrative

³⁹ I also use the word “sickness” as Kleinman does, to encompass experiences and events involving both disease and illness, the domain of medical anthropologists.

resources are also shaped by culturally specified plot structures that are not only “cognitive schemas” in the head, but “politically charged dramas that shape the rhythms of activity and the experiences and expectations of participants” (Mattingly 2010). For a chronic disease like diabetes, what was observed in the field was also that narratives were reconstructive rather than reproductive, an active process through which “the past is reconstructed congruent with current understandings”, the “present explained with regard to the unreconstructed past”, and “both used to generate expectations about the future” (Mattingly and Garro 2000, 70). The narratives presented within this dissertation are also revelatory of the different experiences and expectations that people have depending on their gender, ages, and life stages.

As Kleinman (1988, 8) further points out, illnesses defined as “chronic” have a long expected duration and trajectory from diagnosis to the development of detrimental effects on the body, and can assimilate into “a life course, contributing so intimately to the development of a particular life that illness becomes inseparable from life history”. In Trinidad and internationally, despite difficulties in accurately assessing prevalence and morbidity rates, non-communicable chronic diseases like diabetes are indisputably on the rise. The acute versus chronic temporal dichotomy of the health transition model has been criticised for implicitly privileging biological assumptions about disease that minimize the social and cultural contexts and globalising forces that pattern health and well-being (Manderson and Smith-Morris 2010, 3; Weaver and Mendenhall 2014). Illness narratives, further, have been recognised as transforming clock- or calendrical time into illness-centred time, with illness-associated events being dilated or protracted accordingly.

The focus of these narratives, therefore, is their temporal relationship as played out in individual lives, rather than their chronologic, calendrical progression. The narratives in the

upcoming chapters consider chronicity a social fact, used to explain individual and shared life-worlds, and to question public health discourse and health outcomes for diabetes in this context (Manderson and Smith-Morris 2010). By considering both individual experience and sociocultural context, I attempt to provide a broader and more inclusive alternative perspective on diabetes and its management as a disease process in Trinidad.

The majority of my intimate interactions in the field were with women, who are epidemiologically defined as having higher rates of diabetes in Trinidad than men, and who also constitute the larger proportion of registered patients in most Chronic Disease Clinics (CDCs). This is part of a well-recognised local and international (Vlassof 2007) trend of women engaging health systems more than men, referenced colloquially (and wryly) by one Tanty as “the men and them doh ask for directions when they driving, and doh ask for no help when they getting sick.” Population statistics for women in Trinidad also reveal longer life expectancies which increase the likelihood of chronic diseases. The further perception that diabetes is an Indian disease is well established, despite uncertainties about the derivation of recent epidemiological and statistical data for chronic disease incidence, prevalence and associated disability in Trinidad.

2.2 Life-worlds, cultural schema and explanatory models

Diabetes is a disease that through its symptomatology and management requirements causes changes to people's being in the world. It requires of those diagnosed new forms of disciplining and new regimes of the body around the most basic requirements for life: eating, drinking, and movement through the space. In the intersubjective space of everyday interactions, diabetic regimes of the body also intervene, often requiring a transformation of old relational patterns around commensality, food preparation, food consumption, and the directions of care (for e.g.,

care may be reversed for the first time between parents and their children). The changes wrought by diabetes are shared by persons with diabetes in so far as there are standardised recommendations for the new regimes of the body to be instituted.

I approached fieldwork, however, from the perspective that there were also *shared* worlds of expectation, experience, and practice upon which the diabetes impacted in this particular field. In thinking and writing about what was *shared*, I am trying to invoke the operation of what James Clifford (1988, 10) described as culture's "differentiating functions" that simultaneously enable the "conceiving of collective identity as a hybrid, often discontinuous inventive process." As Garro notes, "culturally available knowledge about illness and its causation can also be seen as a resource that may guide the interpretation and reconstruction of past experience (Mattingly and Garro 2000, 71-72).

I utilised a cultural schema perspective to identify the conceptual frameworks within which diabetes manifest and people acted to ameliorate the impact of the disease and associated illness on their lives. Much work in medical anthropology has focused on shared cultural knowledge, on "representing aspects of the way the world is understood to be within particular cultural settings" (Mattingly and Garro 2000, 73). I drew upon Strauss and Quinn (1997), Mattingly and Garro (2000) and Agar (1980) to consider how people in Debe perceived, organised, interpreted, remembered, represented, made inferences about, and acted in the world to process and mediate their diagnosis of diabetes and its impact on their lives. Cultural schemas, in this approach, are "not distinct things but rather collections of elements that work together to process information at a given time" that are shared with "people who have had some experiences like yours, but not with everybody" (Strauss and Quinn 1997, 49). Thus by engaging the illness narratives and their specific ethnographic contexts, I explore in this dissertation what

was socially and culturally expected and appropriate in the context of diabetes management amongst this community in Debe (which may or may not have been medically expected and appropriate). The narrative case studies in the upcoming chapters are built up from the common elements of people's experiences and narratives, through which people imparted their on-going experience and created expectations for the future (Strauss and Quinn 1997; Mattingly and Garro 2000).

According to Kleinman (1978) explanatory models are articulations, ideas or beliefs about illness which establish systematic relationships between proposed causes of disease, the experience of symptoms, specific patterns of illness behaviour, and decisions concerning treatment alternatives and therapeutic practices: that is, they conceptualise culture in a health domain. This framing allows biomedical models of disease to also be viewed as specific explanatory models, enabling their comparison with patient explanatory models. It also undermines the problematic and delegitimising framing of "belief" solely a characteristic of non-biomedical explanatory models.

In the forty years since the concept was elaborated, the utility of explanatory models have been amply demonstrated by numerous anthropologists to explore chronic disease, especially in contexts of socioeconomic disparity subsequent to migration (Jezewski and Poss 2002; Mattingly 1998; Garro 2000b; Hunt et al. 1998). Mendenhall et al. (2010), using illness narratives from Mexican American patients in a hospital in Chicago, elaborate explanatory models which suggest that diabetes figures as a somatic expression of psychological distress, or "social suffering" in patient narratives, often closely associated with social disparities in health. Configuring an "idioms of distress" framework, they use individual level-analysis of illness narratives to consider how diabetes figures as both a product of social suffering and an

expression of such suffering, a means by which people convey disorder in their social worlds. This, they suggest, may be significant in the comorbid interactions around diabetes and depression.

Garro (2000b) demonstrates that cultural knowledge may also effectively function as explanatory frameworks in illness narratives. Using three case studies of diabetes amongst the Anishinaabe community, Garro elucidates two main explanatory models: diabetes as linked to the individual consumption of sugar, and diabetes as a “white man’s sickness” consequent to environmental and societal changes. Garro’s approach suggests that relating culturally available knowledge to a particular life context does not happen in a straightforward, deterministic manner, since multiple and/or conflicting explanatory frameworks can be applied to individual cases of illness.

Jezewski and Poss (2002) also utilised an explanatory models approach to examine the *susto* (fright) in Mexican American health beliefs in El Paso, Texas. They found that patients described a disease aetiology that pinpointed a profoundly stressful emotional experience as a contributing factor to the onset of their diabetes, and attributed later fluctuations in their blood sugar to emotional stressors. Simultaneously, they also identified more biomedically based factors as more important causes of illness (e.g. heredity, overweight, lack of self care). An integration of biomedical and folk systems of disease causation was additionally noted, which the authors suggest was an acculturation of belief much akin to their own bodily acculturation, achieved by moving across borders. Similarly, Telma Moriera and colleagues (2018, 31) identified as “cultural-bound beliefs” that acted as “barriers” to effective diabetes care for Hispanics the concepts of *susto* (fright), *coraje* (anger), and fatalism (fatalism), since these beliefs affected how the causality and treatment of diabetes were viewed, though they also

cautioned of the need to treat the individual patient rather than viewing “Hispanics as a homogenous group.”

These and other applications of an explanatory model framework also highlight that while patients often elaborate causations from within their own lives, practitioners explanatory models tend to focus on the pathophysiology of illness (Mendenhall 2010, 223). My narrative approach further explores this proposition through the use of Kleinman’s classic questions, intended to elicit patients’ explanatory models, which I highlight specifically in chapter six.

2.3 Non-compliance: A postcolonial disorder of ethnicity?

A general perception exists within the medical context in Trinidad that people with diabetes (and chronic diseases on the whole) are particularly “non-compliant” with dietary and exercise recommendations, and medication regimens. This conceptual frame is problematic for multiple reasons, one of which is that it privileges the authority of the physician, and invokes a reductionistic explanatory model for patient behaviours based on rational models of free choice that erase the structural and systemic constraints within which people live their lives, which also determine what healthcare they can access.

Additionally, in the context of Trinidad, given that ethnicity is a dominant domain of identification and ever-present in the public imaginary, and given that diabetes rates are particularly high amongst the Indian Trinidadian population, a tension exists between the discourse of non-compliance, diabetes, and signifiers of both non-compliance and Indian Trinidadian ethnicity, such as dietary practices. In the entanglement of the dominant, totalising discourse of biomedicine, and its pathologizing of non-Western ethnic practices, echoes of the history of colonialism in Trinidad redound. In this section, I suggest the use of a postcolonial

lens to frame the “haunting presence of the colonial, a spectre often present but in only ghostly forms in current anthropological writings on subjectivity” (Good, Hyde, Pinto and Good 2008).

Compliance has been defined as the extent to which a person’s behaviour coincides with medical care or health advice for taking medications, following diets, or executing lifestyle changes, and has been the subject of considerable attention since healthcare began moving out of primarily clinical contexts into the community (Haynes, Taylor and Sackett 1979). The concept of compliance has been critiqued since the 1970s by medical social scientists as paternalistic, promoting biomedical dominance by undermining patient experiences of therapeutic measures, and redefining them in accordance with biomedical expectations (Zola 1981; Conrad 1985; Trostle, Hauser and Susser 1983; Hunt, Jordan, Irwin and Browner 1989). In response to this critique, the word *compliance* began to be replaced in the health sciences literature by *adherence*, however the concepts continue to be used interchangeably (Guénette et al. 2013; Lutfey, and Wishner 1999; Barbosa et al. 2012; Bezie et al. 2006). Part of the critique associated with the concept of compliance has been that it promotes an emphasis on the individual as a locus of rational decision-making, negating the social contexts in which their actions occur. Stimson (1974, 102, 99) argued that explorations of compliance reflect the physician’s point of view, in which the emphasis is on why ‘people fail to follow doctor’s instructions’. By privileging the physician’s perspective, Zola (1981) similarly posited patients were disempowered in clinical interactions and their poor treatment led to non-compliance.

Central to the issue of compliance, and particularly applicable in contexts of chronicity, is the question of whether people “*can’t* or *won’t*”, that is, whether it is inability or refusal, dysfunction or defiance, as Estroff (1993, 251) crucially points out. Though Estroff explores this in reference to chronic mental illness in the USA, the ambivalence and reciprocal scepticisms she

highlights apply as well to much medical discourse and public sentiment around diabetes in Trinidad. This approach highlights the underlying strain of seeking neither to reward role refusal, nor to punish or neglect those that cannot *actually* contribute at expected levels (Estroff 1993, 252). Within a biomedical⁴⁰ framework, the concept of non-compliance often emphasises or insists that “can’ts” are “won’ts”: that is, the locus of responsibility for morbidity becomes framed as “poor health choices,” wherein patients are *blamed* for their non-compliance.

As the outline of the history of Trinidad in the introduction suggests, colonialism still casts a long shadow in Trinidad, though I must clarify that identifying and deconstructing the postcolonial condition of Trinidad and Tobago in all domains is neither the intent nor within the scope of this dissertation. By colonialism, I refer to the ideas, institutions, and forms of domination that once functioned to establish and maintain European expansion and occupation of most of the global land-mass between 1492 and 1945 in the pursuit of capital, as well as logics of reason, progress, and freedom that supported its political dominance and economic control (Good, Hyde, Pinto and Good 2008; Young 2001). Colonialism was not a single entity, with policies differing with place (e.g. Africa and Asia), in time (i.e. empires established in the eighteenth or nineteenth centuries), and among major colonial powers, including England, France, Holland and, Belgium (Dirks 2004). Despite this, I recognise that many countries that were colonised share many features of colonial and postcolonial history (Dirks 2004; Young 2001).

⁴⁰ As I explore further in chapter three, I consider biomedicine to be a sociocultural system founded epistemologically on a reductionist, scientific empiricism, wherein bodies are considered the seat of both health and disease, and individuals are rational actors capable of making “free” choices independent of larger social, economic, political, or other systemic constraints.

I use the term postcolonial to both describe the period after colonialism, and to signify a set of critical theoretical perspectives through which to identify, deconstruct, and contest some of colonialism's "cultural and broader ideological legacies and presences" (Sidaway 2000, 594) in Trinidad. My uses of postcolonial or references to *the* postcolonial condition thus do not imply a singularity to the forms of colonialism or their subsequent effects in the many countries that were once colonies, as many scholars have asserted before me (Goldberg and Quayson 2002).

The postcolonial approach I am primarily concerned with is the social construction of race and ethnicity under colonialism, and the perpetuation of ethnic rivalries and antagonisms into the present. Historians and anthropologists have described and demonstrated that "divide and rule" strategies were used by British colonial powers to create or highlight, augment, and exploit differences between peoples in ways that perpetuated colonial rule (Morrock 1973; Dirks 2004; Misra 2003). Dirks, in an influential report for the United Nations Development project in which he draws upon the postcolonial politics and challenges experienced by South Asia, states that "...it is impossible to minimise the ways in which the divide and rule policies of European colonial powers have created religious and ethnic divisions that continue to inhere in the body politic of ex-colonies" (Dirks 2004, 31). Morrock (1973), similarly, drew upon the widely different locations of Kenya, Indochina and India to highlight similarities in the strategies used by colonizing forces to separate peoples geographically, classify and categorize them in ways that perpetuated difference, and differentially apply colonial policies and education amongst them, establishing longstanding ethnic antagonisms. As scholars of the Caribbean note, similarly, one rationale for the establishment of the system of indentureship on the heels of slavery was to stymie the rise of the newly-freed slaves through the creation of a competing class, the indentured labourer (Munasinghe 1997). The establishment of this racist antagonism under

colonialism is also highlighted and explored by many scholars of Trinidad and the wider Caribbean, including anthropologists Viranjani Munasinghe (1997, 2001, 2006), Aisha Khan (2004).

As an expression of this racist antagonism, Indian Trinidadian cultural practices also came under critique, widely denigrated as expressions of backward rurality. They were also criticised for their deviation from the European Christian norms. For example, using the highly derogatory term of “coolies,” the 1852 *Trinidad Free Press* editorialised against the “pagan” labourers with “vicious, brutal and superstitious habits,” including brutishness with regard to “clothing, food or other care of the body”, characterised by being “half naked, deeply degraded, and *herb-eating*” (Moore 1995, 180 quoted in Khan 2004, 53, emphasis added). In the inter-ethnic politics early nationhood, Indian and African Trinidadians were repeatedly manipulated to opposite sides of a political divide, particularly when the threat of a united anti-colonial labour movement arose under Uriah Butler. The success of the racialising of politics and the promotion of ethnic divides has continued to characterise local elections since independence. The rhetorical turn of the first Prime Minister of Trinidad and Tobago (who governed for 25 years) also established a legacy of perpetuating colonial era inter-racial antagonisms, which persist in people’s memories until today. I consider these effects to be a “politicising of differences” and part of a postcolonial legacy that continues to linger, and to exert colonial violence in Trinidad long after colonialism’s end.

The medical, clinical, and popular discourses around the dietary practices of people with diabetes, therefore, occur within a larger historically inflected context in which Indian Trinidadian eating practices (as expressions of an ethnic identity) have historically been critiqued as an expression of anti-Indian racism. A tension thus arises between management

recommendations that emphasise dietary change away from ethnically constitutive models of eating, especially if these recommendations are framed as critiques of current dietary practices, rather than substitutions from within the ethnic food lexicon. A conceptual note on the discourse of non-compliance, therefore, is whether it may be perpetuating or recapitulating a form of colonial violence that has been imposed upon the Indian Trinidadian community in the past.

2.4 My location in the field

Every time I have tried to do a piece of theoretical work it has been on the basis of elements of my own experience... It was always because I thought I identified cracks, silent tremors, and dysfunctions in things I saw, institutions I was dealing with, of my relations with others, that I set out to do a piece of work, and each time was partly a fragment of autobiography.

- Michel Foucault, "*So is it important to think?*", in J. Faubion (ed.), *Power* (New York: The New Press, 2000), 458.

I approached this research as an ethnographer, but also as a Trinidadian of Indian-descent, a physician with training and practice in Trinidad, and a female. My personal experiences in each of these social roles have shaped the course and progression of this research in both anticipated and unanticipated ways, which I will elaborate upon briefly.

As an ethnographer, I quieted my own preconceptions and allowed myself to listen, to feel, and to observe what people were saying and were not saying. This encouraged them to

share their experiences with ease, and with the expectation of being understood, eased my way into the community especially at the beginning.

As a young female, unattached at the start of this research, I found myself co-opted by the women in the village, especially the older, married women, who took me under their wing and helped me navigate an context both unfamiliar and familiar. This meant my initial exposure was to a particular perspective of the experience of diabetes, through the female-dominated institutions of family, caregiving, and religious spaces. I believe this unanticipated funnelling of my attentions enriched and expanded my research questions rather than detracting from them.

As an Indian Trinidadian, I was aware of subtleties of interactions and situations wherein the ethnic identity I was also identified by was being referenced, negotiated, invoked, and transgressed. More obvious examples included statements in the field that referenced “our people” and “we kind of thing”, with the underlying expectation that my agreement and inclusion in the category was implicit. Aware of the possibility of being drawn to assumptions by the expectation that I would understand the unspoken, as a member of the group, I was careful to always articulate out loud and ask directly what was being implied, if not at that moment, at another time.

Finally, and most crucially, I first became interested in this research topic as a medical student and a physician working at the San Fernando General Hospital. Experiences at the hospital were my first exposure to the pervasiveness of diabetes in Trinidad, and to the scope of the consequences of diabetes complications to both the patient and their support systems. The hospital was filled with people with “uncontrolled” diabetes due to the disease’s negative effects on almost every organ system in the body and its synergistic effects in producing ill health with other comorbidities. There were people with diabetes in every ward, and some wards had

become almost solely dedicated to managing diabetes complications, such as the “Septic Ward”, which was also casually known as the “diabetic foot” ward. I saw first-hand as a physician the efforts it took for family systems to cope with the diagnosis and patient management. I also saw first-hand how much the biomedical limitations on “patient histories” excised social, cultural and structural causes of illness as a part of the archival process of disease construction. This research was my attempt to address these gaps in the clinical narratives by allowing the people with diabetes to voice their own stories, share the experiences that mattered to them in their lived lives, to reveal what was at stake in the disease process and its management to them, outside of the rubrics of medical history taking.

In the following chapter, I expand on the biomedical model of diabetes, situate its categorisation in global context, and contextualise it to the Trinidadian milieu.

Chapter 3: “Sugar”: Diabetes in clinical, historical, and Trinidadian context

In this chapter I present an overview of diabetes, its history, and locate it as a social object constituted by the development of an international biomedical discourse. I focus particularly on the role of the World Health Organization (WHO) as an international arbiter of biomedical classificatory and diagnostic standards that have been espoused for use in Trinidad and Tobago. Diabetes management in Trinidad, while drawing upon standards of best practice from the WHO and international biomedical discourse around diabetes, is also influenced by perceptions of ethnic identity and everyday acts of identity construction in Trinidad. In this chapter I further examine the widely accepted associations between high diabetes prevalence rates and the Indian Trinidadian community to problematize this emphasis. Through these explorations, this chapter grounds the ethnographies and family histories of the upcoming chapters in the tangible, concrete entity of diabetes, constructed biomedically through techno-scientific measures of the body. The pathological and clinical descriptions of diabetes, how technologies of the body are utilised in diabetes diagnosis and management, and the relationship between diabetes and concepts of race and ethnicity form a backdrop to people’s everyday attempts to manage their disease in Debe. These attempts are performed in the context of the health sector of Trinidad and Tobago, a description of which closes this chapter.

3.1 Diabetes: Clinical definition, complications, classification

The clinical and pathological medical model defines diabetes mellitus as a metabolic disorder of multiple aetiology characterised by chronic hyperglycaemia (elevated blood glucose levels) with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin

secretion, insulin action, or both (WHO 1999, 2). Diabetes is diagnosed by the detection of blood glucose levels habitually above the range of normal. Glucose is a simple sugar produced by the breakdown of ingested food in the gut, and circulates through the body in the blood. It is the main product the body uses to produce the energy it needs for life. In a normal metabolic state, blood glucose levels are tightly regulated within a narrow range for optimum bodily functioning by the hormone insulin. Insulin is secreted by the B-cells in the Islets of Langerhans of the pancreas in response to high blood glucose levels. Glucose thus needs insulin to be absorbed into the cells of the body. In persons with diabetes, the pancreas either does not produce enough insulin or the insulin it produces is ineffective in allowing glucose to enter the body cells. Other abnormalities may also be present, such as the cells of the body being insulin-resistant, so that even if insulin is present it is rendered ineffective. Together, these effects result in the persistently elevated blood glucose levels characteristic of diabetes.

Diabetes mellitus is classified into three main categories. The first two are gestational diabetes and Type 1 diabetes. Gestational arises during pregnancy, and usually resolves when the pregnancy ends. It is caused by insulin resistance, which is discussed below, induced by the hormonal changes of pregnancy. It can cause a range of complications to the foetus and the mother, thus, there is close blood glucose monitoring and control during pregnancy, for which the mother may require insulin. Both mother and child are afterwards considered at higher risk of Type 2 diabetes in later life (Vaag et al. 2012).

Type 1 diabetes is defined as a lifelong disease in which the body is unable to produce insulin due to the autoimmune destruction of the beta (insulin-producing) cells in the pancreas. This results in an absolute deficiency of insulin secretion, that is, the near complete absence of insulin from the body. The resulting blood glucose levels are entirely out of the body's control.

Patients therefore require lifelong external insulin administration for their survival. The symptoms of Type 1 diabetes manifest in childhood, generally much earlier than Type 2 diabetes. Type 1 diabetes has a low estimated prevalence and incidence in Trinidad and Tobago.

The third category of diabetes mellitus is Type 2 diabetes, which is the most prevalent form in Trinidad and Tobago (and indeed the world). In Type 2 diabetes, patients have either an absolute or relative insulin deficiency combined with insulin resistance, and usually a later onset of disease than Type 1 diabetes. Unlike in Type 1 diabetes, insulin is usually present in Type 2 diabetes, however it cannot maintain normal blood glucose levels. It is either ineffective due to abnormalities in its function, or its production is inadequate to compensate for insulin resistance in the body (a relative insulin deficiency). Insulin resistance is caused by a failure of specific receptors sensitive to the presence of insulin on the cells of body tissues (e.g., muscle, liver, and fat). On exposure to insulin, these receptors are supposed to allow the uptake glucose from the blood into the tissue cells, thereby decreasing blood glucose concentrations and making the glucose available for energy production. Insulin resistance occurs when receptors are missing or defective, and is characteristic of Type 2 diabetes (Kumar and Clark 2016). The treatment regimen for Type 2 diabetes includes nutritional and dietary modification, exercise, and medications that range from oral tablets to insulin administration. While people with Type 2 diabetes are not always dependent upon insulin for survival from the outset of the disease, over time their insulin production often decreases and their peripheral insulin resistance increases, necessitating exogenous insulin administration. Type 2 diabetes usually develops in later life, in contrast to the lifelong course of Type 1 diabetes, though it has increasingly been diagnosed at a younger age. It is also known as a complex disease because its risk factors include both environmental and genetic or biological factors (Kumar and Clark 2016).

Complications of diabetes most commonly arise from prolonged exposure of the body tissues to elevations in blood glucose. The pathological consequences are most commonly grouped on the basis of the blood vessels affected. The microvascular (small blood vessel) consequences of uncontrolled diabetes frequently occur early on in prolonged exposure. They include damage to the small vessels of the eye (retinopathy), the kidney (diabetic nephropathy), and nerves (neuropathy). Macrovascular (large blood vessel) complications usually occur later, and include coronary artery disease (leading to heart attacks and chest pain or angina), peripheral artery disease (leading to leg pain or claudication and gangrene) and carotid artery blockage (leading to ischemic cerebrovascular disease, strokes and dementia) (Kumar and Clark 2016).

Such prolonged exposure and its consequences is in part a result of improvements to life-expectancy that have been facilitated by insulin and other technological and scientific advances in diabetes therapy (e.g. oral agents like sulfonylureas). These have enabled persons with diabetes to survive to an older age. This perspective is in keeping with theories of the health transition model that associate global changes in disease patterns with the transformation of societies to more industrialised and developed (Caldwell 1993; Frenk et al. 1991). In this model, the decline of infectious diseases was accompanied by the rise in non-communicable lifelong diseases as health status and patterns of disease changed with improved epidemiology. A combination of improvements to medical care and programs of industrialisation improved sanitation, potable water supplies, vaccinations, nutrition, and child and maternal healthcare.

Also important in this transition were improvements in public health programs, increased access to medical care, and more effective prevention and control of infectious disease (Manderson and Smith-Morris 2010, 4). Dennis Wiedman (2010) has additionally identified an economic transition within countries from agricultural subsistence to industrial wage labour in

increasingly urbanised contexts.

Increasingly sedentary lives subsequent to lower activity jobs, consumption of high fat, nutritionally poor foods in low activity contexts consistently produce poor metabolic health.⁴¹ A persistent framing of patterns of metabolic disease in terms of less wealthy to more wealthy, or “income- and expenditure-driven” distinctions within a population, Lenore Manderson and Carolyn Smith-Morris (2010, 6) point out, misses the health status changes that affect populations everywhere due to globalisation. Simplistic assessments of the health transition that privilege the consequences of “good living” as explanations for the rise in non-communicable diseases have also been critiqued by anthropologists like Steve Ferzacca (2000, 2012), who demonstrates that the poor and those who lack resources, time, information, and services are equally affected.

From an epidemiological standpoint, the group of diseases resulting in the abnormal glucose metabolism categorised as Type 2 diabetes increase in frequency with age, are associated with insulin resistance when abdominal obesity is present, do not always require insulin treatment for survival, exhibit familial heredity, and have higher prevalence in certain population groups (e.g. indigenous peoples in North America, South Asians, Chinese, African Americans in the US, and Hispanics in the US). From a clinical standpoint, there are four major determinants or risk factors for Type 2 diabetes: increasing age, obesity (measured both by body mass index and central obesity)⁴², ethnicity and family history. This clinical or phenotypic description of

⁴¹ While these conditions obtain in Trinidad, they do not explain the fifty-year trends in higher Type 2 diabetes prevalence amongst the Indian Trinidadian population, which was largely occupied in agriculture.

⁴² A BMI greater than 35 m² is considered a significant risk factor for diabetes (Kumar and Clark 2009). The risk posed by abdominal or central obesity, conversely, varies with ethnicity and gender, with a waistline measurement

diabetes, however, covers a wide range of genotypes that are still being identified, ranging from specific monogenic entities to polygenic metabolic disturbances, and have complex interactions with environmental factors (Lebovitz 1999; Kumar and Clark 2016). Social science research has also consistently revealed that the descriptors used for diabetes often obscure the influence of social inequalities upon its incidence and prevalence rates (Rock 2002, 2005; Garro 1995; Hunt, Valenzuela and Pugh 1998).

3.1.1 History of diabetes and the rise of biomedicine

The classic triad of symptoms of diabetes is considered excessive thirst (polydipsia), frequent urination (polyuria) and excessive hunger (polyphagia). Along with excessive weight loss (marasmus), these symptoms have been described or referenced in texts related to human health from antiquity, suggesting that diabetes has been part of the human experience for thousands of years (Eknoyan and Nagy 2005; Schneider 1972). Medical historians believe that diabetes was referenced in Egyptian papyrus circa 1500 BCE (Christopoulou-Altera and Paparamidou 2008; Schneider 1972; Gemmill 1972), in ancient Indian Ayurvedic texts as “honey urine” between 300 BCE and 600AD (Lakhtakia 2013; Engelhardt 2012; Frank 1957), and in Chinese texts as early as 750 AD (Engelhardt 2012). Most Western scholars of medical history attribute the term *diabetes*⁴³ to the writings of Aretaeus of Cappadocia (30 to 90 AD), which also provided the most complete description of diabetes in the ancient world. Aretaeus also located diabetes within the body, confined to its parts, and attributed it to a specific causation (Schneider 1972;

of equal to or greater than 31.5 inches for women, 35 inches for Asian men, and 37 inches or over for white and black men posing the greatest risk (The InterAct Consortium 2012).

⁴³ Greek for siphon, in reference to the characteristic symptom of excessive urination.

Engelhardt 2012; Lakhtakia 2013). In Aretaeus' construction can be seen the roots of biomedicine's characterisation as a hierarchy of increasing rationality that delimits disease to the body and its parts (Good 1994).

Aretaeus' symptom-based definition of diabetes continued to be used for diagnosis until the Enlightenment period of Western medicine. In the post-Enlightenment eighteenth century, however, explorations in new ways of explaining diabetes aetiology, its diagnosis, and its symptomatology reflected an epistemological shift from previous ways of knowing with the development of *biomedicine*. Biomedicine was the product of the reformulation of Western medicine from the late nineteenth century to World War II as a professionalising enterprise, involving specialisations of medicine and nursing, the creation of allied health professions, new assemblages of medico-scientific, technological and pharmaceutical interventions, and the elaboration of new social forms such as hospitals and clinics (Clarke 2009, 50).

Accompanying the rise of modernity, biomedicine epistemologically valorised rational empiricism as the only valid form of objective reasoning, based solely on "objective" findings from the material realm of the physical body, identifying these as the primary locations of "real" causation. Biomedicine became the conventional practice of Western allopathic medicine and provided a "universal, scientific account of the human body and illness", "rooted in a positivist or empiricist paradigm" in which disease is "localized in the body, in discrete sites or physiological processes" (Good 1994, i, 37, 157). Though this approach has been critiqued as being embedded in particular social, political, and cultural values, rather than being the objective "neutral" stance it was assumed to be (Lock and Nguyen 2010; Good 1994), it continues to pervade the field.

The biomedical construction of the disease category of diabetes in the post-Enlightenment period involved the usage of what Foucault has described as *technologies of the body*, which validated their pronouncements through the creation and usurpation of power and knowledge.

One such technology of the body was the medical “gaze”, which referred to the new, active modes of “seeing” that separated the patient’s body from the patient’s identity, also producing its power through the one-way act of observing its subject-patients (Foucault 1973; Armstrong 1983). For example, Thomas Willis subcategorised diabetes into diabetes mellitus and diabetes insipidus⁴⁴ based on the sweetish taste of diabetic urine, rather than the patient complaint of excessive urination, and Matthew Dobson crystallised a sample of sugar from diabetic urine based on this observation one hundred years later (Schneider 1972).

A second technology of the body that Foucault described is “the archives”, by which means medical observations produced power by structuring, organising and legitimating diabetes as a disease and a social object (Foucault 2002). Bruno Latour and Steven Woolgar’s critical work *Laboratory Life* provides a related perspective of scientific knowledge making in the laboratory and clinic as a constructivist process, through which scientific knowledge is legitimated by its construction as fact (Latour and Woolgar 1979). Andrew Pickering (1995) similarly argues that the processes of scientific enquiry and discovery are constructive and negotiated through the act of research itself.

⁴⁴ Diabetes insipidus causes excessive urination and extreme thirst, however this is due to deficiency of anti-diuretic hormones.

Through this lens, the successive biochemical experiments, physiological tests and anatomical pathological explorations of bodily organs that occupied much of the late nineteenth to mid-twentieth century can be understood as the biomedical construction of diabetes mellitus as a social object. These incremental scientific discoveries included: Francis Home in 1780 introducing the yeast test for sugar in diabetic urine; H. W. Wollaston in 1811 estimating the blood sugar in persons with diabetes; Herman von Fehling in 1848 introducing the Fehling test for glycosuria; Paul Langerhans 1893 identifying the insulin-secreting Islets of Langerhans and their sugar-regulating function; and by 1913, Edward Albert Sharpey-Schafer and Jean de Meyer independently postulating that a disturbance in the secretion of “insuline” secreted by the Islets of Langerhans would lead to diabetes.

A concatenation of mechanical and scientific technological transformations, the integration of scientific method into medical practice, and the archiving of observations have thus produced the category of diabetes mellitus and its subcategories, as well as the rationalised medicine of today. Perhaps the clearest exemplar of this process is Frederick Banting’s painstaking, trial-and error experimental approach to identifying, isolating and purifying insulin from the pancreas of dogs in 1921, and demonstrating its effect in controlling the blood sugar of persons with diabetes (Schneider 1972; Engelhardt 2012). The discovery of insulin and purification techniques for usage in humans revolutionised diabetes care, affirming the power of the new biomedical model. Exogenous insulin also constituted a technology through which the disease of diabetes itself would be reconstituted, reclassified, and reconsidered over the successive hundred years to arrive at the current diagnostic and classificatory criteria. Also transformative was the ability to technologically assess bodily processes through non-fatal means

like urine or blood tests. These practices transformed diabetes mellitus from an inevitably fatal disease, especially when occurring in children, to a lifelong “chronic” disease.

Currently, the classificatory categories Type 1 and Type 2 diabetes encompass a heterogeneous range of disorders of blood glucose metabolism, ranging from immunological diseases to interactions between genetic factors and environmental conditions. This classification represents a complex grouping of human experiences of the body (i.e. through symptoms and signs) and assessments of the body through biomedical technologies, which have increasingly intervened in the ways that people experience their bodies. Classificatory systems are crucial to human efforts to make sense of the world, however classifications in turn have an effect on the world by framing and delimiting knowledge, actions, and behaviour, as Geoffrey Bowker and Susan Star (1999) have identified. Melanie Rock (2005) also argues that in the realm of diabetes, this classification effaces social and economic inequalities underling the incidence of disease, and its usage thereby potentially deepens these social inequalities.

How technologies mediate people’s experiences of their bodies has been explored by medical anthropologists for diabetes and a range of other diseases. For example, in research from the Netherlands, Annemarie Mol (2000, 2008) showed how blood glucose monitoring devices intervened between patients with diabetes’ experiences of hyperglycaemia, and their perceptions of their hyperglycaemic state, rendering them more trusting of the numbers on the screen than their bodily symptoms. Similarly, Emily Yates-Doer (2015) has described how in obesity diagnosis in Guatemala, the medical scale is part of the transformation in a patient’s bodily status, a process of constructing a treatable patient body where one had not been before. As Simon Cohn and Rebecca Lynch (2017) also point out regarding reproductive technologies, current highly-sensitive over-the-counter pregnancy tests allow the detection of fertilisation

much earlier than in the past, potentially transforming the reality of what constitutes pregnancy from an interventionist standpoint.

The Western biomedical model of diabetes continues to be the dominant form of healthcare recognised worldwide by governments and licensing bodies, underscoring its legitimation and power (Good 1994; Illich 1976; Zola 1972). While anthropological research has undermined the idea of biomedicine as the singular and monolithic entity of its early critiques,⁴⁵ there continue to be unifying premises that underlie its practice internationally. The international predominance of biomedicine is in no small part a construct of globalised processes of standardisation and classification that attempt to advance with and integrate new scientific and technological advancements. Adele Clarke (2009, 47) describes this as the transformation of medicalization into *biomedicalization*, as complex, multisited, multidirectional processes are extended and reconstituted through emergent social forms of an increasingly techno-scientific biomedicine.

Particularly implicated in the spread of biomedicine and its characteristic efforts at applying the same principles and practices internationally are the standard-making and classificatory bodies, the international arbiters of disease and its classification, such as the World Health Organization (WHO).

⁴⁵ See Margaret Lock (1993), *Encounters with Aging*, on the different clinical constructions of menopause in Japan and the United States despite sharing a dominant biomedical category.

3.1.2 The World Health Organization in diabetes diagnosis and classification

In the early to mid-twentieth century, in addition to efforts by the colonial authorities, a number of international bodies were involved in improving public health in Trinidad and Tobago, with a major focus on communicable, infectious diseases such as hookworm, poliomyelitis, venereal diseases, yellow fever, dengue, and typhoid.⁴⁶ Post-Independence in 1962, the Trinidad and Tobago government sought investments from North America (for e.g., loans from the Inter-American Development Bank and World Bank) and from Canada (for e.g. the Canadian International Development Agency), which were seen as necessary to growth and to decrease its reliance on Britain. Trinidad and Tobago also became a Member State of the World Health Organization (WHO) and the Pan American Health Organization (PAHO).

These bodies came to form major avenues for the provision of ideas, concepts and values in health planning and policy making, with primary health care endorsed by the government (Hezekiah 1990). Surveillance, control and public health efforts were largely performed by the Government of the Republic of Trinidad and Tobago in collaboration with PAHO/WHO. PAHO also became the Regional Office of the World Health Organization. A legal framework was laid out for PAHO/WHO and the government that formed the basis of their relationship and future programs, including “Technical Cooperation Programmes”. Through these and other programs, PAHO/WHO lent their expertise and influence to tasks of assessing the health care sector and suggesting recommendations. For example, the WHO provided technical assistance to formulate the First National Health Plan of 1967–1976 for decentralising the national health care services,

⁴⁶ These institutions included the Rockefeller Foundation (see Palmer [2009, 2010] and Packard [2016] for more discussion), the Medical Research Council of the United Kingdom, the National Institutes of Health (U.S.A.), and the United States Government (Packard 2016). See McCollin (2009) for more discussion of the relationship between the establishment of a US military base in Trinidad and U.S. governmental public health initiatives in Trinidad.

which was however never implemented. The World Health Organization has also been instrumental in including smaller countries like Trinidad and Tobago in an international epidemiological database that acts as a biomedically-framed snapshot of the health of the population at different moments in time. Thus the WHO listed Type 2 diabetes as having a prevalence of 12.5% in 2016 (WHO 2016), down from an estimated 14% in 2011.

The World Health Organization (WHO) has therefore been particularly instrumental in advancing a globalised ecumene of standardised biomedicine in newly-independent ex-colonies, and in countries of the global south, since its formation as an off-shoot of the United Nations in 1948. Its formation and advocacy, as Sandra Harding points out, were also part of the post-World War II efforts at disseminating “Western scientific rationality and technical expertise” to “deliver economic development to poor societies around the globe”, for their own advancement, as supposedly value-neutral, and free of “traditional religious beliefs, myths, and superstitions about nature and social relations (Harding 2011, 1-3). The standards, classification schemes, epidemiological estimations and best-practice guidelines produced by the WHO have had and continue to have significant influence upon smaller nations internationally that aspire to the implied rigour of their evidentiary bases (Brown and Bell 2008). Trinidad accessed the WHO’s expertise directly through the aforementioned “Technical Cooperation Programmes”, and indirectly through the use of standards espoused by WHO for disease diagnosis and management. Unlike in more “developed” countries of the global north, in countries of the global south WHO guidelines have become the “gold-standard” for diabetes diagnosis, treatment, and management, as these countries rarely have the epidemiological expertise, economic resources, or political will to develop standards of their own. In contrast, the standards in use in countries of the global north are often based upon research produced within their populations, disseminated

by national bodies, for example, the American Diabetes Association, or the National Institute for Health and Care Excellence (NICE) in the UK. Most recently, this has been achieved by the collaboration between the Caribbean Health Research Council (CHRC) and PAHO/WHO in the production of Caribbean wide guidelines for the management of diabetes, which are discussed further below.

The WHO's on-going efforts can be understood in part as the Foucauldian (2002 [1969]) "technology of the body" he calls *archiving*, manifest as the repeated convening of international panels of experts (e.g., physicians and scientists) to consolidate and codify the latest scientific knowledge. In the field of diabetes mellitus, this has been the WHO's agenda for numerous meetings in the 1980s and 1990s alone.⁴⁷ The WHO has also repeatedly convened scientific meetings to update the guidelines for diabetes classification, diagnosis, and its complications in 1965, 1980, 1985, 1999, 2006 and 2011, in a reiterative classificatory activity and standard-making process that characterises biomedicine. These guidelines have attempted to balance the integration of techno-scientific measures of the body, and their wide-scale applicability to public health contexts.

The WHO guidelines for diabetes were defined as attempts to balance and combine clinical diagnostic criteria based on technological assessments of the body, and broad disease categorisations related to disease aetiology and progression. The choice of blood glucose as the

⁴⁷ A partial listing of this would include study groups on diabetes mellitus (e.g. Geneva, 11-16/2/85); study groups on diabetes prevention (Geneva, 16/11-20/11/92, Dhaka, 01/01/1983); meetings on the implementation of national diabetes programs (Geneva, 30/5 – 1/6/94, Sweden 01/01/1985); diabetes training courses for international medical schools (e.g. University of Newcastle-upon-Tyne, U.K. 01/01/1987), the creation of collaborating centres in the field of diabetes (01/01/1982, 01/01/1993, 01/06/1995); seminars and symposia on diabetes (e.g. 01/01/1985); and seminars on the clinical epidemiology and public health aspects of diabetes mellitus, (e.g. Cambridge, UK, 20-12/7/81).

defining diagnostic tool, like the designation of the main classificatory categories of Insulin Dependent Diabetes Mellitus (IDDM) and Non-Insulin Dependent Diabetes Mellitus (NIDDM) was further characterised as a compromise between clinical and etiological classification, since it “allowed classification of individual subjects and patients in a clinically useful manner even when the specific cause or aetiology was unknown” (WHO 1985). The resulting diagnostic and classificatory scheme included “both staging of diabetes mellitus based on clinical descriptive criteria and a complementary etiological classification” (WHO 1985). This guideline was negotiated to accord with the guidelines of other influential diabetes bodies, in keeping with the efforts of biomedicine to present itself as a globalised, international force with universal standards of practice. This classification of diabetes mellitus was included in the International Nomenclature of Diseases (IND) in 1991, and in the 10th revision of the International Classification of Disease (ICD-10) in 1992.

The landmark WHO scientific meeting of 1999 introduced two major changes to the 1985 diagnostic and classification schema. Firstly, the classificatory categories were changed in accordance with new understandings of diabetes’ etiological grouping, based upon new epidemiological data and technologies of bodily assessment. This further increased the importance of technological, scientific and biological measures of the body over the clinical context and patient symptomatology. The classificatory categories of “Type 1” and “Type 2” replaced Insulin Dependent Diabetes Mellitus (IDDM) and Non-Insulin Dependent Diabetes Mellitus (NIDDM), which had increasingly been considered “confusing” (WHO 1999). Re-classification shifted the focus of diabetes diagnosis from its clinical management, i.e., the requirement of insulin for its treatment, to potential etiological causes, since it was clear that

patients who were classified as having NIDDM might require insulin for blood glucose control, despite their classification.

The second major change was an alteration in the established cut-off points for the diagnosis of diabetes. This change was intended to catch blood glucose elevations at a point when they were still reversible, prior to the onset of any widespread tissue damage. The absence of tissue damage however meant that many people were asymptomatic at the point at which their blood glucose levels were newly considered diagnostic of diabetes. As will be seen in chapter four, this was often not appreciated by patients who were asymptomatic at that blood glucose level. The change in the diagnostic cut-off points also established a new range for “normoglycaemia” or the normal range of blood glucose, effectively lowering how much glucose in the blood was now considered pathological.⁴⁸ This fasting criterion was chosen to represent a value “at the upper end of the range that corresponds in diagnostic significance in many persons to that of the two hour post-load concentration” established from population based studies, and as an optimal cut-off point to separate the bimodal frequency distributions of fasting plasma glucose concentrations seen in several populations (WHO 1999). It was also chosen as the limit at which microvascular disease, i.e., the early complications of diabetes, began to manifest in specific populations (WHO 1999).

Other cut-off points also altered in 1999 included the category of impaired glucose tolerance (IGT), with the introduction of a new category, impaired fasting hyperglycaemia (IFG). The alteration of these categories was intended to distinguish between persons with diabetes and

⁴⁸ The diagnostic glucose concentration was lowered from ≥ 140 mg/dL to ≥ 126 mg/dl for fasting plasma, and to ≥ 110 mg/dL from ≥ 120 mg/dL for whole blood. A fasting plasma glucose concentration of ≥ 126 mg/dL thus became diagnostic of diabetes, confirmed by a two hour post-glucose load reading of ≥ 120 mg/dL.

those merely at increased risk, among people with elevated random blood glucose levels.⁴⁹ What these changes were intended to achieve was clarification in the categorisation of diabetes for clinical assessment and management purposes. Updates released by the WHO in 2006 and 2011 did not alter the 1999 cut-off points.

3.1.3 Standards for diabetes management in Trinidad and Tobago

In 2006 the Trinidad and Tobago government-affiliated body the Caribbean Health Research Centre (CHRC), in collaboration with experts from the PAHO/WHO, produced an 80-page booklet entitled *Managing Diabetes in Primary Care in the Caribbean* (CHRC and PAHO 2006). The CHRC guidelines focus on Type 2 diabetes, and their criteria are drawn from the WHO guidelines issued in 1999. Physical copies of this booklet can be found in most public health centres.

The guidelines recommend that only individuals who attend clinical settings with identifiable risk factors be formally screened for diabetes, since population-based screening is expensive (CHRC and PAHO 2006). This recommendation endorses the opportunistic screening that is currently performed in Trinidad, which results in an estimated 50% of all persons with diabetes remaining undiagnosed, given the long, latent, asymptomatic period in which blood glucose levels are elevated sufficient for diabetes to be diagnosed despite the absence of

⁴⁹ The cut-off points for IGT were lowered from <120 mg/dL to <110 mg/dL producing a new diagnostic range: a fasting value of >110 mg/dL with a two-hour post-glucose load measurement of ≥ 120 mg/dL. In IFG, a patient's normal fasting blood (or plasma) glucose concentrations were higher than normal blood glucose levels but lower than the diagnostic cut-off for either IGT or diabetes. Thus IFG was diagnosed with a fasting glucose between 100 to 110 mg/dL with a two hour post-glucose load level of <120 mg/dL.

symptoms (Bahadursingh et al. 2014). The listed risk factors⁵⁰ are however non-exhaustive; dependent upon prior results from consistent medical care; and dependent upon the clinical perception of the attending physician. They may thus result in the exclusion of individuals with atypical or subtle symptoms. This places the onus of responsibility upon individuals in Trinidad to seek out opportunities to be screened for diabetes.

Free screening can be obtained through “screening clinics” held intermittently by non-governmental organisations, businesses, or volunteer groups, or on attending public health centres with specific complaints. Screening can also be obtained on a fee-for-service basis from private physicians, pharmacies, or private diagnostic labs. A senior consultant in Trinidad estimated that over 60% of the diagnosed persons with diabetes in the public health sector in Trinidad received their diagnoses incidentally, that is, after seeking health services for another unrelated complaint. He also believed that this percentage would be greater if one considered only persons who were asymptomatic despite meeting the clinical criteria for diagnosis.

Screening tests:	<ul style="list-style-type: none"> • Random Blood Sugar (RBS) assessed by glucometer • Fasting Plasma Glucose (FPG)
Diagnostic cut-off points:	<ul style="list-style-type: none"> • FPG ≥ 7.0 mmol/l (126 mg/dL) • 2 hr plasma glucose ≥ 11.1 mmol (200 mg/dL)
Diagnostic criteria:	
<ul style="list-style-type: none"> • positive random blood sugar and symptoms of diabetes (e.g. polydipsia, polyuria, polyphagia) • positive fasting plasma glucose test : post 8-hour caloric fast, venous glucose levels ≥ 126 mg/dL (7.0 mmol/L) • oral glucose tolerance test : 2 hours after 75 g oral glucose load, venous glucose levels ≥ 200 	

⁵⁰ Risk factors include overweight (BMI ≥ 25 kg/m²); age ≥ 45 years, physical inactivity; diabetes in a first degree relative; prior gestational diabetes or delivering a baby > 4 kg; polycystic ovarian syndrome; history of IGT or IFG, HDL-C level ≤ 35 mg/dL and/or triglyceride level ≥ 250 mg/dL; persons of Asian and African descent; presence of coronary artery disease and/or hypertension; presence of other vascular complications (CHRC and PAHO 2006, 7).

mg/dL (11.1 mmol/L)

Figure 1.5: CHRC and PAHO (2006) screening and diagnostic guidelines for diabetes in the Caribbean.

The guidelines further recommend that on-going clinical management should be performed by a multidisciplinary team approach, dependent upon the resources of the country in question (CHRC and PAHO 2006). The team would include a medical doctor, nurse, diabetes educator, nutritionist/dietitian, podiatrist/chiropractist, pharmacist, and social worker, with access to specialists (e.g., endocrinologist, physiotherapist, psychologist, ophthalmologist, and nephrologist). Despite its status as one of the most affluent countries in the Caribbean, however, multidisciplinary teams are not standard in public health settings in Trinidad, and the diabetes care available varies dramatically across the country. There are few dedicated diabetes clinics run by specialists, with most patients instead being treated within more general Chronic Disease Clinics (CDCs) run by general practitioners trained to provide overall public health care. The nutritionists and dietitians working in the public health sector are much in demand and as such, only patients with complex comorbid conditions tend to be referred to them, to the detriment of patients with uncomplicated diabetes. There are also few diabetes educators in Trinidad, so their services in the public health sector are limited. The majority of diabetes care is thus provided by physicians, nurses, nursing aides, and pharmacists. Referrals to specialists in the public sector take place in the case of severe complications, with protracted wait-times.

Recommendations for diabetes management universally include “lifestyle changes”, most commonly weight management, increased exercise levels, and decreased consumption of refined

carbohydrates, fats, oils and fried foods, salt, and red meat. Depending on disease severity, therapeutic drugs are also prescribed, ranging from oral antidiabetics (e.g., metformin or sulfonylureas) to various types of injectable insulin. Patients on insulin are prescribed diascan machines to test their blood glucose levels daily to titrate their dosages of insulin, and also so they can identify the insulin-induced low blood sugar (hypoglycaemia). Patients are advised to keep daily diaries of their blood glucose level readings, both so they can understand their own blood glucose fluctuations for finer control, and to share with their physicians at their next clinic visit for assessment of control. Food diaries are also recommended to correlate with their blood glucose readings. Anecdotally, however, it is very uncommon for patients to either keep track of their diascan readings or record them, and even less common that they keep food diaries in the public health setting in Trinidad.

Annual assessments of the systems most commonly affected by diabetes are also recommended, to assess for end-organ damage caused by diabetes.⁵¹ Patients are considered to have met their management goals if there have been improvements in the “objective” measures of disease control, such as weight loss or lowered blood pressures. The most crucial measure of blood glucose levels, however, is a patient’s glycosylated haemoglobin (HbA1c) level. This biochemical marker in the blood indicates blood glucose control over the previous three months, with higher readings directly correlating to more prolonged periods of elevated blood glucose

⁵¹ This includes their weight, body mass index, waist circumference, blood pressure, diet, mental health, tobacco smoking and alcohol use; physical examinations of their feet, eyes, and mouths; laboratory investigations of their glycated haemoglobin (HbA1C), lipids (cholesterol), creatinine and microalbuminuria (for kidney function), and an electrocardiogram for assessment of cardiac function in persons over 40.

levels.⁵² Blood glucose testing is widely available as a point-of-care test within public healthcare delivery centres (i.e. clinics and health centres), however HbA1c is only processed at centralised labs to which the blood samples must be sent, causing delays up to a few months between the administration of the test and receipt of results by physicians. This also causes delays in recommendations for patients to alter their management regimes in response. Due to financial constraints on the system, HbA1c testing is usually performed once a year in public health settings, though it is commonly repeated every three months in private health settings.

In the following section I explore another dimension to diabetes diagnosis and management in Trinidad, that of its relationship to race and ethnicity.

3.2 Race, ethnicity, diabetes and genetics

Type 2 diabetes mellitus is currently considered to result from complex gene-gene-environmental interactions for which family history is a strong risk factor, therefore being implicitly heritable (Kumar and Clark 2016). The genetic causes of some forms of Type 2 diabetes mellitus are also recognised as not having a simple mendelian pattern of inheritance (Walston et al. 1995), bringing into question simplistic evolutionary theories of single gene causation such as the “thrifty gene” hypothesis first suggested by James Neel (Neel 1962; Zimmet 1995; McGarvey 1994). In the post-Human Genome era, the emphasis of cutting edge research into diabetes therefore focuses on exploring complex interactions between environment, heredity and genetics.

⁵² The normal range is between 4% - 5.6%. Levels between 5.7% and 6.4% indicate increased risk of diabetes, while levels greater than 6.5% are considered diagnostic of diabetes by the guidelines of the American Diabetes Association, though not in the public health setting of Trinidad.

This research approach is informed by aggregated international epidemiological data that shows variations in diabetes prevalence rates with geography and ethnic groupings. For example, in 2000, the International Diabetes Federation (2001) estimated that Trinidad and Tobago was amongst the top ten countries in the world with the highest prevalence rates of diabetes (14.1%), while the countries having the highest numbers of individuals with diabetes included India, China, and the United States. Thus epidemiological and global health approaches to diabetes have identified specific racial and ethnic groups as particularly associated with the disease. Epidemiological research into the linkages between race, ethnicity, and diabetes also continue (for e.g., Chow et al. 2012; Oldroyd et al. 2005).

The use of racial categories in both genetic and epidemiological research is viewed as problematic by anthropologists, who consider race and ethnicity to be social constructs with little biological basis, being instead mechanisms through which people are categorised in accordance with existing power relations (Wade 2004; Ignatiev 1995; Dressler, Oths and Gravlee 2005).⁵³ Some biological scholars and epidemiologists have defended the use of racial classifications for research as having utility, suggesting that race acts as a proxy for population variability and reflects genetic differences in disease risk and its heritability (Marshall 1993 in Harding 1993; Risch et al. 2002). Root (2001) usefully summarises three tenets that underlie medical research arguments in support the use of racial categories: (1) the assumption that particular physical characteristics divide the races, (2) that these characteristics are heritable and express genetic differences and (3) that these genetic differences are concordant and result from differences in descent. However, a systematic review by Ma et al. (2007) of articles published in three highly

⁵³ This is particularly illustrated by the historical use of racial categories to create and perpetuate discrimination.

reputed biomedical journals found that race/ethnicity was sub-optimally determined and reported in primary research. In a review of health services research from 1966 to 1990, David Williams (1994, 266) similarly found that the conflation and interchangeable usage of race and ethnicity ascribed to heritable biological traits essentialised cultural practices as well. Indeed, as Stuart Hall (1997, 3) notes, race is often used as a “floating signifier”, a placeholder in a classification schema that operates as a system of power, where the classification reproduces fixed boundaries of expected order.

Medical anthropologist Michael Montoya (2007) critiqued the usage of “racial taxonomies” by clinical diabetes scientists, who used it to “parse populations and social history to rationalise their categorical choices” (Montoya 2007, 180). As Ian Hacking (2005) has also pointed out, while the ascription of a racial identity may be intended as mere description, and does not necessarily imply a hierarchy, its usage as a category in research is inherently evaluative: it may allow the circumvention of explicit engagement with the complex interaction of social, environmental, economic, and other factors that are in fact having an effect on the measured outcome.

Anthropological approaches to the genetics of diabetes have attempted to broaden narrow and reductive biomedicalised perspectives that map the disease onto biological race and ethnicity. For example, in researching the relationship between diabetes, genetics and race, anthropologist Montoya (2007) followed Mexicano/a DNA samples from their collection points on the Texas border to examine the “production, circulation and consumption of diabetes [genetic] knowledge” (10) by diabetes scientists, and the concomitant production of racial taxonomies. He showed that the genetic scientists’ quest to categorise populations and “reconcile diverse frames of epistemological reference” (Montoya 2007, 114) involved the antipolitical

processes of “reductionism, scientism, biologization” (180), i.e. processes of biomedicalization. Together, these processes erased the forms of inequality often underlay the development of diabetes.

Similarly, Mariana Ferreira and Gretchen Lang (2006) argued that a focus on the “bad genes” of indigenous populations that cause diabetes undermines an understanding of the effects of colonialism and resultant structural issues such as stress, poverty and discrimination of which diabetes is the true manifestation. Carolyn Smith-Morris (2006) also explored the epidemic of diabetes among the Pima Indians of Southern Arizona. She found a divide between the Pima view and the medical view of gestational diabetes, with the medical view being given greater primacy and the community’s stories of illness being presented in ways “peppered with ethnocentric oversimplifications” (Smith-Morris 2006, 89). Smith-Morris instead focuses on the deepening an understanding of effects of rapid historical changes to Pima culture, economics, and environmental influences, and how their effects converged in producing genetic change.

The use of racial and ethnic categories that are biologised (Montoya 2007; Whitmarsh 2009) or have ambiguous meanings in epidemiological and genetics research into diabetes however continues (Hunt and Megyesi 2008). In the following section, I outline the research conducted into diabetes in Trinidad.

3.2.1 Diabetes rates and ethnic and racial attribution in Trinidad

The earliest health research publications on diabetes in Trinidad consistently used “race” and “ethnicity” as categories to describe and compare the state of disease within the population. Gillespie (1951), for example, identified diabetes mellitus as a “common disease in Trinidad” among the “hospital-attending (i.e., poorer) population”, for whom a free private clinic was

organised in the capital city of Port of Spain, noting that patients were mostly “negroes” with a small proportion of “East Indians”, “Chinese”, “Europeans”, and “people of mixed blood” (Gillespie 1951, 545). Wattley (1959) similarly noted that an excess of “East Indian” people were being admitted to the hospital in South Trinidad with acute myocardial infarction, as a percentage of the total population of the hospital, the other races admitted for myocardial infarction (the listed races included Coloured [i.e. Negro & mixed], White, Chinese, Syrian), and their general percentage of the population.

Pyke and Wattley (1962) later attempted to identify the distribution of diabetes based on the age, sex, weight and parity of patients at a hospital diabetic clinic in south Trinidad. They found that persons with diabetes were heavier, women numbered more than men, and the parity of persons with diabetes was greater than in controls without diabetes. Additionally, they noted that amongst the male patients, there was a “preponderance of East Indians (72 per cent) when compared with the same population” (Pyke and Wattley 1962, 24). Wright and Taylor (1958) attempted to find the incidence of diabetes in the Trinidad population by testing the staff and families of the Shell Trinidad Limited Company. Their stated purposes in doing so were firstly to accurately quantify the disease incidence, which was believed to be very high, and which they suggested might have been magnified by physicians’ repeated exposure. Secondly, they referenced previous research that suggested that the same disease or condition might have “an entirely different incidence in different races in the same area “ (Wright and Taylor 1958, 124).

From the earliest publications on diabetes in Trinidad, the group comprising the descendants of Indian indentured labourers has thus been characterised as having higher prevalence rates of diabetes when compared to the other major ethnic groups present within Trinidad. Poon-King, Henry and Rampersad (1968) conducted the first population-level

epidemiological research into diabetes rates, performing a stratified random sample of 23,900 people from the total population of Trinidad between 1961 and 1962, screening them for diabetes and following up for five years. They reported that 1.89% of the sample satisfied their criteria for diabetes, one of the highest reported prevalence rates for the region.

They also reported that “diabetes is more common among East Indians (2.37%) than Negroes (1.44%)” across all socioeconomic groups, with almost equivalent prevalence in urban areas and sugar-cane districts (2.67% vs. 2.56% respectively) (Poon-King, Henry and Rampersad 1968, 155). Later, the landmark St. James Survey found diabetes incidence rates of 37 per 1000 person-years in men and 29 per 1000 person years in women, while the incidence of diabetes was 23.5 per 1000 person-years in “Indians,” significantly higher than in “Africans” (Miller et al. 1989, 1996). This survey ran from 1977 to 1985 and recruited 2,491 participants from the urban St. James community, comprising 786 “African”, 598 “Indian”, 147 “European” and 467 “Mixed descent” adults who were followed and assessed over a 10-year period for the development of coronary heart disease, hypertension, diabetes, and associated morbidity and mortality. The St James Survey documented a high prevalence of diabetes, especially among the “Indo-Trinidadians” (23% among females and 20% among males), compared to the rates in the “Afro-Trinidadians” (17% among females and 8% among males) as well as twice the rates of coronary heart disease (Miller et al. 1989, 1996).

These landmark epidemiological studies of large sections of the Trinidad population confirmed the prevailing opinion that diabetes and cardiac disease were more prevalent among the descendants of the Indian indentured labourers than the descendants of the African slaves. More recent studies of diabetes prevalence have however been ambiguous in describing their methodologies for determining prevalence rates between the different designated “races”. For

example, Gulliford and colleagues (1995), who conducted protracted research at the Port of Spain General Hospital, estimated that diabetes accounted for 13.6% of hospital admissions and 23% of hospital bed occupancy in 1995, and found similar percentages once again in 1997 (Gulliford 1995, 1997). No population figures were however available for the number of new cases or repeat patients, as these were not recorded or collated by the Ministry of Health.

While race and ethnicity have historically been the focus of diabetes research in Trinidad, research into the genetics of diabetes has been scarcer. The few studies that have been conducted have suggested a greater impact played by environment than genetic architecture, in producing the ethnic disparities seen in disease (Hegele et al. 2001).

Wide-scale population-based epidemiological surveys of diabetes rates among adults have been supplanted largely by self-reported studies, such as the 2005 Survey of Living Conditions by the Central Statistical Office of Trinidad and Tobago, which reported that of 2086 community dwelling respondents, 10.4% of the poorest, and 17.6% of the richest had self-reported diabetes. Most recently, over 2008 – 2009, Chadee et al. (2013) similarly carried out a self-reported survey with 14,793 responses. They found the prevalence of diabetes to be 19.5%, with the highest disease prevalence among Indo-Trinidadians.

The prevalence rates reported by the World Health Organization ranged from approximately an estimated 14% in 2011 (WHO 2013) to 12.5% in 2016 (WHO 2016). The International Diabetes Federation (IDF), meanwhile, has successively listed the national diabetes percentage prevalence in Trinidad for adults between the ages of 20 to 79 years as: 14.1 in 2000; 7.9 in 2003; 11.5 in 2006; 11.4 in 2009; 12.95 in 2011; 13.89 in 2013; 14.5 in 2015, and 12.0 in

2017.⁵⁴ These percentage prevalence rates show high variability, and appear to fluctuate in some successive years, despite a widespread perception of rising prevalence rates in Trinidad and Tobago.

3.2.2 Critiques of estimations of diabetes prevalence in Trinidad

Most epidemiological data released for Trinidad and Tobago is qualified as “estimates” by the listing bodies, such as the Central Statistical Office of Trinidad and Tobago, the WHO, or the IDF. These prevalence rates are usually synthesised from research conducted locally. This research is not always epidemiological in formulation, and is often conducted on different samples of the total population and extrapolated to the whole. As the historical overview of Debe in the previous chapter indicates, however, settlement patterns, yearly life cycles, and population distribution over the Trinidadian landscape is still heavily influenced by its history, and is thus variable. The representativeness of even a random sample from a specific region of Trinidad is thus questionable.

The epidemiological data from the WHO and IDF also show variability or fluctuation over the years, calling into question their validity. The IDF clearly indicates, indeed, that its prevalence estimates for Trinidad in 2003 and 2013 are “extrapolations” from research in Jamaica (Wilks et al. 1999). Jamaica has a significantly different ethnic and racial population composition than Trinidad, with different economic, social and structural forces at work within their population. From the standpoint that uses race as a proxy for genetics, the different

⁵⁴ These figures are taken from the International Diabetes Federation Diabetes Atlases from 2000 to 2017 (IDF 2000; IDF 2003; IDF 2006; IDF 2009; IDF 2011; IDF 2013; IDF 2015; IDF 2017).

populations of the two countries should result in different prevalence rates. Thus extrapolating from another population to produce diabetes prevalence rates for Trinidad, as the IDF did, has the potential to be highly misleading. The WHO, however, rarely lists the studies from which it draws its prevalence estimates. Currently, therefore, though the official prevalence rate for diabetes in Trinidad and Tobago is listed as 12.5% by the WHO, the ambiguity of the methods and data sources used make this estimation debatable.

The epidemiological data generally indicates that diabetes incidence and prevalence rates in Trinidad are highest within the Indian Trinidadian population, however rates are also high amongst the African descent population of Trinidad when compared to North American or European Caucasian populations. These ethnic designations deserve closer scrutiny, as there are ambiguities to the designation of racial and ethnic groupings used in health sciences research conducted in Trinidad. The early epidemiological studies performed by Poon-King, Henry and Rampersad (1968) and Miller and colleagues (1996) describe how study participants were assigned to specific racial groupings, however their methods leave open to interpretation the basis and consistency of the categorisations in use.⁵⁵ In the more recent self-reported studies, additionally, there is ambiguous language used on the census forms: as is noted in the preceding

⁵⁵ Poon-King, Henry and Rampersad (1968) stated that, “Of the 23,700 people who took part in the survey, 48% were Negro, 39% were East Indian, 10% were of mixed race and 1% were people of other races – i.e., compared with the whole population – a close correlation in the percentage of East Indians and a slight preponderance of Negroes (which is partly explained by the fact that many people classified as mixed in the 1960 census, *appeared to be* dominantly Negro and were classified as such by the survey team)” (Poon-King, Henry and Rampersad 1968, 155, emphasis added). The authors thus state that the survey team is partly responsible for the ascription of race, on the basis of assumptions about phenotypic characteristics and their relationship to race. The St James Survey from 1977-1989 similarly stated, “Ethnic composition was determined from grandparental origins. Subjects *judged to be* at least 75% common genetic stock were classified accordingly (African, Indian, European, Chinese, Lebanese, Syrian); otherwise they were regarded as 'Mixed' “ (Miller et al. 1989, 809). This description is ambiguous as to who is doing the “judging”, and on what basis, leaving it open to interpretation that ethnicity is again being ascribed on the basis of phenotype.

chapter, the “ethnic groups” designated on the Central Statistical Office forms conflate as equivalent race, ethnicity, and geographic origin.

A survey of the health science research into diabetes conducted in Trinidad has shown that few to no studies attempt to define the terms race or ethnicity, even when these categories under investigation for comparative purposes.⁵⁶ Racial and ethnic terms are also often used interchangeably within the same study, and the concepts conflated.⁵⁷ This is consistent with the critiques of the usage of race for research by medical social scientists, who find that race and ethnicity are often poorly defined, engaged in under-theorised and uncritical ways, and thereby conflated with social, economic, and cultural factors (Gravlee and Sweet 2008; Harding 1993; D.R. Williams 1994; Montoya 2007).

Despite the highlighted ambiguities and inconsistencies to the designations of prevalence in Trinidad, the available evidence has produced a discourse in professional medical contexts that links diabetes with the Indian Trinidadian community. For example, as an older physician explained about practicing in a public community health context, “You know how they say in medicine, when you hear hoof beats, think horses not zebras? Well in Trinidad, when you see somebody walk through your clinic door, if they Indian, you think diabetes, if they African, you think hypertension.”

⁵⁶ Based on a review of the 200 most recent articles on PubMed with the terms ‘diabetes’ and ‘Trinidad’ that used race or ethnicity as a demographic category.

⁵⁷ The literature reviewed used a range of different racial and ethnic terms to categorize the population of Trinidad and Tobago, occasionally using both racial and ethnic designations in the same article to refer to the same purported population.

3.3 Structure of the health care sector in Trinidad

The current structure of the health sector of Trinidad and Tobago consists of two parts: a system of nationalised free public healthcare provided to all citizens funded by taxes, and private healthcare on a fee-for-service basis or through employer-provided insurance. This division increasingly manifests the social inequity in wealth distribution in Trinidad, as many who can afford to flee the nationalised public healthcare sector for the private sector, aided by the public sector's fragmentation into privatised parts due to neoliberal restructuring policies. It also recapitulates in transfigured postcolonial form the historical, colonial roots of the present healthcare system, in which the ruling elites received private health services, institutional services were provided for the labouring classes, and the most socially disadvantaged and disabled were dependent upon charitable care.⁵⁸

There is a high degree of dissatisfaction with the health care system as it currently stands, evidenced by: regular public outcry in the media, an increase in medical malpractice lawsuits (Kowlessar 2011), government issued reports on the public health sector and public health care delivery (including Gafoor et al. 2007; Charan 2011; Welch et al. 2016; Welch and Sirjusingh 2017), and a growing body of health research literature documenting its failings (for e.g., Bahall 2018a, 2018b, 2012; Apparico et al. 2007; Pinto Pereira et al. 2009).

⁵⁸ See Jayawardena (1963) and Bissessar and Haqq (2001) for more discussion of healthcare provision under colonialism.

3.3.1 Public Healthcare

Public healthcare is a two-tier system in Trinidad and Tobago. The first tier consists of the Ministry of Health (MOH), headed by a Minister of Health, usually an elected member of the ruling political party. The Ministry sets the national health agenda, oversees the system, administers policy in the health sector, and funds the activities of the Regional Health Authorities (RHAs). It is also responsible for developing legislation, regulation guidelines, monitoring and evaluation, and research related to health.

At the next tier are five semi-autonomous Regional Health Authorities (RHAs). The RHAs deliver health services and administer the public health care facilities of Trinidad and Tobago on a geographic basis. They were formed by an Act of Parliament in 1994 as an effort to decentralise healthcare from the Ministry of Health, after a recession in Trinidad and Tobago caused cut-backs in public services in accordance with International Monetary Fund (IMF)-recommended, neoliberal structural adjustment policies.⁵⁹ There are four RHAs in Trinidad and one in Tobago. The public health care facilities administered by the RHAs in Trinidad include three general hospitals with tertiary care capacity, two district hospitals, four specialist hospitals (psychiatric, maternity, thoracic and a combined radiotherapy, physical medicine, and gerontology facility), and a general hospital in Tobago. Trinidad also has 84 local health centres, while Tobago has 18.

⁵⁹ For an exploration of the role of the IMF in the implementation of austerity measures in Trinidad in the 1980s and its effects, see *Capitalism: An Ethnographic Approach* by Daniel Miller (1997). For a critique of the underlying bases of this political choice see *Enough is Enough* by Davison L. Budhoo (1988). In addition, for a summary of the findings of the United Nations Economic Commission on Latin America and the Caribbean (ECLAC) on the effect of 20 years of neoliberal economic policies in the region, see article by Peter Zirnite (1996).

The South West RHA (SWRHA) is responsible for health care delivery in Debe and its environs and is based in San Fernando, the second largest city in Trinidad. Its coverage area encompasses roughly one-third the surface area of Trinidad, including many rural locations, and it serves approximately 500,000 to 600,000 people, arguably the largest population of all the regional health authorities. The only tertiary institute within the SWRHA is San Fernando General Hospital (SFGH), which has been expanded from its original colonial-era structure to include newer wings over the years. SFGH is located in the southern city of San Fernando, and has fewer tertiary care options than the two other general hospitals located to the North of Trinidad.

The SWRHA administers SFGH, Point Fortin Area Hospital (a secondary, district health care institution) and 33 health, outreach, and extended health care centres, commonly known as local or community health facilities/centres. Community health facilities offer a variable range of basic, primary care services via outpatient clinics including: cervical screening, child health clinics, immunisation, CDCs, testing and counselling for HIV, dental services, diabetic clinics, dressings and wound care, family planning, general practice, home visits, pre-natal clinics, post natal clinics, social work services, psychiatric clinics, school health, dermatology/skin clinics, and wellness clinics. Expanded community health facilities provide more services and function for longer hours, for example District Health Facilities, which are open for 24 hours and provide secondary health services.

The official number of public hospital beds in Trinidad is 2.7 per 1000 people, comparable to the US at 2.9 and significantly higher than the ratio in Latin America and the rest of the Caribbean (2.0). Physicians, health care administrators, the media, and the general public however continue to have a perception of chronic bed shortage. This is particularly acute in the

large geographic area of Trinidad served by the SWRHA, where post-call admissions may result in over-full wards with as many occupied emergency trolleys as hospital beds. There are no dedicated specialist tertiary care facilities available for children and women in the SWRHA, resulting in a mandatory minimum thirty-minute drive by ambulance to the nearest public hospitals with these specialisations.

Successive governments have promised the expansion of the health care infrastructure in South Trinidad, however it was only under the People's Partnership that the most recent visible and successful efforts were achieved. In 2014 an Administrative Complex in San Fernando was converted into the advanced, 216-bed San Fernando Teaching Hospital, connected to the San Fernando General Hospital by a skywalk. A Children's Hospital and Multi-Training Facility in Couva was constructed in 2015 to provide another 230 beds (including 80 for children), plus centres for training 300 students from UWI's School of Medicine, Nursing and Pharmacy. However, after the election of a new government in 2015 it has remained empty, due to uncertainty over its function and a purported lack of personnel and financing to fully equip and staff it (Welch et al. 2016).

Entry into the public health sector at the local level occurs by joining a local health centre. Patients may be joined to a local health centre in two ways: a) by going to the walk-in clinic at the health centre, being assessed, and then registered with a specific clinic, or b) by referral to the health centre with a letter from a public hospital, private hospital, or private practitioner. If a patient receives a referral letter from a public hospital ward upon discharge, they are expected to receive further community based care and management through their local health centre. The onus lies on the patient for follow-up: the local health centre is not notified that the patient has been referred there prior to the patient's arrival with the referral letter. There

is no way of tracking whether they indeed registered with their clinic after hospital discharge.

There is currently no electronic medical records system within the public health sector, so patient notes are still taken by hand and files are moved around from one institution to the other based on patient registration numbers.

3.3.2 Private Healthcare

Private health care is provided in Trinidad and Tobago by individuals and institutions on a fee for service basis, with services primarily paid for out-of-pocket or through employer-provided private insurance. Historically, private physicians in Trinidad catered to the needs of the elites, while hospital- or institutional-based care was geared towards its lower classes. After the end of colonialism, however, the government of Trinidad invested in public healthcare infrastructure and built new, state-of-the-art hospitals such as the Mount Hope Women's Maternity Hospital and the Eric Williams Medical Sciences Complex as a marker of its investment in the population and its Independence.

A significant leap in the number of private healthcare institutions and providers occurred in the 1980s (Bissessar and Haqq 2001). Private healthcare again experienced a jump after the restructuring of the health care system in 1994 produced the system of Regional Health Authorities that decreased the job-security of health workers by making them contractual employees rather than public servants with associated benefits. By one estimate, 75% of the upper-middle- and upper-classes solely access private healthcare in Trinidad currently.⁶⁰ Physicians, dentists, pharmacists, and opticians are licensed to open and operate individual

⁶⁰ Personal communication with health sector administrator who preferred to remain anonymous.

offices. Privately owned and operated clinical laboratories and diagnostic testing facilities have mushroomed even within the smaller towns in Trinidad like Debe. These promise a faster turnaround of results than is available at public health centres, and patients can also directly access their own results rather than requiring the results to be disseminated to them by a physician.

Private health care is also available from institutions such as tertiary-level private hospitals and secondary care “nursing homes”. Private hospitals solicit customers based on their differences from public hospitals, namely that they have a “patient-centric” approach of placing the patient first, cleaner and better-run facilities, and more direct access to physicians. Private patients also expect to receive their care directly from more experienced doctors and specialists than are accessible in the public sector. Patients also have more options for privacy, having the choice of individual rooms rather than wards for a fee. Private hospitals have higher nurse to patient ratios; and the staff is generally expected to have a more consumer-driven approach with patients than is the norm in public hospitals. Tertiary care is a high demand area, making it perhaps the most lucrative area of private health care practice in Trinidad.

The Ministry of Health has regulatory powers over private hospitals in Trinidad and Tobago according to the Private Hospital Act of 1960. All private hospitals are required to apply for a license to operate. However, once the license is obtained there are currently no mechanisms in place to monitor or regulate the functions of these facilities or the quality of care that they deliver. While laws and regulations for medical care have existed for years, in the absence of a functioning legal framework that standardises assessment service quality, they are effectively useless. This gap in the system was recognised by the government of Trinidad and Tobago, which advertised the formation of a standardised Accreditation System for both private and

public health institutions in 2008. They also released plans to establish a Health Services Accreditation Council to oversee the accreditation of health care facilities, requiring a concomitant assessment of services. To date, however, no official quality-of-care standards have been introduced, nor have official bodies for the assessment or enforcement of quality-of-care standards.

Currently, therefore, the ultimate authority for regulating individual practice lies with the licensing body for medical practice, the Medical Board of Trinidad and Tobago, which has the option of striking individuals off its register and rescinding their licenses in cases of gross malpractice. There is no precedent for regulating care provision at an institutional level.

Private health institutions are indirectly regulated by the Central Bank of Trinidad and Tobago through the latter's regulation of private health insurance. The Central Bank conducts risk-based examinations to ensure that insurance companies are covering risk and have implemented measures to mitigate risk. For insurance companies that provide long-term health insurance (over five years in duration), the Central Bank mandates the following: a) they must have an actuarial risk-assessment; b) they must submit audited returns once a year and c) they must submit un-audited returns once a quarter. Health insurance companies thus determine which private institutions and providers they are willing to reimburse, based on these risk metrics. Risk in this context, however, is more related to the potential financial exposure of the health insurers than to any quality of care metrics.

Private providers are paid at the point of service by the patient, or if referred by the public institutions, by the Government of Trinidad and Tobago through disbursements (vouchers) from the RHAs. Private insurance is the most common form of payment for individual patients, most often provided by their employer as part of their employment benefits. Less frequently, payments

are made in cash by those without insurance, or through the Government voucher system.

Patients may be referred from the public sector to obtain services from private institutions when public service providers are overwhelmed, with vouchers or reimbursement from the RHAs. This is common practice for a number of procedures including haemodialysis,⁶¹ some investigations, and Intensive Care Units when public ICUs are fully occupied. The proposed introduction of a National Health Service, similar in principle to the existing National Insurance Scheme, would modify the payment mechanism to private providers and reduce the number of patients paying out of pocket, however that has yet to be introduced.

Health care workers may be employed concurrently in both the public and private health sectors. There is currently no legal mandate requiring health care workers to be employed exclusively in either sector, despite repeated recommendations to this effect from the 1940s onwards.⁶² The senior-most doctors in the public sector, also known as “Specialist Medical Officers” or “Consultants” have responsibility for managing specialist services, conducting procedures, and usually lead teams of more junior doctors who provide more day-to-day, less crucial care. Consultants however also conduct private medical practice to supplement their income. It has become common practice, however, for Consultants to have limited presence in the public sector clinical settings, despite being categorised and remunerated as full-time employees of the Regional Health Authorities. Most health care services delivered in public health settings, are therefore the work of their junior staff (for e.g. in hospital wards and clinics).

⁶¹ This policy change was implemented in 2015 by the then-Minister of Health, Dr. Fuad Khan, who authorized 16 private health institutions to provide dialysis treatment to patients with renal failure through an External Patient Programme (EPP) with remuneration from the EPP or the Regional Health Authority (Paul 2015).

⁶² The Russell Committee report of 1944 and the Julien Commission of 1957 into the state of healthcare in Trinidad and Tobago issued recommendations that private practice be forbidden to government medical officers (McCollin 2009), a recommendation which has been repeated in other reports like the Gafoor Report (Gafoor et al. 2007).

This common, standard practice in Trinidad largely goes unremarked within the medical establishment, but has been the cause of public outcry and lawsuits for medical negligence or malpractice. Indeed, as recently as 2016, a governmental committee was convened to review the levels of health care delivery by the Regional Health Authorities and to “Rationalise the system of public sector doctors in private practice” (Welch et al. 2016). A common critique that arose was that senior doctors preferentially devoted their time to their private practices due to the higher rates of remuneration received, to the detriment of their public health care commitments, as well as in competition with State services for patient business (Welch et al. 2016; Hassanali 2017). The medical establishment in Trinidad however has little interest in mandating public or private exclusivity to clinical practice, which would cause significant financial losses.

As the number of private institutions have increased, so too has the practice of working in both settings, since the formation of the RHAs mandated that health care workers become contract-limited employees instead of public servants, with a concomitant loss of job security. In addition, Consultant positions in the public sector are very few in number, while specialisation continues to be pursued by qualified physicians, resulting in an underutilisation. Lower- and mid-level more junior doctors (Interns, House Officers and Registrars) therefore comprise the majority of the staff at both public and private hospitals, and there are many junior doctors and registrars with equivalent experience to consultants, if not with the same level of qualifications.

In recent years, there has been a dramatic rise in media reports about alleged medical malpractice at medical institutions in Trinidad, with accusations of improper, negligent, or inhumane patient treatment. These reports and accompanying medical malpractice suits have focused for the most part on the public hospitals, for which the Minister of Health ultimately

owes a responsibility to the people of Trinidad and Tobago, and not on the private hospitals, which are not audited by the public.

3.3.3 Governmental initiatives for managing diabetes and the concept of “non-compliance” in Trinidad

Chronic diseases exert a significant pressure on the public health-care sector: diabetes care is costly, with 12% of global health care expenditures spent on people with diabetes in 2010 (Zhang et al. 2010). Chronic diseases were four of the top five causes of death in Trinidad and Tobago in 2016 in a continuation of the trend for the previous 25 years (Central Statistical Office 2017).

To ameliorate the population effects of these diseases, previous governments of Trinidad and Tobago initiated efforts specifically targeting chronic diseases. Patients diagnosed with chronic diseases receive continuous care and follow-up at CDCs held on multiple days of the week at local health centres throughout the country. In 2003, the Chronic Disease Assistance Program (CDAP) was also introduced to expand the distribution network for prescription drugs and medical supplies, to ameliorate the overcrowding at public sector pharmacies. CDAP provides all citizens with a list of commonly prescribed medications and medical supplies for free, to treat the most common chronic diseases. The chronic diseases include: diabetes, asthma, arthritis, glaucoma, cardiac disease, high blood pressure, mental depression, thyroid disease, benign prostatic hyperplasia, epilepsy, hypercholesterolaemia, and Parkinson’s disease. These supplies are available with prescription through local health centres and also at over 250 private pharmacies throughout Trinidad, via a public-private contract partnership arrangement.

Since the implementation of CDAP in 2003, there have been mixed responses to the program. Small studies conducted in 2007 (Bobb et al. 2008) and 2011 (Maharaj et al. 2011) have shown mixed outcomes for persons with Type 2 diabetes, with an increase in the accessing of therapeutic pharmaceuticals since the introduction of CDAP. Critics say, however, that the program unduly benefits private pharmacies which have private-public partnerships, and receive compensation from the government for the import, stocking, and dispensation of the generic CDAP medications. This critique is consistent with the early predictions that the RHA system would benefit multinational corporations such as the pharmaceutical companies, at the expense of taxpayers (Phillips 1994). For many pharmacists, including those I interviewed in Debe, much of their inventory now consists of the generic drugs which are prescribed via CDAP, that have become their most reliable prescriptions. The generic drugs prescribed for diabetes via CDAP include Metformin HCL, glibenclamide, gliclazide and different formulations of insulin. There has repeatedly been controversy around the effectiveness of these drugs, as recently as 2017, when the Minister of Health Terrence Deyalsingh questioned whether some drugs distributed through the CDAP were “substandard” (Doodnath 2017).

The pervasive perception within the health sector that chronic disease patients are non-compliant is reflected in the health sciences literature produced within Trinidad as well. This literature repeatedly correlates poor blood glucose control (evidenced by high blood glucose levels and elevated HbA1c) and/or poor health outcomes (i.e. the development of morbid complications) with poor compliance and continued “unhealthy lifestyles” (for e.g., see Islam et al. 2013; Harnarayan et al. 2014). Most research is produced by physicians and is directed towards a physician audience, consistent with the critique that compliance reflects a doctor centred perspective (Conrad 1985) that unduly privileges questions about how well patients

follow medical advice, thereby obscuring the complexity of patients' behaviour through the emphasis on why "people fail to follow doctors' instructions" (Stimson 1974, 99).

Pinto Pereira et al. (2009), however, performed a retrospective study of 646 persons with Type 2 diabetes managed in the public health sector in Trinidad between 1997 and 2005, which identified that clinical management falls short of Caribbean guideline recommendations. Recommended assessments such as waist circumference and BMI assessments were not performed at all, and HbA1c was only rarely measured (Pinto Pereira et al. 2009). Yet despite insufficient and inconsistent clinical management, almost half (47.2%) of physicians indicated that they advised patients on "treatment compliance" (Pinto Pereira et al. 2009). This suggests a transferral of responsibility onto patients for their disease control even in the absence of clinical support, and it further suggests a heavy reliance on blood glucose control through the taking of medications, independent of the larger framework of diabetes management outlined in the CHRC guidelines. As the upcoming ethnographic chapters reflect, these guidelines themselves are based on a superficial grasp of the factors that are truly implicated in even the most cursory of recommendations for diabetes self-management in the lives of people in Debe.

Chapter 4: Food as love, identity and community: Asymptomatic diabetes and dietary practices within a community context

This chapter explores the roles and relationships that food enacts in people's life-worlds as a part of ethnic and religious identity formation, sociality, and notions of a good life, through the ethnographic case studies of two women, Tara and Tanty Dularie. These ethnographies challenge the utility of universal biomedical recommendations for individuals to change their dietary practices by demonstrating how inextricable these practices are from people's larger contexts of integration into social milieus of family and community.

Food-related activities in Debe are shown to be both highly gendered and a means by which people materially constituted themselves every day: physically through the act of consumption and absorption, symbolically, through the signification of what foods were consumed and how, and socially, through the establishment of community cohesion and support networks. What is revealed is that diets are processual social objects constituted by and enacting meanings such as love, family, respect, religious observance, and communal solidarity.

What these ethnographies also demonstrate is the common attribution of "non-compliance" to patients in chronic disease, and how complex non-compliance is in practice. The characterisation of Indian Trinidadian dietary practices as particularly pathognomonic of chronic disease on the whole is also highlighted.

4.1 Tara

4.1.1 Communal cooking: Commensality, religiosity, identity

I met Tara at a Ganesh puja held at the Amar Trace Mandir (temple), where she was a vibrant part of its highly active Mandir Group. Tara was in her late forties, about five feet five inches tall with a taut, broadly curved belly against which she would balance whatever she was cutting, peeling, kneading or slicing; I rarely saw her with her hands still. Tara insisted that she was “too young” for me to call her Tanty, which broke the ice. She was the head cook of the Mandir Group and was known in the village for her sweet hand (being a good cook), especially for what was called “authentic Trinidad Indian food” and “traditional prayers food”. As was the case with most active mandirs in the area, the Amar Trace Mandir Group comprised mainly women, who arranged schedules for mandir cleaning and organising before and after prayers, obtained materials for ritual prayers (e.g., ritual leaves, flowers, betel nut, camphor), prepared the bedi (altar) anew for each puja, and supported the activities of the pundits. Perhaps the most crucial role of the Temple Ladies, however, was preparing the “prayers food” for the communal meals that were characteristically served after ritual celebrations at the mandir.

“Prayers food” referred specifically to what people called “traditional” Indian Trinidadian vegetarian dishes served at Hindu ritual ceremonies. All foods cooked on the premises of a Hindu temple, to be served in a Hindu temple, or to be served in celebration of a religious ceremony, had to be vegetarian. Prayers food therefore included talkaris, chokhas, dals, rotis, rice, sweets, and parsaad (blessed, ritual sweet food) but no meats. All foods also had to be prepared in accordance with religious proscriptions, including that the food must be vegan; no meat must ever have touched the utensils and pots being used; menstruating women should not be involved in its preparation; and particularly those who prepared the parsaad should have been

fasting from meat. For prayers performed at home, however, people varied in the degree to which they observed vegetarian and non-vegetarian separation: in addition to using dishes in which only vegetarian food had ever been prepared or served, some people also cleared out all the meats from their refrigerators and freezers so that there was no meat on their premises when having a puja. Others just used dedicated cookware. Still others did not observe the exclusion of menstruating women from the performance of food, ritual preparations, or the rituals themselves. These religious proscriptions were generally most emphasised and upheld by the male pundits and the older women in the community.

Tara was very familiar with these proscriptions, as were the other women of the Temple Group who assisted with preparations and cooking. Additionally, none of the food prepared could be tasted before it was sanctified by being offered at the altar, thus cooking tasty prayers food was a particular skill.

Many Hindu prayers, such as yagyas, took place over consecutive nights, with food being served on each night, while at others food was served only on the last night. Large volumes of food therefore had to be prepared freshly during the day. The most festive meals had the widest variety of talkaris (side dishes) made in the largest volumes, and were commonly served on the last days of the prayers. Yagyas involved the performance of a puja (ritualised prayer to the Gods); the recitation and interpretation of Hindu religious texts by the pundit; a hawan (offering of food-stuff to a sacred fire); the performance of aarti (veneration of the deities and respected elders); the sharing out of parsaad (blessed ritual sweet food) and communal partaking of a feast, consistent with Vertovec's (1992) description.

One Saturday, I assisted Tara with preparing the meal for the last night of a Ramayana yagya that was being held the following day at the Amar Trace Mandir. The whole village was

expected to attend, approximately one hundred and fifty people in all. At five am that Saturday morning, we drove to the Southern Wholesale Produce Market, and Tara chatted with the vendors while she bought forty pounds of potatoes, thirty pounds of dasheen bush bhaji, and pounds of bodi, chataigne (local chestnut), onions, garlic, ginger, and fresh herbs. The next trip was to Mainline Grocery along the Debe Main Road, where Tara bought twenty pounds of dried channa (chickpeas), three ten-pound bags of rice, two twenty-pound bags of white flour, thirty pounds of white sugar, large bags of salt, curry powders, and many litres of Sunflower vegetable oil. Back at the mandir, other women had already begun preparations. A pile of potato peels was collecting next to the even larger pile of washed potatoes; a knobby-skinned pumpkin was being chopped with a cleaver on a wooden cutting board on the floor; ten pounds of garlic was being peeled clove by clove; onions were being chopped, and herbs finely diced and ground in food-processors.

Tara was the head cook of the Temple group, which meant that she directed the food preparation, while the other women helped. While the cooking would be done on the following morning, the Sunday morning of the prayers, there was still much food preparation to be done the preceding day, including the peeling, cutting, grating, and chopping of vegetables. The food preparation proceeded like a dance to which the women knew the steps, and knew too the tricks to such large-scale preparation. For example, potatoes had to be cut into large cubes about the size of a thumb, to prevent them dissolving completely while being curried the next day. Dipping one's fingers in oil before handling garlic cloves would prevent a burning sensation. The seed-casing of the many seeds of the unripe chataigne (local chestnut) were inedible, and therefore had to be extracted from the meat of the fruit and individually peeled before the flesh could be made into a coconut-milk curry. Dasheen-bush (taro leaves) bhaji stems had to be peeled of a

thin membrane before cooking, as this could irritate the lips and tongue. The pounds and pounds of onions and garlic had to be chopped or grated to different sizes, to be used in different ways.

There were also cooking practices Tara and the Amar Trace Mandir ladies believed were unique, that they used to make their food especially tasty. For example, the dried chickpeas were soaked in water overnight, then rubbed with handfuls of sugar and freshly ground herbs and “soaked” (marinated) again before cooking. Cubed potatoes were immersed overnight in water in which Nestle brand “Maggie” vegetable stock cubes had been dissolved. The parsaad (blessed ritual sweet food) was better if made not only with refined white flour, but with cream of wheat as well that gave it an “extra fluffiness”. People in the village with deep freezers had cut up and frozen mangoes when they were in season, making curried mango possible even though fruit trees were no longer bearing.

Tasty food in Debe was also reflective of the particular processes of Indian Trinidadian identity construction: food was tasty when communally shared and agreed upon notions of *authenticity* were achieved through it. Taste, in this context, was aligned with taste as defined by Pierre Bourdieu (1984) in his foundational text *Distinction*, wherein he identified French patterns of consumption as reproducing social and class distinctions and relations, rather than solely aesthetic expressions of individual preference. Tasty food in Debe was also reflective of the particular processes of Indian Trinidadian identity construction: food was tasty when communally shared and agreed upon notions of *authenticity* were achieved through it. The characteristics of “tasty” communal prayers food included broader organoleptic properties (i.e., its taste, smell, texture and appearance) than solely its flavour. They included as well as its investment with ritual purity through the proper observance of proscriptions in its preparation. Within these traditional taste expectations, however, individual elaborations on the accepted food

preparation practices revealed cooking as an iterative performance through which tradition was preserved and simultaneously transformed. This was consistent with the context of a local, diasporic community in which “authenticity” was simultaneously sought and attenuated by history and distance, as was discussed in the introduction.

The practices of communal food preparation were also more than simply feeding large numbers of people. It was understood that the entire community would “help out”, since the yagya was a village event. A steady stream of women joined us in the Temple over the course of that Saturday, with up to fifteen women working in the kitchen at any one point in time. Mostly adults with a few teenagers, women came from up and down Amar Trace, with a few friends from neighbouring villages. When they arrived they were directed by Tara or one of the Temple Ladies to where they were needed, or they fell in next to friends, picking up the rhythm of the work and the chatter with the ease of long practice. After a couple of hours work, they’d leave to attend to other responsibilities. Effectively, there was an informal shift system at work.

There was a constant process of socialising that also occurred with the bustle. Young wives chatted about their babies, women with school-aged children were asked about their Secondary Entrance Exams⁶³ preparation, and a new bride was teased about her newly married status. A continuous hum of conversation filled the space along with the laborious work, punctuated often by cackles of laughter; gossip and jokes were exchanged; there was an air of mundane festivity. While these interactions were taking place at least a hundred pounds of foodstuffs were washed, peeled, diced, chopped, ground, grated, sliced, and soaked. Most of the

⁶³ SEA exams results determine the ranking of secondary school into which students transition at 11 years of age, after primary school.

Temple Ladies stayed on until all the work was done. The process of food preparation therefore created and affirmed women's community bonds through an act of collective engendering. By the time dusk had fallen outside, the tables and counters in the kitchen were laden with large plastic basins and pots, in which the prepared ingredients awaited their cooking in ghostlike hillocks beneath dampened muslin sheets.

The preparations had been done on Saturday, but the actual cooking for the Ramayana started at dawn on Sunday morning. Food is always cooked fresh for these events because there was a general consensus that the fresher the food, the better for you. Alan, one of the husbands of the Temple ladies, set up five ring-stoves on the floor of the kitchen annex, for enormous three- and four-foot diameter aluminium pots that were the property of the temple. Ingredients were added and the contents of the pots were stirred with four-foot long wooden dabras (spatulas). The air filled with the sound of sizzling and bubbling, and the mouth-watering scents of frying onions, garlic, cumin, turmeric, curry leaves, and coriander. Two women hefted a twenty-pound bag of flour in the air, pouring it into hot oil to make the parsaad. Without having to measure, Tara told them when to stop, and when to stir, and when to add more. She used no recipes, and I was told that no recipes exist for cooking food on this scale "the right way". This was part of Tara's skill, born both of innate capacity and long practice: the ability to estimate without measuring the proportions of spices, herbs, oil, and seasonings needed for each dish. Since prayers food is sacred and cannot be tasted prior to being offered sacrificially in the ritual puja, Tara had to assess the readiness of each pot by the scent of its contents.

By the time the yagya began, the food had been cooked, the kitchen annex of the temple cleaned, and tables and benches arranged for the communal feeding. The final menu consisted of channa and aloo, curry mango, curry chataigne, bhaji, curry pumpkin, fried bodi talkari, and

stewed (soya) chunks⁶⁴, along with white rice and paratha roti. People collected a washed sohari (banana) leaf from a pile and seated themselves at the long tables to eat in shifts. Servers, mainly men from the community, passed between the tables carrying large food-filled serving bowls, sharing out the food to all who indicated they wanted “more” or if it was “nuff” (enough). Servers returned to the kitchen for refills as needed, making their rounds until their bowls were empty and no new people came to the tables to eat. Seconds were encouraged, and the light, flaky paratha roti was shared out by the handful. The communal eating was as much a part of the yagya as sitting down to listen to the discourse. There were some who came only to eat, especially teenagers and men in their twenties, which was understood and accepted. “You don’t need to listen to satsangh to get the blessings,” a seventy-two year old Tanty confirmed.

Another important part of the event was the sharing out of parsaad. Also known as mohanbhog (food of the God Krishna), parsaad is a ritual sweet food prepared as an offering to the gods at every puja. The recipe varies slightly with preference, but it is ghee- (clarified butter) and sugar-rich, and flavoured with spices and nuts. The pundit blessed a taria (tray) of parsaad during the puja by offering a portion of it to the Gods and the sacred fire. The sanctified parsaad was then returned to the kitchen and mixed back in with the bulk remaining in the pot, thus blessing all of the cooked parsaad. Small servings of parsaad were then parcelled into bags, along with a slice of banana, a grape, a peeled chunk of sugarcane if available, and an Indian sweet or two, like barfi or kurma. The parcels of parsaad were then shared out to all who had been present, as well as to people who had not attended, dispensing blessings to all. The measure of a satsangh, it was known, was not only or even primarily the quality of the singing and

⁶⁴ Soya chunks have become a common protein substitute for meat in vegetarian Indian Trinidadian cooking.

discourse, but the quality of the food, and the variety and abundance of the dishes. Tara's cooking made the satsangh a marked success. Her reputation for having a "sweet hand" was confirmed.

The communal meal prepared by Tara for the yagna, from its provisioning to its cooking to its consumption, also symbolically and materially reiterated integral forms of sociality, affirming bonds of camaraderie, reciprocity and kinship within the village setting (Vertovec 1992, 2011; Khan 1994, 2004, 2001; Munasinghe 2001). These bonds were forged through narratives of shared origin, and shared histories of labour, oppression and settlement to produce a community as extended kin (Khan 2004, Haraksingh 1988, Munasinghe 2001, Vertovec 1992). Food practices also served to consolidate identity, as is common amongst diasporic communities internationally (Vertovec 1997; Sutton 2001; Counihan 2012). Practices of communal commensality were recapitulated multiple times a year in Debe, for religious observances such as pujas that ranged from the private and familial, to the large-scale mass celebrations such as weddings, or yagyas described above. Biomedical diabetes recommendations that attempt to manage "lifestyles" must therefore contend with the collective weight of the historical and social habitus into which they are expected to be applied.

Apart from cooking for community events, Tara was also employed by individual families to cater their home events – both religious ceremonies and family parties. After the yagna, I asked Tara if she had ever cooked a meal like that for the people with diabetes in the community. How and what had she cooked differently? Tara was puzzled by the question. "I don't cook for the hospital," she replied. I clarified - had anyone with diabetes in the community asked her to cook food differently since they had this diagnosis? She responded:

Yes, plenty people have sugar, but they never ask for any special food or what have you. The reason people does be asking me to cook for them, *the most important thing*, is the taste. People want tasty food, that is why they does ask me to cook. They know from the taste what is good food and what is not, when it cooked with love. Look, last Monday the Ladies' Group make a river-lime and they ask me to curry the duck. This was just after the puja and before we had to start fasting for this yagna, so I take a nice-size duck from the yard, curry it up good, and all of them cook something and bring too. But they and all like to taste my hand and that is why I getting more orders now. And I know ladies in the Temple Group have heart and sugar, Tanty Ally had a heart attack last year, but she still love she curry mango.⁶⁵

Participation in yagyas, satsanghs, pujas and festival observances in the community entailed engaging in repetitive, structured communal patterns of commensality that were also consistent, on a large scale, with Mary Douglas's (1972) characterisations of actions that defined the boundaries of a group's symbolic and emotional existence. In view of the longstanding Othering of Trinidadians of Indian origin, additionally, I would argue that these practices of commensality became even more entrenched. As Douglas (1972, 52) also notes, "whenever a people are aware of encroachment and danger, dietary rules controlling what goes into the body would serve as a vivid analogy of the corpus of their cultural categories at risk."

Similarly, Wilk (1999) has argued about Belizean cuisine that "food is a particularly potent symbol of personal and group identity, forming one of the foundations of both

⁶⁵ Curry mango preparation requires high volumes of sugar.

individuality and a sense of common membership in a bonded group” that is defined in Belize through an explicit contrast with an externalised “other”. In the context of Debe, the result is cooking practices like Tara’s, which were as much resistance to the erosion of identity-defining cultural practices as ingrained social habit.

4.1.2 Tara’s cooking for the family: Love, caretaking, and structuring their lives

Tara invited me to her house to “learn to cook good”. She lived with her husband Mohan and their teenaged son Vivek “in the bush,”⁶⁶ she said laughingly and pointed to the overgrown former cane-lands around their property. The rurality of their location had allowed them to buy a large plot of agricultural land to build their modest house, after pooling money received as wedding gifts and from the sale of Mohan’s deceased parents’ home. Both Tara and Mohan were from poor cane farming background in Debe. They had met in secondary school, which Tara never finished, and married as late teenagers, moving in with Mohan’s parents until the elderly couple had died.

Tara, Mohan and Vivek lived in a small concrete galvanized-roof flat-house set back from the road, a multi-roomed re-articulation in brick and tin of the mud huts that once dotted that landscape, indicative of their modest means. A breezy gallery with two hammocks to the front of the house was where we sat to ole’ talk (have idle conversation). Beyond the chicken coop next to the house was the duck pond, and beyond that was the “garden” (a subsistence produce plot) of over an acre where the family grew peas, bodi (string beans), baigan (eggplant),

⁶⁶ “Bush” is usually a pejorative term used for country areas that evokes rurality, underdevelopment and backwardness when compared to other parts of Trinidad, as well as lands overgrown with tropical fecundity, as Rebecca Lynch (2016) also describes.

pumpkin, carailie (bitter gourd), ochro (okra), eddoes (taro root varietal), dasheen (taro root varietal), citrus fruits, and scotch bonnet, pimento and bird-peppers. Both Tara and Mohan cultivated the garden, though Mohan did more of the “hard work” of cutting trees and pruning.

Their lifestyle was not extravagant, and indeed I soon realised they depended on earnings from a patchwork of different jobs to make ends meet. Mohan was the main wage-earner, from driving a taxi and doing odd jobs in the village. Tara reared and sold their chickens and ducks, butchering them at home to either sell the meat, or to cook to order. She sometimes “helped out” by watching the parlour of an elderly neighbour whose children no longer lived with him, though whether this resulted in any pay was unclear.

For many village women like Tara, who did not work outside of the home, much of their time was oriented around food - growing it, buying it, and preparing it. There were the daily tasks of cooking meals multiple times a day; the weekly tasks of making grocery (grocery shopping), making market (shopping for fresh produce), and making garden (planting or reaping produce from kitchen gardens); and the seasonal tasks of preserving fruits and produce for later use. While these food-related rituals also structured time over the course of the year, the kinds and volumes of food related work varied significantly with socioeconomic class, which was highly heterogeneous in Debe. Tara and other women who worked primarily in the home were more far more likely to be engaged in the tasks of food preservation, as were those who still made garden, and those who were poorer.

Tara however accepted as natural the expectation that she would do all the cooking in the household, and indeed, justified this as a reasonable division of labour considering that Mohan worked long hours as a taxi-driver. Even as a schoolchild, growing up with her parents, Tara and

not her brother had been one in the kitchen with her mother before school on a morning and at night, which is partly where she learned to cook “so good,” she explained.

The work of feeding has been characterised by feminist scholars like Marjorie Devault (1991) as part of the unremunerated labour that is primarily engaged in by women, rendered invisible by its framing as “caring”, and therefore naturalised to the female gender, which also erases its arduous nature. Wage earning or not, women were universally the main cooks within households in Debe, and were primarily invested with the responsibility of managing the physical sustenance of the family, which seemed to be a universally gendered expectation. Yet as Counihan has also demonstrated, food practices are also a way in which women gain and hold private power in a state society, as part of the “power that comes from being needed” (Counihan 1988). Food practices are therefore polysemous, not only functional sustenance of the physical body, but also constitutive of a form of gendered power.

For Tara, her power lay not only in the necessity of cooking, but also in cooking *good*, tasty food, and cooking as an expression of love. In Mohan’s hearing, one day, she boasted, “I always had sweet hand, but I only uses to cook for the family, that is why Mohan put me in house⁶⁷.” This was said partly in jest, but Tara was also fishing for confirmatory compliments. Mohan laughed, and agreed.

Everybody want to know what it is, how to cook so, but is just to take your time and cook with love. When food cooked with love, it taste good... You could taste the love in the food.

⁶⁷ To “put in house” is a colloquial way of describing marriage.

Mohan reminisced about their early “courtship” days by saying, “She did treat me real good, if you see the food she cook for me, curry conch, stew lobster, everything.” For Tara, having no work outside of the home through which she earned a regular income, her skill at cooking was sometimes the only way in which she could exert a form of power by showing both everyday love and special forms of affection. Her everyday love she demonstrated by cooking fresh food, on time, and making sure Mohan and Vivek never went hungry. “Even if is only a handful of ochro from the garden self, once you makin’ garden you cyah go hungry, that is why I always make sure this garden thriving,” she explained as we harvested produce from her garden once. She also showed her love to her husband and son through preferential treatment. Whenever she made curry mango, for example, if Mohan was absent, Tara would put a small dish aside for him, as it was his favourite talkari, even if it meant doing without herself.

Other women in the community did the same, at communal and family events, setting aside plates of food for their spouses, ensuring that whatever special dishes had been made were saved for them in their absence. Cooking a favourite meal or a well-loved dish was thus a way of showing intimate affection. It implied not only knowledge of the person’s preferences but also a consideration of their needs that was the essence of love as caretaking. Cooking, and food preparation more generally as an act of familial love, is a transcultural act well documented in the anthropological literature from many different contexts (Wikan 1990; Counihan 2004; Sutton 2001). Thus Cook islanders may prepare foods to pass customs inspections before taking them to overseas family, as expressions of love (Alexeyeff 2004); Mexican mothers may find ways of sneaking sugary soda into their children’s schools against school rules and health advice (Roberts 2015); Florentines use food as a vehicle for family cohesion and love (Counihan 2004),

and Debe housewives make their spouse's favourite dishes and save some for them if they are not present. Food production and preparation therefore encompassed deeply entangled domains of love, gendered responsibility, and power for Tara and women like her in Debe.

Tara had learned much of her “traditional Indian cooking” from her own mother, but had learned even more by being very active in the village Mandir Group. She had developed a reputation for being a very good cook and people had begun to seek her out as a cook for their communal events at which specialised large-scale cooking was required. Having a reputation for a “sweet hand” also meant that when family came over for a lime or a celebration, Tara would be expected to share some of her skill with them by making complex and delicious meals.

Kaloungie (stuffed bitter-gourd)⁶⁸ and curry cascadoo (cascadura fish) were a favourite of hers and Mohan's. These would be just a part of a larger meal consisting of three or four different talkaris and fresh rice or roti. The groans of pleasure, compliments on her cooking, requests for another serving, and the sound of the pot-spoon scraping the last of the sauce from the pot was “music to my ears”, Tara said. She was generous with her cooking, often taking some over to cousins or sending Mohan with a bowl for a family member who lived further away. She also always cooked extra “in case people want more”. In between cooking, Tara also performed the routine tasks of household maintenance – washing and hanging out clothes, managing household finances, doing household shopping, and intermittently taking care of an ailing neighbour.

⁶⁸ Preparation of this meal is very involved, requiring the bitter gourds to be deseeded, soaked in salt water, boiled, and then deep fried after being stuffed with curried herbs, tomatoes and tamarind. Curried cascadura fish was similarly stuffed then simmered in a coconut curry sauce with pigeon peas.

Of all these tasks, the one she most thoroughly enjoyed and found most rewarding was cooking for the family. “To know that people enjoying your food, that is the most satisfying,” Tara explained. By the practice of being known for preparing good and tasty food, Tara had converted the gendered social role necessity of culinary caretaking into a source of power and creativity. She was also able to achieve a sense of prestige from these practices. In this she displayed what Counihan (2013) described as “differential consciousness”, or the ability to acknowledge and operate within demeaning and disempowering structures and ideologies but at the same time to generate tactics that resist domination.

Tara’s cooking was structured around, but also structuring of, the family schedule and day. She woke up every day at 4.30 am to make lunch for Vivek to take to his secondary school in Princes Town, to which he caught a ride from a friend at 6.00 am. She also cooked a separate breakfast meal for the family at this time. Breakfast was usually sada roti (flat griddle-cooked breads) and a chokha (roasted vegetable side-dish), while lunch was usually rice, dal (pulses), and a talkari (general term for a side dish prepared in an Indian Trinidadian style). This is a classic, characteristic Indian Trinidadian breakfast, and vendors selling sada roti for breakfast have in recent years popped up along the Debe Main Road.

Vivek and Mohan preferred meals that included meat, usually chicken, which they most commonly ate curried, in a cumin sauce, or stewed, though the family fasted from meat on Mondays and Thursdays, like many other Hindus. After lunch, Tara usually cooked an evening meal for the family. Tara took pride in cooking food “fresh” for her family, often multiple times a day, though there were usually also leftovers from dinner in the fridge that they could heat up as needed for a snack between meals.

Cooking “fresh” was still the norm for most of the housewives I met in Debe. Tara regarded eating “stale food” regularly with some disapprobation and disdain by saying, “Fresh food is good food” and “food is always tastiest when it just cook.” Working women, like Meena, Tanty Indra’s daughter in law with whom I lived, however, were likely to cook fewer meals, store leftovers in the fridge and to have and use microwaves. They were also more likely to buy food so as not to have to cook. Tara never did this, explaining that “You never know when buy food was cook, it could be stale and reheat and you think you getting good food”. Most days, Mohan was out of the house late into the evening, but whenever he came home Tara ensured that food cooked that day was available for him and for Vivek. Vivek, however, had started doing odd jobs in the village and with his earnings would sometimes buy Kentucky Fried Chicken from the branch on the Debe Main Road, bar-b-queue lamb, or grilled shrimps from a food stall along the Main Road. When he did, and he brought some home to share with his family, Tara would often eat a piece herself. Thus disdain for outside food appeared to be more a habitual expression of a larger cultural value than a tenet of Tara’s practice, born of tight economic circumstances in the family. Whether from necessity or otherwise, Tara’s food preparation practices structured the day through everyday ritual, similarly to Sutton’s (2001) description of the practices on Kalymnos.

Cooking was therefore never an individual or entirely functional act, but an act of her early and continuing love for her spouse and her maternal love for her son, simultaneously therefore an expression of her social role as a wife and a mother. Tara’s cooking was a form of culinary caretaking and embodied nurturing that was integrated into her and her family’s lifeways.

4.1.3 Sugar, diabetes, and food

While we were cooking one day, I casually asked Tara if anyone in her family or extended family had ever been diagnosed with diabetes. I was very surprised when Tara answered equally casually, saying simultaneously that nobody had sugar - *and* that she had been diagnosed with sugar herself.

No, nobody have diabetes in my family. Only I, I have a trace of sugar. Last year I went doctor for a female complaint and the doctor say I have a trace of sugar. The nurse tell me they see a trace. The doctor say to cut out the sweets and bring me back the next day for a blood test and I had was to fast, then he tell me come back in three months for a check-up to see if I will need more medicine, but I was feeling good. I never like plenty sweet ting anyway... in the clinic, they say I have a trace of sugar. They send me to get blood draw [phlebotomist] but since that day I doh feel sick at-all, at-all. I feeling same way, and I does work real hard, so I never worry about it. I does do plenty thing, everyday work. Cleanin' house, making garden ... All day we does spend outside, inside is only to cook and sleep. Yes, they say I have sugar, but only a trace.

To Tara's best understanding, she had only a "trace" of diabetes, and this was not sufficient for her to feel that she needed to change her dietary or exercise habits in any way. In part, this was because of her bodily experience: "I doh feel sick," Tara said, more than once. She had not experienced any of the typical biomedical symptoms of diabetes mellitus, to the best of her knowledge. Neither had she experienced any of the symptoms that her neighbours with

diabetes described, some of which had no translation into biomedical symptomatology – bad feeling, malkadie, bodily weakness, junjunie (pins and needles), or an “internal fever”.

Her absence of symptoms lead to incongruence between her embodied experience and the perfunctory diagnosis she had received. Tara described a very brief diagnostic clinic appointment, in which the doctor “didn’t even sound me”, that is, hadn’t even examined her or conducted auscultation with his stethoscope, which she considered necessary components of a medical appointment, that would indicate its seriousness. He gave very broad recommendations for “lifestyle changes,” the majority of time in the appointment being spent filling out a Chronic Disease Assistance Program (CDAP) prescription for metformin (the most commonly used drug for Type 2 diabetes) and writing in her notes. Tara recounted that her doctor, who was also Indian Trinidadian, had told her to “cut out the prayers food, and meethai (Indian sweets), and stay away from paratha and dalpuri; he say all them things does send the sugar up.” The total appointment, she said with a laugh, lasted no more than five to ten minutes: again, an indication to her of its lack of seriousness, and of the lack of seriousness of the diagnosis. “He didn’t have the caring, he could care less if I living or dead,” she explained, as she also dismissed his medication.

Her doctor had not, additionally, told her how or what to substitute for the recommended excisions from her diet. There had been no dietitian referral, no food-substitute list provided. Indeed, few local health centres in Trinidad are provided with this information, far less physical materials for dispersal to patients. Dietitians are commonly referred only when there are complex dietary needs, such as for patients with kidney failure who must severely restrict their salt content. As the dietitians I interviewed explained to me, if all patients with diabetes were also referred to them, the system would crash.

The only other suggestion Tara remembered was that she needed to exercise to least half an hour three times a week. She scoffed at this as far less exercise than she usually engaged in anyway, “When I hanging up clean clothes on the line I standing in the hot sun sweating for more than half an hour,” she explained. How much sweat was expended was her measure of exercise rather than any change in heart rate or increased muscular activity. Thus the medical recommendations, brief as they were, seemed irrelevant to her. Indeed, every time I visited Tara’s house, she served me an iced glass of sweet drink (carbonated soda), and drank one herself.

Given the asymptomatic early stages of the disease of diabetes and its high estimated prevalence in this community in Trinidad, I was not surprised to meet other people in the village who were walking around with abnormally elevated blood glucose levels diagnostic of diabetes, who did not consider themselves to have diabetes. Two older men described themselves, like Tara, as having a “trace of sugar”, implying the absence of full-blown disease despite their medical diagnosis. As a neighbour who had also been diagnosed with diabetes explained, it was only a “trace” because it didn’t have any effects on her. The people I spoke with in Debe who had been diagnosed with diabetes but were not ill changed little in the ways that they lived, like Tara. They rarely described dietary substitutions, carbohydrate portion control, avoidance of all sweets, or increased exercise, all disease management recommendations, because the disease caused fewer changes to their life-worlds than adopting these management recommendations would have caused. Kleinman’s (1988) distinction between disease and illness proves useful in considering their experiences: they had the disease, but no illness.

The biomedical recommendations for disease management, or the burden of proactively treating and managing chronic illness, have been broadly described in the biomedical literature

as the treatment burden (May, Montori and Mair 2009; Sav et al. 2013a, 2013b). Current recommendations both in Trinidad and internationally place this burden entirely on the diagnosed individual, through the recommendations for lifestyle changes listed in the previous chapter, and through therapeutic recommendations that present the act of medicinal dosing as simple matters of proper co-ordination with meals. What was revealed over the course of fieldwork, however, was that dietary practices were very difficult to transform in accordance with these biomedical recommendations.

Tara only went to the Debe Health Centre when she was feeling unwell, and earlier that year had gone to the general practice clinic after she experienced a “female complaint.” After a random blood glucose assessment she had again been told that her sugar was too high, and that she had an infection of her “female parts” because of her high sugar. She showed me the packaging of an antifungal drug that she had taken to clear it up, but after the symptoms subsided Tara once again stopped going to the clinic since she found the idea that she was sick laughable, as well as believing that she only had a faint “trace” of the disease. “The sugar (diabetes) doh trouble me, like the machine [glucometers] and them break and all,” she explained when I asked her if she had tried to cut down on how much sugar she ate and drank. She thought it more likely that the biomedical machines measuring her body had “broken”, or were wrong, since their readings were incongruent with her own sensorium, and she thus saw no need to change her daily practices, including her practices of cooking and eating.

It would also have been difficult to do so, since as the preceding section indicates, her cooking not only provided the physical sustenance on which her family depended but the structure around which their days were scheduled. In cooking this way, she had found no space for the biomedical category of “dietary management”. When asked if she had ever considered

cooking differently at home, Tara laughed, and said, “But if I cook so, who go eat?” Since cooking played a double role of necessity and power in Tara’s life, to change her cooking habits in ways that she understood as making food less tasty would have decreased her sense of empowerment as she engaged in complex everyday tasks that would otherwise be drudgery. To change her diet in accordance with the clinical recommendations would also mean cooking “selfishly”, marked contrast to her expectations for herself as a mother and wife, and her family’s expectations of her as well.

These expectations were not only bonds but a power of intimacy that she wielded in the household. Her cooking was a manifestation of her generous, open-handed and open-hearted mother-love, a pot in which there was always enough, that was always delicious. To transform her cooking away from this, to manage a disease with an invisible presence in her life, was inconsistent with Tara’s understanding of her place in the world, her own expectations for herself, and the dimensions of her life which gave her a sense of worth, prestige, and allowed her to express her love. Her “unwillingness to comply” with the diabetes dietary recommendations therefore reflected more than a simple lack of knowledge, and more than a simple unwillingness to change, which is often underwritten by the moralistic undertones of “non-compliance”. Instead, Tara’s actions began to suggest an active resistance to a threatened biomedicalization of her life-world, which she was performatively engaging through living life as “normally” as she could – without attending the diagnosis herself.

The impetus to cook more diabetes-friendly meals arose in only three instances over my time in the field: once when a younger doctor joined the Temple’s congregation and wanted to raise awareness of diabetes in the community and again when a younger pundit visited a temple in Debe and gave a guest oration. The idea of cooking with less sugar to meet the possible

diabetic requirements of her community was novel and amusing to Tara, who at first thought that such a request could only apply to a hospital setting, in which medically approved diets were mandated. This attitude was consistent with her dismissal of the need to alter own diet to manage her “trace of sugar”. Changes to the communal meal preparations in the temple did occur once, when a pundit in a larger temple in Penal consulted a cousin who was a doctor, and they came up with a “traditional Indian” meal which was not as carbohydrate and sugar heavy as the usual festive fare.

This did not imply a lack of awareness amongst the community of the effect of carbohydrate- and sugar-rich, late-night meals on their diabetic control, as is addressed in later case studies in this chapter. When people heard I was interested in the causes of diabetes in the community, a twenty-five year old man handed me a bottle of sweet drink after a satsangh and laughingly told me that this was the cause, “This is diabetes in a bottle”. However there was little integration of this awareness into deeply ingrained communal dietary practices, in the setting of village religious commemorations.

4.2 Tanty Dularie

4.2.1 Eschewing community for health: Lifestyle management through isolation

After some time in Debe, I realised that I hadn’t seen a particular neighbour, Tanty Dularie for months; she had not been at any of the yagyas on Shambho Trace or Amar Trace that had been held over the previous month. Tanty Dularie was sixty-five years old and lived a few houses away on Shambho Trace. Her son and brother had migrated to the USA many years previously, and she was alone in Debe except for some relatives of her husband (five years deceased), with whom she was not close.

Tanty Dularie had clearly told me she was “a diabetic,” having been diagnosed incidentally at her local health centre when she went there for another complaint, and was still asymptomatic after three years of attempting to control her blood glucose using only dietary changes and the anti-diabetic drug metformin that she received for free from the Chronic Disease Assistance Programme (CDAP). She confided in me that she had the sugar “bad”, even though she had no symptoms. The next time there was a prayers in the village, I caught Tanty Dularie slipping out of the back entrance. She explained guiltily that she couldn’t stay to eat because it sent her blood sugar too high, stating “The food is why I can’t go to none of these prayers.” She added that she was glad nobody had thought of bringing her parsaad, because that she couldn’t refuse, refusal of the blessings being sacrilegious by the elder members of the community. Tanty Dularie explained that she stopped going to the pujas and prayers in the community during the festive season and beyond because she could not refuse to eat. “If I go to every puja, and I take even a little bag of parsaad, a little bit of roti, the next day my sugar high high, and I feeling sick, and I know that my medicine not going to work good.”

It was prayers food in general, Tanty Dularie believed, that made her blood sugar high. She first realised this after she got a diascan machine and began checking her fasting blood glucose every morning. She had got one from her brother in Long Island, New York, along with machine-specific blood glucose test strips. The first time she used the machine was on a morning after a Ramayana. She was terrified when she got a reading of over 250 mg/dL, since after a similarly high reading at the clinic they had increased her dosage of metformin to twice a day. Tanty Dularie knew this was a consequence of the “rich” food she had the night before at the puja, and therefore began decreasing the volume of food she ate each time she went to a satsangh.

As she continued to check her blood glucose after prayers, she began to believe that there was no safe amount of food she could eat. Once she partook of any of the food, her blood glucose levels would be between 150 and 200 mg/dL in the morning, and even higher. She also felt tremendously guilty for refusing the offered *parsaad*, which was akin to “refusing God blessing”, even if she didn’t share in the whole meal. She also found it impossible to sit at the communal table and have “just a little bit” of food. The people serving would pass her semi-empty plate and ask cajolingly if she wanted more, or would serve her without asking. She could not keep refusing the offered food.

How I could tell them I not eating? No matter how much time I tell them give me a ‘little’ bit, a little *choonky* [very small] bit, they will want to *take care of*⁶⁹ me and give me a nice serving. I can’t throw away *parsaad*, that is sin. I too shame to tell them is because my sugar will get too high. So I just stop going to eat with everybody prayers. And sometimes I stop going prayers at all self.

Tanty Dularie used the word “shame” in reference to an unwillingness to volunteer her diabetes status out of a sense of privacy, however it lead me to question where this sense of shame arose. She tried to continue to help at nearby communal meal preparations, but she had developed heel spurs, and her feet ached with protracted standing. While the bodily discomfort Tanty Dularie experienced was independent of her diabetes, the emotional discomfort was subsequent to her diagnosis. Communal activities nearly inevitably involved congregating

⁶⁹ Emphasis added.

around foods, and Tanty Dularie gradually decreased her participation in these events as she felt this was the only way to get her blood glucose levels down. As she felt herself incapable of controlling her diet when eating in communal contexts, she began avoiding events. She did not want to have to discuss her disease status in order to explain her refusal of parsaad, prayers food, sweet-drink, Indian sweets – all the foods which are commonly shared boundary objects of hospitality, tradition, religiosity, and identity, and as such were integral to the social processes in her community. Slowly, over the course of the three years since her diagnosis, she became isolated from the highly integrated community she had been living in for fifty years.

While some of the neighbours knew she had a diagnosis of diabetes, they did not associate her increasing reclusiveness with her disease. To her immediate neighbours, including my hostess Tanty Indra, this suggested that Tanty Dularie was holding herself aloof from village activities, and negative associations began to be ascribed to her absences, such as that she had become “stuck up” since her son had moved abroad. Tanty Dularie ceased to be a regular invitee to social events: ladies from the village did not “drop in” to visit her as they once had, and the number of telephone calls she received had also decreased, so much so that she wondered out loud to me once whether it made sense to keep paying the bill for her land-line, except that she needed a way for her son to contact her reliably, and she didn’t always have her pay-as-you-go cell phone charged or topped-up with minutes. The disregard of the village was not active malice, but a slow erosion of awareness of her due to her physical absence from village activities. It was enhanced by the fact of her age, her solitary home circumstances, and her absence from any regular working environment. Those who noted her absence also assumed she was regularly traveling to visit her son in New York, which was not the case. Tanty Dularie had last visited her son soon after her diagnosis two years previously, and then only for three months.

As she became increasingly distant from the community in Shambho Trace, she began to visit and spend days and weekends with her own cousins and maternal relatives living in Penal Rock Road, some distance from Debe. She had not lived in Penal Rock Road for twenty years, however, and did not have her own home there, she felt herself on “sufferance” while she was there as well. A niece who commuted to work in San Fernando every day would pick her up and drop her back home when necessary. Though she did not describe anyone within the community as shunning her socially, blaming her for poor choices that resulted in her poor diabetes control, or body-shaming her for her “big belly”, the social isolation she experienced subsequent to her attempts to manage the disease was a similar result. This suspension outside of community decreased her likelihood of being missed, and increased her isolation.

Tanty Dularie was of age to receive the standard Senior Citizens’ Grant from the Government of Trinidad and Tobago Social Welfare Division. She had worked for her whole life – as a home-maker and in the family garden plot – but never for a wage. She had therefore never contributed to the Retirement Benefit income supplementation offered to the elderly by the Government through by the National Insurance Board. Her sole income therefore consisted of \$1,950 Trinidad and Tobago dollars per month. Her son was a taxi-driver in Long Island, and regularly wired money to her bank account or via Western Union, but the small sums he could send were sometimes not worth the fees. She owned the family house outright, her husband having paid off the loan he had taken from the bank to build their house before he died. Her major expenses, she confided in me, were therefore her food, transportation, and medications, though she received her anti-diabetic medications for free from CDAP.

She attended the local health centre religiously, but to do so she sometimes had to take a taxi since she could not walk that distance. She also took a taxi to go to the nearby grocery and

the weekly produce market, especially if she had to get bulky items that she could not carry herself. She shopped for groceries every week or two, carefully budgeting her money that way and ensuring that food did not waste uneaten. She could sometimes supplement her income by selling hot pepper-sauces that she made from the plentiful scotch-bonnet pepper plants in her garden. In her garden she also grew bodi (string beans), a few tomato plants, baigan (eggplant) plants and ochro (okra) with which she supplemented her diet, but she was able to maintain it only minimally because of her foot pain, so many of the plants were beginning to go to seed.

Tanty Dularie cooked all her own food when she was not visiting her relatives in Penal Rock Road, the most reliable way to keep her blood glucose levels low. She ate simply, mainly parboiled rice and whole-wheat sada roti with dal and various talkaris and chokas, cooked with little oil. She had become almost entirely vegetarian in practice, though she did not refuse meat if others cooked it for her. Having to cook only for herself, she found herself no longer enjoying her own cooking. Despite this, she did not buy food from any of the many nearby food-stalls and restaurants. She was “too set in her own ways”, did not have the extra income, and also explained to me that “outside” food often was not made “clean” or with care and love. When she was visiting her relatives, or when a neighbour dropped food off for her (a common practice in the village), she could usually eat the “home food” by limiting her portion sizes without causing too high an elevation in her blood glucose. When people had prayers and invited her, she stayed home instead. Her meals at her home had therefore become solitary, and as she described them to me, very simple.

Despite her increasing social isolation, Tanty Dularie did not feel shamed by anyone within the community for her diabetes diagnosis, and did not keep it a secret. However, she was

inevitably upset after her three-monthly Chronic Disease Clinic appointment at the local health centre. After one appointment, she described the experience.

The young doctor there, he does insist that I going prayers and eating the food, or I eating sweets and parsaad. Every time my sugar high he always asking what I eat the day before, if I gone satsangh, if my sugar always this high when I checking it home. I does forget to mark down what my readings, but when I mark it down and carry in the book he does say the sugar over high, like I not taking any medicine. Then he say it so high because I only eating the wrong ting and I not taking my medicine. I always taking my medicine, every morning and every night is two tablet half-hour before I eat. Plenty times whole day before clinic I does fast from food, eat little bit, little bit, but my sugar still high when I gone clinic the next day, and then the doctor does still buff me up and doubt me when I tell him I watching what I eat. Last time he ask me if I eat roti the night before. I stop going puja and all so I wouldn't have to eat prayers food. The sugar still high, high. Is a young boy, younger than mih son and he feel he could buff me up so, and then I come home and I feeling worse than when I gone clinic because he telling me how I making my sugar worse ... This time I doh do nothing, nothing any more with the sugar.

Tanty Dularie's description of her clinic visit suggests that the doctor ascribed her consistently high blood glucose levels to an active disregard of the dietary and therapeutic recommendations. That is, like many physicians in public health settings in Trinidad, he

considered her “non-compliant”, a perspective that privileged his medical authority and attributed Tanty Dularie’s poor markers of glucose control to her failure to observe medical recommendations, rather than a failure of the recommendations themselves.

Tanty Dularie was frustrated by her physician encounters. She found the doctor’s disbelief of her frustrating, and she found his attitude disrespectful. “He is a young boy, he younger than mih son,” she said, indicating that she did not feel he granted her the respect due her age. Despite this, she said that she trusted his advice and recommendations, since “he have the knowledge”. Yet the knowledge he had, or his method of conveying it to her, was insufficient to enable Tanty Dularie to manage her diabetes. Instead, what she described was a clinical encounter of very short duration, in which the end result appeared to be a foregone conclusion.

When I walk in the room, the doctor done writing, writing, writing. He done write up the CDAP prescription form before I even sit down. He looking down at the file, he check the blood pressure and the sugar the nurse check that morning, he say it looking high if I eat roti last night. Then he ask me quick quick if anything new happening and how I going. He looking through the notes to see if my blood [test results] and dem come back, then he sign the CDAP and he done. He didn’t even sound me [auscultate with the stethoscope] self, he eh even check me pressure again. He just start writing as soon as I come in, and then he still writing when I walk out the door again. Like he done know what happening with me before I come in the door. He done make up he mind, he not bothered with me.

Physicians in practice at local health centres of the SWRHA revealed a context in which the few doctors assigned to each Chronic Disease Clinic are “overwhelmed” by the numbers of registered patients. Clinics containing more than a hundred patients might have to be seen by two or three doctors in a single clinic day. This has resulted in a shortened time allocation for therapeutic consultations, with ten minutes being the estimated upper limit, rising to 15 minutes where there is a change in the patient condition: new complaints, abnormal investigative results, abnormal screening, or new information in their medical file from another source such as a public hospital admission. The corollary of this time limitation is, however, an emphasis on documented evidence of a change in the disease status of patients rather than their own experience. Physicians, additionally, considered patients like Tanty Dularie who had “uncomplicated but uncontrolled diabetes” as more likely to be “non-compliant” and subject to “poor self management”.

A patient who describes their diabetic state as a touch of sugar doesn’t fully understand that there’s no going back on a diagnosis of diabetes. They haven’t recognised that their lives have changed completely, and that they therefore need to begin taking care of themselves in entirely new ways, transforming their lifestyle, altering their diet, getting more exercise, changing the way they cook, taking their medication on time and in strict relationship to meals. There is often an adjustment period between the diagnosis of diabetes and when patients truly begin to recognise that they are diabetic, and unfortunately, that often only happens after they experience the dramatic long-term sequelae of diabetes such as a coronary event. Before that, patients are very often unwilling to accept their

diagnosis and highly non-compliant. After that, patients are more likely to begin taking care of themselves and taking responsibility for their health.

The measurement of non-compliance however lies entirely within the physician's purview: proof of non-compliance ranges from an inability of the patients to describe their adherence to their medical regimen, to a lack of improvement in the objective measures of diabetes control in patients who claim to be compliant.

You know if a patient is non-compliant. They don't know the names of their medications, all they could do is describe the shapes and colours and sometimes not even that. They don't know what they're supposed to be taking when. They don't know that they should be eating less or what they should or shouldn't be eating. Or if they saying one thing to you and their results showing something else, you know they not telling the truth. They can't take responsibility, or they're too set in their ways. Then it's clinic appointment every three months and no change or no improvement.

There were variations on this theme in multiple conversations with physicians in practice in the public sector. Non-compliance was an accepted fact, viewed in a number of different ways. Some physicians viewed it with understanding, saying things like, "Patients can't help it, you living one way for fifty years and then all of a sudden you have to change what you doing, I myself mightn't be able to do that." Others pointed to assumptions of genetic predisposition amongst Indian Trinidadians to explain the high prevalence and people's "near-inevitable

progression to severe morbidity,” as one doctor put it, an attribution of genetic determinism. For most physicians, however, even those who associated the high rates of uncontrolled diabetes they saw in their practice to other causes, at some point implied that non-compliance was the ground state of patients in the public sector. This was seen as the result of “an unwillingness or inability to change their practices and listen to the doctor’s advice.” This unwillingness or inability was far more often located within the locus of the individual than within their larger social contexts.

Pharmacists, too, described patients as “non-compliant” with their medications yet “greedy for the freeness.”

They come to the clinic or the drug store and they want all the [free] CDAP medicines right away. Then the medicines go back home with them and sit-down in the plastic bag gathering dust until they next clinic visit. They hot-foot to the drug store again and want all the medicine, but they don’t listen to how to take them or they don’t care. Then when they get sick is the medicine not working, not them.

There is a popular notion in Trinidad that Trinidadians like “freeness” or “free thing”, based on the perception of governmental support and attempts at establishing political patronage having created a “gimme gimme” society. In combination with the commonly accepted view of widespread non-compliance, patients were blamed for their continued poor blood glucose control, perceived as unwilling to make healthful changes, wilfully ignorant, and uncaring about their disease state. Aside from locating sole responsibility for their disease state and progression within the individual patient bodies, these perceptions constitute a processual discrediting of

patient standpoints, and their diminishment from what Goffman has described as a “whole and usual person” into a “tainted, discounted one” (Goffman 1963, 3). The social identity construction of stigmatisation, through which “the reaction of others spoils normal identity” (Goffman 1963, 3) has been extensively studied for other contexts, though less so for diabetes.

Of note, however, was that Tanty Dularie did not feel stigmatised or discredited within her larger social contexts, only in her engagement with the medical establishment. It is this stigma that caused her to fast the day before her clinic appointments, trying to find ways of avoiding the elevations in her blood glucose on the clinic days especially that facilitated this misattribution and diminishment of her personhood. She was trying to transform not only her disease control, but to also transform her perception in the eyes of her physicians and nurses from a “bad patient” to a “good patient”.

Link and Phelan (2001) expanded on Goffman’s early work to elaborate on the ways that stigma operates through structural discrimination, which institutionalises the disadvantages of stigmatised groups. Tanty Dularie’s response in combination with the medical personnel perspectives I encountered strongly suggest that the public health sector deserves further scrutiny for the potential stigma which chronic disease patients experience within it. The labelling and stereotyping of patients as non-compliant, and the associated status loss by being typified as “good” or “bad” patients has the potential to lead to discrimination. The forms this discrimination takes within a health institution setting may range from the passive disregard of patient experiences in recommending or prescribing therapeutic care, to the active allocation of fewer resources within the clinics to asymptomatic chronic disease patients under the assumption that the medical care provided is wasted anyway. Stigmatising processes manifest in many domains of patient lives, and may also have an effect on through their disregard for the social

underlying medical recommendations that assume patient individuation as the locus of action and responsibility.

For example, Tanty Dularie felt it necessary to circumscribe her sociality in order to meet her medical requirements. She repeatedly made this choice, and it resulted in a marked and increasing degree of social isolation. She was lonely. She was not bitter about this loneliness, but loneliness demarcated the space of her home and her everyday life, even when she was with her extended family and outside of Debe. Loneliness had become an integral part of her illness narrative. The choice she saw before her was to give up the social support net through which she received emotional, mental and physical supports of various kinds – in order to delay the progression of her disease.

4.2.2 Non-compliance as an Indian Trinidadian pathology

The majority of people in Debe who had been diagnosed with diabetes had changed little in the ways that they lived, like Tara, and most had the disease, but no illness (Kleinman 1988). It was further likely, too, that there were many people in the village walking around with abnormally elevated blood glucose levels, oblivious to the fact that they would likely be clinically diagnosed as having diabetes. Indeed, both Tara and Tanty Dularie were diagnosed with diabetes only after they went to the clinic for another complaint, which was not uncommon in Debe or wider Trinidad, in the absence of universal screening.

Even after diagnosis, however, most people in Debe with asymptomatic diabetes described themselves as having a “trace of sugar”, like Tara did, implying the absence of “full-blown disease”. Those who had no illness rarely changed their everyday lives, because the disease of diabetes caused fewer changes to their life-worlds than adopting diabetes management

recommendations would have. The biomedical recommendations for disease management and the burden of proactively treating and managing chronic illness have been broadly described in health sciences literature as the treatment burden (May, Montori and Mair 2009; Sav et al. 2013a, 2013b).

Current recommendations both in Trinidad and internationally place this burden entirely on the diagnosed individual, through recommendations for lifestyle changes listed in chapter three, and through therapeutic recommendations that present the act of medicinal dosing as simple matters of proper co-ordination with meals. However, dietary practices in particular were rarely an individual activity in the Debe context, proving difficult to transform in accordance with biomedical recommendations.

For Tara and Tanty Dularie, a diagnosis of diabetes in the absence of symptoms revealed a strong relationship between dietary practices and the instantiation of family, identity and community. Food and food practices were central to crucial forms of sociality that maintained their identity constructs and social bonds. Dietary management, for these two women, was engaged in entirely different ways: for Tara, her own everyday practices were entirely privileged over the medical recommendations, which she also saw as irrelevant to her life because of the absence of any symptoms. But even for Tanty Dularie, who was far less integrated into everyday rhythms of immediate family life, engaging the medical dietary recommendations still meant circumscribing her sociality and her identity.

Physicians and patients in the public health sector both associated diabetes with chronic non-compliance. In 2018, an advertisement campaign also made apparent an association between the Indian ethnic marker of food and chronic non-communicable disease. A series of advertisements appeared on billboards across Trinidad, posted along major highways. On the

upper half of these billboards was the picture of a smiling, brown-skinned woman, with long, straight hair, with a plate of yellow-hued food in front of her, alongside text in quotations marks that read: “I like my Curry, but I love my heart.” On the lower half of the billboard was a picture of a bottle of Jamieson Omega 3-6-9 Complete vitamins, adjacent to text stating: “Clinically proven to REDUCE cholesterol.”

The use of the word “Curry” in the advertisement, the image of turmeric-imbued food, and the woman with long, straight hair serving the food were all signifiers of Indian Trinidadian identity in Trinidad. The association between these signifiers and cardiac disease, one of the major causes of death in Trinidad and one of the complications of diabetes, clearly linked ethnicity to chronic non-communicable and metabolic diseases. This advertisement designated an ethnic identifier to the generic category of “curry” implying *all* Indian Trinidadian food, and critiqued the entire category. Assumptions of disease predisposition linked “race” (i.e. the woman’s phenotypic appearance) with “ethnicity” (i.e. the cultural signifier of food), and specifically with metabolic disease in Trinidad. The result was a pathologization of Indian food, which is crucial cultural identity marker.

The issue of the relationship between Indian Trinidadian ethnicity, food, and higher rates of diabetes was one Ezenwaka and Kalloo (2005) addressed with biochemical research: “...it is perceived that frequent consumption of roti, a popular dietary carbohydrate food among people of East Indian origin, has some relation with higher diabetes prevalence in this ethnic group” (29). Their research however countered this perception, since they found that commercially prepared whole wheat bread, not roti, caused the highest elevation in triglycerides (fats in the blood) among both subjects with diabetes and without (Ezenwaka and Kalloo 2005). They also found that “the correlation coefficients between incremental glucose and triglyceride in patients

of East Indian origin, and indeed in all subjects groups, were lowest after the ingestion of *roti*” (Ezenwaka and Kalloo 2005, 29).

The critique of diabetogenic elements of food practices thus becomes difficult to disentangle from a global critique of the “culture”, when the culture on the whole is represented and pathologized as in the advertisement described. The critique of non-compliance also echoes of Dr. Eric William’s characterisation of this community as a “recalcitrant” or *unwilling* minority, from the early years of Trinidad’s process of nationhood formation.

A global critique of a culture, foundational to individual identities, is also likely to result little change, especially when this identity has already been formulated in conditions of alterity as a resistance to forms of oppression. It is also difficult to “unhear” echoes of violence against subject bodies as carriers of a “debased” culture. This could also aid in the general perceptions of non-compliance to which this population is subject.

Chapter 5: Living *normal* with sugar: Successfully managing asymptomatic diabetes

This chapter is focused on the lives and narratives of Meera and Tanty Radha, and broadens the consideration of how diabetes and its management produce transformations in lifeways in the particular setting of Debe. Meera and Tanty Radha had both been diagnosed with diabetes while asymptomatic. Unlike the narratives in Chapter 3, both women were succeeding at transforming their life-worlds to control their blood glucose consistently, while also “living life as normal”. At stake for them were their sense of personal identity and life continuity, which they considered themselves to have successfully negotiated through the choices they made around their disease status. Their successful efforts at control were uncommon amongst my interlocutors in the village setting in Debe. While there were other people in Debe who regularly took their medications, ate differently, or exercised, only Meera and Tanty Radha had altered so many dimensions of their lives both successfully and consistently with medical recommendations. Both women also expressed these as attempts at integrating “lifestyle changes” into “normal lives” without feeling that they had compromised on either.

5.1 Meera and making a normal life with sugar

Meera was forty-five years old, of medium weight, and quick to smile when we met while preparing for an Amar Trace Ganesh puja. She showed me that it was necessary to first slice the local, bumpy-skinned pumpkin before peeling it, which was then easily and neatly accomplished

using a potato peeler, without discarding too much of the meat. She later invited me to her home to talk about sugar.

Meera's house lay along a curve on Amar Trace, close to a junction between Amar Trace and another stretch of road that was quite busy and well-settled. We sat under one of the palm-thatched sheds that dotted her asphalted front yard. The front yard served as both an outdoor dining area and parking for her family's restaurant and bar. Meera and her family lived in the top floor of their two-storey concrete house, and ran their family business, Traveller's Bar (not a rumshop, Meera was careful to clarify), out of the bottom floor. Traveller's was one of five bars and rumshops along that stretch of Amar Trace, but was particularly popular because of the tastiness and variety of the cutters (snacks or appetisers) that Meera and her husband Anand sold as well. Their specialties included deep-fried chicken wings, shrimp and chicken fried wontons, and ever-popular deep-fried Indian snacks such as phulourie (balls of split-peas dough), saheena (battered rolls of spinach), baiganie (eggplant in batter), aloo pies (seasoned mashed potato in a batter) and samosas (ground vegetables or meats in a crisp pastry envelope), all served with spicy chutneys (sauces). Every Friday and Saturday evening rows of cars were parked out front as people stopped off on their way home and filled up the sheds with their conversations, beer bottles, and Styrofoam containers full of snacks. While Meera and Anand cooked the snacks together in a kitchen behind the bar, Anand manned the till and managed the music system, which usually pumped out fast-paced local chutney music that spilled from the bar down the hill into the road. Meera and Anand had a teenaged son and daughter who were both in secondary school in San Fernando. After-school lessons occupied much of their time in the evening, and they were not involved in running the bar.

It was a good thing that the bar had become so popular, since Meera and Anand had sunk their life savings into setting it up ten years previously. Anand had lost his job as a machinist with Caroni (1975) Ltd in 2003. Meera had been a housewife since the kids were born, though she had previously worked as a secretary for an insurance firm in Debe. After he was laid off, Anand made ends meet by driving a taxi and working part-time as an electrician on small construction jobs, though he was not formally licensed. By the time the downstairs of their house had been converted to a bar and stocked, Meera had decided to run it, while Anand assisted, but continued his taxi-driving. Business at the bar had taken off when they asphalted the large open front yard and set up tables under open-air sheds that caught all the evening breezes. Customers could sit outside and enjoy their drinks with fresh air and a view. Business doubled when they began serving cutters as well as alcohol.

When I first met Meera, she unselfconsciously volunteered that she had been diagnosed with diabetes diagnosis five years previously.

You see, my mother Dolly had sugar, she got it in her forties, so we grew up knowing she had it. And we knew - the doctors used to tell us is genes, we could get it. So we always, since we knew she had it, we always look at what we eat. Right? And from the time she had it, my family had always, you know, changed the diet. Because long ago people, poor people, they eat whatever they plant, and it was only the same thing over and over, but now you getting all kind of different vegetables and stuff like that, so you could just eat vegetables. But back then, it was just roti and whatever talkari in the morning. What happened long ago, when I was small, was a little bit of talkari and a lot of roti, so the carbs was plenty, right? So that's how we looked at it, and you know, we kind of changed

that way of eating. We eat more vegetables. From the time we know she had diabetes, once she was diagnosed, the whole household changed, yeah. We used to eat white roti, so it changed into wheat bran, like that. Whenever she went clinic, they would give her a little lecture on diet and stuff, and she would come and tell us. When you have diabetes, in the clinics, they does educate you about your eating habits. She changed the diet when she was diagnosed. Because of my father, who was very strict and concerned, and know how serious the sugar could turn out to be later on - diet change one time. He push for that right away, and he used to remind her to take her medicines, and he was very strict on her diet. He didn't have sugar. He had pressure and heart problem, but he was never diabetic.

Meera had started to go for regular medical check-ups and screening at the primary care clinic of the local health centre from her mid-thirties, since she had learned from attending diabetes clinics with her mother that “early detection was key”. She had also been diagnosed with gestational diabetes in her second pregnancy, and had been told that this indicated an increased likelihood of future diabetes. Though epidemiological data on total incidence and prevalence in Trinidad is lacking, gestational diabetes is a well known to clinicians, and has been found to increase in incidence with obesity, greater age, family history of diabetes, a previous history of gestational diabetes, and Indian Trinidadian ethnicity⁷⁰ (Clapperton, Jarvis and Mungrue 2009). When Meera was forty, she had a positive screening test because of her disease

⁷⁰ Clapperton, Jarvis and Mungrue (2009) found from a retrospective study in Trinidad that “South East Asians” (i.e. Indian Trinidadians) were 2.7 times more likely to develop gestational diabetes than Africans and 5.5 times more likely than “Mixed”.

risk, and was diagnosed with diabetes by fasting blood glucose and two-hour post-prandial blood testing. “It was like a relief. No more waiting and wondering, but we was already almost like that already,” she said, referring to the “diabetic diet” that she and her family had been on for years prior to her diagnosis.

Meera and Anand were both involved in making meals for the family, taking turns with running the bar, seeing to patrons, and making dinner upstairs for the family. The children had cereal for breakfast before school (“unsweetened, no sugar”, Meera added) and took a sandwich or dinner-leftovers for lunch. The family tended to cook once a day in the evening – downstairs for the after-work patrons of the bar, and upstairs for their main family meal of dinner. Preparation for cooking the cutters for the bar was intricate and time-consuming. It involved making different kinds and consistencies of batter, preparing the fresh vegetables they commonly used (spinach, eggplant, onions, garlic, ripe mangoes for the chutneys, tamarind), and standing for a long time standing over the stove, frying.

Of necessity and choice, their go-to family meals were considerably less involved - steamed or sautéed vegetables with a sauce, often a Chinese stir-fry sauce or Chinese “Oyster-flavour” sauce. While these were high in salt, Meera explained, they were diluted in the large volumes of vegetables used. Or they might make a chokha, a fresh salad, and either rice and dal, pasta, or “thin sada”, a very thin plain roti. Meera and Anand tended to have chicken or fish with every other meal, only having fatty and high-cholesterol lamb, duck or goat meat for a special occasion. Meera occasionally skipped eating one of the components of the meal too, if she felt that she had overindulged earlier in the day.

Meera and her family’s diet had changed after she was diagnosed with gestational diabetes to include a lot more vegetables with every meal, and smaller portions of rice and roti

than she and her husband were accustomed to eating. A diabetic diet was a healthy diet, Meera said, because if you looked at the educational diet charts on walls of the clinics you could see that the diabetic diet looked just like those food charts – a lot of vegetables, a little portion of carbohydrates, a little piece of meat. She had paid to see a private dietitian while pregnant to get advice on portion sizes to manage her gestational diabetes, and had successfully done so only using diet, without taking any medications. The family's diet had stayed that way after her pregnancy, and after her diagnosis there were only a few more adjustments to be made.

“Sometimes we try the quinoa, and we buy brown rice when we find it in the grocery, these are low-carb options good for everybody to eat,” she explained. To get the quinoa, she paid a premium price at the largest grocery along the Debe Main Road, which was a half an hour drive from her house. At that grocery she would also stock up on other staples she had learned were “low glycaemic index,” she explained, which meant that they caused her sugar to rise more slowly after her meal than high glycaemic index foods would. “Everything Indian people does eat is high glycaemic index,” she laughed, “You have to train yourself to find other things to eat.”

People had a hard time eating like that, she said, because it wasn't the usual kind of food. “People don't see it as good food,” she explained. “The taste might be there, but Trini people like to eat till they belly bus' [burst]. You know the saying, is better man belly bus' than good food waste!” The most difficult part of her diabetic diet was therefore the smaller carbohydrate portion sizes that she had to get used to, while other spices could substitute for the lower salt and lower fat content of the foods. Family meals were almost the opposite of the cutters made at their bar, mostly deep-fried and tended to be flavoured with high-salt and high-sugar condiments. When asked whether the family's diabetic diet had changed their cooking for the bar, however,

she explained that she could not alter her cooking practices for the cutters, since she would lose customers if she gave them anything different: “If we make cutters [diabetic friendly], nobody would come!”

Meera had also started going for early morning walks with a few neighbourhood women who were also interested in “taking care of their health.” Meera was aware of the health education efforts linking “obesity and belly-fat” to diabetes, and actively worked on maintaining her waistline trim, “But it might just be cause I vain so,” she also said with a smile. A group of three women of around her age met in front of her bar at five am before the heat of the day had set in, all wearing wide-brimmed hats to block the “dew” and the incipient sunshine, and sometimes carrying sticks for support and protection. They then walked along the long and winding Amar Trace, heading away from the busier intersections. Amar Trace had no sidewalks, only overgrown drainage ditches dug into the earth that ran along the roadway on either side, so they walked on the verges of the road next to these ditches, standing aside in single file whenever a vehicle zoomed by. Luckily the road wasn’t usually busy at that time of morning, since the main traffic was on the Debe Main Road. They walked about a mile every day before the sun got too hot for them and their other responsibilities pressed. “Is a nice walking gang,” Meera laughingly said, brandishing her stick. They had tried carpooling to the nearest community recreational ground to do their walking, but as they didn’t want to get caught in the morning school-going traffic along the Main Road, they preferred to walk through the village. “The sticks mainly for the dogs,” she also explained, “stick wouldn’t do nothing against bandit. But this part of Debe still safe.” Safety was another reason they chose to walk in the village, instead of in the recreational ground. Meera also took part in the free yoga classes held at a nearby Temple once a

week, which she said helped her flexibility and decreased her stress levels. She was often the youngest person there, the others being mainly elderly women and a few men from the village.

Meera was very familiar with her markers of diabetic status, and diabetes-associated medical terminology. She had a “diascan machine” that she used occasionally to check her morning fasting blood sugar. She had bought this herself, along with the strips as needed, since they were only free from the Chronic Disease Assistance Program to patients taking insulin. When she first got it, she checked her blood glucose twice every day (“fasting and two hours after dinner”) and kept a food diary as well. She no longer needed to do this as the family had worked out recipes that worked for her and for their tastes, and she only checked every so often “as a baseline”. Meera also knew her most recent HbA1c level that she called the “three month test”, which was 6.5%, checked twice yearly privately and read at her local health centre. She was working to get this lower, but described it as a “good level” since she was controlled only on dietary changes and metformin, the least potent of the blood glucose management drugs. The doctor at the local health centre also did a panel of tests of her “organ function” once a year. Some, such as blood tests for her kidney function, were available through the health centre, but since she was willing and able to pay, she also went to a private laboratory in San Fernando to do others that her Chronic Disease Clinic doctor also ordered. She then took the results back to her local health centre to have them read and interpreted. According to her doctors, she was “doing real good, everything top-notch”.

Meera had also recently joined the private outpatient clinic of an internal medicine specialist, which she attended once a year for her own “peace of mind” and for which she paid out of pocket. This doctor also occasionally recommended tests, which she also did privately. The private consultations alone were a significant investment, as they cost \$400 Trinidad and

Tobago dollars per office visit, approximately \$56 to \$58 United States dollars. Investigations performed at private medical centres also ran into the hundreds of dollars, which is why she preferred to have them done for free at the local health centres, even if she had to wait for months before the results were available and routed back to the health centres. In the interim, she had integrated into her everyday the health promotion advice she'd learned from the clinic.

The most important thing of all if you have sugar, is the diet and the medication. Once you watching what you eating, and keeping track of your medications, you could manage real good with sugar.

Despite strict efforts, Meera's mother Dolly had not succeeded in controlling her diabetes, and she died from a heart attack at the young age of 52. Meera believed this might have been because Dolly resisted taking insulin, and tried for a long time to manage her sugar exclusively through oral hypoglycaemics prescribed by the public health clinic doctors, and dietary changes. Nevertheless, it was Dolly's template of daily "sugar control" that Meera drew upon in her own life. Like Meera, Dolly had been a housewife after marriage, since her husband (Meera's father) had earned enough as a mechanic working for an oil company to support the whole family. Unlike Meera, Dolly had not finished secondary school, leaving when she was fifteen and marrying Meera's father at twenty. Dolly's experiences with diabetes and failure to control it were an integral part of Meera's life-course narrative, one which she incorporated into her understanding of the disease and self-management choices after being diagnosed. For example, she mentioned in passing that she would never refuse to take insulin, since she knew that sometimes that was just the "only way" to control the sugar, and she was already familiar

with how to administer the drug from administering it to her mother. The experiential dimension of a diabetes diagnosis was sufficiently familiar, at one degree remove, that she accepted the medical prognosis and acted on it to match her self-management practices with the recommendations received from the doctors. Meera's family had provided her with a schema for dealing with diabetes long before she was diagnosed.

Meera's efforts at diabetes management, however, involved her entire family and community. Her husband Anand cooked diabetic friendly meals for the family with and for her, helped her keep track of her doctor appointments, and drove her for investigations. He was also considering becoming vegetarian, both to support her and because he had a history of high cholesterol in his family. Their family histories of illness, for both Meera and Anand, had shaped the ways they chose to live their lives. They both spoke about their family histories of illness as making it "almost their karma", that is, inevitable that they would get the diseases. Meera's invocation of diabetes as her "karma" was however not an abandonment of herself to her fate but more a matter-of-fact acknowledgement that she had the disease, as her mother had before her, because it was "something in the family line, something in the blood".

Meera and Anand's continued efforts to change their lifestyles and those of their children further suggested that they were not fatalistic about their chances of succeeding in "beating the disease". Their son wanted to become a doctor, so he had read up about diabetes and accompanied Meera when he could to her clinic appointments. He'd learned a lot from the health promotional lectures that were sometimes delivered in the waiting room of the health centre while patients was waiting to be seen. He too accepted whatever his parents cooked, despite liking meat he ate the vegetable-heavy diet, as did his sister, who was very close to Meera. The

women from Amar Trace who formed part of her “walking gang” were also involved in trying to live a healthy lifestyle, and as such formed a support network for Meera too. She attended the communal cooking activities in the village, and some Temple activities, though she did not always eat, or if she did, ate sparingly. “They over-have does give you too much white flour, too much buss up shut and thing,” she told me musingly. “If I eat just a little bit so, next day my sugar shooting up high-high. I does go, but I does slip away before eating.” As a business person, she was still however actively engaged the community, and maintained ties through her involvement in the Temple Group, and through her yoga class.

At various points in our interaction, Meera repeated elements of her illness narrative, and it became clear that this was a narrative which had been emplotted over a long period of time: she had thought about this and articulated it to others. Through this narrative she had made sense of her own life, her own health journey, and the possibility of early mortality like her mothers. The diagnosis of diabetes therefore fit into a larger phenomenological life-course narrative for Meera, which even in the absence of symptoms, resounded with her life experience.

5.2 Tanty Radha and the imperative of health

Tanty Radha was sixty years old when we met at the Amar Trace Mandir, where she had come to drop off some donations for the Ganesh Puja. She was about five foot six inches and characteristically had her diamante-rimmed pair of cat-eye glasses perched on her head, above well-groomed bright auburn hair, and a well-rounded body which moved briskly as she spoke. She lived with her husband Shiva close to the Debe Junction on Amar Trace in a two-storey white and grey concrete house with architectural flourishes throughout, such as a split roof, a

wraparound front porch, Juliet balconies at the upper-storey windows, and an extensive, paved, open-air back shed where some of her husband's goods-trucks were occasionally parked.

Tanty Radha had recently retired as a senior administrator in a department of the local government, and considered herself a “no-nonsense kind of person” who was still actively involved in various volunteer organisations and was helping with the transition in leadership at her job. The only difference she described between working and being retired was that she was no longer required to handle the traffic to make it to work every morning. Her mother and father were from Debe too, and had owned extensive agricultural lands there which they sold off to put her and her siblings through school. She had gone to a prestigious, all-girl secondary school in San Fernando, followed by a bachelor's degree in education in St. Augustine, at the University of the West Indies, where she met and married her husband Shiva. Shiva had built up a mid-sized import-export business after university, its main office located in San Fernando, and he was also involved in some construction projects. The couple had two children, both of whom were at the University of the West Indies and lived off-campus in a shared apartment which their parents rented for them.

The first time I visited her home, Tanty Radha offered me a glass of iced water. This was unusual, since at most households I visited in the village, I was customarily brought an iced glass of “sweet-drink” (as soft-drink or soda is known locally⁷¹) as a demonstration of hospitality.

⁷¹ As Daniel Miller (1997) notes the term 'sweet drink' is used by most Trinidadians for carbonated beverages, and is not considered a “luxury or expendable item of consumption but is understood by most Trinidadians as a core necessity, constituting the ordinary drink of the mass population. For further discussion see *Capitalism: An Ethnographic Approach*.

I stopped offering people sweet-drink since nowadays you don't know who have diabetes and who don't have diabetes, and people feel ashamed to refuse what you offer. I know that since I have sugar, I can't accept what people give me to drink, and then people feel I being out of place and rude. But that's what it is, I have diabetes and I have to take care of myself first.

Tanty Radha had been diagnosed with Type 2 diabetes two years previously, on a routine check-up at a private nursing home⁷² in Southern Trinidad. Her visit was covered by her husband's health insurance policy, which he had taken out many years previously when he first started his business. She had been having a biannual check-up with a well-known internal medicine consultant at this nursing home since the age of 55. An elevated random blood glucose screening test had prompted her doctor to order a fasting blood glucose test followed by a two-hour assessment and an HbA1c. All tests confirmed the diagnosis.

My HbA1C - that's the blood test, the one that tells your sugar levels for the last 3 months - that was around 10 the first time I had it done. So the doctor prescribed metformin and gave me advice about exercise, and referred me to see the dietitian who has her clinic in the nursing home. She sat down with me and went through the food charts - what is high glycaemic index food, what is low glycaemic index food, what substitutions I could make for the high glycaemic foods. Another way she showed me

⁷² Nursing homes in Trinidad are private health-care institutions offering secondary and some tertiary health services, with limited in-patient facilities and hospital beds. Patients, or their insurance companies, pay a premium to receive their care directly from consultant-level physicians instead of the junior doctors who are the main care providers in the public hospitals.

was the score for each food – vegetables I could eat any amount, salad, meat there was a portion, carbohydrates each kind was a different portion size. I realised that most of my life I had been eating three and four times the carbs to veggies ratio. And she calculated what my daily caloric intake should be. My doctor keep bringing me back to his clinic every two or three months to get checked up again, and little by little we brought down the sugar. He added Januvia⁷³ some time last year. Now my HbA1C is between 8 and 8.5 [mg/dL] and I know I could get it even better than that, without having to go on insulin.

Tanty Radha did not want to start insulin, because she had heard that once started it would be nearly impossible to stop while maintaining her blood glucose sugars in a comparable range. She had also read online that administering insulin sometimes suppressed whatever insulin production was still taking place from her own body, which she did not want.⁷⁴ “The best thing would be if I could take some herbal medicine, but I don’t trust those herbalists and bush doctors we have, they only after you money and they have no good reputation,” she said once while we were chatting.

I don’t make no joke about taking my medicines. Some of them, I started to get them from CDAP, but then my brother told me not all the medications on CDAP work, so I

⁷³ Sitagliptin.

⁷⁴ In people with Type 2 diabetes, insulin resistance often increases over time, and endogenous insulin production decreases, making exogenous insulin administration a long-term necessity. it is unlikely that similar levels of blood glucose control would be achievable without insulin, by the time it is required. It is not proved that external insulin administration decreases internal or endogenous production.

began buying them from the pharmacy. Also my doctor put me on some, like Crestor⁷⁵ and Januvia, that aren't on CDAP, and I get them from the same pharmacy, only because it's brand name you know it will work. But I bought my own [blood glucose] monitor and strips to check my sugar when I started on Januvia, and I keep my journal and everything. My doctor didn't start me right way on insulin because he said he thought we could manage the sugar with lifestyle and drugs first, and I real happy, because I real don't want to have to stick myself ... But if I have to, I have to, I will do what I need to do for my health. My morning sugars are good, always under 120 [mg/dl] but my night-time sugars are sometimes a little high, like 190 [mg/dL] and then I know I have to cut out the sugar I'm eating, or I'm eating foods with sugar by mistake.

Tanty Radha focused on the biochemical markers of diabetes control in her descriptions of her diabetic condition repeatedly over the course of our interactions. She had experienced no symptoms of the disease and no effects to her daily functioning prior to being diagnosed. After diagnosis, her accounts of the changes to her bodily sensations focused more on the side-effect profiles for the medications that she had experienced and overcome. She described significant gastrointestinal discomfort upon starting Glucophage⁷⁶, which gradually subsided after a period of months, and difficulty swallowing the tablets, which were large. She had first used a pill-cutter to size them, but over the past 2 years she grew used to the twice-daily regimen and no

⁷⁵ Rosuvastatin.

⁷⁶ Metformin.

longer required it. Tanty Radha had also experienced some nausea when she started the Januvia, but that had decreased when she began to take it in closer relation to her meals.

Aside from her twice-daily medical regimen, Tanty Radha had also entirely changed her diet over the course of the preceding three years. She had become a full-time vegetarian, instead of fasting from meat only on a Monday and a Thursday, which pleased her mother, who was also vegetarian, but for religious purposes. Her vegetarianism had also changed how she cooked for the family.

Since then I am vegetarian, I only cook and eat vegetarian food. My husband doesn't have diabetes, but he has it in his family so he might get it later on. I am very strict about my diet - that is all I cook so that is what he does eat. But when he driving home on an evening, I know he and sometimes my son does stop by the chicken place and buy a little bar-b-que chicken or lamb, or curry duck from the in the stand round the corner. I can't afford to do that, the littlest thing does send up my sugar.

She had also joined a gym, and tried to walk more instead of “driving everywhere” she had to go, however she laughingly said that, “Nowadays the sun hotter than long time.” She went to the gym and had a personal trainer there at least twice a week, and had decided to start Zumba fitness-dance classes on a third day just so she wasn't “stuck in the house”. She still had a problem with her “belly fluff”, however, her abdominal circumference measuring 52 inches. This “central obesity” is implicated in much diabetes research for increasing insulin resistance, leading to poor diabetes control.

Tanty Radha went for private medical care to a consultant in internal medicine for her primary care. Each visit cost \$400 TTD, and she saw him at least once every three months, when a new HbA1c test was ordered to assess her previous 3 months of control. Once a year she also had kidney function tests, total cholesterol, liver function tests, an ECG, urine tests for microalbuminuria and had her eyes checked for diabetic retinopathy by an ophthalmologist. All of these tests were covered to some degree by her private health insurance, but the insurance costs themselves were high because of her age – she paid approximately \$14,000 to \$20,000 TTD per year. These healthcare costs would have been inconceivable to Tara, and were out of Meera’s reach, but as Tanty Radha said, “You can’t put a price on your health.” She also added, “I don’t feel sick, but I know that is the tricky thing about diabetes – you going along real good and then all of a sudden you get a heart attack and you don’t know how come.”

Tanty Radha had integrated the management of the diagnosis of diabetes and its expected progression into her life using techno-scientific measures of her body that she was provided by the best medical care she could access in Trinidad. She was as yet asymptomatic, and her transformations of lifestyle were intended to delay the progress of the disease as long as she could, since she expected that her disease would progressively get worse. A crucial part of that was keeping her HbA1c at the right level, since this was considered more reflective of the long-term control than her daily blood glucose measurements. This was a constant struggle for her. She “felt shamed” when her twice-yearly HbA1c check-up revealed increases rather than the steady decrease that she was aiming for with the transformation of her “lifestyle”. She was also constantly trying to lose weight, since her doctor had told her that losing her round belly would allow her insulin to work more effectively.

The thing is the food. I eat real simple food now, but it look like no matter what I eat, my sugar does go up. I could look at a barfi and my sugar going up. I try dieting, I try eating what the dietitian tell me, I try cutting out the meat, and my sugars still high. Every time I eat even a little bit of sada roti or worse yet paratha that goes right up. If it was just the random sugar I wouldn't mind, but my HbA1c goes up too, and then I look like I don't care about my health.

The strain of having to watch everything she ate had made Tanty Radha consider the last-resort option her internal medicine doctor had suggested: what she called “metabolic surgery”. This surgery is performed laparoscopically, through keyhole incisions with miniaturised surgical tools, which a surgeon then uses to wrap bands around the stomach or excise part of it to shrink its size, all under camera guidance. Laparoscopic bariatric surgery had shown success internationally in lowering blood glucose sugars, insulin resistance, and in many cases, reversing diabetes entirely in patients with obesity (Schauer et al. 2017). At the time this research was conducted, its popularity in Trinidad was just beginning to grow since it was only available through private healthcare, not in the public healthcare systems. Tanty Radha's private physician had suggested this as an option for her since she had found it difficult even after five years of efforts to lower her HbA1c levels much below eight. “It's the worry about eating that I don't want to have, that and the inevitability of insulin,” Tanty Radha explained. “I don't know if I will get it, but if things keep going so, and I know my organs are getting damaged by the sugar, I will have to really think about it hard.”

Tanty Radha had the surgery after I had left the field. One year after the surgery her appetite had decreased, her weight had dropped dramatically, her HbA1c's were all within a

normal or less than normal range, and by the diagnostic criteria for diabetes, she no longer the disease. This complete reversal had not changed her lifestyle dramatically, she said, except in that she no longer had to be as circumspect in what she ate, though she still didn't indulge in sugary foods in any way. She was extraordinarily thankful with the change in her life, and with not having to second-guess every bite of food that she took.

5.3 Same road, different journeys

Tara, Meera and Radha all lived on Amar Trace, while Dularie lived one street over. Like most people I interacted with in Debe, they were all asymptomatic, and diabetes-related illnesses had not had much impact on their lives. Despite living along the same road and all having asymptomatic diabetes, however, these women's lives were very different. The case studies of this and the preceding chapter provide some insight into the difficulties of expecting a single standardised set of biomedical recommendations to fit as diverse a group of people as diabetes affects in Trinidad. Diversity, among these case studies, refers as much to the diversity of their life circumstances and structural contexts. These women's experiences also reveal different engagements with explanatory models for diabetes in the Debe community.

Tara, Dularie, Meera and Radha lived within the same village and often attended the same communal Hindu religious events at the Amar Trace Mandir, where I first met them, but their life-worlds were very different. Tara's life was largely oriented around the village and populated by a smaller social network: her catering business was an extension of her home and social role in the Temple Group, she took a leading role in temple group activities that were localised to the community and regional space, she performed a significant portion of the housework and family labour through cooking, cleaning and household maintenance activities.

Similarly, Dularie's life was delimited by the village and the road on which she lived, though she did have relatives living outside of the area whom she kept in touch with. Meera and Radha's lives were more oriented outside of the village and populated by a more expansive and socioeconomically diverse social network. Meera's life included engaging with businesses and suppliers for her bar, who came from all over the country. Radha's job had taken daily her into the nearby city of San Fernando for most of her adult life and she still went "into town" regularly, while her post-retirement activities included engaging with charitable and other groups active throughout the country, her children were grown and at university, a hired housekeeper cleaned her house once a week.

Their experiences of diagnosis were also different from the start: Tara and Dularie received the diagnosis as an accidental finding when they went to the local health centre for another complaint; while Meera and Radha were diagnosed because they sought out consistent screening, in Meera's case because of her family history, and in Radha's case because of the advice of her private physician. Their perception of the disease presence and impact upon their lives was similarly different. To Tara, the diagnosis was as incidental as the manner in which it was discovered and she had made no changes acknowledging the presence of disease. To Dularie, failing to maintain consistent blood glucose levels despite her best efforts, the burden of continuously treating the disease was far greater than the symptoms themselves. To Meera, a diabetes diagnosis was an expected development given her familial predisposition. To Radha, it was a bracketing event, a watershed moment that divided her life into a before and after, and a moment of significant transformation to her life-world and her own sense of being in the world. To Tara, in the absence of experiential, bodily manifestations of diabetes, she had only "a touch of sugar". Dularie, Meera and Radha, meanwhile, perceived themselves as having full-blown

diabetes, which they were carefully managing in order to avoid having to take insulin as the disease progressed.

Choices of where and how to assess and treat their diabetes post diagnosis were also revelatory of structural constraints. Tara and Dularie accessed the public health care institutions exclusively, mainly for cost reasons. The inconvenience of having to wait (sometimes for hours) to be seen in the walk-in clinic setting, to Tara, was significantly overshadowed by the convenience of not having to pay or to make her husband lose a day's work by dropping her to the more distant San Fernando General Hospital. Dularie had no choice but to use the local health centres, having no way of getting herself to an alternative venue, and no extra money to do so. Dularie had neither a home computer nor the Internet, and was not technologically literate. Tara did not have a home computer, but did have Internet access on her phone, which she used to communicate with a known group of friends and family through a large Whatsapp group, where the main exchanges she shared with me seemed to be daily memes of jokes, prayers, chain letters, and greetings to each other.

Meera accessed a mixture of public and private healthcare, like many other middle class Trinidadians. Radha, meanwhile, utilised only private healthcare, had access funds and to health insurance that mitigated much of the costs of private health care, and saw a consultant regularly as a matter of course. She had close relations who were physicians, and regularly accessed the Internet as a source of information about her diabetes, as did Meera.

Radha and Meera both clearly accepted the biomedical model of diabetes and its care. The integration of diabetes management into everyday interpersonal relationships and social support networks allowed them to continue to meet their life-course expectations or what Bury and Holme (1991) have termed their "social clocks" despite the diagnosis and disease

management; and the larger structural constraints of healthcare provision within which diabetes is managed in the public health and private health settings of Trinidad that facilitated their perception of successful disease management.

Asymptomatic individuals Debe varied considerably in their acceptance of the biomedical model of diabetes causation and management. While the WHO guidelines diagnose diabetes as present or absent on the basis of a 1 mg/dL difference in blood glucose levels, accepting this binary classification also requires the acceptance of an entire biomedical paradigm: one in which techno-scientific measures of the body are more authoritative and valid than individuals' lived experiences in their own bodies, expert advice carries more weight in determining patterns of everyday life and sociality, and lifelong practices of self-identity and their sense of value are expected to change, to meet medical recommendations.

Chapter 6: Living with the symptoms of diabetes: Explanatory models and beliefs

In this chapter, I draw upon three ethnographic and narrative case studies to explore the effects of uncontrolled Type 2 diabetes mellitus on people's lives, tracing their experiences of symptomatic progression to the development of complications and increasing debility. These narrative case studies were chosen in part because of the transformative effects of their symptoms and complications not only on their own but their entire family's life-worlds. These life-world transformations occurred both because of the disease process, associated and resultant illness, and because of the treatment burden of managing the disease.

These case studies were also chosen because they exemplify the most common health beliefs and explanations for diabetes and its management that I encountered in the field, though the frequency of these beliefs was not systematically quantified. These case studies show that the same people utilised both a biomedical and a folk health explanatory model to explain their symptoms, disease onset, and causation. Different explanatory models were also tactically invoked at different points in time and to different audiences. What must be noted, additionally, is that people were sometimes more willing to share medical details of their conditions with me when they learned of my medical background, and to speak in medical jargon with me that they had picked up in their clinical contexts.

These case studies, additionally, highlight the ways that income precarity and poverty, poor healthcare access, stress, familial and community support (or lack thereof) and the physical demands of particular jobs interact to intensify the experience of illness. This focus is intended to

unpack the general category of non-compliance that is often applied to persons with the complications of uncontrolled diabetes in Trinidad. The narrative approach also demonstrates that even in these singular illness narratives, broad networks of support are evident, as the disease process requires more than the single individual implicated in management recommendations for caretaking to occur.

6.1 Having “kidney”: Deoraj

Deoraj was a 64-year old former manual labourer whose first words to me were: “I suffer with sugar, heart, and kidney,” noting soon after that he also “had pressure”. In village Trinidad, people say they “have heart” when they suffer from diseases of the heart, such as heart failure or “having kidney,” to refer to a disease of the kidneys. “Having pressure” similarly means one has high blood pressure. Deoraj’s detailed illness narrative however went far beyond the usual invocation and seating of disease in a particular malfunctioning organ. From the start, his narrative included medical jargon and technical terms such as paracentesis, haemodialysis, fluid overload, and water retention, which he clarified he had learned from the health professionals who cared for him. Even though Deoraj did not always use these terms as medical professionals would have them, by including them as a part of his illness narrative, Deoraj metaphorically claimed a biomedically-oriented ownership of his illness, and demonstrated an adherence with a biomedical explanatory framework throughout his narrative.

Deoraj was born and raised in Debe, the sole child of poor cane cutters with Caroni (1975) Ltd, labourers whose yearly income rose and fell with the agricultural cycle of planting and reaping cane. His father was also a “hard drinker” (alcoholic), but his mother had saved enough from her earnings over the years to buy a plot of land for them to build the wooden house

they moved into when he was a teenager, and that he inherited upon their death. His parents died young, his father at fifty-five from a massive heart attack (most likely because of his drinking, Deoraj believed) and his mother in her early sixties after a stroke that left her paralysed for years. Both parents had been diagnosed with diabetes, but he didn't recall them taking any medications. Deoraj now knew, however, that it was inevitable that he would get sugar, since they both had it – he had it in his blood, he stated.

Deoraj worked as a manual day-labourer in construction. He married Sumintra quite late by Debe standards, when they were both in their forties, and she moved into his parents' old wooden house with him. With the help of friends and relatives, Deoraj constructed a new concrete house for his new wife to the back of their wooden house, in which they continued to live. By the time the new house was mostly complete their son Shiva had been born. Soon after that, at 45 years old, he fell from scaffolding at a construction site. "I never fall from scaffold before... it had to be the sugar already working in me. The sugar working in me long, long time before I know," he said. When taken to the Accident and Emergency department of SFGH the doctors told him he had a "damaged knee," "borderline diabetes"⁷⁷ and "pressure". His knee was treated immediately and he was discharged with a referral to the Chronic Disease Clinic at his local health centre for follow up of his \diabetes and hypertension. After he recovered from the acute trauma of his fall, and upon his wife's urging, he followed up on the referral at the Clinic.

To attend the clinic, Deoraj had to miss a full day's work (losing between ~TTD\$150-300, or USD\$21-42), waiting for hours with the other "eighty-plus" patients before his number was called. He recalls being prescribed "sugar tablets" (anti-diabetic medications).

⁷⁷ This phrase is thematically and discursively similar to and used interchangeably with "a trace of sugar".

I didn't realise how serious the sugar was ... they didn't tell me I could get so sick ... they tell me a whole set a thing, I cyah remember. I uses to be a little bit slack [lax] with the medicine and them. I couldn't remember to take it with me to the job in the morning, and too besides I didn't want everybody thinking I sick. If I working late, I wouldn't have it with me either. Then the sugar take me, and it take me bad, bad.

Deoraj's wife Sumintra added that she didn't believe Deoraj had taken any of the recommended medications until he actually began to feel ill: "And too besides, you only take it when you have bad feeling [generalised feelings of ill health], so I don't know if the medicine had time to work self," Sumintra said. Deoraj had been prescribed sugar tablets (anti-diabetic tablets) and pressure tablets (antihypertensive oral medications). Working as a day labourer, however, he found it impossible to anticipate his meal-times and maintain his medication regimen as prescribed. The drugs also gave him gastrointestinal side-effects that made working uncomfortable, a cough, and he felt even more "giddiness" (dizziness) while on heights.

He also went to clinic appointments infrequently. To go to the clinic he had to take a taxi (shared private taxi) or a maxi-taxi (taxi-van with a set route), since their house was deep within the countryside, there was no public bus system, and they had sold their car for capital while building their house. Given that he was sole-breadwinner, with a young child, and with everyday demands like diapers, formula, as well as needing extra money to furnish their house, and also because he "didn't feel sick," Deoraj found he couldn't justify the cost either of the transportation to the clinic or the hit it would cause to his earnings. "While I could work I did

work,” Deoraj stated, “I know about hard work.” He did not see the necessity of losing a day’s for a ten-minute consultation, especially because he felt better without the medications than when taking them. Attributing to himself the blame of a non-compliant patient, Deoraj however added sadly, “I was a very bad patient from early on, and that is how the sickness take me so.”

After he stopped going to the clinic, Deoraj began to notice his feet and calves swelling, with the swelling sometimes extending above his knees by evening time. He was working on multiple construction projects on every day of the week, and by night-time his legs would be so swollen he could hardly bend his knees. He took to turning down jobs involving heights, since he also found himself clumsier, and was afraid that he would fall and be injured. He had to work longer hours to “take care of the family and make ends meet”, especially they had a new baby.

One day, “out of the blue”, he found himself having difficulty breathing: “Water in mih chest was choking me, from inside out, I eh get no air, I was deading.” He went to the emergency services at the local health centre but was sent by ambulance as an emergency straight to the medical ward of SFGH. The generalised swelling and shortness of breath were the result of his body retaining fluid in many places, including his legs and abdomen. He was told his sugar had caused damage to both kidneys, and his kidneys were “rotten”, that is, he had chronic kidney failure. He was kept on the ward for two weeks then discharged with a regimen of oral medications and insulin. He was told he had “kidney” (chronic kidney failure), from the sugar (diabetes) and pressure (hypertension).

Most of his medications and blood glucose monitor were free from the Chronic Disease Assistance Program, however he was asked to purchase his own medicines for kidney failure. He could not afford this, so he did not buy them. Though he was also told to check his blood glucose levels twice a day at home, and prescribed a pre-mixed formula of insulin, he still found it

difficult to do. “I was still learning, I was still a bad patient,” he said. “I come out of the hospital an old man, a list of medications as long as my arm, only able to eat pap [soft mushy foods eaten by seniors with no teeth].”

In view of his kidney failure, Deoraj had been prescribed “kidney diet” and referred to a dietitian. She recommended simple substitutions of locally available foods, such as green fig (green bananas) instead of white rice or sada roti; fish instead of chicken or goat; smaller portion sizes, and drastically lower salt and sugar intake. These recommendations were not welcomed by Deoraj, who said that the kidney diet had “no taste”, and could hardly keep down the “pap”. Sumintra, a devout Hindu and practicing vegetarian, could not cook separate meals with her schedule taking care of their baby, so she simply cooked with less salt overall.

Sumintra said, “I know it was not the best, but it was the best we could do ... we try everything, every which way, and it wasn’t good. The man had to eat, and he was the only one who need the food, the way he was getting small-small (losing weight) with the kidney.”

Deoraj rarely checked his blood sugars at home despite having a home blood glucose monitor.

I only uses to check when I feel the sugar high ... I know when that is because I did get sweats, like an internal fever, and I also used to feel very tired, more tired than when I used to work out in the fields. When I take the insulin when the sugar was low, the insulin would send the sugar too, too low, and I would get the shakes. I almost pass out [faint] a good few times from the sugar being too low, and I break out in a cold sweat and I feel like I was going to dead. But every time I checking the sugar, chooking [poking] up mih finger an’ dem for the blood is only normal, normal mih sugar looking. Then the [blood glucose] strips and them, they run out before the clinic time come, and the

pharmacy wouldn't give me no more without the CDAP. I couldn't get to the clinic for that appointment to get the CDAP, so by the time I went I done forget about checking the sugar.

As his symptoms waxed and waned, Deoraj tried going back to work on the days when he felt well enough. The medications helped rid him of some of the water he was retaining, decreasing his short-breath, but he often felt weak and looked "sickly", and soon he was being avoided or turned down by contractors who had previously employed him. By this time, Shiva was in primary school, and Sumintra found work as a cashier at a neighbourhood grocery-store. Deoraj found odd-jobs as a village handyman, and occasionally "helped out" neighbours to sell produce at the Debe marketplace, where he was simply required to sit and manage the sales. To maintain themselves, Sumintra also kept up their back-yard kitchen garden growing vegetables, and cousins who lived nearby would also occasionally drop off a box or a bag of whatever was in season in their gardens. "So long as we have a little land, we does always eat," Sumintra said emphatically.

At one of his infrequent Chronic Disease Clinic appointments some time later, Deoraj was found to have dangerously high random blood glucose and the permanent swelling of his legs extended into his thighs, "like two sausage". His abdomen was swollen "like a pregnant lady" and he had an uncomfortable sensation of "sloshing in the belly" when he walked. The clinic doctor sent him to the medical ward of San Fernando General Hospital (SFGH) by ambulance, where he was told his kidney failure had worsened, was given "water tablets" diuretics to decrease the water retention, and his insulin dosage was increased further. Emergency paracentesis to drain the fluid from his abdomen was performed, followed by a

“blood cleansing” (peritoneal dialysis) while on the ward. Peritoneal dialysis is no longer medically recommended for the management of kidney failure due to the high risk of infection as patients with kidney failure are already immunocompromised, however there was a back-up of in-patients at the hospital awaiting use of the dialysis machines. When he was stabilised, Deoraj was referred to the SFGH Dialysis unit and added to the “kidney clinic” for future management.

Returning home after being discharged from the hospital, “like the house grow a hundred feet,” Deoraj said. He had built the house himself, in expectation of a comfortable life for himself and his new wife, but could barely climb the staircase to the top floor. It was a typical village two-storey “concrete house” – the open-sided ground floor consisted of a bare concrete foundation and pillars that supported the upper floor, where the kitchen, living and dining rooms, bathroom, and bedrooms were located. The cool South-East Trade Winds blew through the pillars of the open ground floor, and the family, like many others in the area, had two hammocks permanently suspended there to “catch the breeze”.

Seeing his father’s discomfort, Shiva got the front bucket seat from an old Ford Escort car, added pillows and cushions to it for comfort and to keep his father seated fully upright, and leaned it against a pillar underneath the house. It was the most comfortable seat in the house, Deoraj said with a laugh. As awareness of his debility spread through the village, someone from the temple donated a wheelchair, but it soon became uncomfortable for him to move in and out of with only his wife’s help, and there was no ramp from the edge of the concrete foundation of the house to the ground. The village road had no sidewalks, and was potholed and rough, so navigating them in a wheelchair he could not accomplish by himself, and Sumintra was not up to it either. Deoraj came to spend more and more time in the car seat under the house, using the wheelchair only when going to the clinic or hospital.

Despite a long-standing fear of needles, Deoraj felt dramatically better after every blood-cleaning haemodialysis appointment at the SFGH Dialysis Unit. The unit was, however, open only from 8.00 am to 4.00 pm on weekdays, and there were only six working dialysis machines at the time serving the whole population of chronic kidney disease patients attending the SFGH, prolonging the time between appointments sometimes to months. In 2015 the Ministry of Health arranged for public health institution patients with chronic kidney failure to receive haemodialysis at 16 private institutions via a voucher system, in an effort to decrease these protracted wait times. Deoraj had however developed kidney failure before the voucher system was established, and could not afford to pay up to \$2,000 for private treatments, every two weeks. When the shortness of breath and swelling of his abdomen became unbearable, Deoraj would go to Accident and Emergency at SFGH, and be sent directly to the medical wards for paracentesis and emergency peritoneal dialysis as a stop-gap measure. All the medical teams at SFGH came to know him and called him a “repeat customer”, he recounted, with degree of pride.

The paracentesis and peritoneal dialysis were uncomfortable, and not recommended so regularly. In the absence of other options, however, these procedures ended up being done roughly once a month. Deoraj showed me his distended abdomen, pocked on the sides with small round hyper-pigmented scars from the needles, like pits on the surface of the moon.

Deoraj could no longer work. He received a small disability allowance from the Government of Trinidad and Tobago, which he had applied for with the assistance of the clinic doctor. Sumintra found another job at a fast food-stand in Debe frying up Indian delicacies, while maintaining her shifts as a cashier at the grocery, and taking care of the household, her husband, and her son.

Shiva, their son, had stopped school at the age of 17 and apprenticed to a mechanic along the Debe Main Road, and his earnings helped the family's income too. Shiva was also considering buying an "old car" that he could fix up to be able to take his father for his doctor appointments, instead of having to rely on friends and family members. Sumintra mentioned that their neighbours, family members, and old friends would drop-in to check Deoraj regularly, but that he wasn't always "in the mood", "in a good mood", or "feeling good" to see them. Deoraj admitted that sometimes he was "ashamed" of being seen like this – "a big belly, two skinny foot, and cyah [can't] move nowhere". Whenever there was a "prayers" in the village, however, someone would drop off some parsaad, or a take-away box or two of food. Deoraj's cousins from the village or other villages nearby also helped Sumintra on occasion, when she needed things done in the household. These efforts made everyone's everyday life more liveable, despite Deoraj's ill, immobile, and increasingly distressed state.

One day, Deoraj was told that a routine ECG showed his heart had been damaged by a heart attack, defined as a "silent heart attack" since he had felt no symptoms, a common complication of heart disease amongst persons with diabetes. In combination with his existing chronic kidney failure, the congestive heart failure resulted in a global worsening of his symptoms and even more short-breath and discomfort. Surgical interventions such as coronary artery bypass surgery were ruled out from the outset, since "they wasn't sure I would get up from the table after they open me up". Deoraj described himself as "playing the waiting game" - waiting to see what would happen next with his disease, waiting to see if there would be some kind of improvement if they increased his medications further, waiting for what another step in his decline.

At the time I met him Deoraj was receiving haemodialysis every two weeks. He was nevertheless constantly short of breath because his kidneys and heart were failing. As his body could not rid itself of fluid efficiently, it collected in his lungs. In all our conversations, he could speak only in short bursts of a few words, in between gasps for breath. With the help of his son, Deoraj climbed up the stairs at night to sleep, and climbed down again in the morning when he awoke. “I is a old man, now, the sugar take away my strength, my legs, even my breath,” he said. The hammocks had been restrung between pillars at right angles to his car seat so the entire family could sit together. Friends and relatives dug a latrine (pit toilet) for him in the back yard. Another relative gave the family an old four-burner gas stove, which was placed in a corner under the house, on which Sumintra cooked meals near to Deoraj “for company”. An old wooden picnic table and two benches were installed near the hammocks. Under the house had become the new living space, where the family had re-oriented their lives around the immobile Deoraj. Whenever I drove past the house, I would look out for his upright figure, sitting in his car-seat all day long, keeping vigil over the village.

6.1.1 A narrative of biographical loss

Deoraj’s illness narrative was shared over days, but spanned a transformative illness experience of over fifteen years. It was internally coherent, progressing through stages of increasing debility, though it developed non-linearly, lingering on some early experiences with more emphasis than more recent and debilitating episodes, for e.g., the first time he noticed his feet were swollen, in contrast to his development of heart failure. In so doing, Deoraj was highlighting the moments when what Becker (1997) has described as appearance of disruption that interrupted the continuity of his life-course up until that time. These emphases were his attempt at redefining his

life through recognising in his narrative what he had not recognised at the time: the significance of these symptoms, and their eventual worsening.

I posed Kleinman's classic questions⁷⁸ to elicit explanatory models to Deoraj, and he clarified that from diabetes was the main cause of his complaints: "Is the sugar cause this, that is the cause of all the trouble," he explained. It started, he believed, because he wasn't taking good care of himself, he was working himself too hard because he wanted to take care of his family and he had just had a baby, and he had always had sugar waiting in the blood because his parents had it before him. The problem with his blood was the sugar – it was too high, and the sugar couldn't go anywhere so it made him sick. It made his blood "toxic," it was so sweet, it was too sweet, the sweetness was a poison to all the organs in his body. His sickness wasn't always so bad [severe], but because he hadn't taken care of himself, because he was a bad patient and didn't follow the doctors, the sugar had taken hold of him and taken over. The main problem was his breathing, now, and his heart. The only thing left to fear about the sugar was where it was taking him next – right into the ground, he said one day, and then began to laugh.

Deoraj's explanatory model was entirely consistent with the biomedical explanatory model for diabetes, a fact in which he took pride. He had learned a lot from the doctors and nurses, he explained to me, since he didn't know much when he just got sugar, and now he knew so much more. Deoraj explained too that if only he hadn't been such a bad patient early on, he could have prevented all this from happening. In calling himself a bad patient, Deoraj invoked a

⁷⁸ These questions include: what do you call the problem; what do you think has caused the problem; why do you think it started when it did; what do you think the sickness does and how does it work; how severe is the sickness, and how long will it last; what are the main problems it causes for you; what do you fear most about your sickness; what kind of treatment do you think you should receive; and what are the most important results you hope to get from treatment.

paternalistic model of medical authority to frame himself as a disobedient passive recipient of medical instructions. Adhering to this explanatory model was therefore an expression of his close interaction with and internalisation of this biomedical framework over the years of illness, and prolonged exposure to the medical establishment.

This negated the social and structural constraints on his ability to meet the requirements of his therapeutic regimen: the limitations placed by his job as a manual labourer on his inability to time medical doses and to manage side-effects; his unwillingness to lose income for any reason as sole breadwinner and new parent; the distance and inaccessibility of the clinic in the absence of public transportation; and even his expressed lack of understanding of physician explanations of the disease and its expected progression when he was first diagnosed. Social class, poverty, and educational level were therefore all implicated in the development of his illnesses, which the focus on compliance elides. Being framed as a bad patient also scaffolded the development of complications as a punitive consequence of his disobedience.

Structural constraints to the health care system were also suggested in his narrative. For example, Deoraj received no care from a multi-disciplinary team, a social worker or a diabetes home care nurse who might have been able to tailor his therapeutic regimen to his work and home constraints, after his first diagnosis. The protracted wait times at the clinic, the long duration between appointments, the few spaces available publicly for haemodialysis and the regular use of the stop-gap measure of paracentesis all suggest an overburdened health care system. Larger systemic problems in health care access were also suggested in his inability to navigate public spaces as a disabled person to get where he needed to go, which had resulted in his virtual marooning on a car-seat, under his own house.

6.2 Grief, love, and diabetes stress: Tanty Basdaye

Tanty Basdaye was a seventy-two year old Indian Trinidadian woman, with a gently teasing sense of humour and progressively worsening vision when I met her. She lived in the same house she had inhabited for the fifty-five years since her marriage, a single-storey concrete-house. It was situated on a slight rise with a large, wrap-around gallery (porch), and many fruit trees dotted throughout the extensive lawns. The gallery had an overhanging galvanized tin roof and front door was always open.

Her husband's family had been large-scale dairy farmers and wealthy, until dairy became unsustainable. Tanty Basdaye also came from agricultural background though her father had also had a small retail business that had given her and her husband a good start in life. Her husband's family house was now more elderly than Tanty Basdaye, and looked small juxtaposed to the adjacent two-storey houses of her son, Bano and daughter, Leela. When her children were young, Tanty Basdaye had done her entrepreneurial best to ensure that they needed nothing and received a good education: convincing her husband to borrow money from his parents to buy a sewing machine, she had taken classes in San Fernando and become a seamstress, sewing dresses for women and school uniforms for children in the village. She had cultivated a separate garden plot herself, and sold the extra produce at the marketplace to buy them extra school supplies. Her children and grandchildren spoke of and to her with a gentle reverence.

Tanty Basdaye attributed the onset of her diabetes to the “shock” and “stress” she experienced when her husband died suddenly, 12 years previously, when she was 60 years of age. It was after this shock that she began to notice identifiable symptoms of diabetes.

After Balram died, I thought that was it. We was very, very close, we grow up neighbours together in this same village. We used to plant rice together and cane in the cane season, and I used to be there head and head with he, until he tell me to stay home and take care of myself, baby on the way, time for him to take over. He treat me real good, and then he die young-young, just-so, just-so when the grandchildren was growing up. Is a heart attack he die from. I don't know, I don't know how I could go on, but my daughter Leela tell me I must stay, I have a grand-daughter Kavita, I have a grandson Anand just born, and then I gone clinic and I find out I have sugar. I was feeling giddy giddy (dizzy), and I was only crying all the time, and the stress bring on the sugar.

Believing the dizziness she was experiencing was a result of the “grieving” and “stress” of having lost her husband, it was a few months before Tanty Basdaye sought medical attention. When she eventually was seen, and diagnosed as with diabetes, she realised that the “stress” that had actually “brought on” or caused the diabetes. She considered the severity of her symptoms to be “bad strain of sugar”, a direct consequence of the particularly severe “shock” and “stress” of her husband’s passing. She did not think that she had Type 2 diabetes prior to her husband’s death, convinced that she would have known “in her body” if she had the sugar.

The doctors recommended she start on insulin immediately because her sugar levels were “over [very] high”. However she was anxious about having to stick herself with needles every day, and opted instead for medical management using the combination of antidiabetic drugs: metformin, sulfonylurea drugs and ACE inhibitors, available for free through CDAP. I learned which tablets they were since she pulled out a large bag left-over tablets to show me, also conveying her repeatedly unsuccessful attempts at controlling the sugar with medications,

perhaps due to the fact that she didn't always take the tablets. Her daily blood glucose sugars continued to be high, so she was transitioned to a combination of metformin and insulin.

Her granddaughter, Kavita, was training to be a nurse at the time, and became "very strict" with Basdaye about maintaining her medical regimen. She went with her grandmother to all the clinic appointments she could manage. Kavita also arranged it so she could administer insulin to Tanty Basdaye every morning on her way to work and every evening when she came back home, until Tanty Basdaye learned to self-administer. Yet the symptoms progressed from dizziness to a general "bad feeling" (malaise) which rarely went away, except immediately upon the administration of insulin. She also developed early symptoms of kidney and eye disease, as "the sugar got worse".

When I visited Tanty Basdaye, she served me a glass of sweet-drink and Bourbon biscuits, cream-filled and sweet, with typical village hospitality. Neither of these items should have been part of her diabetic diet, but she partook of both unhesitatingly and absently, as a matter of course, even as we sat in her porch chatting about diabetes.

Is when the eyes start going that I realise the sugar was bad, bad, bad. I know my kidneys wasn't so good, they tell me this in the clinic, but I didn't know next thing was the eyes. I thought long time that I might get sugar because my father had it, but not my mother, and I was hoping I would take after she, but then BAM, Balram dead and I get the sugar. And I get it bad right away. Everything go wrong. I was giddy, I get an internal fever, I get infection in my mouth, and then I get swelling and junjunie in the legs.... none of that eh gone away for the whole twelve year I suffering with this sugar. I try using all the medicine, until my little grand[daughter] tell me I must start the insulin and I start it, but

it still doh work...last year I find everything looking blurry, blurry, everything I seeing getting a fuzzy way. The doctor send me to the eye [ophthalmology] clinic in Sando [SFGH], and they tell me I getting cataracts and the sugar damaging inside my eye, I have to go cataract clinic, I have to go laser surgery ... Is then I know how *severe* I get this sickness. It does affect everything in the body. You can't get away from it ... I does eat good, every day Leela telling me, Ma, come by we for lunch, I make some carailie for your, come by we for dinner, I make some stew chicken with cinnamon because that good for the sugar. But still this sugar don't go down. I take all my medicine, I take all my prescription and the grand [granddaughter] does give me insulin at night, and still this sugar only high, high so. Is the shock of losing my Balram. Since he gone *I lost my bearings in the world.*

Leela, Tanty Basdaye's daughter, lived nearby with her family and Tanty Basdaye ate most meals with her family, as she since her husband's death. Leela worked as a clerk in the Borough Corporation, but she still found time to cook most of her mother's diabetes-friendly meals when she was cooking the family meals. She also brought them over if Tanty Basdaye did not join the family. As none of Leela's immediate family was had a diagnosis of diabetes, she sometimes cooked separate meals for Tanty Basdaye. This was infrequent, as Tanty Basdaye explained that Leela had a "sweet hand" and her family enjoyed when she cooked even the simplest, most basic meals that Tanty Basdaye could also share.

Dal and bhaat [rice] and tomato chokha, nothing could beat that for taste when the tomato fresh from the garden and the right hand cook it. That is very good diabetic food too.

Pumpkin, ochro – any talkari [vegetable side dish] and a little rice and dal good for the sugar. Leela have a sweet hand like she mother. I does still garden [grow a kitchen garden], it always have some tomatoes, carailie [bitter gourd], pigeon peas, ochro [okra], baigan, dasheen bush bhaji [taro leaves], bird pepper, other little things ... Leela husband does garden for me, and the food does taste best from your own garden, even though it have Debe Market on a Saturday.

Tanty Basdaye considered herself to be managing her diabetes very well. “I am *very good* with my medicine, I take it every day, like clockwork,” she said. However, like most other elderly patients with diabetes in Debe, she did not recall the exact names, dosages, or timing of her medication regimen, even though she was now only on two tablets. She was able to describe the shapes, sizes and colours of some tablets, but wasn’t sure how many or at what times she took them. Leela, her daughter, and Kavita, her granddaughter, were both instrumental in helping with her medications: they had bought Tanty Basdaye a labelled plastic pill dispenser and arranged her medications in it weekly. Tanty Basdaye would sometimes run out of one medication before her scheduled clinic appointment, but was able to buy them from the local pharmacy where she was well known, or request a refill of her CDAP prescription. Tanty Basdaye took the bag containing all her medications to her clinic appointments, and to the occasional check-ups she required at the Ophthalmologic Clinic at SFGH in case the doctors wanted to know what medications she was taking.

Kavita pulled me aside one day to confide that her grandmother was very “non-compliant.” Tanty Basdaye always asked for dessert after eating dinner, Kavita said, and if it wasn’t a low-sugar or sugar-substitute dessert she would eat it anyway. She never refused a bag

of parsaad. She ate whatever fruits were in season, including unlimited quantities of the very sweet Julie mangoes from the trees in her garden. She also often asked for second servings of rice or roti with her meals, complaining with an impish grin that she was being “short-changed”. If Kavita had not started administering her grandmother’s insulin, she was unsure that Tanty Basdaye would have taken any medications at all. Her daughter or granddaughter accompanied her on all her clinic visits, and both had a clear understanding from the doctors about the possibility of worsening illness associated with diabetes, making the point to Basdaye multiple times without it seemingly having any effect. “So long as I taking my insulin, I good,” was Tanty’s sole response.

Tanty Basdaye was on the SFGH waiting list to have “cataract” , or lens replacement surgery for cataracts, the formation of which are accelerated by diabetes. Despite dire warnings about her worsening health, Tanty Basdaye focused on doing those things that continued to make her “feel good”, which included eating good food, spending time with her family, and attending community events such as village yagnas, Ramayana readings and pujas, where she was a local fixture and got to spend time “old blagging” with her neighbours and friends. “You done losing everybody you love when you getting old,” she explained one day to me, “It don’t make sense we have to give up on every other good thing in life too.”

6.2.1 Stress, herbs, and diabetes onset

Tanty Basdaye’s narrative focused less on the ways in which diabetes impinged on her life and her experiences of the world, and more on the shock, grief, and loss to which she attributed both disease onset and severity. Indeed, her narrative repeatedly returned to the true meaning of her disease state: that it was a somatic expression of the love (and loss of love) between her and her

husband. His loss had triggered a measureable, physiological change in her being, i.e., the onset of the disease of diabetes, though it had already been in her blood before. Cheryl Mattingly (2010) highlights that narratives are also dramas, focused on the eventfulness of social action that are culturally shaped, healing, and story: agentive acts in which experience is refigured and received and a picture of life is arrived at that is situated between the past and the future (Mattingly 2010, 52-53). Which explanatory model made her life more manageable? Her testimony to the depth of her love for her husband, and the power of their bond, which was what had made her diabetes come on so severely? Or the biomedical explanatory model that she had met the criteria for diabetes some years before her diagnosis, unknowingly?

Tanty Basdaye's responses to Kleinman's classic questions would therefore be that her sugar was caused by grief and shock at the unanticipated loss of an immense love. The process at work was sugar damaging her body, to which she had no resistance because she had "lost her strength" with her husband. The severity of her sugar was related to her shock and grief being similarly severe. As she would always miss her husband, this was a protracted loss which she would have to get used to. Finally, while she believed in the strength of the treatments she was taking (especially the insulin), she also thought that biomedicines were simultaneously ineffective and dangerous, so she was trying to manage the sugar with "bush medicines" too.

Bush medicines included plants that grew wild in the forests and uncultivated lands, which were known to be good for different things in the body, such as cooling, heating, and cleansing the blood. Herbal medicines were similar to bush medicines, in being non-biomedical, but were more commonly cultivated than found in the wild. These categories were not clear-cut, and both Leela and Tanty Basdaye said they only knew a little bit, hearing and learning about it from other people with diabetes in the community, and from older heads who knew much more

about how to take care of one's health in general. Cinnamon, for example, was supposed to bring down blood sugar, so Leela soaked a stick of bark in a litre of water overnight, and Tanty Basdaye drank the water the next morning. Also good for the sugar was green carailie (bitter gourd), the juice from both the ground gourd and the mashed and strained leaves, which was very bitter, but very strong too in bringing down the sugar. Other people in the village had said that shining-bush (the *Peperomia pellucida* herb) tea, made from infusions of the leaves, would help with the sugar, but that had to be used sparingly because the herb was strong, especially in combination with insulin. Periwinkle tea was also good for the sugar, and some people used it alongside their biomedical medicines. Noni (holy basil) juice was good for pressure, which Tanty Basdaye also had, so she would let it ferment it in a bottle exposed in the sun for a few days, then drink it.

Tanty Basdaye mentioned none of these remedies to her clinic doctor when she went, however. She didn't consider it important, since they weren't medicines the doctor was in charge of. When I asked other people in the village, it turned out that many people took some form of non-biomedical herbal or bush medicine in an intermittent way. They often took them in addition to their biomedical drugs, and few to none of them told their doctors. Tanty Basdaye also added that a good place to learn about these bush medicines was the clinic. Not from the doctor, but sitting in the clinic with other patients, waiting to be seen for two to three hours was a good time to chat, and to find out what other patients were doing to help with their sugar.

Folk health practices in Trinidad have been explored by social scientists from the 1970s onwards, and what I found in Debe was consistent with previous research. Early research by Wong (1976) for example, describes traditional folk medicine practices of Blanchisseuse, which despite being at the opposite end of the country, shares many similarities with Leela's, Tanty

Basdaye's, and other descriptions. Wong (1976, 103) found that these practices were used in conjunction with "modern" medical facilities, by "nearly everyone". They were also used both for illnesses with medical equivalents, and illnesses known only to folk medicine (Wong 1976, 104). More recently, Clement, Baksh-Comeau and Seaforth (2015) found a similar retention of traditional knowledge of medicinal plants in rural Trinidad, including their usage in accordance with humoral theories of medicine.

Illnesses treatable by herbs were additionally divided into "hot" and "cold" categories, which required remedies with the opposite properties (Wong 1976; Aho and Minott 1977; Lans 2006, 2007). "Cold" illnesses included the common cold, asthma and influenza, while "hot" illnesses included infections, chicken pox, measles, infant rashes, and teething problems. Causes were related to external factors such as getting a chill or internal factors such as "too much heat in body", "hot blood" or "food too heated" (Aho and Minott 1977, 352). Similarly, curative or prophylactic treatments were often described using "cooling" of the body as the main idiom of expression. Cheryl Lans (2006) describes a subtle difference articulated in her research of this theory as "cathartic" rather than "hot/cold" with the emphasis being on the removal of heat by cooling, rather than on the establishment of a balance between both hot and cold. Herbal remedies are taken to remove the heat from the system, in the form of cooling teas, purges or baths, and other measures may be taken to stimulate the blood and treat 'cold' illnesses.⁷⁹

⁷⁹ Hot-cold theories of disease belong to a humoral system of health beliefs prevalent throughout Latin America (Foster 1987, 1988). All substances are attributed inherent symbolic thermal qualities, and a person is constantly exposed to fluctuating temperatures due to these inherent qualities of substances ingested and environmental exposures. Foods, herbs and medicines, illnesses, mental states, natural and supernatural forces were grouped in according to their inherent humoral quality (Logan and Morrill 1979). Health requires an equilibrium of temperature, maintained by monitoring thermal influences on the body, while illness results from an excess of either hot or cold and is treated according to the "principle of opposites" – a "Hot remedy for a cold illness or a Cold

Despite being based upon a different disease aetiology model for diabetes than biomedicine, Tanty Basdaye saw no contradiction in simultaneously taking herbal or bush medicines and biomedical therapeutics. In this, her practices were consistent with what Wong had found over forty years previously. Her actions also exhibited what Littlewood (1988, 2007) has described as the empirical and pragmatic usage of bush medicine in Trinidad, in which the selection of which bush to use was not governed by grand overarching principles, but by which one *might* work.

The last point that deserves highlighting from Tanty Basdaye's narrative was the extent of support she received from her familial and social network that facilitated her medical management, both the biomedical therapies and folk therapies she took. She was able to continue her everyday activities and life through the concerted efforts of her family, especially her daughter and granddaughter. It helped that her daughter was sufficiently economically well positioned to take the time to care for her mother, as well as geographically close, and therefore able to extend to her whatever support she needed. Her children were established in their jobs, her grandchildren were grown and pursuing their own careers, and she was a part of their extended households, despite living in a different physical structure. Her granddaughter's ability to regularly administer insulin, her daughter's "sweet hand" with diabetic friendly food, and an extended social support net of elderly women also suffering with diabetes were all external but integrated methods by which her diabetic control had been engaged. Despite the divergence of her explanatory model from the biomedical model, her therapeutic regimen continued to be

remedy for a hot illness" (Foster 1987, 335). While theories of humoral pathology are found in all ancient Chinese, Indian and Greek cultures, Foster traces this particular "Hot-Cold dichotomy" to origins among the Spanish colonisers of the Conquest and the post-Conquest period, part of the accepted medical doctrine, arising from Hippocratic-Galenic traditions (Foster 1987, 363).

largely in accord with its recommendations through the efforts of the larger social network by which she was supported, just with the “little extra help” from bush medicine.

6.3 Harriram and the diabetic foot

It start as a little, little black mark on my toe. The first thing was only a little-little black mark on my big toe. Then the doctors tell me the toe rotten, they have to cut it off, because nothing else could cure it.

Harriram was a truck-driver for a mining company at the time he noticed the mark on his toe, often driving the full length of the highway from North to South Trinidad multiple times in a single day. His job meant he was on the road and necessarily sedentary for long stretches, eating a large breakfast and lunch packed by his wife Geeta in the early morning hours, and a large dinner when he got home after 6 pm. There were also snacks and meals from roadside vendors, and he would buy multiple “Cokes” (generically used to refer to black coloured sodas) and chocolates for the drive, as he “had a sweet tooth.” Geeta worked in San Fernando as an office administrator, and their two children were in post-secondary education. The eldest, his daughter, had almost completed a Management degree at the University of the West Indies in St. Augustine, while his younger daughter was at a technical institute training in San Fernando, training to be a food safety technician.

Harriram was from a family of twelve, born and raised in Penal, where his mother still lived in his childhood home. His parents had farmed cane, but his father had also been a tractor and large vehicle mechanic, giving the large family a much-needed source of additional income.

“I wasn’t much into schooling,” he explained, “But I did like driving, and I could maintain a truck good.” After he was married, he and his wife had first rented near the quarry where he used to work, then found a piece of land to buy and build their house on. Hard work and sacrifice had allowed the family to save enough for Harriram to buy his own truck, which gave him a much greater degree of autonomy over his own time, and he preferred it that way.

Harriram was 51 when he began to experience numbness in his feet. “I didn’t even notice it at first,” he said, but he eventually found himself losing a sense of how hard he was pressing on the accelerator and brake pedals in his truck. He also began getting shooting, “electric-shock type” pains through the soles of his feet. His driving was affected. Truck driving in Trinidad, though sedentary, is physically demanding work with long hours and poor conditions. Harriram’s truck would be loaded up at a quarry, usually in a rural area. Rural road networks are poorly maintained, with pits, potholes, no guardrails, and are usually narrow but bidirectional. Drivers have a habit of swerving out of their lanes to avoid potholes, truck drivers no less than smaller vehicles. Motor vehicular accidents are very common, though fatalities occur more often on the highways than the smaller roads. Harriram began to have some near misses driving to and from the quarry. Additionally, the heat of the tropical sun is not kind over long stretches of driving, unless drivers have air-conditioning, which Harriram did not have in his truck. He began to feel very fatigued early in the day, to lose weight, and to have a general “bad feeling” or malaise.

Harriram went to a well-known pundit to be “jharayed”, to relieve his symptoms. Jharay is a Bhojpuri term for a ritual procedure performed in Trinidad to remove the “evil eye” or “bad eye”, a malign influence cast on an individual by another person or persons, both intentionally or unintentionally. The procedure involved the intoning of ritual prayers or mantras while brushing around the affected person’s body with a broom, and burning herbs that are cast away from them

along with the evil influence. The prayers intoned are most commonly in Sanskrit or Hindi, and once the correct mantras are known, anyone can jharay anyone else. Some, like Harriram, believe that jharay is most “effective” when performed by a holy person, most commonly a Hindu pundit or a Christian priest, who may make a good additional living from providing these services.

The manifestations of the evil eye are very diverse. For seemingly non-specific symptoms like Harriram’s, many people in Debe first assumed they had “bad eye”, and got jharayed, waited to see if the jharay had worked, and then sought medical attention. Harriram was jharayed twice by a pundit, with no effect on his symptoms. The numbness and tingling in his feet did not resolve. One night, after a day of pronounced pains, he noticed the black spot at the end of his big toe. At the urging of his wife, he went to SFGH. He was screened and confirmed as having diabetes, with an extremely high random blood sugar reading of over 400 mg/dL. He was sent for an x-ray of his foot and then to the “septic ward”⁸⁰ of the hospital for further management.

On the ward, the surgeon consultant told Harriram that his toe was “rotting from the inside out” because of his very high blood sugars, and the fact that he was a cigarette smoker only made it worse. The team of doctors also said they would have to “debride” or cut the dead black flesh from his toe until healthy, bleeding flesh was exposed. In addition, depending on what the x-ray showed, they might have to cut off his entire toe. Harriram was horrified, and refused any further treatment at first. He considered discharging himself against medical advice,

⁸⁰ The septic ward of SFGH housed all patients with active infections who were receiving antibiotics, as well as those awaiting surgical interventions such as the lancing of boils, excision of highly infected flesh, and the amputation of infected limbs.

but a young doctor convinced him to let them investigate how far the “rot” went: if the rot extended into his foot it might give him “blood poisoning” (septicaemia) and threaten his life. Harriram said, “It take me into a deep depression, the thought I could have lose my toe, but the doc tell me is better to walk with a cane than to burn on Mosquito Creek [Hindu cremation grounds].” The debridement worked, and he was allowed to keep his toe. He was sent back home with a huge gauze bandage around the toe, on insulin. He joined the Chronic Disease Clinic and the dressings clinics at his local health centre, and his wife took over the driving of the family car every week to have them changed.

The toe appeared to heal, and the shooting pains in his foot subsided though the sensation in his foot did not return. He took his oral medications faithfully, and checked his blood glucose levels once a week. Harriram however refused to self-inject insulin before lunch, using what he ruefully described as “an excuse, a bad excuse” of being unable to take the insulin with him in the truck since it had to be kept cold due to fear of the needle. He acknowledged that this was an excuse – “It have containers I coulda use, I coulda take it in a cooler, I coulda wrap it up in ice self. But I wasn’t thinking about the sugar, I was thinking about the hassle of driving and always this needle watching me out of the corner of mih eye.” If he was out driving too late, he additionally would eat dinner without taking the insulin, and his blood sugars were never fully regulated within the range recommended by the clinic doctor. He took advice about wearing whole, covered shoes while driving, however while walking outside his house one day he stepped on a nail. The numbness in his feet meant he didn’t notice, until his daughter saw the smudges of blood his foot left on the floor.

Harriram went into the hospital again, thinking it would be a simple matter of getting antibiotics and having the injury bandaged. Instead an x-ray showed that an infection that started

at the wound had spread all the way up reached the small bones of his foot. After a trial period of intravenous antibiotics was accompanied by the infection spreading further, the doctors explained that more treatment would likely produce no change, and Harriram was scheduled for an amputation of his right foot and leg below the knee on the following day. He again resisted, but less so once he understood that blood poisoning could follow the bone infection, which could also continue spreading upwards until his entire leg was affected. “The blood poisoning could make me lose my whole leg and kill me faster than the sugar, so I say cut off the damn foot.” He returned home with no livelihood.

I didn’t know how to do nothing else and I couldn’t drive at all any more with just one foot. But from the day they cut my toe, I swear I never smoking again. I eh touch a cigarette since. I start smoking cigarette when I was a teenager, and it was the easiest thing to help keep me awake while I driving long, long distance. The cigarette does damage you. I did know about the lungs, but I didn’t know about the blood vessel and the heart and the kidney – everything the cigarette does damage. And too besides the sugar is a killer. I didn’t know I had sugar, but I know the sugar does cut you up inside. My mother have sugar long time now, it does make she real sick sometimes but other times she good, good. It all depend on what you eat and taking care of yourself. You have to take care of yourself all the time when you have sugar, and once they cut off my foot, I eh want to lose nothing else, so I had to start.

Harriram was issued an artificial limb by the social services associated with the hospital and instructed how to use it. It took six months for the stump to heal sufficiently for him to use

the limb, over which time he used crutches to move around and a wheelchair in his house.

Walking was hard, but easier than if he hadn't been able to keep his knee, he explained. Geeta and Harriram also cut out all sweets from their diet, and since he was no longer driving long distances, he was no longer buying multiple sweet drinks for the drive. They began eating less carbohydrate-heavy meals and more vegetables.

Unbeknownst to Harriram, while he was undergoing problems with his foot, Geeta had begun the process of starting a small grocery under their house, on their ground floor. While he was at home, healing, he also was overseeing the renovations to transform it into a grocery. Geeta made an appointment for them at a nearby private general practitioner, who showed both of them how to self-administer his insulin “easy easy”, and Harriram began self-administering more. He became more confident in “feeling his sugar” rather than using the blood glucose monitor, however he visited the private general practitioner every two weeks to check his blood sugar levels and adjust his insulin levels accordingly until they were stable. Harriram still continued to attend the Chronic Disease Clinic, where he got his CDAP prescriptions and through which he had other once-yearly investigations. His last HbA1C, he told me with pride, was 8, and headed down.

Harriram also believed, however, that with the amputation of his foot, the maljo (evil eye), “badmind” (negative emotions) and jealousy that had surrounded him for years and had contributed to his diabetes had also dissipated. It was this belief in the potency of others’ negative emotions towards him that had pushed him to seek jharay for his symptoms in the first place.

Maljo is commonly attributed to people one interacts with regularly, though they may themselves be unaware of causing it. The fact that after the loss of his foot his blood glucose

began be controlled, the pain in his remaining foot subsided, and he was able to take more control of his life he attributed to people's jealousy having subsided.

There is people, you understand, who see you succeeding in things in life and they eh put in the work, effort, the sacrifice, but they jealous. They sit down in they broken-down house and looking at what you have, and they envious. They have badmind. They give you maljo [evil eye]. They ain't even have to do nothing – is not like they do obeah [black magic] on you, nutting like that. Is just the thought, the jealousy, is like a wickedness come onto you from them. That is what happen too for this sugar to come on so. What the doctor and them say is true to help with the sugar, because they have plenty knowledge. But the badmind of people who living all around you, that come into your life too. That is what make the sugar come on so, that is why I lose the foot. But like when they take 'way the foot, they take 'way the maljo one time [at the same time]. Since I come back home, too, every evening I lighting a little deya [oil-filled clay lamp] and saying "Om Namah Shivaya" nine time, and putting it on the edge of the driveway. I don't know who I get maljo from, but that is a little more protection.

At the time I met the family, Harriram had become proficient at getting around on his artificial right leg with a cane and was very busy starting their grocery. "Is good to work from home, I could eat when I need to eat, I could take my insulin from the fridge, I could do what I have to do when I need to do it, and the grocery air conditioned too. This is a very good thing, and too besides my daughter could run it after we." Harriram's narrative emphasises the importance of having future plans to look forward to, in the creation of an empowering

therapeutic employment.

Geeta still worked in San Fernando, though she was to soon quit her job and help with the business. Since Harriram owned his truck, he was also able to rent it out, and so the family continued to gain an income from his previous job. The family was full to bursting with plans for the future. Aside from ensuring Harriram's continued mobility, they were primarily preoccupied with ensuring the children finished their schooling, as neither he nor his wife had been able to attend post-secondary institutions, which were financially out of reach when they were growing up. The diabetes and indeed his loss of a limb was absorbed into a larger narrative of striving and succeeding. The spectre of future illness, life-disruption, or losses to diabetes was subsumed under the expectation that the pervasive badmind had subsided, and they could meet new challenges and overcome them as they needed to.

6.3.1 Maljo and badmind as explanatory models for diabetes

As Harriman shared his narrative, he at first appeared to draw upon a typical biomedical explanatory model to explain his illness: unrecognised and therefore uncontrolled diabetes progressively causing both systemic and local tissue damage, resulting in the development of a traumatised and infected foot, or “diabetic foot”, and amputation. Amputation is an extremely common consequence of diabetes in Trinidad, accounting for 80% of all major amputations performed in hospitals across Trinidad from 2000 to 2004 (Solomon et al. 2008). However, as we spoke more, Harriman also began to utilise a “personalistic ethnomedical” explanatory model in his illness narrative (Lans 2001; Foster 1976). Believing his illness symptoms to be the consequence of the evil eye, he at first sought “spiritual healing” (Lans 2001, 38) through the

jharay ritual, and simultaneous with the loss of his foot, he later attributed the control of his symptoms to the removal of the evil eye as people's jealousy of him subsided.

The concept of maljo or the evil eye is pervasive throughout Trinidad, described in literature pertaining to folk health beliefs for multi-ethnic and multi-religious contexts in rural Trinidad in much the same terms as Harriram. Wong called it a "folk belief" relating to "bewitchment", or the malign influence or power of an individual's will over another, producing illness of non-natural aetiology, for which the treatment involved both herbal and magical/spiritual elements such as infused baths and prayers (Wong 1976).

Belief in "maljo" or the Evil Eye was also described by Aho and Minott (1977, 352) as prevalent among a sample population from Laventille and Blanchisseuse, often the involuntary result of envy, and causing "blight", the symptoms of which either a gradual wasting away or death within twenty-four hours of a child who had previously received an admiring comment or glance. The maljo could only be removed or "cut" by specific ritual acts performed by persons of power, either a Spanish Catholic prayer or a Hindu ritual "jaray" (Aho and Minnot 1977, 353). People of one religion in Trinidad might choose a priest of another religion to remove the evil eye, out of a belief in their greater potency for this particular "ailment".

Lans (2001) most closely identified maljo or "mal yeux" (bad eye) as occurring when "a jealous or envious person looks at a person or animal and verbally admires it" after which the object "begins to decline and could die" (Lans 2001, 38-39). Though children and young animals were believed to be particularly subject to maljo in Debe, it was not uncommon for adults of both genders to seek to be jharayed, as Harriram was. Roland Littlewood (1988, 2007), amongst others, has identified that there are "personalistic" systems of medicine co-existing with biomedicine in Trinidad, under which maljo would fall. These systems are engaged

opportunistically, and as with Harriram, there was no perception of a contradiction to their usage alongside biomedical therapeutic efforts.

Harriram's engagement with multiple explanatory models to explain his illness experience was not unusual in the field, nor was his invoking of the spiritual or supernatural simultaneous with the materiality of the biomedical model. From a beginning filled with shock and horror at the potential loss of a toe, Harriram had reached a seemingly serene acceptance of the loss of part of a limb. His narrative reformulated an experience of loss into one of possibility – the subjunctivising elements at the end of his narrative were focused on the possibilities the future, including the betterment of his children's lives (Becker 1997). As Khan (2004) has previously identified, there is tension within the Hindu community over the performance of rituals, the world of supernatural phenomena, and a critique of superstition as baseless and backward (see Khan 2004, 111-115 for a more detailed exploration of this concept).

6.4 Symptomatic manifestations of disease severity: the experiential understanding of having sugar “bad”

Deoraj, Tanty Basdaye and Harriram were each diagnosed with diabetes after a dramatic injury, though only for Deoraj was the injury not directly related to a symptom of diabetes itself. In each case, managing the disease required transformations of their life-worlds, which they were able to effect to varying degrees because of the different levels of social support and structural constraints within which they operated. In each case, the greater the social support, the more their symptoms of diabetes were controlled, the better their diabetic measures such as blood glucose sugars and HbA1C measurements, and the slower the progression of their symptoms.

While medical diagnostic criteria for diabetes identify a single diagnostic cut-off point

that distinguishes between the presence and absence of disease, the measures of disease chronicity and severity are far less precise. Individual experiences must also be considered evidence for severity, in proportion to the disruption of their life-worlds caused by the sickness. Deoraj's narrative and the way in which the progressive symptoms were integrated into his life course narrative of job loss, function loss and gradual immobility identifies the artificiality of binary distinction between "diabetes diagnosis" as a temporal marker of the presence of diabetes, and "end organ disease" as a temporal measure of poor control. Deoraj's narrative also highlights the problematics of an emphasis on diabetes diagnosis and assessment dependent upon technoscientific measures of the body, when such measures are neither familiar nor convincing in and of themselves; or expectation that these instruments would be capable of changing whole-life chronicities of financial, social, and structural insufficiency.

The differences people displayed in their reference to a biomedical explanatory model for their disease and its management were also revealing. Deoraj's progressively worsening condition had gradually resulted in a complete dependence on the hospital, clinics, and associated structures of clinical care for continued comfort and indeed life. His narrative was one of transition from knowing nothing about his disease to becoming highly knowledgeable about disease transformation and its management. His deep entanglement in biomedical care provision pathways was evident in the medicalized language he used in his narrative, despite its occasional medical inaccuracies. Consistent with the attribution of greater religious fervour to "converts," Deoraj often sounded like a convert to biomedicine.

Deoraj, Basdaye and Harriram however all displayed familiarity with the biomedical explanatory model for diabetes, and all invoked it at various points in their narratives. Yet the biomedical explanatory model was not the only one used. Plural explanatory models were

invoked to explicate their experience of diabetes onset, severity, the lack of resolution of symptoms, and the progression of disease. Over the course of this research, I gradually found there were many glancing references to the ethnomedical herbal system of treatment, and the personalistic system of disease aetiology, in people's everyday conversations about their illness. Older women chatted and exchanged suggestions and refinements on how to prepare the noni juice, or the cinnamon water infusion. People shared stories of success or failure, where both were sometimes embodied in the same incident, such as a hypoglycaemic crisis when using both herbal or bush medicines and biomedical ones.

Patient explanatory models, especially when the patients are elderly, of lower socioeconomic status, and diagnosed after serious complications had already occurred, often tended to be experientially based and phenomenologically derived. Individual explanatory models co-existed with shared and normative explanatory models, such as Basdaye's emphasis on stress as the precipitant of her illness. Many people with diabetes in Debe however described "stress" as both a precipitant and determinant of their blood glucose levels, those who checked their sugars using glucometers validating these claims with numbers.

What is left open for future exploration, however, is the extent to which competing explanatory models and the practices they engender might underlie patient choices not to follow medical recommendations, and therefore the medical perception of "non-compliance" within this community.

Chapter 7: The collective work of “self-management”: Lifestyles and the work of caregiving

As the previous chapters suggest, it quickly became clear in the field that while the disease category of Type 2 diabetes mellitus was applied to a single individual, the illness of “sugar” was often processually experienced by a collective. This collective most commonly included immediate family members, but also friends, neighbours, members of a Temple Group, pumpkin-vine family, and the others with whose lives diagnosed individuals were enmeshed in various ways, and to varying degrees. The atomistic individual of biomedical recommendations, capable of rigorously extricating themselves from their social context to perform “self-management” was invisible, if present at all. Recommendations for “lifestyle-management,” similarly, unfolded from singular pursuits of eating and exercise by people with diabetes into complex and multi-layered life-worlds in which not only they but also their family members and entire social context were imbricated.

The narratives in this chapter explore the collectives of care mobilised to manage sugar through a focus on primary caregivers. I interviewed twenty-eight caregivers in Debe: eighteen women and ten men. The women interviewed were or had been primary caregivers for spouses and parents, while the ten men were more often co-caregivers for spouses and parents, with the assistance of wives, daughters, or paid helpers. The work performed by caregivers is commonly obscured by a biomedical discourse that emphasises self-management, health education efforts that formulate “non-compliance” as an individual choice, and a fragmented healthcare system in which continuity of care for chronic diseases suffers.

The two histories and narratives highlighted in this chapter were chosen for their depictions of lives that were entirely disrupted and subsumed by the responsibilities of caregiving. Their similarities suggest the cultural schema within which many women in Debe operated. Their differences, however, suggest larger structural restraints within which these cultural schema operate, such as socioeconomic inequalities, differences in access to care networks, and disparities in medical care provision that are a haunting reminder of the structuring of the health sector in the colonial period to facilitate greater care to the elites.

Assuming primary role of caregiver for an adult spouse also emerged as a dissonant identity transformation for both women, who struggled to reconcile caregiving demands with their own expectations for themselves at that particular moment in their life course.

7.1 Sumintra and the pressures of caring

Sumintra was fifty-eight when I met her, of medium height, with gently creping skin beneath her grey-black hair and drawn lines on her face. She had married Deoraj, whose illness narrative is presented in Chapter 6, when she was “very old, forty years old.” He was persistent in wooing her after they met at a few village weddings in Debe. She was from Penal, where her parents still lived, her father a cane-cutter and her mother a market vendor. Sumintra had dropped out of secondary school at fifteen because of her “lack of interest in studies”. Though her brother and sister had married and moved into their own homes, she continued living with her parents, selling in the market alongside them, and caring for the family home and her parents as they aged. She had expected to keep doing, until her unexpected marriage caused her to move to Debe to live with Deoraj in his parental home. The symptoms of Deoraj’s illness began to manifest after Sumintra became pregnant with their only child, Shiva. Deoraj’s illness progressively

worsened after Shiva's birth until he was completely home-bound and relatively immobilised by chronic kidney and heart failure, seventeen years later. Sumintra's life was now dominated by the requirements of caring for her ill husband, and caring for her son and household.

To support the household after Deoraj stopped working, Sumintra found a job outside of the home, selling Indian snacks at a food-stand. Deoraj's care was however her primary responsibility, and she often stayed at home when he was feeling particularly ill or to accompany him for a medical appointment. Deoraj's job loss caused extreme familial income precarity, which is a recognised consequence of the unpaid work of caregiving (Devault 1994; Berecki-Gislof, Lucke, Hockey and Dobson 2008; Nguyen and Connelly 2014).

Sumintra always spoke to me privately, away from her husband so as "not to hurt his feelings", for example in the upstairs kitchen while cooking lunch, or in the upstairs living room with the television on. Deoraj could no longer climb the stairs, and she joked once that this meant she had her *own* house, since she could run things upstairs "as I like them". Yet this joking belied a constant distress that bubbled up in all conversations over the time of our interaction.

If I did know he would get sugar so bad, that the sugar would take him so, I don't know if I woulda marrid him. I doh tell him dis, but everybody [in the village] know it true. I was happy, happy with my parents and had no bother, and since I come to my husband house, I does see dem once a month if at all... I doh have the time to go see them, and they too old, they can't drive. But what you go do, is my husband, and he suffering too, though he always smiling and laughing. He is a good man... But is hard, I have it real hard, all dem Temple ladies know how hard

I have it. From the time I get married, is only one sickness after the next sickness, and the baby growing up so I had was to take care of him too...

Deoraj's daily life was therefore circumscribed by his illness, and so was Sumintra's. Her movements out of the home were limited. As Deoraj's symptoms became increasingly debilitating, Sumintra became his main source continuous medical care.

Whenever he take sick, is a new set of hardship... every [new symptom] is a set of trouble ... First time he gone health centre I had was to walk him in, his foot swell up so big, he couldn't balance self. Then the ambulance take him to the hospital I stay behind, because how I go come home from there? My cousin lend he car to visit three times, but we can't go every day, is not we car, Shiva in school and have to study his lesson when he come home. I take taxi one day and it was plenty, plenty money. Then Deoraj is a stubborn man, he eh want to take his medication, he eh want to take his insulin, and the trouble that fall on him come from that. Every day I have to say quiet quiet like, Deoraj, here, look yuh sugar tablet, yuh injection, you feeling you could take it today? When he had plaster [bandages] on his foot and belly, I had to change it every day with what they give we from the clinic, because he can't reach no more. And when he was working he would say to stop bothering him, he feeling good, he feeling strong... then when he come back from hospital he would take it for some days, and then like he forget. Since he get kidney, he get more and more quiet and taking the medicine, but the medicine eh helping enough, the dialysis and when they drain he belly it does help, but like the medicine doh change nothing ... It too late now. Except the water tablet [diuretic], that one does help

him sleep at night. Every night I have to make sure he have four, five pillows below he head, the bedhead raise up on two brick, I sleeping in Shiva room and Shiva sleeping on the living-room couch until we get a next bed ... I can't sleep so high. Deoraj have a urinal to pee from the bed, the water tablet [diuretic] does make you pee plenty, every night he filling it up, I empty it and wash it out in the morning, I put a plastic on the bed so it stay clean, he is a very clean man but this kidney real bad ... the next thing I worried about is when he have to go toilet and will need help, right now he don't need help, but I feel like he will need help soon and I will have to be home here all the time then.

Managing Deoraj's illness thus necessitated that Sumintra perform multiple categories of work. Corbin and Strauss (1985) classically identified three types of work performed in the managing of chronic illnesses at home: illness work, everyday life work, and biographical work. Sumintra's narrative demonstrated each of these forms of work. Sumintra performed "illness work" by reminding Deoraj to take his medications, changing his bandages, helping him up and down the stairs, propping him up so he could breathe at night, emptying his urinal, scheduling and reminding him about his haemodialysis appointments, and cooking him a medically recommended diet. She also did the "everyday life work" of cooking, cleaning, taking care of their property, ensuring that bills were paid, that Shiva was clothed, fed, sent to school, and grew up with a semblance of everyday normalcy despite his father's incapacitation.

Far subtler was the "biographical" or emotional work that Sumintra did, which involved protecting her husband's concept of himself as his body and life fell apart. Thus she shared her narrative in private, to avoid injuring his feelings when she expressed disillusionment with her marriage and distress at her changed life circumstances. She was cautious, non-confrontational,

and indirect (i.e. “quiet, quiet”) when making suggestions to him about taking his medications, so as not to undermine his sense of autonomy over his life. Sumintra also expressed support for Deoraj’s explanations for not having taken his medicines regularly. She avoided blame, attributed the development of “kidney” and “heart” to an inherently progressive quality of diabetes stating, “the sugar does take some people bad so.” She affirmed his own illness narrative repeatedly, even while in private she sometimes bitterly blamed Deoraj for the worsening of his disease, pointing out that he failed to stick to the doctor’s recommendations, momentarily adopting the “doctor’s” point of view and attributing to Deoraj non-compliance..

Yet Sumintra also expressed a deep understanding of Deoraj’s inability to take the medications as recommended. How could she not? She was intimately familiar with his exhaustion on returning home at the end of a long day at a work-site, familiar too with asking him what he had eaten for the day and being told he had only had lunch, or on occasion had only had time to drink a sweet drink. The structural constraints of manual labour, and the demands it placed on her husband’s body she already knew. Sumintra repeatedly held the space for Deoraj to maintain his self-identity by protecting his social role of provider and head of the household.

As I spent more time with Sumintra, I recognised that she performed substantially more medical care-work than simple nursing tasks. She constantly operationalised her everyday living around ensuring that Deoraj obtained the necessary daily, weekly, and monthly care that he needed to improve or maintain his condition, both in home and in medical contexts. Nona Glazer (1990) described this as “work transfer”, which began in the 1980s in the U.S.A, as health care facilities shifted their earlier responsibilities for the sick to the family, where women family members began to do for free the work once done by paid health service workers. Sumintra and other women in her position were therefore forced to become amateur nurses, as well doing “the

administration and monitoring of complex nursing-medical regimens once done only in acute care hospitals” (Glazer 1990, 480).

Much of the logistics of managing Deoraj’s condition involved getting him to the locations for his health-care appointments for cheaply as possible, given the family’s income precarity. The necessity of constantly strategizing his next visit to receive clinical care reaffirmed the regional problem of poor access to public health-care to those without private transportation, which often meant the ill or disabled were dependent upon a patchy and unreliable public transportation network. For Deoraj’s biweekly haemodialysis, Sumintra said, “We have it set up now so he cousin does come every fortnight and take him to the Dialysis Centre, and wait for him in San Fernando, then bring him back. This cousin is a good, good man, and every now and then we give him a two-hundred for gas, because Deoraj couldn’t even walk to the taxi-stand self with his sickness.” When Deoraj’s condition became particularly bad, Sumintra could usually find a “drop” to the hospital directly from a moving roster of siblings, cousins, extended family and friends, whose numbers she kept on her pay-as-you-go cell-phone. Sumintra was thereby engaging in the mobilisation of a community of care for Deoraj, drawn primarily from relations, but also acquaintances, neighbours, and anyone who was willing to help. In so doing, she was also knitting together the public and private domains previously separated by sociological models of work into the “seamless web of social relations” that Glazer (1990) suggested that women’s unpaid work in health care delivery be reconceptualised as.

Sumintra described the strain of being pulled in different caregiving directions by her absence from her parents’ life.

My parents getting old too, they living quite Penal, but I doh get to see them plenty – is only some days I get to go and help them out, and I used to be the main one helping out in the house ... but is years now Deoraj need me home here every day. Is a good thing my sister and brother living nearby, my sister seeing them every day and helping them out.

The cultural schema within which Sumintra operated placed caregiving as an expectation of three of her social roles: that of wife, daughter, and mother. The anticipated forms of caregiving in each of these roles were different, and varied in expected duration and intensity: caregiving increases along a temporal axis with one's parents' age in particular. The intrusion of diabetes into her life had created an imbalance in her ability to meet these multiple caregiving demands, making her feel that she had failed in her responsibilities. The distress she experienced was similar to the “social role strain” described by Korean women with Type 2 diabetes, who expressed resentment at having to sacrifice themselves in favour of others as a consequence of the disease (Park and Wenzel 2012).

However, Sumintra's distress was also the result of an interruption of her biographical narrative of herself, and the gradual erosion of her self-identity occurring through the rigours of the caregiving. In this, she was also demonstrating an “unsettled self-identity” that results from chronic diabetes, much as Manderson and Kokanovic (2009) found for patients with diabetes in Melbourne consequent to their illness.

I attended a Temple Group that Sumintra also attended, which is where I had been introduced to her. Within that group, Sumintra was held up to me on multiple occasions as an ideal wife, as someone who had it “real hard” but was continuing to meet the expectations not

only of her family but of the wider community in taking care of her husband. In this characterisation, there was an element of approbation of the self-sacrifice she displayed, which was also consistent with the cultural schema of wifely responsibility. One of the Temple Ladies invoked the Ramayana in explaining it to me thusly, “Sumintra like Sita – she gone into exile for her husband.” In the epic Ramayana story, the prince Rama is unjustly exiled from his kingdom to the forest for fourteen years, where his faithful bride Sita and his brother Lakshmana accompany him. I asked Sumintra what she thought about this characterisation, and she laughed with a little pride, then added ruefully, “But when this exile ending? Is more than fourteen years now.”

Sumintra, Deoraj and Shiva lived in a state of constant income precarity that had only been alleviated the year previously when Shiva finished high school and become a mechanic’s apprentice along the Debe Main Road. This allowed him to bring home two to three hundred dollars every week, which was pooled with the money Sumintra earned to provide the family’s daily necessities. Shiva had also gradually assumed responsibility for household handyman jobs like fixing mechanical things, cutting the grass around the house, and cleaning the latrine that had been built in the back yard for Deoraj when necessary. Supplemented by her earnings and their subsistence “garden”, they never lacked for “good food” to eat, which was “the most important thing”, Sumintra stressed repeatedly throughout our interaction. “Sometimes an electric bill have to wait for a month, sometimes the water bill, but we always have food to eat.” The family did not have a household phone, though both Sumintra and Shiva had a cell-phones, which they used to keep in touch.

Sumintra’s hopes for her future and her everyday living now hung upon her son, Shiva.

Shiva is a good boy too, a real good boy. He grow up seeing his father sick, sick, and he is a dutiful son. He used to rub Deoraj foot when he was a little boy and Deoraj was just getting the sugar, now he come big, working as a mechanic, he bringing home money and does give it to me to take care of thing... I can't wait for him to marrid and bring home a dulahin [new bride]. Then we could live like family, I could get a little help.

In referring to a “dulahin”, Sumintra was wistfully invoking the expectation Shiva would bring his wife into their household after marriage, as she herself had been brought, and also a cultural expectation that Shiva's new bride would assist her with housework. By “living like family” she was also implying a sharing of responsibilities, including that of caregiving for both Deoraj and Shiva. Sumintra therefore also shared the gendered expectations of the caregiving role, as a part of her cultural schema of what it meant to be “family”. When Sumintra spoke about his dulahin, however, Shiva uncharacteristically interjected briefly.

Nowadays you living in your own place, you renting if you have to... Once you married you need your own house, to keep your wife happy. A happy wife is a happy life...

This statement, brief as it was from the laconic Shiva, suggested that he had different life-course expectations not only for himself but for his future wife. How this would be manifest in the future, if he was to marry, was yet to be seen.

Sumintra's narrative, however, was also interwoven with references to assistance received from members of their family and the community at large (for e.g., ladies of the Temple Group; parents of Shiva's friends; the pundit from the temple) that enabled them to cope in the

everyday and with the demands of Deoraj's illness, despite their income precarity, poor access to healthcare, and the poor continuity of care Deoraj received from the public health sector. For visits to the hospital and occasionally to the clinic, the family had been able to borrow a car from "cousins" living along their street on multiple occasions, while another cousin took Deoraj to his haemodialysis appointments. If she was late returning home from work or from the temple, a neighbouring housewife who "kept an eye on Deoraj" would "drop off" for him a simple meal of whatever it was they were eating. When Deoraj became increasingly immobilised, and could not easily climb to the second floor of his house, his friends and "pumpkin vine cousins" from the village came together to build him an outhouse in his back yard. These interactions all demonstrated the networks of care that Sumintra and Deoraj had mobilised to assist with managing Deoraj's diabetes. His management, therefore, was often a communal effort.

Similarly, the Temple Group of Sumintra's nearby temple would always "put aside" some food in foil and Styrofoam containers for her to take for Deoraj so Sumintra didn't have to "cook fresh" for every meal, without her having to request it. In conversation with the other women of the Temple Group, there was the vague implication that giving food to Sumintra and Deoraj constituted a kind of "seva" or selfless service to the community.⁸¹ Indeed, Sumintra also got the flexible job she had at a food-stall, that paid a few hundred a week, through her Temple Group network, when it was unclear how much her help was actually needed in running their business. This work served not only as crucial financial assistance for the family but as a relief from the continuous demands of caregiving.

⁸¹ Seva refers to Hindu selfless service done in the name of the divine for which no reward is expected. It can range from alms-giving to the needy, such as the distribution of hampers to poor households at Diwali and Christmas-time, to the donation of medical skills through holding free screening clinics in rural villages.

A shared cultural schema within the social and kin networks that underlay the community in Debe thereby facilitated Deoraj's illness management and Sumintra's continued dependence on them for support. The burden of caregiving, distributed across these networks, included everyday actions like the cooking and sharing of food, to more constant demands like job that she had found through "contacts" that provided the family with their income. On-going efforts at communal care-giving were however also dependent upon Sumintra's continued efforts at maintaining linkages and integration into the family and community, through the temple group, through attending family events, and also through "helping out" when others needed assistance that she could provide, for example, in preparing for events, or occasionally watching a young child whose parents needed to run errands. These demands existed in constant tension with the everyday life work of caring for Deoraj.

As Sumintra pointed out, despite everyone else's support, the final responsibility for her husband lay in her hands – and she was exhausted by it, constantly in distress, and rethinking her life choices as a consequence.

I go wedding and I tell young people is a good thing they marriding young, you only young once, is better to share the youth time together because when you get old, is only trouble and heartache coming into your life. Old age not easy, nah. If you can't get married young, don't married at all. Is hard work when the children young, but children does grow up. Is much harder when you old and you have to *take care of your husband, no matter how much you do it with love.*

Neither Sumintra nor Shiva ever suggested that Deoraj would eventually need more permanent institutional care at a health or nursing facility. Sumintra said, “He is my husband, while I living I can’t send him to no poorhouse, unless I get sick too, then the Lord will have to intervene.” There are few to no public facilities such as hospices for long-term care of severely ill and debilitated persons like Deoraj, so the burden of care falls entirely on their families while they are not in acute episodes of distress. The “poorhouse”, however, continues – an institution dating from Trinidad’s colonial period, where the destitute poor were housed by a Catholic religious order for a nominal sum. There are few remaining poorhouses in Trinidad and their conditions may have improved dramatically since Victorian times, but a deep fear of them as places one went to die neglected linger in the community. “I could never send somebody I love there to dead,” Sumintra said on one occasion. Another time, she said, “If you love somebody you have to take care of them, that is your responsibility.”

7.2 Prisoners of the body

Tanty Mona was “sixty-eight years young” when I first met her, a bright eyed woman who had co-run the family retail and distribution business with her husband, Pappy, for much of her adult life. Their four children were grown and prospering: their eldest son Alan had taken over the family business, their second eldest daughter Melissa worked in an office as an accountant, their third daughter Shelly had started a “clothing boutique” (i.e. a clothing store) in nearby La Romaine and their youngest son Adesh was soon opening his own retail business too, after a few false starts. Mona invoked the concept of “long time” repeatedly in her narrative as a contrast to the present, “Long time we work real hard, setting we-self up ... We scrimp and we save, we

tighten we belt, we eat dal and bhaat (rice and dal) day in and day out, we try to set a good example for the children.”

Of cane farming parentage herself, she and her husband Pappy had been cane farmers on Caroni lands, while also starting a small-scale business reselling imported foodstuffs that were repackaged locally. Cane=farming took them through the lean years while the business was growing, and children were young, but with the oil boom of the 1990s the family grew financially “comfortable”, just before Caroni (1975) Ltd was shut down and they lost their farming livelihood. Mona and Pappy still lived in the large two-storey concrete house they had built after their business took off.

Nine years previously, Pappy had suffered a sudden, massive heart attack followed by a cerebral stroke. It left him paralysed on the right side of his body and with a severely weakened and spastic left side. He also lost the ability to speak, though his comprehension appeared unimpaired. While Mona had known that Pappy had “sugar and pressure”, he had rarely spoken about it, so she didn’t either. He had been diagnosed with diabetes and high blood pressure in his sixties but since the symptoms “didn’t take him too bad, he eh care ... I used to see him taking his tablet, and I thought everything was okay, everything was good. He didn’t talk about his health, and when the children get big they busy getting married, then the grandchildren come, and the business still going – everything was busy, busy still.” Pappy had also smoked from the time she met him in his youth, and this habit persisted “as a stress relief” even after his son took over running the business. He also “used to like a little drink now and then”, said Mona, suggesting rather than stating he had a tendency towards alcoholism.

In the early days after his stroke Pappy could lever himself with help into his manual wheelchair from the hospital bed they had acquired for him, and wheel himself around the house

and garden using one hand. Mona, his children, and grandchildren took turns keeping him company and pushing him around the house and grounds. Pappy and Mona's grandchildren still remembered him as a vital presence in their lives, and the young people would sometimes load him into a car to go to the beach, a wedding, or a river-lime, wheelchair and all. Mona accompanied Pappy wherever he went. "He needed somebody who know him, and could tell the children what he want to do, when he want to leave, when he was getting tired... At the clinic I had to be there, when the doctor say to do something, I had to make sure I know because is I who had to do for him ... when Pappy get the stroke I come his voice and hand and foot too."

Pappy had been taken to SFGH for his acute care after he had the heart attack and stroke, but when his condition did not change, his family came to believe there was nothing more to be gained from public health institutions. They instead began taking him to a private physician at a private hospital in San Fernando, who also made home visits. This would have been an expensive proposition, as a single private office visit for a consultant physician can range from \$600 to \$1200 Trinidad and Tobago dollars (about \$90 to \$170 USD). Mona was the impetus behind most of the health-care decisions, though she also sought support and advice from Alan and Melissa as she sometimes found it difficult to make choices without Pappy's vibrant and decisive voice. "Everything I do now, I do for Pappy, but how to know what will make him happy?"

After his initial diagnosis, Mona had also found a physiotherapist through the private nursing home to make home visits. The physiotherapist taught Mona and her daughter exercises to maintain the mobility of Pappy's left side and prevent the development of painful

contractures⁸². Melissa had taken leave from her job to help out in the immediate aftermath of Pappy's heart attack and stroke, and she and her mother Mona did the exercises with Pappy every day: unbending the claw of his right hand slowly and repeatedly, extending his elbow, putting a ball into his left hand for him to squeeze, to maintain the strength and range of motion of his fingers.. When Melissa went back out to work, she would still visit very regularly, and also hired a helper to come in every day to cook and clean for her mother and father. The helper, a woman called Girlie, also did the physiotherapy exercises with Pappy when Mona could not.

After some time, however, Pappy began expressing agitation and resistance every time they attempted to exercise him, groaning wordlessly, shaking his body, and jerking his left hand away. He would open his left hand so the ball fell out. Believing he was in pain, Mona at first decreased the frequency and then stopped the exercises entirely. Over the course of a year Pappy went from being able to pull himself up into a seated position with his weaker but still functional left side, to being recumbent most of the day, lying on his back or his side. He still did not want to restart the exercises, despite this.

Mona believed that this was when Pappy fell into a “deep depression” and lost the will live. Mona, too, developed a “heaviness in her chest” when she saw this, since “it was like I fail as a wife, and he started to sink”. Pappy began to gradually develop contractures throughout his body that eventually made movement more and more difficult on his left side. His right side became rigid. Pappy was moved from their rooms on the ground floor of the house to the upstairs, which was more comfortable for Mona being nearer to their bedroom. A new, hydraulic

⁸² A contracture deformity is the permanent shortening and hardening of muscles, tendons and ligaments that occurs when muscles lose their ability to move, and often leads to rigidity, pain, and locking of joints.

and electronic hospital-bed was obtained for him, and was set up in the living room. From then on, for the five years since, Mona had looked after Pappy in the living room.

Mona spoke with me in the gallery of their house, after offering me the expected glass of sweet drink and some biscuits. Trucks rumbled up and down the sloping driveway to the adjacent warehouse, and there was the constant hum of nearby activity. Yet it was easy to hear Pappy's intermittent moans through the open front door of the gallery, which led directly into the living room where he lay on the hospital bed. Occasionally, while Mona spoke, he would rattle the bed-head, call out wordlessly, and rock on the bed so it creaked. Mona would pause for a second, peering into the house, before continuing her speech. She called out every now and then, "I hearing you, I hearing you, settle down. What you want? I hearing you."

Unlike Sumintra, Mona did not temper her speech or seek privacy from her spouse in describing her dissatisfaction with her changed life conditions as a consequence of Pappy's illness.

Is like we both come prisoner. He [Pappy] come a prisoner in this body, and I come a prisoner of this house. I can't go nowhere, I can't do nothing, any little thing I do outside of these four walls I have to come back quick-quick to take care of him. He don't need much, but when I not here, he get vex, he get agitated, he rattling up the bed and shouting loud. He dashing away food and drink, he getting fever and getting more sick. He *need me here all the time* and *I come prisoner to his body too*. I can't even leave him with anybody else, he does get so vex he does refuse to eat the food, and then he can't sleep he groaning whole night, he in so much pain. This life is pain but he suffering. I could only do so much.

The stroke had also affected the small muscles of Pappy's throat, Mona explained, so swallowing anything that wasn't pureed caused him to choke. Their helper pureed Pappy's meals and gave them to him in a cup with a large straw. On good days, Pappy could feed himself by drinking from the straw, or by letting the helper spoon-feed him. On bad days, which were becoming more frequent, he would refuse if anyone else but Mona fed him, moving his left arm to strike the food away or closing his mouth tightly and refusing to eat. Mona alone could administer his medications, too.

After consultation and monitoring, Pappy's physician worked out the most minimal regimen of medications that could be administered to control his diabetes, hypertension, and cardiac condition. Insulin was at first prescribed twice daily, but Mona was perturbed by his inability to indicate the symptoms of hypoglycaemia so they changed to oral medications, which she ground up before administering them. While some of the pharmaceuticals Pappy was prescribed were available for free via CDAP, Mona instead chose to purchase the non-generic versions from the pharmacy directly since she believed they were more effective than the generic drugs. This belief about the generic drugs available on CDAP was so common in Trinidad that it was addressed in a Senate speech by the Minister of Health in 2017, attempting to assuage concerns that the quality was less acceptable (Ghouralal 2017). Heeding these concerns, Pappy's family paid out-of-pocket for all his medications, which Mona said was "a financial stress on top of everything else".

It expensive, having sugar, having stroke ... Each medicine is a few thousand dollars a month, and you need more and more. I can't do nothing more but take care of him and wait, and like he waiting too, for his jail time to done. We all waiting. But while we

waiting, things getting worse for him, and when things worse for him, they worse for me. I can't go nowhere, he does get vex. I can't do nothing away from he, he get vex. Going up and down the stairs to go to the doctor is real trouble to move him now, so we have to pay \$2400 for a home visit from his special doctor. Then Girlie can't bathe him, is his son or another one of the boys have to bathe him, because he get too heavy with the stroke for us to lift him up. Otherwise is a wipe down in the bed, and if we don't do it every day, he does still start to smell bad. He used to like so much cologne ... Then he can't use the toilet any more, he have to be in [adult diapers]. Every time we changing the diapers is cry he used to cry, and I watching this strong man get weak weak and small, small. Melissa come and change his diapers, I change his diapers, Girlie change his diapers – the only one couldn't do it is Alan, Alan say he would bawl if he see his father so. Then when he lie down too long in one position, he start to develop bed-sores ... we only did know because it was starting to smell bad. We take him in to the hospital, they cut the sores out and fill the hole with medicine, and then he get better again, but ever since then he always getting one or two sores on his hip again. All this we do for him, everything we have to do for him, we have to come his two good hands and two good legs and his mouth and all, to talk when he would have talk. But is too much for one body. Is too much, is too much.

Through this and other statements, it was clear that Mona, her daughter Melissa and her daughter Shelly to a lesser extent considered bodily caregiving for Pappy part of their responsibility in a way that Alan and Adesh did not, suggestive of the fact that caregiving was seen as a gendered responsibility and part of the life-course more for the daughters than for the

sons. The children visited Mona and Pappy every weekend, however the demands of caregiving and its isolation had worn Mona down. “This was supposed to be the sweet years, when you have grands [grandchildren] and could play with them and take care of them without worries, and now is only medicine, hospital, taking care of the old man.” Mona’s life course expectations had been transformed, not only by the necessity of managing Pappy’s diabetes for him, but by the medicalisation of her world subsequent to the work-transfer that was required for his unremitting care (Glazer 1990). Using the three dimensions of work that Corbin and Strauss’ have identified, Mona was primarily responsible for Pappy’s medical care through the administration of drugs, but had support from a variety of sources for the performance of the other work of the home. Despite her complaint about financial stress, Mona also had to employ fewer coping strategies than Sumintra, since the family was not in a situation of precarious income.

Mona, however, never considered putting Pappy into a nursing facility for round-the-clock care. The “poorhouse” may have been the only option Sumintra could access because of financial constraints, but Pappy’s family had the economic wherewithal to send him to a recently established facility.

He is my husband, what I will do with myself if he stick up in there, the nurse and them doing whatever they want to him? Is better he stay in his own house where he could be comfortable and his family could see him whenever they want.

Mona and Pappy no longer received as many visitors, family or otherwise, as they once did. As his illness progressed and he increasingly lost the ability to interact, visitors and their social lives had largely dried up except for their immediate family and some cousins.

This sickness, it come as a shock to the family. We used to have bhajan mala and Ramayana regular, every year we holding it downstairs around the house with big tents and plenty good food ... the whole village would know to come. Mike truck used to pass around inviting everybody. Everybody know Pappy. I used to have the best pundit come, singing the best song, have the best singers from Chaguanas come down for the bhajan mala. Yet time pass and is like everybody forget he now. Only some of his old workers still come to visit. Some family too. But plenty people, they don't know how to deal with the change, with how much things change in Pappy and in me too. They come, and they hear him trying to talk and making noise, or they see him shaking up the bed with his one hand, and they get 'fraid and they don't come back. Is hard for me to see him like this too. But when you go 'round the fire⁸³ is fire you have to walk for your husband.

At my last visit, Mona told me that she had recently been diagnosed with diabetes herself. Mona was stricken, tired, and fearful of her appointment. Yet the next time I visited her, after her clinic visit, she was buoyant and energised. "The clinic is a good place to meet people," she explained. "We sit there waiting to see the doctor and get to old blagging [chatting] and the time

⁸³ Mona is referring here to the Hindu ritual of marriage where the bride and groom circumambulate a sacred fire seven times.

just pass. I learn plenty things from the other patients about what to do to help with my sugar. Now I could try these things with Pappy too.” The diagnosis and her enrolment in the Chronic Disease Clinic had given her a boost by introducing her to a new social space outside of the home, which she could also attend without guilt, since it was “to keep me good enough to take care of my husband.”

Mona’s caregiving narrative repeatedly defaulted to a description of Pappy’s illness: its onset, the worsening of symptoms, her and her family’s efforts at alleviating his condition or ameliorating its effects in their lives. She focused far less on her own state of mind or feelings, though her words were underlain throughout with a deep sadness. Yet in moments of action, such as when she showed me how she prepared Pappy’s lunchtime meal, or picked herb seasonings from kitchen garden she had started, Mona was energised - vivacious, solicitous, and engaging. These moments were fleeting, but they suggested to me the person that others in the village described as vivacious and astute, and someone to whom others turned for patronage and support.

After Pappy’s illness Mona also began to get insomnia, which she attributed to “waking up late, listening for Pappy to call”. The family found a full-time helper from “lower down the main road” in Debe, who moved into the house, sleeping in one of the rooms adjacent to the living room where Pappy slept. Despite being grateful for the help, Mona began to feel that her world had “shrunk to the space of this house” containing Pappy, bounded by his illness and his care. In this and a few other statements, Mona’s sense of being trapped was made clear. She was trapped as much by Pappy’s illness as by the social role of wife, which required she continue to provide his care despite also having continuous live-in help. She was trapped by Pappy’s

expectations that she would always be there, and by her acquiescence to the role requirements of constant presence.

7.3 The load of caregiving

As this chapter shows, caregiving was a social role expectation and part of the gendered life-course schema for women in Debe in particular, both for themselves and for others. It was expected of women in multiple social roles: as the mothers of children, the daughters to elderly parents, and the wives of ailing husbands. At the same time, caregiving constituted only a *part* of their expected social roles, and bearing so much of the burden for an extended period had begun to undermine their ability to meet these expectations. Their other expectations of this temporal phase (post-child rearing, post-retirement) was unprecedented and burdensome for both. It led to fatigue, to symptoms of strain and a toll on their mental health.

Despite being the primary caregivers, Mona and Sumintra's narratives differed dramatically in one significant way: Mona's greater access to economic resources enabled her mobilisation of care for Pappy that decreased for her all categories of work identified by Corbin and Strauss's (1985). Her work was shared with her adult children and hired helpers ranging from the unskilled live-in caregiver, to a physiotherapist, to a senior physician who made in-home visits. Sumintra instead depended on help volunteered by family and friends to cope with the demands of caregiving. At another level, however, Sumintra's reaching out to friends and family for help with coping with the logistical demands of providing care to Deoraj also resulted in the strengthening of familial and friend networks through contact, communication, and requests for favours. In this kind of networking, I found myself reminded of Marcel Mauss' (1990 [1924]) gift relationship, as interpreted by Bourdieu (1977,1998), who identified that the

characteristic of the gift was not necessarily an altruistic expectation of no return, but the existence of a temporal delay between the giving of a gift and the receipt of a return gift, that allowed the misrecognition of what was effectively an exchange through a form of double-consciousness. Such gifting relationships with an implicit reciprocity were demonstrated repeatedly in Debe through the flows of food from one familial household to another, such as the gift of surplus mangoes, avocados, or other fruits and vegetables that were plentiful in season; or of cooked dishes known to be favourites of particular members of a household. These happened frequently both in Tanty Indra's household, and to and from Tara, among others with whom I spent time in the field. They also reinforced notions of kinship as formed by the sharing of food, which has many echoes throughout Trinidad as a basis for common sociality (Carsten 1995). Based upon such gifting relationships, rather than on Mona's more direct consumer relationships, Sumintra's social network had expanded within the community, and formed deep bonds.

Mona and her family, conversely, were known as wealthy, and had long-established patterns of patronage within the village, of the *mandir* and its activities, and of other poorer people in need of help. Her solicitation of help was therefore grounded more in more visible and direct forms of reciprocity than Sumintra's, since asking for the kind of help that Sumintra requested would have been seen in the village as disingenuous and "advantageous". Mona would have been seen as taking advantage of the situation of her husband's illness to lay claim to more than her fair share of assistance or resources from the village had she requested unremunerated assistance. This was not to say that Mona was not still well liked or remembered by the community, she was still brought bags of *parsaad* whenever prayers were held in the village that she could not attend, and occasionally gifts of food from her neighbours. These gifts were however framed as expressions of remembrance or favours to the family that it was fully

expected they would someday repay; unlike the seva that Sumintra received with no expectation of return.

Diabetic illness, the resultant changes to people's lives, and the demands of managing it thus challenged not only the identities of individuals diagnosed with an illness, but the identities of those around them as well, especially that of the caregivers. Everyday forms of socialisation additionally iteratively constructed caregiver identities as gendered (e.g., future or current "wife" or "mother") and cultural (as Indian Trinidadian or Hindu) norms. The cultural schema underlying these identities is oriented here around gendered familial roles, which have differential rights and obligations. Inability to meet competing caregiving demands (for e.g., for parents and for a spouse) produced social role strain with negative mood effects for Sumintra (Gaugler 2010). These effects were most dramatic at the moment of transition to their new roles. The international literature agrees that for the elderly and ill, the most important resource is a caring family, and that caregiving is highly gendered (Dressel and Clark 1990; Hirst 2002; Broom and Lenagh-Maguire 2010).

Feminist scholars have also highlighted that much of the work of caregiving is rendered invisible by its unremunerated performance in the private space of the home, along with other work of the home that women in particular perform (DeVault 1994; Daniels 1987; Glazer 1984). As illness progresses, however management increasingly required a larger cast of actors than the self.

Nona Glazer's (1990, 1993) concept of the "work transfer" of health care services and responsibility from clinical public sphere to private home contexts is particularly useful here, producing as this does a medicalisation of the world.

As Heaton (1999) has also highlighted, the emphasis on “self-management” in diabetes has shifted the expectation of medical caretaking from medicalised spaces such as the clinic to the invisible spaces of medical caregiving in the space of the home. A common perspective that also emerged from fieldwork was the patriarchal belief that caregiving was an expression of an essentially female nature, the discussion of which is beyond the scope of this chapter.

The severity of Sumintra’s and Mona’s husbands’ illnesses had placed excessive demands on them and disrupted their stage-based life-course expectations, however they continued to demonstrate a major tenet of the cultural schema that emerged over the course of fieldwork: caregiving was perceived to be their primary responsibility as wives. By the usual conventions of the cultural schema, however, their caregiving responsibilities only ended with the passing of their spouses.

Both women expressed self-sacrifice as a value of their social role, putting them in an impossible situation: they could not take time for themselves without feeling selfish in so doing since self sacrifice was also a characteristic of their roles as wives, nor was there time to take for themselves because of the demands of caring for their spouses. However, it is necessary to frame their actions within the wider context of Debe as well. There were many stories circulating in Debe of people whose spouses left when they became ill, spoken of with both condemnation and commiseration. There were others in the community as well. Two older women on Lalbeharry Trace were known to have put their fathers in “old folks homes” when they became unable to care for them. One elderly spouse on Lakshman Trace had left his terminally ill wife and moved in with a younger woman elsewhere in Debe while his wife was still alive. One family had migrated entirely to Canada, leaving behind their elderly mother. There were stories too of people with strokes or dementia in their older years, who rotated in and out of the hospital, being

dropped off by their families at Accident and Emergency, admitted to the medical wards for assessment, and then discharged when physicians could no longer take medical responsibility for their continuing decline. They often turned up again at Accident and Emergency the day after their discharge, ending up spending weeks and months on different hospital wards.

Sumintra's and Mona's choices of continuing their attention to their spouses should therefore not be construed as rote repetitions of rigid and confining social roles, in which they could do no more than mechanically meet demands set by culture or custom. Both women, while experiencing distress at their choices, which were also structured by larger realms of poverty and familial responsibility, also engaged in a range of agentive actions every day. Engaging their particular understanding and investment in the cultural schema of which they had experience and knowledge can therefore be framed as a choice, an agentive act, as it was certainly interpreted by many in the community. Their *choice* to continue caregiving was valued, and seen as a model example of a particular cultural schema, which was made only more evident by the actions of those in the community who made the choice *not* to follow it. It was because of their choice to continue caregiving in conditions of extremity that I heard about them within the community too. All the counter narratives served as cautionary tales and public shaming about what one was *not* to do, thereby inversely supporting the cultural schema.

Both Sumintra and Mona were enmeshed in the "work transfer" that Glazer (1984) identified as a shift in responsibility for care provision from clinical settings to the home. While Glazer identifies this work transfer from clinical to home contexts as subsequent to healthcare-delivery changes in the capitalist healthcare context of the US, the concept has proved portable to Trinidad despite its nationalised and universal healthcare. Similar structural limitations obtain in both contexts: healthcare provision is a constant struggle to manage the bottom line. The medical

work transfer that has resulted moves much of the management of chronic diseases into the space of the home to the intimate, caregiving and feminine gendered spaces of the home and community. These spaces are constructed by and of women's work.

By women's work, I refer the hidden, unremarked and unseen, the "invisible work" of the private sphere goes unremarked and unremunerated (Smith 1987, Collins 1998, DeVault 1994). What this work constitutes is comprehensive, and has been defined as falling into three categories by Corbin and Strauss (1985): medical care; the work of maintaining everyday life; and the reiterative process identity construction, or "biographical work". For Sumintra, Deoraj's illness necessitated that she perform all three categories of work. She administered medical care by physically nursing him and planning and scheduling his treatments; she fed and supported his everyday life; and she subtly supported his notion of independence and his avoidance of blame for his medical condition, despite indicating privately that she thought he bore some responsibility for the progression of his condition.

A consistent theme amongst caregiver narratives was that of guilt over their lack of recognition of "how bad" their loved one's disease state was early on, and their lack of intervention or assistance before it became full-blown illness. Sumintra and Mona both expressed this, Sumintra by saying that she didn't know Deoraj wasn't taking his medicines, and Mona by pointing out that she didn't know how bad he had the sugar and pressure, or that he should have stopped smoking. These feelings of guilt and self-blame may however be more reflective of their depression, which has also been identified in the caregivers of stroke patients (Jessup et al. 2014; Camak 2015). Depression has also been found to have negative consequences on the wellbeing and development of complications in persons with diabetes, and

may have had similar effects in Pappy's case (Roy and Lloyd 2012; Holt, de Groot and Golden 2014; Novak et al. 2016).

As was referenced previously, treatment burden refers to the biomedical recommendations and strategies for proactively treating and managing chronic illness, which include the “lifestyle” changes” of exercise, dietary change, and appropriately timed meals and medicines (May, Montori and Mair 2009; Sav et al. 2013a, 2013b). As the preceding narratives suggest, however, these recommendations do not take into account the complex social, cultural, economic and relational dimensions of patient life-worlds. Neither do they take into account that the treatment burden will eventually fall upon the carers if illness worsens and subsumes both patient and caregiver. As such, alleviating the treatment burden, or what Corbin and Strauss identified as the work of medical care, becomes one way of relieving the overall burden that caregivers shared in their narratives.

Chapter 8: Engendering the life course: Schema and their transformation

In this chapter I explore some of the major expectations of the life course in Debe, and identify the shared elements that constitute cultural life-course schema (Garro 2000) for men and women. I also examine how these expectations and schema are disrupted by illness associated with diabetes (Williams 2000; Becker 1997; Gardner 2002).

The life course concept invoked here is linked to the sequential phases over an individual's lifespan that are not absolutely chronologically demarcated, but have been determined by a wider societal context over the passage of historical time – the entanglements of people's social roles, relationships, social status, gender, and social class (Gardner 2002; Hatch and Wisniewski 1995; Robinson 1990; Garro 2000, Estroff 1993). This concept of the life-course also draws upon an ideal of continuity that is mediated through bodily knowledge and experience, which chronic diseases interrupt.

Cultural life-course schema, meanwhile, I consider the “interpretive processes that mediate our understanding of the world” that are shared, “built up from various kinds of common experience” (Garro 2000, 285). As such, this chapter explores the extent to which life course expectations function as cultural schema (Garro 2000; D'Andrade and Strauss 1992) or what I will call *pathways to a good life* that are disrupted by diabetes. These unspoken pathways very often operate in the background of people's lives, unvoiced except when there is rupture or divergence from the schema.

8.1 Stages of the life course

In the field, I found that cultural life course schemas were sequentially and chronologically linked to the social role expectations of each life-stage. Drawing on the narratives of the preceding chapters helps reveal the shared expectations of the life course stages in Debe.

For example, in chapters four and five, Tara and Meera talked about their childhoods, about going to school while living with their parents, which they continued to do into young adulthood. Marriage marked their entry into a new life stage, and with it came movement into homes of their own with their husbands, as they assumed the roles of wife, householder, and soon thereafter, parent. The life course stages they identified were therefore childhood, followed by young adulthood, then by a stage of simultaneously being a wife, householder and parent. Each life course stage was associated as well with residence: first the parental home, then their own homes.

These stages and their progression were similar in Tanty Dularie and Tanty Indra's narratives, except that residence after marriage, during the householder stage, was with their husband's families, which was a traditional expectation upon marriage at the time. As older women, Tanty Dularie and Tanty Indra also described an additional life stage, that of being a grandparent and no longer working. For Tanty Indra this meant living with her adult, married son and his wife, while for Tanty Dularie, whose son had migrated, it meant living alone or with extended family for short periods of time. At the same time, Tanty Indra considered the religious education of her grandchildren to be her responsibility, and took them to temple with her every time she could. She called them over whenever she was making meethai or parsaad for prayers, as they were still young enough, she explained, to be encouraged by the thought of getting to eat the sweets at the end of all the work of cooking.

The men in Debe described similar life stages, with different patterns of residence in the older generation. Older men's wives had come to live with them and their families, or in houses that they themselves had built before marriage.

Thus in Debe, men and women largely shared expected life course stages and their progression, differing primarily in residential or spatial location, and between generations.

For each of the life course stages described, there were also embedded expectations of social roles. For example, while reminiscing one day with a neighbour about "long time days", Tanty Indra laughingly recalled the gleeful abandon of running around barefooted through puddles as a child, against her mother's express wishes, which she defended by saying that the job of a child is to play. Yet when she recounted that she got "licks" (a spanking) for being covered in mud, she added that licks "was a good thing," as it was her mother's job to keep her "in line," and prevented her from "running wild." To this her neighbour nodded in agreement, adding that she knew that so long as she was living under her mother's roof, she would have to follow her rules, which "nowadays children" didn't understand. Tanty Indra agreed.

The life stage of childhood therefore accompanied the social role of play, within the spatial domain of parental residence and responsibility. The life stage of motherhood, conversely, accompanied a social role of childrearing, which included discipline and caretaking of the child, and the setting of limits to facilitate this. Adulthood on the whole, for both men and women, was accompanied by expectations of caregiving for the younger and older generations.

Men's social role expectations across the life-course exhibited one marked difference: men experienced a greater emphasis on providership as an expression of their adulthood and in their role as parent, householder, and spouse. This providership was presented as a particularly male form of caregiving, an expression of love and support that complemented the work that

women did in the home. “A happy wife is a happy life,” said Deoraj one day as we sat chatting under the house, “When I married Sumintra, I had to give she all the things she need to make she happy, but this sugar come and take me bad so, and I couldn’t do it no more.”

Life course stages and their framing might also have been grounded in a deeper, more tacit and unexpressed Hindu notion of what constituted a good life in Debe. One day in the Amar Trace Mandir, a pundit referred in his discourse to the “grihastha” or householder stage of life as one of the “ashramas.” I learned that the Vedic Upanishads refer to four stages through which every life should ideally go: brahmacharya (student), grihastha (householder), vanaprastha (retired) and sannyasa (religious renunciate). The homology between these stages and people’s notions of a good life in Debe suggested to me an unstated understanding and application of this particular Hindu philosophical tenet that was guiding people’s life expectations in Debe. These stages, however, and their associated roles are not exclusive to the Indian Trinidadian community, or the Indian scriptures either. Whether described as “ashramas” or not, these life stages formed a general understanding of the expected progression of the life-course, as Becker (1997) has highlighted. However, while notions of life-course are universal, the ways in which people perceived its particular progression, and their expectations of each life-stage were what made it culturally specific to shared, collective understanding of “a good life.”

People’s discussions and reminiscences about how times had changed, contrasting “long time days” with “nowadays”, further helped in revealing what the cultural schema of the life course were. Long time days, for the older people over seventy years of age, referred to a shared past of hard agricultural labour (“when it wasn’t sugarcane time it was rice time,” explained Tanty Moona), lean growing up years when their parents could only afford to feed them “salt and roti,” arduous everyday lives when going to school meant cutting cane before daybreak then

walking long distances through the “hot sun” to get there, or dropping out of school at ten years old to help out with the family work, and their perseverance through these struggles. For younger people, like Tanty Indra’s sons Arjun and Naveen, “long time” also meant a childhood of studying hard, sitting examinations that allowed access to higher education and a better quality of life.

Despite the emphasis on difficult circumstances in these recollections, they were also nostalgic in that these past selves were young, strong, active, and could meet the demands that hardship imposed. Life was also simpler, places were safer, food was better, purer, came from their gardens, or their neighbours’, and children were safer, there was less crime. There was less talk about global warming or El Nino (a weather system affecting countries around the equator); the seasons were predictable and the sun wasn’t as hot. People used to live good together, and you know your neighbour like your brother or sister.

This particular ambivalence, the tug and pull of nostalgia for younger, more able bodies, and a simpler life, this was particularly characteristic of the life-course schema that people with diabetes described in Debe.

“Nowadays,” conversely, was discussed as a time of less need, greater ease in Debe – more vehicular transport and conveniences like groceries and pharmacies – but also higher prices, less tightly knit communities, and less closely familial relations. “Long time you have wedding, is three hundred people showing up to help, and three hundred people showing up to eat, nowadays you have wedding, is fifty showing up to help, and three hundred showing up to eat,” said one old Tanty to explain why a neighbour was holding her daughter’s wedding at a private rented hall outside of the community, by invitation only, instead of in her house with everyone in the community being invited. Long time days, while based in an agricultural reality,

were also mythologised in the remembering, becoming part of a nostalgic metanarrative of a shared Indian and Hindu community and identity (Sutton 2001; Anderson 1983).

The shared nature of this conception of “long time” and its contrasting with “nowadays” provided useful insight into how people constructed their biographies, and upon which their life course schemas were based. The category of long time allowed the demarcation of a set period in temporal terms, in which were packed particular metaphors that facilitated “people’s efforts to puzzle out their sense of difference, to make sense of the dissolution of order in their lives, to align themselves with normalising discourses, and to resist those discourses in favour of alternatives” (Becker 1997, 196). These efforts at puzzling out difference and sameness in temporal terms, contextualised by illness, were what constituted the shared, cultural life-course schema in Debe.

In the following section, I draw out shared themes from life course and illness narratives to highlight differences in the gendering of the life course.

8.2 Women’s life course expectations

8.2.1 Relationships, social roles and continuity

The narratives of female interlocutors were in general moulded relationally, around familial social roles and their associated expectations over the course of their lives: roles as daughters, wives, and mothers.

Tanty Poonia, for example, was eighty-five years old when we met, and she introduced herself entirely as a compendium of her relations: as the mother of seven, the grandmother of fifteen, and the great grandmother of eight. She was one of the older women interlocutors from Debe, and had seen the village become a town around her as she aged. Tanty Poonia had moved

in with her daughter Rookmin and her family fifteen years before for company and assistance. Rookmin was herself a grandmother and a retiree at sixty years of age. We met in the gallery of Rookmin's flat brick house, while a Hindi soap opera on Zee TV blared from cable television through the open door. Every so often, tears escaped from Tanty Poonia's eyes and rolled down her seamed, dark cheeks, which she wiped away unselfconsciously with the backs of her godna-tattooed hands.

Tanty Poonia's illness narrative was always situated in her life history in relation to her family relationships. For example, her diagnosis of diabetes was framed from the outset by the social role of motherhood.

When I have my last child they tell me I have sugar. I was old, thirty-five years when I had him, they keep me in Sando hospital. I stop eating plenty sweet thing, I stop using sugar until after he born. I use only a little honey, a little gur [lump sugar with molasses still in it] in my coffee. Now and again one of the children would bring me a set of Sweet N' Low and I could use that. Long time days you feeding the baby with gripe water and flour pap to keep him happy, and you eating sweets to keep your strength up, but I stop all of that even after he born. Even when is Diwali time and I making meethai, I barely tasting that self to know if it good. But the sugar still take mih eyes.

Later in her narrative, however, Tanty Poonia attributed the onset of full blindness to a relational cause: her shock at the actions of her eldest son, Prem. Upon his father's death fifteen years previously, Prem had inherited the remainder of family agricultural lands located deeper in South, and then without consulting any family members, Prem had immediately put the lands up

for sale. He had then taken the proceeds entirely for himself, not sharing any of it with his siblings or mother, who was already ailing by that time.

I gone blind from shock. When my oldest, my Prem [her eldest son], he take the land he father and he ajaah [paternal grandfather] work on, so hard, and he sell that – that is when the sight left me. The shock and the suffering ... that he coulda do that to all ah we. I didn't raise him so, but he come big man now. He coulda ask if anybody in the family want to buy the land self. I know two ah dem did want a piece too ... but he father leave it to him and he do what he want. When I hear the land sell my eyes gone black. I eh see nothing else since.

Prem's selfish act of selling the land therefore felt particularly painful to her, since it felt like a failure of her mothering as well as his abandonment of familial obligations. His actions challenged her belief that she had raised him with an awareness of the proper respect due to those he loved. This experience was doubly traumatic because it mirrored Tanty Poonia's experience with her brothers and sisters, who had also inherited family lands when their parents died. Her inheritance had however been contested hotly by siblings in the courts, and lead to years of litigation and acrimonious relationships with the extended family. Contention over property, specifically land, therefore had a history in the family. This acrimonious history Tanty Poonia never expected to arise amongst her children as well. "They grow up knowing that family is family. We had to take care of each other," she said.

Blindness presented a further challenge to Tanty Poonia's identity as a mother, and as the sustainer of kin-based relationships. She was no longer sufficiently independent in ways that

allowed her to intercede between family members to improve family relations in the wake of the acrimony created by Prem's actions. She was unable to do what she had done within her own family, which was intercede over the years to ensure that family members were invited to "every wedding, satsangh, barahee (ritual celebrating the birth of a child)". This unremitting effort had paid off when the estranged family members resumed contact "so the children could know each other." This kin-related networking was an understood expectation of the life course for women, though it did not feature in the male narratives. It was also interrupted by the interpolation of illness.

The network of relations within which women navigate their everyday illnesses were also where they turned in times of need. While at Rookmin's house, we were served sweet-drinks and biscuits by a woman I was introduced to as Angela, whom I later learned was a third cousin from a branch of the family previously estranged by the property dispute. Angela "helped out" for minimal remuneration a few days a week, since Rookmin often had to attend to other tasks when Tanty Poonia needed assistance. Angela was trustworthy enough to be a part of the family because she *was* family, though from a less wealthy branch. Rookmin and her husband were middle-class, but the range of middle-class in Trinidad, and in Debe, is wide. His salary as a civil clerk in the Municipal court plus Rookmin's pension kept them "comfortable" (which is also a euphemised socioeconomic category with a broad range). Yet the kinship connection was what enabled them to employ Tara, since it was understood she was doing the household a favour, despite also being paid. Reliance on the kin network, which was maintained through the females of the household, produced forms of support that assisted in managing the work of illness in indirect ways.

8.2.2 Self-care and self-sacrifice

In conversation, Tanty Poonia casually mentioned that after her last pregnancy thirty years before her vision had gone, she had been told she had “sugar,” but just a “a touch.” Her diabetes hadn’t been “so bad” that she needed insulin, and she was busy with life, her children ranging in age from fifteen years old to newborn. She explained that she was so busy “taking care of thing” that the sugar “never bother her too much”. While the older children could take care of themselves and the younger ones to some extent, she was still responsible for the everyday work of cooking, cleaning, domestic animal husbandry, grocery shopping, clothing the children and managing the household, while her husband and her eldest son worked in the fields. Her mother and father-in-law lived in a nearby board-house, and at this time her mother-in-law helped tremendously with the childrearing. “The only thing she couldn’t do was nurse the baby,” Tanty Poonia said with a laugh. This still left minimal time to be concerned about her diabetes management. This period of her busy life was concerned with her role as a mother, wife, and householder: there was no space in her narrative for diabetes, just as there was no time to consider it at the time.

When she was in her fifties, her eldest daughter (now a working adult) noted that she was rapidly losing weight and had low energy, and took her to the doctor, where she was diagnosed with diabetes “again”, but “this time for sure.” She was prescribed insulin, but didn’t take it, in part because it was too expensive to be regularly purchased. It was only when she was “about sixty-five” that she noticed her eyesight going, as “things begin to get fuzzy kinda way and dark”. Her eldest daughter took her in to an optometrist, who identified “pressure in the eye” (glaucoma) and put her on medicated eye drops. The optometrist also referred her to the local health centre and the ophthalmology clinic at the hospital to be assessed for the cataracts.

However, because she said “mih eye was so bad” the cataract surgery would not have improved her vision.

Question: Why didn’t you go to the doctor more and take care of the sugar after you found you had sugar again when you were in your fifties?

When I was fifty-four, and Ram was sixty, he get sick bad, bad. He get a heart attack, and then he get a next heart attack, and then he heart fail. He couldn’t walk far without short-breath, he couldn’t go out in the field, he couldn’t do nothing. That was when Prem start doing all the farming, and I had to take care of Ram.

Thus Tanty Poonia’s mildly failing health in her fifties, after a confirmed diagnosis with diabetes, took a back seat to the dramatic decrease in the health of her husband, which impacted not only him but their entire extended family. Her son Prem had also been forced to take over the agricultural production of the family land when his father began ailing, which Poonia supported by helping with his children while he was at work, and her daughter in law was at work too. Thus in her fifties, Tanty Poonia was taking care of her husband Ram, his ailing parents who still lived in an adjacent house, raising domestic animals, helping “make garden”, and “minding” her grandchildren. A typical day involved waking up at daybreak to take care of the animals and make breakfast for her husband and her parents-in-law next door, then having her daughter and son drop off their four children for her to “mind” for the day, then making lunch and dinner, putting children down for a nap, taking care of the household and the kitchen garden, and then making dinner for everyone. Within this routine, Tanty Poonia explained with a laugh, there was no time for her to even “feel sick”.

The theme of not feeling sick despite a diabetes diagnosis has been addressed in the previous chapter on asymptomatic diabetes, since the early, insidious damage to tissues often does not impact on phenomenological life experience. Tanty Poonia's narrative, however, leaves it open to consideration whether her life-world was truly un-impacted by her disease, or if she was so involved in fulfilling the expectations of her social roles that she did not recognise or attend to its symptoms.

"Self-sacrifice" was a characteristic expectation of her gendered social roles as wife, daughter-in-law, and grandmother, at this point in her life course. The expectation of self-sacrifice especially in the role of mother and grandmother came up repeatedly over the course of fieldwork. For example, while sitting and chatting with a group of older women in the temple, I brought up the question of mothering and being a wife. Different perspectives were shared, including the following:

When you is a mother, you does forget to eat to feed your own child. Not one grain of rice does pass your lips before your child finish eat.

A wife does know how to do without so he [your husband] could have 'nuff to eat, that is how you could be a good bahu [wife].

When your children crying, you does forget about yourself.

Grandchildren does keep you busy, busy and only make you laugh, you don't have time for no worries. That is the reason they does keep you young.

These statements valorised self-sacrifice as a foundational characteristic of the particular female-gendered social roles, in which care-giving was expected, even to the exclusion of the self. Similar sentiments arose repeatedly over the time I was in the field, in conversations where there was usually rueful commiseration with other wives/mothers/daughters-in-law/grandmothers. In uttering these statements, women were asserting and affirming the value of self-sacrifice as a part of womanhood that formed part of the collective cultural schema. They were also, however, commiserating with each other over their adherence to this schema, and thereby also boasting. Similar attitudes were also repeated in Hindu religious spaces. Frequently heard commentary lauded the role of the wife, emphasising the importance of “being home with the children while they young”, as a “natural expectation” of wife- and motherhood. Yet as many scholars of Indians in the Caribbean have pointed out, patriarchal constructs of gender roles within the community that are often held up as cultural ideals are “hard to practice in reality under the force of exigencies like the need for cash” (Khan 2004, 80). Indeed, Indian women have worked side by side with Indian men in the sugarcane plantations from the time of indenture, though for less pay (Brereton 1981).

Self-sacrifice was embedded in normative notions in the community about foundational social roles. It was accompanied by the expectation that kin-based networks would become stronger and more important along a gendered spectrum, in combination with the self-sacrifice that was expected of social role performance as wives and mothers. For example, a woman in the community, Reshma, lived with her parents for a month after the birth of her first child. When she was ready to go back out to work at 3 months old, she was able to leave her daughter with her parents, who hired additional help, in lieu of daycare. Vindra, yet another woman in the

community, left her husband and school-aged children to live in New York for six months of the year, working as a domestic worker, in-home caregiver, or nanny, for which she earned U.S. dollars off the books and therefore untaxed. The other half of the year she came back home to Trinidad and worked in the clothing store that she and her husband had set up out of their house, and were slowly building through their joint earnings. Here the notion of self sacrifice was demonstrably different, since the sacrifice involved was Vindra's ability to express her love for her own children in direct physical ways, in order to meet and her family's long term needs by earning well.

There was an age-related component to this expectation: women over the age of 60 were more likely to identify self-sacrifice as a value than younger women.

The expectation of self-sacrifice as a foundational component of female gendered social roles indirectly countered the notion that self-care should be a priority. This had significant implications for Tanty Poonia, as her illness narrative suggests. Metaphors for self-sacrifice very often emphasised food and eating practices that prioritised the feeding of others over the self, including in meal choice, timing, and volume. For people with diabetes, the right meals at the right times in combination with medical regimens are crucial parts of everyday disease management.

8.2.3 Caregiving

Caregiving is explored in more depth in chapter seven. It was also a common life-course expectation for both males and females adults in Debe. Caregiving was particularly a taken-for-granted expectation of the female social role, especially in the capacity of wife and daughter.

Tanty Poonia's daughter Gayatri described the expectation of caregiving for aging parents as "the natural order".

It is the natural order for us to take care of our parents when they getting old, they raise us up until now and give us everything when we was small. When they get old, is their turn for us to take care of them. That is the responsibility of a child.

Gayatri had therefore always expected to take care of her mother when she aged, and adjusting to her complete loss of vision was just another step in that process of caregiving. She was grateful that she had the means to employ assistance, but also acknowledged that her mother's loss of vision was a weight as they could no longer share the simple things they once used to, like watching the soaps on Indian cable television station Zee TV. Tanty Poonia continued listening to the soap operas, but being unable to read the English subtitles, she lost out on a lot of the plot twists unless Gayatri was there to watch and narrate it to her.

There was clearly a temporal dimension to the expectations of caregiving – the expectation was that one would have some respite when one aged. Tanty Poonia's daughter, for example, insisted that her mother come live with her when Tanty Poonia's eyesight finally grew so bad that she could no longer cook for herself. "If I don't insist, she wouldn't have come," Gayatri said, while Tanty Poonia smiled. "It was her turn to let people take care of her." Thus for Tanty Poonia, having diabetes and even the development of the dramatic complication of blindness did not appear to interfere significantly with her life course expectations, since the progression of her social roles continued despite it. The blindness, however limiting, was philosophically borne by Tanty Poonia, though she also mourned the loss of her ability to

effectively contribute to the household of which she was now a part. “If I coulda cook self, I coulda help Rookmin little bit,” she said, “but the eyes gone and they not coming back.”

8.3 Men’s life course expectations and their disruption

8.3.1 Work and masculinity

The narratives of men in Debe were often moulded around their life course stages, and integrated with their social roles as provider.

For example, Krishna Mamoo⁸⁴ focused heavily in his life course narrative on the development of his business, and the ways in which his illness and experience of a stroke had interrupted this. When I met him, he was 70 years of age, and had largely recovered from the stroke. His narrative was interspersed by reflections and insights on his life course expectations as a consequence of its resolution. He lived with his wife Ann on an intersection on the Debe main road and had started an auto-parts store beneath their house many years previously. Business had grown steadily and peaked in the 1990s. The store had put his two sons and two daughters through university, including one son who was now a doctor, and a nurse daughter who had been trained in England. He had scaled back further expansion of his business after his children grew up. Krishna Mamoo was fifty-eight and still running the store when he had a heart attack. He was found to have massive blockage of multiple coronary arteries, and had “open heart” or coronary artery bypass grafting surgery in a private hospital. He recovered well, and was started on a stricter regimen of medications to manage his diabetes and hypertension. He

⁸⁴ Mamoo is a Hindustani word for “uncle” and is used as a term of respectful address for all older males in the community.

continued to run his business, however, and was considering handing it over to one of his sons when he got a stroke ten years later. He became paralysed on his right side with severely slurred speech. After a year, however, the paralysis resolved, leaving only a lingering weakness and mild speech impediment.

Krishna Mamoo attributed the stroke in no small part to the “stress” and “tension” of never having let up on working, despite getting older. It was the stress of working that he also blamed for not taking care of his medical condition. The cumulative stress had also caused the sudden onset of his stroke.

The stroke come like a lightning bolt. One day I sitting downstairs in the shop, good-good, next thing I know somebody hit mih head with a bat – the pain was so strong. I fall off the stool and pull everything on the ground on top of me. I lose mih senses. My face, this side [gestures to his left side], it all get heavy heavy, like when you go by the dentist, and my tongue get heavy and I could hardly talk. I couldn’t feel this foot and I couldn’t even move it. Mih body was shaking, I feel so weak. The doctor tell me I had a stroke from the pressure and sugar ... I lucky I could talk at all and I wasn’t paralysed more. But to me, this stroke, it take everything away. I couldn’t work. I couldn’t lift mih hand to open a car-door, far less drive the car, far less run the shop. I build that shop from a parlour and all my children grow up in there. Then this stroke come and it all gone. Most I could do was sit in the wheelchair asking [his unmarried daughter] to fetch mih this, fetch mih that. I couldn’t live so. I was never a man so.

I used to be a busy, busy man. Up till I get the stroke I running the shop myself. Every day I meeting suppliers. I checking stock. I checking in with my manager and them to make sure everything in top shape in the shop. I always working, always busy, too much tension in my life, but I was used to it. I didn't know that I had so much stress collecting, I didn't visit my grandchildren enough. Grandchildren are the nectar of life. They used to love to see me in my red truck, they know I bringing them a little something. My cousin living next door, he own that shop too. I know him and his wife was in school with we too. We grow up together pitching marble in this road here long time, before Debe change so. After the stroke I couldn't meet nobody. I couldn't talk good. Everything had to happen slow, slow now. I couldn't even see my cousin, self, stick up in this wheelchair. I couldn't handle Ann seeing me so.

Q: Why you didn't want to see them?

I was too shame. The stroke ... I wasn't able to do nothing. I couldn't walk, I couldn't eat properly, they had to bathe me and change mih clothes... Every day, you going along good good, you happy, you take care of your family, everybody grow up good, the children settle, you getting ready to enjoy the grandchildren when bam, something take you like this. Getting old not easy. This sugar and pressure does sneak up on you when you not watching. When you not thinking about it, it working in you. I work so hard to give my family everything, and then for this sickness to cut me down so and take it all away from me.

In Krishna Mamoo's narrative above, the incapacitation following the stroke erased a primary role in his life, that of a working man and provider. The stroke made him dependent, incapable of work, and took away a primary social identity, which was a severe challenge to his concept of masculinity. For Trinidadian Indian men in Debe, being a provider or breadwinner was a foundational identity. In their narratives and the narratives of their spouses, the loss of the ability to work was often the most significant marker of the severity of their illness. Men commented on becoming "useless" when they could no longer work, "locho", a Trinidadian word for someone who mooches off others. This characteristic was also found in the illness narrative of Deoraj Mamoo in chapter six.

The emphasis on the social role of provider or breadwinner differs from the illness narratives of the women I engaged with in Debe. The older women, however, also considered the loss of the ability to provide to be emasculating and a "failure" in someone who could no longer meet a primary expectation of being a husband. One wife who had been suddenly invested with the care and responsibility of her husband soon after their late marriage, in the following chapter, for example, said:

I didn't married to come hand to mouth. That is not why you get married. And Deoraj, he was a hard worker and a good, good man. But you never know how the sugar will take you. He work and work but it still take him, and then he couldn't manage no more and I had to go out and work.

Deoraj Mamoo also felt himself "suddenly get old" when he was no longer able to work as he once did. The loss of provider status and subsequent loss of masculinity was similarly

associated with a “sudden” aging amongst the men I spoke with in Debe, though the suddenness also referred in some cases to the recognition of aging rather than its onset. Illness was a negative life-course expectation of aging, but the acceptance of illness varied with the suddenness of the onset of severe debility. At any age, illness severity was considered emasculating if it prevented independent mobility, social engagement, the driving of a car, or continued work.

I know how to work hard but sugar take that away from me. It make you weak, weak and it numb the foot. I couldn't walk outside in the garden self no more after I get sugar. I couldn't even drive the car.

- Amar Mamoo, 65 year old male with diabetes for 7 years

I get old fast after I get sugar. I couldn't do anything I used to do before. My wife had was to do everything for me. You know how that hurt a man?

- Vishnu Mamoo, 73 year old male with diabetes for 10 years

The sugar sap mih strength. I get a bad feeling all over mih body when I get sugar. That is how you know you have it. Your body is not your own any more. You can't do nothing when the sugar bad. But you could manage it, if you take care of yourself, and then it come under control.

- Surujdeo Mamoo, 75 year old male with diabetes for 20 years

Aging was not, however, portrayed solely in a negative light for and by men in the community. Aging was an accepted part of the life course, in that it meant enjoying the ability to

stop working, and being able to put aside the responsibility of being a provider. Some older members of the community were also described as “older heads”, elders who were a source of wisdom, especially about “traditional” practices and values: thus getting old also meant gaining respect within your own family and extended family. Grandparenthood was an enormously positive social role transition, an achievement with the expectation that one would be able to “play with”, “spoil up” and “love up” one’s grandchildren. As Krishna Mamoo says above, “Grandchildren are the nectar of life.” Being a grandparent further affirmed one’s status as an “older head” in the community. Having become a grandparent lent weight to pronouncements about traditional values and expectations of parenting, child-rearing, and working. This was as important for men as it was for women, though grandmothers engaged in the labour of child-minding (cooking, changing, bathing, feeding) more than grandfathers.

Interestingly, men who continued to work in whatever capacity, earning even as they aged, were respected more within the community for their continued familial contributions. There was also a correlation between prominence in the community and the arranging, hosting, or funding of communal events such as Ramayanas or satsanghs. For those of a higher socioeconomic class who had always been religiously oriented, it was expected that they would demonstrate increased piety as they aged through the hosting or funding of communal religious events or increased attendance at temples. This was the case with Krishna Mamoo, who attributed the return of his mobility to the Hindu prayer session he and his wife held after he had the stroke. As he stated:

We had a satsangh after I get the stroke. Everybody come. We had the best singers in the country, [our pundit] have plenty gyaan. I sit down upstairs in the wheelchair and listen,

and after that I start to get better. My foot start to work better, everything start to get good. God does work in mysterious ways. I know that I had to be thankful, so thankful that God let me come back to take care of things and spend time with my grandchildren again.

8.3.2 Change in the flow of time

“Long time, life was hard. You wake up five o’ clock in the morning and everybody going out to cut cane when is crop time [reaping season]. Even if you didn’t plant that year, you cutting the neighbour cane or your uncle cane. Those fields gone now. Then you come home and bathe then you walk to school. When it was time for exams, you studying by candlelight or flambeau when the current [electricity] gone. Long time, it had time. When I start secondary school my parents stop me from cutting cane so I could study. They wanted a job for me with soft hands. I get my passes in school, and I get a job in the bank, then I get married. We start the shop, the children come, everything get busy busy. The children grow up while I was busy. Same thing what happen with the sugar and pressure. I was busy taking care of the business, I had no time to take care of myself. The tablets you have to take a half hour before you eat, and then you have to eat at this time and this time, then you have to watch what you eat, and you have to do this and do that... I take the tablets, but I didn’t have time for all of that. Then all of a sudden – BAM! [he raises his voice] – stroke. I wasn’t busy no more. Time slow down all of a sudden. All I had was time. Everything slow down, things take so long, you always waiting. So much time in the private hospital, so much time before I could get a

physiotherapy appointment, so much time before I see this doctor or the next doctor. I was always waiting, like I get old fast-fast. Ole age is not easy. But the sickness was the hardest.”

- Krishna Mamoo

Krishna Mamoo’s illness narrative was a paced description of temporal changes. There was an individual temporal progression over his life-course: the slow time of his childhood was followed by action and a busy life in adulthood, as he engaged the social roles of provider and householder, to the slowed time of a sick person, dependent upon others for his care and “always waiting”. While he perceived himself as still in his productive, active years, his stroke and illness falsely introduced a slowing down of time, interrupting the expected progression of his life course. His life course narrative is therefore temporally entwined with his social roles: child, student, working-man, husband and father, and then ill person. The forced slowing down with the stroke and its management is an unexpected and sudden change into a temporal register of old age, which is portrayed negatively here. Yet Krishna Mamoo also referred in his narrative to his joy in his grandchildren and his anticipation of a time when he could hand his shop over to enjoy more time with them. This therefore suggests that it is the precipitate and unexpected nature of the slowing down imposed by the stroke that is problematic for him, not the expected and somewhat voluntary slowing down of “old age”. The illness associated with diabetes produced its own temporality that created a dissonance with his prior expectations of the progression of time. Bury and Holme (1991, 94) have described this as an interruption in one’s “social clock”, which “guides our expectations of events within the biographical context.”

Krishna Mamoo further referenced “long time” days in his narrative. References to the past by the elderly in many cultures often have a patina of nostalgia, reflecting as they do the individual histories and biographies of youth before the onset of old age. As Birth (1999) has noted, however, the concept of “long time” in Trinidad also refers specifically to “stories of work and discipline in the past.” Long time was hard because of the manual labour of the cane fields. This labour is gone, as are the cane fields themselves with the closure of Caroni (1975) Ltd. Implicit in this narrative is that the cane fields taught him the capacity for hard work, though he had also got away from the cane by working in a bank and later working for himself. Working in the cane continues to be invoked in multiple narratives through the idiom of “long time”, a complicated mix of acknowledging past hardships and pride at “how far we have come” through such labour.

Krishna Mamoo’s narrative also invokes the difference in the temporality of an agricultural seasonal cycle compared to the commercial cycle that replaced it in his life. Time was marked differently when sugar cane and rice cultivation and processing were the majority occupation in the Debe region. Time was marked by the seasons of rain, and the crops. The end of the dry season was the labour intensive crop time for sugarcane, while the rainy season was the less intensive growing season. Farming was a communal activity that Krishna Mamoo and his peers were expected to engage in communally, even though his parents aspired to more for him.

8.3.3 Chronicity and death

As Mattingly has pointed out, “There is more than one kind of death possible, of course. Serious disability may allow you to live for years and years, for an entire span of life, and yet force death

of self and the painful recreation of some new self” (Mattingly 1998,1). In Krishna Mamoo’s illness narrative, death and “uselessness” arose repeatedly when he spoke about his illness experience.

Most I could do [after the stroke] was sit in the wheelchair asking [his unmarried daughter] to fetch mih this, fetch mih that. I couldn’t live so. I was never a man so. All I could do was wait to die.

The stroke was like a call from God. I was never a useless man. Then the stroke come, and I find myself sitting down, waiting, waiting, like I waiting to die.

Q: What you mean, you could only wait to die?

If my legs didn’t start back working, I wouldn’a be able to live. That is not a life. I think I woulda just fade away. Or I woulda fall down and just dead, just so. To be lock up in the wheelchair, or have the wife trying to lift me up and take me everywhere... that is not a life I could have live.

The stroke had a radical, dramatic effect on Krishna Mamoo in a number of ways, but perhaps most significant was its effect on his perceptions of mortality.

When I was busy running the store I never think about dying. My mother still living with my sister, and my father pass away ten years now, but I never imagine it could have

happen to me. Then when I get the stroke, I feel like I was already dead, only my body was waiting to go. I was halfway there.

The living “death” of the stroke was the most dramatic break in Krishna Mamoo’s life course schema thus far, despite having been diagnosed for years with diabetes and hypertension. His experience of chronicity was filled with the “imprecision, elisions, and slippages that occur in reference to chronic disease, with the presumptions of consistency in patterns of disease, and in the capacity for its management and control” (Manderson and Smith-Morris 2010, 3). The absence of a change in his bodily experience of illness prior to the stroke had prompted little change in his practices of disease management, since by his phenomenological account he was not ill. Instead, it was the recommendations that he follow a rigid medication regimen in accordance with rigid meal times that made him feel ill. “I couldn’t be taking tablet all the time like a sick man, I couldn’t take all the enjoyment out of my life just because the numbers was telling me to,” he explained. The diagnosis of the disease and indeed its management expectations could not impose a change to his bodily habitus, prompted as they were by an external, biomedical locus of control. For this self-made man, with a biographical narrative of personal motivation, machinated measures of his own body were not sufficient to prompt management changes.

Instead, it is only when his narrative of self is re-inscribed by the onset of the stroke that Krishna Mamoo fully comes to terms with his illness, and the possibility of his own mortality. The understanding of his mortality through his own flesh is what prompts a change in his personal identity to having “sugar and pressure”. It is only after the stroke, additionally, that he begins to realise how dependent illness can make him, rather than seeing himself as the source of

support for his family. These multiple recognitions and the change in his identity and social roles beyond his life course expectations thus far leads to what he described as “a depression”.

I get a depression, when I did get the stroke. When I realise I would be able to move, that I might never again be able to move ... that start a depression. I didn't want to talk, I didn't want to do nothing. Ann had to stay home and sit down by me, watch TV with me, talk to me. Is years since we had so much time together, but she put everything else aside. And then after we had satsangh and the pundit come home a few times, the depression start to lift.

Over the course of fieldwork, as the narratives accumulated, there were many in which there was strong evidence of depression. People described a sense of hopelessness, a loss of pleasure, a fatalistic expectation of inevitable decline, a loss of energy to pursue their goals, and sadness. Despite this, however, none of the persons I interviewed admitted to having a diagnosis of depression, or to taking any medications for this disease. This may be, in part, because depression and mental health illnesses are stigmatised in Trinidad. However, the biomedical recommendations for diabetes management in Trinidad also do not specify that patients be screened for depression as a correlate to their diabetes.

It was questionable, however, whether the depression associated with diabetes was purely an organic phenomenon arising from biologically-derived alterations to brain chemistry, or a condition of their social and structural disenfranchisement that was further manifest as symptoms of diabetes itself. For Krishna Mamoo, it was the “uselessness” and dependence of his transformed social role of stroke-patient that prompted the most sadness and depression. “I

couldn't do nothing, I couldn't even take care of myself," he said, "I had to depend on the family for everything." Yet in brief conversation with his wife, Ann, she described him as "a fighter" who "fought off the stroke". As she had always done, she continued to make his meals, run the household, and assist with the running of the store while he was ill, only seeking help from his children with the everyday tasks of storekeeping. To Ann, therefore, there were dimensions to Krishna Mamoo's reliance on her that were on-going and the stroke was thus a change in degree rather than an entirely new imposition. To Krishna Mamoo, however, his return to mobility was the most important return of independence that he experienced, and with it, his depression disappeared.

Krishna Mamoo's narrative was an unusual one. There were no other interlocutors in the field who experienced a stroke whose symptoms resolved so dramatically. As such, the resolution of his symptoms, though it returned him to lesser functioning than he had prior to the stroke, was still a return to a familiar social role in his life course schema: that of the elder, the grandparent, the retiree. When he recovered from the stroke, the depression lifted. Even with decreased mobility and weakness, he was "on course" again. He described himself as no longer thinking about death, though he knew death would come. He spent as much of his time with his grandchildren as possible, and was already planning extravagant birthday parties for them, as well as an anniversary party for his wife. He was also planning a trip to visit his nurse daughter who now lived in England.

Before the stroke, I had no time, when I had the stroke, I had no chance to do nothing,
and now I don't have the stroke, I have to take the time I have.

- Krishna Mamoo

8.4 Fluidity, change, and ideals

The concept of the life course and the schema which are engaged in this work show thematic differences in the role expectations for men and women though the stages themselves remain roughly the same. The life courses for both men and women appeared to be defined in relational terms, with individual identities being subordinate to their familial social roles.

For women, the life course was framed as a progression from child to daughter to wife to mother to grandmother. Each social role was accompanied with expectations of responsibility, with childhood being the period of fewest expectations and responsibilities, and responsibility compounding from filial to spousal upon marriage.

For men, it was a progression from son to provider/husband to father to retired/grandfather. Men's social roles were thus not only oriented towards the family space, however, but also to the public space of earning. Of note was the fact that despite a generalised expectation within the cultural schema that women would engage in the majority of childrearing and caregiving (i.e., their social roles were more oriented towards towards familial tasks) most women that I encountered in Debe had worked, were working, or were planning to work to earn money, whether inside or outside of the home, to contribute to the family purse.

For both men and women, caregiving appeared to be a significant role that was expected of them over the course of their lives, though for men it occurred more after they entered the "householder" social role. For women, unmarried daughters also had the expected and accepted social role of caregiving for their parents. Men were also expected to earn as a part of their caregiver role, while women were expected to shoulder the physical acts of nursing, often as an extension of their culturally mandated biological predispositions to nurturing. Men and women,

similarly, shared notions about the social role and life course expectations of their opposite gender, for as Tanty Poonia stated, “When everybody know what they job is, the family running smooth-smooth.”

These temporal expectations were not sufficiently disrupted by a diagnosis to transform their practices until the onset of debilitating illness. In the overarching context I encountered in Debe of somatic experiences being privileged over biomedical constructions of disease, it was therefore not surprising that diabetes manifest in these people’s lives as the onset of severe illness. The tensions and contradictions that arose with the onset of illness often had as much to do with the illness and its requirements for management themselves as to do with the impact it had upon their expectations of gendered roles, including their caregiving ability in the case of the women, and their transitioning from providership in the case of the men. In these illness narratives, what constitutes people’s humanity struggles within the larger contexts of oppressive conditions not only of illness but of living: having little money, having to make do, having to find ways of coping.

Chapter 9: Conclusion

The ethnographies, narratives, and stories of this dissertation demonstrate that Type 2 diabetes mellitus, in its prevalence, associated illnesses, and requirements of management, imposes a significant burden on people diagnosed with the disease, their families, and the networks they mobilise to provide care. The practices of everyday life in Debe, including eating and commensality, participation in integrated religious observances, and meeting the life-course expectations of “a good life,” are the means by which people (and their families) develop and maintain enmeshed networks of family and community through which diabetes care is enacted when people become sick. These practices are also the means by which Indian Trinidadian ethnic identity is instantiated for many people, which is an important and integrated domain in their lives.

The deep involvement of familial networks in diabetes caregiving demonstrated in this ethnographic material additionally forms a trenchant critique of rubrics for diabetes management that are based on individuated, atomistic constructions of the patient as autonomous individuals, engaging in rationalist models of choice, solely responsible for their own self-management and care. It also highlights disjunctures between efforts within the public health care system and the measures of chronic disease these efforts are intended to improve, such as decreased overall morbidity from disease, and “compliance” with dietary, exercise and therapeutic regimens. Governmental efforts such as dedicated Chronic Disease Clinics, free medications, and free blood glucose monitoring instrumentation are framed by the biomedical construction of the individuated patient, and are thus oriented towards individual practice and delimited to the

medical domain, rather than reflecting some of the structural constraints to people's abilities to access and enact health and care recommendations in Trinidad.

These constraints include: (1) poverty and income instability, which affected people's ability to obtain transportation to the clinics, to attend protracted appointments with concomitant income loss, or to access healthier "lifestyles" through more expensive substitutions for everyday foods or dedicated exercise facilities; (2) disorganisation and fracturing of the public healthcare sector, manifest in overloaded clinics, long wait times for appointments, protracted gaps between appointments, failures in continuity of care, lack of integrated multi-disciplinary care teams, and lack of regular access within the public health setting to tests and procedures necessary to achieve the metrics of adequate care within this setting itself (for e.g., regular glycated haemoglobin testing or haemodialysis); (3) inconsistency between the recommended "lifestyle" changes and deep-seated ethnic and cultural practices which instantiate everyday identity for people with the disease, for example, the absence of systematic investigation into and widely available information on culturally compatible, lower-glycaemic index dietary substitutions.

The long, early, asymptomatic phase of Type 2 diabetes and its estimated prevalence within the Indian Trinidadian community suggests that there are many persons in the community who meet the criteria for diabetes but remain undiagnosed. Many people who have been diagnosed, however, privilege their somatic experiences over biomedical techno-scientific measures of the body through which its diagnosis and pathology are materialised, especially before the onset of symptoms or complications that intervene in their life-worlds. With disease progression, consistency with the medical explanatory model of disease generally rose with people's greater integration into the system of medical care provision. Alternative, non-biomedical explanatory models were also present, based on both (1) concomitant ethnomedical

systems in Trinidad, such as “maljo” (i.e. personalistic medicine) and “bush medicine” (i.e. herbal remedies) and (2) personal investments of illness narratives with specific, life-world related and emotionally charged meanings, such as grief, stress, and loss.

Some people also expressed a deep underlying mistrust of the public institutions of care provision, its representatives (such as doctors and nurses), and the medications prescribed, which may have acted as a limitation to their attending clinic appointments, taking the medications, and following medical advice. This was framed by some, like Tara and Dularie, as a “lack of care and concern” on the part of doctors and these institutions, an expression of a breakdown in the therapeutic relationship partly reinforced by the overburdening and decline of the public healthcare system, manifest in shortened clinic appointments and long durations between visits. Others, like Tanty Radha, expressed a distrust of the public-private systems through which the generic medications provided via CDAP were obtained, which extended to the medications themselves. Others, like Deoraj, expressed an ambivalence about the role of the public hospitals entirely, since they were dependent upon “repeat customers” to have continued necessity. These generalised expressions of institutional ambivalence and alienation, however, also raised the question whether these responses were reiterations of deep-seated institutional mistrust resulting from perceptions of discrimination that inhere to many other institutes in Trinidad’s postcolonial history. They also bring into question whether the stigma experienced by patients perceived as non-compliant in this system, such as Tanty Dularie, was in fact further compounded by institutional legacies that subjugation of the bodies of the colonised.

This research also highlights the tension between the concept of non-compliance and the actualisation of forms of support and caregiving in people’s lives in Debe. Maintaining daily and yearly practices of family and community cohesion around dietary practices forms a crucial part

of people's sociality and the configuration of their life-worlds, causing them to struggle with integrating diabetes management recommendations into these forms of sociality, especially around diets.

A popular critique advanced of people with diabetes in Trinidad additionally frames them as particularly non-compliant with recommended changes to diets, exercise practices and medication regimens. Simultaneously, longstanding epidemiological research efforts and popular discourse have emphasised the racial or ethnic attribution of diabetes in Trinidad, localising it to the Indian Trinidadian community despite high levels of diabetes also being found in the African Trinidadian community. In the context of Trinidad, where a tacit invocation of ethnicity underlies much discourse, and where ethnicity simultaneously remains a dominant domain of identification and the production of social integration for Indian Trinidadians, a tension exists between the characterisation of people with diabetes as non-compliant and Indian Trinidadian ethnicity, specifically related to Indian Trinidadian dietary practices. This has produced a perception within Trinidad at large that Indian Trinidadian dietary practices are particularly diabetogenic and pathological. This pathologization of culture is reminiscent of colonial-era anti-Indian racism, which ascribed pejorative features to non-European ethnic markers, including practices of eating and drinking. As such, this may recapitulate colonial violence, actualized through the totalizing and globalized force of biomedicine. The emphasis on a racial or ethnic attribution to diabetes also focuses attention on the presumptive ethnic attributes of the community, rather than on systemic, structural, or social factors that may be at work.

Physicians in treating patients with diabetes in Chronic Disease Clinics in Trinidad are taught to give general recommendations about decreasing sugar intake, avoiding simple carbohydrates, decreasing abdominal girth, and increasing exercise, in accordance with the regional CHRC guidelines, but in local health centres this advice tended to be non-specific, generic, and varied as well from physician to physician, who were operating as well within a larger setting of slow structural disintegration. It is possible that there has been acceptance of the linkage of Indian Trinidadian ethnicity and diabetes that has resulted in an overemphasis on pharmaceutical clinical control of diabetes, with little emphasis on lifestyle transformation, and instead an earlier transition to more rigid medical regimens, which patients are less able to perform in their everyday lives, leading to perceptions of non-compliance. A fatalism about disease progression consequent to the emphasis on diabetes as an “Indian disease”; notions about race as a proxy for genetics; a general perception of non-compliance; and a fractured healthcare system all combined to produce a context in which diabetes management was as variable across the landscape of Trinidad as the population within it.

9.1 Suggestions from the field

Diabetes imposed a treatment burden not only on diagnosed individuals, but on their social networks as well, whose life-worlds were transformed and identities and social roles also came under strain in meeting associated demands. Over the course of this research a number of critiques and recommendations arose from the field regarding how to lighten this burden, not

only for the people diagnosed with diabetes, but for the entire social system in which they were enmeshed.

The primary transformation people noted to their lifeworlds was not necessarily the increase in the overall work of caregiving that they had to do, but the transformation in its nature: the process of familiarizing themselves with the medical management requirements of their family members was an on-going job, in addition to finding ways to meet these management needs.

This was often exacerbated by intra-familial dynamics such as the unwillingness of a spouse to heed the exhortations of their partner, or an elderly parent to listen to their child. All caregivers therefore spoke about the need for more medical support and resources. Medical support included more frequent physician appointments and clinical time, so that they could communicate with the physicians and ask the questions they needed answers to; or non-face-to-face time such as enabling communication via text messaging, which even middle aged to elderly people did.

Other recommendations included increased training about, increased availability of, and increased integration of supportive care measures into their homes, where the majority of caregiving took place. People asked for hospital or specialist nurses to provide in-home care and training to the families; nursing aides with specialisation in in-home care to visit at least every week to check on appropriateness of medical regimens and diets; dedicated vehicles outfitted for transporting disabled persons from the government or the public hospitals to facilitate access to medical appointments; more stable financial assistance than is currently available given the income precarity caused by chronic and complicated illness; and elder care “camps” or classes where the elderly could gather to socialize and relax without their families having to worry about safety or the care their loved ones were receiving. I was surprised that multiple caregivers

suggested that their private spaces be even further medicalized than they already were in meeting the demands of the ill family members. However, as one of the older heads in the village explained, “If the doctor or the nurse say it has to be so, it has to be so. If we say so, they feel they doh have to do it. Then is we to blame when they get worse too.”

9.2 Future directions

In *The Logic of Care*, Annemarie Mol (2008) asks, “Is a collective the sum total of a number of individuals added together, or can we only understand what individuals are if we first learn about the – various – collectives to which they belong? And should public health be improved by asking individuals to change their behaviour, or by interfering with the conditions in which collectives live?” These questions remain at the heart of this study. Based on these findings, the answers to Mol’s questions are a dialectical “Yes.” Collectives (families, communities, villages, ethnic groups, temple groups, persons with a diagnosis of diabetes, persons in the same clinic, etc. etc.) must be understood as such in order to achieve change for any one AND for all of their members. Public health, taken here to refer to the improvement in the quality of life for as many people at the same time as is possible, requires BOTH individual behaviour change (with the understanding that individuals comprise complex interstices of enmeshed relations with their worlds) AND changes in the conditions in which collectives live.

The people who were most successful in Debe in improving the quality of their lives after the disruption of diabetes achieved this both through day to day practices of care. These practices were both performed as individuals, and as parts of wider collectives, by casts of various sizes: ranging from a single spouse, to a family, to an entire Temple Group of ten to fifteen women. A focus on practices, rather than outcomes, suggests that the most “successful” practices were not

those that clung to rigid categorizations, but were characterised by people's ability to "accommodate the exigencies of the disease with the habits, requirements and possibilities of daily life" (Mol 2008, 11). I posit that the most successful diabetes "management" occurs not as a transaction (for e.g. between the health care sector and the patient) and not as a matter of following rules (for e.g. eschewing contexts of sociality for one's health), but in the intersubjective space of creating and maintaining relationships that produce the "logic of care." The ultimate goal of the logic of care is relational, it creates a relationship in which "various actors (professionals, medication, machines, the person with a disease and others concerned) might best collaborate in order to improve, or stabilise, a person's situation" (Mol 2008, 23), and is thus geared toward "not only the patient, but those around them as well." In the logic of care, patients are thus not treated as a target group, but crucial members of the care team who deserve support in the form of advice, encouragement, and consolation that is geared towards those around them as well (Mol 2008, 23).

By this formulation, the successful management of diabetes that we should consider might depend not only on the successful management of blood glucose levels through close monitoring, but of "attending to the balances inside, and the flows between a fragile body and its intricate surrounds" (Mol 2008, 34).

Bibliography

- Agar, Michael. 1980. 'Stories, Background Knowledge and Themes: Problems in the Analysis of Life History Narrative'. *American Ethnologist* 7 (2): 223–39.
- Aho, William R., and Kimlan Minott. 1977. 'Creole and Doctor Medicine: Folk Beliefs, Practices, and Orientations to Modern Medicine in a Rural and an Industrial Suburban Setting in Trinidad and Tobago, the West Indies'. *Social Science & Medicine* 11 (5): 349–55. [https://doi.org/10.1016/0037-7856\(77\)90193-7](https://doi.org/10.1016/0037-7856(77)90193-7).
- Alexeyeff, Kalissa. 2004. 'Love Food: Exchange and Sustenance in the Cook Islands Diaspora'. *The Australian Journal of Anthropology* 15 (1): 68–79.
- Appadurai, Arjun. 1990. 'Disjuncture and Difference in the Global Cultural Economy'. In *Global Culture: Nationalism, Globalization and Modernity*, edited by Mike Featherstone, 295–310. London: Sage.
- . 1996. *Modernity at Large: Cultural Dimensions of Globalization*. Minneapolis, MN: University of Minnesota Press.
- Armstrong, David. 1983. *The Political Anatomy of the Body: Medical Knowledge in Britain in the Twentieth Century*. Cambridge: Cambridge University Press.
- Bagoo, Andre. 2013. 'Politics before Food'. *Trinidad and Tobago Newsday*, 18 May 2013. <https://archives.newspaper.co.tt/2013/05/18/politics-before-food/>.
- Bahadursingh, Sarasvati, Catherine Mungalsingh, Terence Seemungal, and Surujpal Teelucksingh. 2014. 'Acanthosis Nigricans in Type 2 Diabetes: Prevalence, Correlates and Potential as a Simple Clinical Screening Tool - a Cross-Sectional Study in the Caribbean'. *Diabetology & Metabolic Syndrome* 6 (1): 77. <https://doi.org/10.1186/1758-5996-6-77>.
- Bahall, Mandrekar. 2012. 'Reform of the Trinidad and Tobago Health Service: The Limits of Decentralisation'. *Social and Economic Studies* 61 (4): 105–29.
- . 2018. 'Health Equity and Access to Health Care in Trinidad and Tobago'. *World Journal of Public Health* 3 (3): 83–92. <https://doi.org/10.11648/j.wjph.20180303.13>.
- Bahall, Mandrekar. 2018. 'Health Services in Trinidad: Throughput, Throughput Challenges, and the Impact of a Throughput Intervention on Overcrowding in a Public Health Institution'. *BMC Health Services Research* 18 (1): 129. <https://doi.org/10.1186/s12913-018-2931-2>.

- Barbosa, Carla Dias, Maria-Magdalena Balp, Károly Kulich, Nicola Germain, and Diana Rofail. 2012. 'A Literature Review to Explore the Link between Treatment Satisfaction and Adherence, Compliance, and Persistence'. *Patient Preference and Adherence* 6 (January): 39–48. <https://doi.org/10.2147/PPA.S24752>.
- Barth, Fredrik. 1969. *Ethnic Groups and Boundaries: The Social Organization of Culture Difference*. Boston: Little, Brown & Co.
- Basch, Linda, Nina Glick Schiller, and Christina Szanton Blanc. 1994. *Nations Unbound: Transnational Projects, Postcolonial Predicaments, and Deterritorialized Nation-States*. Langhorne, Pa.: Gordon and Breach.
- Becker, Gaylene. 1997. *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley: University of California Press.
- Bezie, Yvonnick, Maria Molina, Nicolás Hernandez, Rui Batista, S. Niang, and Dominique Huet. 2006. 'Therapeutic Compliance: A Prospective Analysis of Various Factors Involved in the Adherence Rate in Type 2 Diabetes'. *Diabetes and Metabolism* 32 (6): 611–16. [https://doi.org/10.1016/S1262-3636\(07\)70316-6](https://doi.org/10.1016/S1262-3636(07)70316-6).
- Bhabha, Homi K. 1994. *The Location of Culture*. London; New York: Routledge.
- Birth, Kevin. 1997. 'Most of Us Are Family Some of the Time: Interracial Unions and Transracial Kinship in Eastern Trinidad'. *American Ethnologist* 24 (3): 585–601.
- . 1999. *Any Time Is Trinidad Time: Social Meanings and Temporal Consciousness*. Gainesville, Fla: University Press of Florida.
- Bissessar, Ann Marie, and Edison Haqq. 2001. 'The Historical Development of the Health System in Trinidad and Tobago'. In *Health Care Reform: Policy Content and Process in the Caribbean, Study No 2*, edited by Mary Hadley and Anne Mills. PhP Publication, No. 34. London: London School of Hygiene and Tropical Medicine.
- Bissessarsingh, Angelo. 2012. 'Evolution of Indian Cuisine'. *Trinidad and Tobago Guardian*, 12 May 2012. <https://www.guardian.co.tt/news/evolution-indian-cuisine-6.2.422202.15c668a46a>
- . 2014. 'Debe in History'. *Trinidad and Tobago Guardian*, 14 May 2014, Sunday Guardian edition. <http://www.guardian.co.tt/article-6.2.382799.cb88904538>
- Bobb, Astral, Danielle Gale, Sherisse Manmohan, Amanda Mohammed, Francia Seetahal, Penny

- Small, and Kameel Mungrue. 2008. 'The Impact of the Chronic Disease Assistance Plan (CDAP) on the Control of Type 2 Diabetes in Trinidad'. *Diabetes Research and Clinical Practice* 80 (3): 360–64. <https://doi.org/10.1016/j.diabres.2007.11.010>.
- Bourdieu, Pierre. 1984. *Distinction: A Social Critique of the Judgement of Taste*. Boston, MA: Harvard University Press.
- . 1998. *Practical Reason: On the Theory of Action*. Stanford, California: Stanford University Press.
- Bourdieu, Pierre, and Richard Nice. 1977. *Outline of a Theory of Practice*. Cambridge; New York: Cambridge University Press.
- Bowker, Geoffrey C., and Susan Leigh Star. 1999. *Sorting Things Out: Classification and Its Consequences*. Inside Technology. Cambridge, Massachusetts: MIT Press.
- Brah, Avtar. 1996. *Cartographies of Diaspora: Contesting Identities*. London ; New York: Routledge.
- Braithwaite, Lloyd. 1953. 'Social Stratification in Trinidad: A Preliminary Analysis'. *Social and Economic Studies* 2 (2/3): 5–175.
- Brereton, Bridget. 1974. 'The Foundations of Prejudice: Indians and Africans in Nineteenth Century Trinidad'. *Caribbean Issues* 1 (1): 15–28.
- . 1981. *A History of Modern Trinidad*. London: Heinemann.
- . 1985. 'The Experience of Indentureship: 1845–1917'. In *Calcutta to Caroni: The East Indians of Trinidad*, edited by John La Guerre, 21–30. St. Augustine (Trinidad): University of the West Indies.
- . 2002. *Race Relations in Colonial Trinidad 1870-1900*. Cambridge ; New York: Cambridge University Press.
- . 2007. 'Contesting the Past: Narratives of Trinidad & Tobago History'. *NWIG: New West Indian Guide / Nieuwe West-Indische Gids* 81 (3/4): 169–96.
- Broom, Dorothy H., and Aodhamair Lenagh-Maguire. 2010. 'Gendered Configurations of Diabetes: From Rules to Exceptions'. *Journal of Gender Studies* 19 (2): 195. <https://doi.org/10.1080/09589231003695997>.
- Brown, Tim, and Morag Bell. 2008. 'Imperial or Postcolonial Governance? Dissecting the Genealogy of a Global Public Health Strategy'. *Social Science & Medicine* 67 (10):

- 1571–79. <https://doi.org/10.1016/j.socscimed.2008.07.027>.
- Burri, Regula Valérie, and Joseph Dumit. 2007. *Biomedicine As Culture: Instrumental Practices, Technoscientific Knowledge, and New Modes of Life*. New York: Routledge.
- Bury, Michael, and Anthea Holme. 1991. *Life After Ninety*. London ; New York: Routledge.
- Caldwell, John C. 1993. 'Health Transition: The Cultural, Social and Behavioural Determinants of Health in the Third World'. *Social Science & Medicine*, Special Issue: Reflections, 36 (2): 125–35. [https://doi.org/10.1016/0277-9536\(93\)90204-H](https://doi.org/10.1016/0277-9536(93)90204-H).
- Camak, Deborah Jacks. 2015. 'Addressing the Burden of Stroke Caregivers: A Literature Review'. *Journal of Clinical Nursing* 24 (17–18): 2376–82. <https://doi.org/10.1111/jocn.12884>.
- Campbell, Carl C. 2014. *The Young Colonials: A Social History of Education in Trinidad and Tobago 1834-1939*. Barbados: University of the West Indies Press.
- Carsten, Janet. 1995. 'The Substance of Kinship and the Heat of the Hearth: Feeding, Personhood, and Relatedness among Malays in Pulau Langkawi'. *American Ethnologist* 22 (2): 223–241. <https://doi.org/10.1525/ae.1995.22.2.02a00010>.
- . 2011. 'Substance and Relationality: Blood in Contexts'. *Annual Review of Anthropology* 40 (1): 19–35. <https://doi.org/10.1146/annurev.anthro.012809.105000>.
- Central Intelligence Agency. 2018. 'The World Factbook — Central Intelligence Agency: Trinidad and Tobago'. 2018. <https://www.cia.gov/library/publications/the-world-factbook/geos/td.html>.
- Central Statistical Office. 2006. '2000 Population and Housing Census Demographic Report'. Government of the Republic of Trinidad and Tobago, Ministry of Planning and Development.
- . 2012. 'Trinidad and Tobago 2011 Population and Housing Census Demographic Report'. Government of the Republic of Trinidad and Tobago, Ministry of Planning and Sustainable Development, Central Statistical Office.
- . 2018. 'Review of the Economy 2017 - "Changing the Paradigm: Putting the Economy on a Sustainable Path"'. Government of the Republic of Trinidad and Tobago.
- Chadee, Derek, Terence Seemungal, Lexley M. Pinto Pereira, Mary Chadee, Rohan Maharaj, and Surujpal Teelucksingh. 2013. 'Prevalence of Self-Reported Diabetes, Hypertension

- and Heart Disease in Individuals Seeking State Funding in Trinidad and Tobago, West Indies'. *Journal of Epidemiology and Global Health* 3 (2): 95–103.
<https://doi.org/10.1016/j.jegh.2013.02.002>.
- Charan, Richard. 2011. 'SWRHA Docs Meet after "barbaric Medicine" Report'. *Trinidad and Tobago Express*, 30 March 2011.
- Charon, Rita. 2006. *Narrative Medicine: Honoring the Stories of Illness*. New York: Oxford University Press.
- Chow, Edward A., Henry Foster, Victor Gonzalez, and LaShawn McIver. 2012. 'The Disparate Impact of Diabetes on Racial/Ethnic Minority Populations'. *Clinical Diabetes* 30 (3): 130–33. <https://doi.org/10.2337/diaclin.30.3.130>.
- CHRC, and PAHO. 2006. 'Managing Diabetes in Primary Care in the Caribbean'. St. Augustine, Trinidad and Tobago: Caribbean Health Research Council.
- Clapperton, M., J. Jarvis, and K. Mungrue. 2009. 'Is Gestational Diabetes Mellitus an Important Contributor to Metabolic Disorders in Trinidad and Tobago?' *Obstetrics and Gynecology International* 2009. <https://doi.org/10.1155/2009/289329>.
- Clarke, Adele E. 2009. 'From the Rise of Medicine to Biomedicalization: U.S. Healthscapes and Iconography, circa 1890-Present'. In *Biomedicalization*, edited by Adele E. Clarke, Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman, and Janet K. Shim, 104–46. Duke University Press. <https://doi.org/10.1215/9780822391258-004>.
- Clement, Y. N., Y. S. Baksh-Comeau, and C. E. Seaforth. 2015. 'An Ethnobotanical Survey of Medicinal Plants in Trinidad'. *Journal of Ethnobiology and Ethnomedicine* 11 (September). <https://doi.org/10.1186/s13002-015-0052-0>.
- Clifford, James. 1988. *The Predicament of Culture: Twentieth-Century Ethnography, Literature, and Art*. Cambridge, Massachusetts and London, England: Harvard University Press.
- . 1994. 'Diasporas'. *Cultural Anthropology* 9 (3): 302–38.
- Cohn, Simon, and Rebecca Lynch. 2017. 'Diverse Bodies: The Challenge of New Theoretical Approaches to Medical Anthropology'. *Anthropology & Medicine* 24 (2): 131–41.
<https://doi.org/10.1080/13648470.2017.1334395>.
- Conrad, Peter. 1985. 'The Meaning of Medications: Another Look at Compliance'. *Social Science & Medicine* 20 (1): 29–37. [https://doi.org/10.1016/0277-9536\(85\)90308-9](https://doi.org/10.1016/0277-9536(85)90308-9).

- Corbin, Juliet, and Anselm Strauss. 1985. 'Managing Chronic Illness at Home: Three Lines of Work'. *Qualitative Sociology* 8 (3): 224–47. <https://doi.org/10.1007/BF00989485>.
- Counihan, Carole M. 1988. 'Female Identity, Food, and Power in Contemporary Florence'. *Anthropological Quarterly* 61 (2): 51–62. <https://doi.org/10.2307/3317156>.
- . 2013. 'Mexicanas' Food Voice and Differential Consciousness in the San Luis Valley of Colorado'. In *Food and Culture: A Reader*, edited by Carole M. Counihan and Penny Van Esterik, Third. New York, NY: Routledge. <https://doi.org/10.4324/9780203079751-22>.
- Counihan, Carole M., and Steven L. Kaplan. 2005. *Food and Gender: Identity and Power*. New York: Routledge.
- Dabydeen, David, and Brinsley Samaroo, eds. 1996. *Across the Dark Waters: Ethnicity and Indian Identity in the Caribbean*. Warwick University Caribbean Studies. London: Macmillan Caribbean.
- Debysingh, Molly. 1986. 'Cultural Change and Adaptation as Reflected in the Meat-Eating Habits of the Trinidad Indian Population'. *Caribbean Quarterly* 32 (3/4): 66–77.
- DeVault, M.L. 1994. *Feeding the Family: The Social Organization of Caring as Gendered Work*. Chicago: University of Chicago Press.
- Diamond, Irene, and Lee Quinby, eds. 1988. *Feminism and Foucault: Reflections on Resistance*. Boston: Northeastern.
- Dirks, Nicholas B. 2004. 'Colonial and Postcolonial Histories: Comparative Reflections on the Legacies of Empire'. Human Development Occasional Papers (1992-2007) HDOCPA-2004-03. Human Development Report Office (HDRO), United Nations Development Programme (UNDP). <https://econpapers.repec.org/paper/hdrhdocpa/hdocpa-2004-03.htm>.
- Divestment Secretariat. 2003. 'The Restructuring of the Sugar Industry'.
- Doodnath, Alina. 2017. 'CDAP Drugs May Be Substandard'. *Loop TT*, 12 May 2017. <http://www.looptt.com/content/cdap-drugs-may-be-substandard>.
- Douglas, Mary. 1966. *Purity and Danger: An Analysis of Concepts of Pollution and Taboo*. New York: Praeger.
- . 1972. 'Deciphering a Meal'. *Daedalus* 101 (1): 61–81. <https://doi.org/10.2307/20024058>.

- Dressel, Paula L., and Ann Clark. 1990. 'A Critical Look at Family Care'. *Journal of Marriage and Family* 52 (3): 769–82. <https://doi.org/10.2307/352941>.
- Dressler, William W., Kathryn S. Oths, and Clarence C. Gravlee. 2005. 'Race and Ethnicity in Public Health Research: Models to Explain Health Disparities'. *Annual Review of Anthropology* 34 (1): 231–52. <https://doi.org/10.1146/annurev.anthro.34.081804.120505>.
- Eknoyan, Garabed, and Judit Nagy. 2005. 'A History of Diabetes Mellitus or How a Disease of the Kidneys Evolved into a Kidney Disease'. *Advances in Chronic Kidney Disease* 12 (2): 223–29. <https://doi.org/10.1053/j.ackd.2005.01.002>.
- Engelgau, M. M., T. J. Thompson, W. H. Herman, J. P. Boyle, R. E. Aubert, S. J. Kenny, A. Badran, E. S. Sous, and M. A. Ali. 1997. 'Comparison of Fasting and 2-Hour Glucose and HbA1c Levels for Diagnosing Diabetes. Diagnostic Criteria and Performance Revisited'. *Diabetes Care* 20 (5): 785–91. <https://doi-org.ezproxy.library.ubc.ca/10.2337/diacare.20.5.785>.
- Engelhardt, Dietrich v. 2012. *Diabetes Its Medical and Cultural History: Outlines — Texts — Bibliography*. Heidelberg, Germany: Springer Science & Business Media. <https://doi-org.ezproxy.library.ubc.ca/10.1007/978-3-642-48364-6>.
- Estroff, Sue. 1993. 'Identity, Disability, and Schizophrenia: The Problem of Chronicity'. In *Knowledge, Power, and Practice: The Anthropology of Medicine and Everyday Life*, edited by Shirley Lindenbaum and Margaret M. Lock. Comparative Studies of Health Systems and Medical Care. Berkeley: University of California Press.
- Ezenwaka, Chidum E., and Risha Kalloo. 2004. 'Glycaemic Responses after Ingestion of 3 Local Carbohydrate-Based Foods in West Indian Patients with Type-2 Diabetes Mellitus'. *Clinical Nutrition*, Featuring abstracts of the 26th Congress of ESPEN, 23 (4): 631–40. <https://doi.org/10.1016/j.clnu.2003.10.012>.
- Fernandez Trillo, Miguel, and Cilla Benjamin. 2010. 'Socioeconomic Baseline of the Sugar Related Areas in the Framework of the National Sugar Adaptation Strategy: Trinidad and Tobago'. Final Report Letter of Contract N° 2009/209666-Version 1. European Union.
- Ferreira, Mariana K. Leal, and Gretchen Chesley Lang, eds. 2006. *Indigenous Peoples and Diabetes: Community Empowerment and Wellness*. Carolina Academic Press Medical Anthropology Series. Durham, N.C: Carolina Academic Press.

- Ferzacca, Steve. 2000. “‘Actually, I Don’t Feel That Bad’: Managing Diabetes and the Clinical Encounter”. *Medical Anthropology Quarterly* 14: 28–50.
- . 2012. ‘Diabetes and Culture’. *Annual Review of Anthropology* 41 (1): 411–26.
<https://doi.org/10.1146/annurev-anthro-081309-145806>.
- Finch, C. F., P. Z. Zimmet, and K. G. M. M. Alberti. 1990. ‘Determining Diabetes Prevalence: A Rational Basis for the Use of Fasting Plasma Glucose Concentrations?’ *Diabetic Medicine* 7 (7): 603–10. <https://doi.org/10.1111/j.1464-5491.1990.tb01457.x>.
- Foster, George M. 1987. ‘On the Origin of Humoral Medicine in Latin America’. *Medical Anthropology Quarterly* 1 (4): 355–93.
- . 1988. ‘The Validating Role of Humoral Theory in Traditional Spanish-American Therapeutics’. *American Ethnologist* 15 (1): 120–35.
- Foucault, Michel. 1973. *The Birth of the Clinic*. Translated by A. M. Sheridan Smith. New York: Pantheon Books.
- . 2000. *Power: Essential Works of Foucault, 1954-1984*. Edited by James D. Faubion. Translated by Robert Hurley. Essential Works of Foucault, 1954-1984, v. 3. New York: New Press, : Distributed by W.W. Norton.
- . 2002. *Archaeology of Knowledge*. Translated by A. M. Sheridan Smith. Routledge Classics. London: Routledge.
- Freilich, Morris. 1960. ‘Cultural Diversity among Trinidadian Peasants.’ Ann Arbor, Michigan: University Microfilms.
- Frenk, Julio, José Luis Bobadilla, Claudio Stern, Tomas Frejka, and Rafael Lozano. 1991. ‘Elements for a Theory of the Health Transition’. *Health Transition Review: The Cultural, Social, and Behavioural Determinants of Health* 1 (1): 21–38.
- Gafoor, Gladys, W. Hosein, Y. Pilgrim, G. Wilson, and G. Frankson. 2007. ‘Report of the Commission of Enquiry into the Operation and Delivery of the Public Health Care Services in Trinidad and Tobago, Vol. 2’. Ministry of Health. Report of the Commission of Enquiry into the Operation and Delivery of the Public Health Care Services in Trinidad and Tobago. Government of the Republic of Trinidad and Tobago, Ministry of Health.
- Gardner, Katy. 2002. *Age, Narrative and Migration: The Life Course and Life Histories of*

- Bengali Elders in London*. Oxford ; New York: Berg.
- Garro, Linda C. 1995. 'Individual or Societal Responsibility? Explanations of Diabetes in an Anishinaabe (Ojibway) Community'. *Social Science & Medicine* 40: 37–46.
[https://doi.org/10.1016/0277-9536\(94\)00125-D](https://doi.org/10.1016/0277-9536(94)00125-D).
- . 2000a. 'Cultural Meaning, Explanations of Illness, and the Development of Comparative Frameworks'. *Ethnology* 39: 305–34. <https://doi.org/10.2307/3774049>.
- . 2000b. 'Remembering What One Knows and the Construction of the Past: A Comparison of Cultural Consensus Theory and Cultural Schema Theory'. *Ethos* 28: 275–319.
- Gaugler, Joseph E. 2010. 'The Longitudinal Ramifications of Stroke Caregiving: A Systematic Review.' *Rehabilitation Psychology* 55 (2): 108–25. <https://doi.org/10.1037/a0019023>.
- Ghouralal, Darlisa. 2017. 'Minister: CDAP Drugs Safe'. *Loop TT*, May 2017.
- Gillespie, J. E. O'N. 1951. 'Diabetes Mellitus in Trinidad, British West Indies: The Relationship of Symptoms to Frequency of Insulin Injections'. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 44 (5): 545–50. [https://doi.org/10.1016/0035-9203\(51\)90034-X](https://doi.org/10.1016/0035-9203(51)90034-X).
- Global Burden of Disease Collaborative Network. 2017. 'Global Burden of Disease Study 2016 (GBD 2016)'. Institute for Health Metrics and Evaluation.
- Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. Spectrum Book. Englewood Cliffs, N.J.: Prentice-Hall.
- Goldberg, David Theo, and Ato Quayson. 2002. *Relocating Postcolonialism*. Oxford: Blackwell Publishers.
- Good, Byron J. 1994. *Medicine, Rationality and Experience: An Anthropological Perspective*. Cambridge ; New York: Cambridge University Press.
- Good, Byron J., and Mary-Jo Delvecchio Good. 1982. 'Toward a Meaning-Centered Analysis of Popular Illness Categories: "Fright Illness" and "Heart Distress" in Iran'. In *Cultural Conceptions of Mental Health and Therapy*, edited by Anthony J. Marsella and Geoffrey M. White, 141–66. Culture, Illness, and Healing. Dordrecht: Springer Netherlands.
https://doi.org/10.1007/978-94-010-9220-3_5.
- Good, Mary-Jo DelVecchio, Sandra T. Hyde, Sarah Pinto, and Byron J. Good. 2008. *Post-*

- Colonial Disorders*. Berkeley: University of California Press.
- Gravlee, Clarence C., and Elizabeth Sweet. 2008. 'Race, Ethnicity and Racism in Medical Anthropology, 1977-2002'. *Medical Anthropology Quarterly* 22: 27–51.
- Guénette, L., J. Moisan, M. -C. Breton, C. Sirois, and J. -P. Grégoire. 2013. 'Difficulty Adhering to Antidiabetic Treatment: Factors Associated with Persistence and Compliance'. *Diabetes & Metabolism* 39 (3): 250–57. <https://doi.org/10.1016/j.diabet.2012.12.005>.
- Gulliford, M. C., C. V. Alert, D. Mahabir, S. M. Ariyanayagam-Baksh, H. S. Fraser, and D. I. Picou. 1995. 'Diabetes Care in Middle-Income Countries: A Caribbean Case Study'. *Diabetic Medicine* 13 (6): 574–81. [https://doi.org/10.1002/\(SICI\)1096-9136\(199606\)13:6<574::AID-DIA113>3.0.CO;2-C](https://doi.org/10.1002/(SICI)1096-9136(199606)13:6<574::AID-DIA113>3.0.CO;2-C).
- Gulliford, M. C., S. M. Ariyanayagam-Baksh, L. Bickram, D. Picou, and D. Mahabir. 1995. 'Counting the Cost of Diabetic Hospital Admissions from a Multi-Ethnic Population in Trinidad'. *Diabetic Medicine* 12 (12): 1077–85. <https://doi.org/10.1111/j.1464-5491.1995.tb00424.x>.
- Gulliford, M C, S M Ariyanayagam-Baksh, L Bickram, D Picou, and D Mahabir. 1997. 'Social Environment, Morbidity and Use of Health Care among People with Diabetes Mellitus in Trinidad'. *International Journal of Epidemiology* 26 (3): 620–27. <https://doi-org.ezproxy.library.ubc.ca/10.1093/ije/26.3.620>.
- Hacking, Ian. 2005. 'Why Race Still Matters'. *Daedalus* 134 (1): 102–16.
- Hannerz, Ulf. 1996. *Transnational Connections: Culture, People, Places*. London; New York: Routledge.
- Haraksingh, Kusha. 1988. 'Sugar, Labour and Livelihood in Trinidad, 1940-1970'. *Social and Economic Studies* 37 (1–2): 271–91.
- Harding, Sandra. 1993. *The 'Racial' Economy of Science: Toward a Democratic Future*. Indiana University Press. <https://muse-jhu-edu.ezproxy.library.ubc.ca/book/12810>.
- . , ed. 2011. *The Postcolonial Science and Technology Studies Reader*. Durham and London: Duke University Press. www.dukeupress.edu/the-postcolonial-science-and-technology-studies-reader.
- Harnarayan, Patrick, Shamir O. Cawich, Shariful Islam, Shiva Ramsewak, and Vijay Naraynsingh. 2014. 'Self-Directed Treatment for Lower Limb Wounds in Persons with

- Diabetes: A Short Report'. *Patient Preference and Adherence* 8: 1173–77.
<https://doi.org/10.2147/PPA.S68680>.
- Harris, Marvin. 1966. 'The Cultural Ecology of India's Sacred Cattle'. *Current Anthropology* 7: 51–66.
- Hassanali, Shaliza. 2017. 'Public Doctors in Private Practice'. *Trinidad and Tobago Guardian*, 31 May 2017. <http://ftp.guardian.co.tt/news/2017-05-30/public-doctors-private-practice>.
- Haynes, Brian R., Wayne D. Taylor, and David L. Sackett, eds. 1979. *Compliance in Health Care*. Thorofare, N.J.: The Johns Hopkins University Press.
- Hegele, Robert A., Matthew R. Ban, Christine V. Carrington, and Dan Ramdath. 2001. 'Allele Frequencies for Candidate Genes in Atherosclerosis and Diabetes among Trinidadian Neonates'. *Human Biology* 73 (4): 525–31.
- Henry, Carol, Dan Ramdath, Judy White, and Sharon Mangroo. 2013. 'Engaging Youth In Creating A Healthy School Environment: A Photovoice Strategy'. *Journal of International Education Research; Littleton* 9 (1): 97.
- Hezekiah, Jocelyn RN. 1990. 'Postcolonial Nursing Education in Trinidad and Tobago'. *Advances in Nursing Science* 12 (2): 28–36.
- Higman, B. W. 1978. 'African and Creole Slave Family Patterns in Trinidad'. *Journal of Family History; Minneapolis, Minn.* 3 (2): 163–180.
- Hintzen, Percy C. 1997. 'Reproducing Domination Identity and Legitimacy Constructs in the West Indies'. *Social Identities* 3: 47–76. <https://doi.org/10.1080/13504639752168>.
- Hirst, M. 2002. 'Transitions to Informal Care in Great Britain during the 1990s'. *Journal of Epidemiology and Community Health (1979-)* 56 (8): 579–87.
- Holt, Richard I. G., Mary de Groot, and Sherita Hill Golden. 2014. 'Diabetes and Depression'. *Current Diabetes Reports* 14 (6): 491. <https://doi.org/10.1007/s11892-014-0491-3>.
- Homer, Louis. 1999. 'Son of an Indentured Labourer Recalls How Gandhi Village Got Its Name'. *Trinidad and Tobago Express*, 30 May 1999, Sunday Express edition, sec. Section 2, page 3.
- Horowitz, Michael M. 1960. 'A Typology of Rural Community Forms in the Caribbean'. *Anthropological Quarterly* 33 (4): 177–87. <https://doi.org/10.2307/3316554>.
- Horst, Heather, and Daniel Miller. 2005. 'From Kinship to Link-up: Cell Phones and Social

- Networking in Jamaica'. *Current Anthropology* 46 (5): 755–78.
<https://doi.org/10.1086/432650>.
- Hunt, Linda M., Brigitte Jordan, Susan Irwin, and C. H. Browner. 1989. 'Compliance and the Patient's Perspective: Controlling Symptoms in Everyday Life'. *Culture, Medicine and Psychiatry* 13 (3): 315–34. <https://doi.org/10.1007/BF00054341>.
- Hunt, Linda M., and Mary S. Megyesi. 2008. 'The Ambiguous Meanings of the Racial/Ethnic Categories Routinely Used in Human Genetics Research'. *Social Science & Medicine* (1982) 66 (2): 349–61. <https://doi.org/10.1016/j.socscimed.2007.08.034>.
- Hunt, Linda M., M.A. Valenzuela, and J.A. Pugh. 1998. 'Porque Me Tocó a Mi? Mexican American Diabetes Patients' Causal Stories and Their Relationship to Treatment Behaviors'. *Social Science & Medicine* 46: 959–69.
- IDF. 2000. 'IDF Diabetes Atlas 2000'. Brussels, Belgium: International Diabetes Federation.
- . 2003. 'IDF Diabetes Atlas: Second Edition'. Brussels, Belgium: International Diabetes Federation.
- . 2006. 'IDF Diabetes Atlas: Third Edition'. Brussels, Belgium: International Diabetes Federation.
- . 2009. 'IDF Diabetes Atlas: Fourth Edition'. Brussels, Belgium: International Diabetes Federation.
- . 2011. 'IDF Diabetes Atlas: Fifth Edition'. Brussels, Belgium: International Diabetes Federation.
- . 2013. 'IDF Diabetes Atlas: Sixth Edition'. Brussels, Belgium: International Diabetes Federation.
- . 2015. 'IDF Diabetes Atlas: Seventh Edition'. Brussels, Belgium: International Diabetes Federation.
- . 2017. 'IDF Diabetes Atlas: Eighth Edition 2017'. Brussels, Belgium: International Diabetes Federation.
- Ignatiev, Noel. 1995. *How the Irish Became White*. New York: Routledge.
- Illich, I. 1976. *Medical Nemesis: The Expropriation of Health*. New York: Bantam Books.
- Islam, Shariful, Patrick Harnarayan, Shamir O. Cawich, Steve Budhooram, Vinoo Bheem, Vijai Mahabir, Shiva Ramsewak, Imran Aziz, and Vijay Naraynsingh. 2013. 'Epidemiology of

- Diabetic Foot Infections in an Eastern Caribbean Population: A Prospective Study'. *The Permanente Journal* 17 (2): 37–40. <https://doi.org/10.7812/TPP/12-126>.
- Jacob, Debbie. 2011. 'Which Is Healthier - Doubles or Pie?' *Trinidad and Tobago Guardian*, 6 February 2011.
<http://www.guardian.co.tt/neo/NeoProxy.dll?app=NeoDirect&com=6/2/459395/979f65abaa>.
- Jayaram, N. 2006. 'The Metamorphosis of Caste among Trinidad Hindus'. *Contributions to Indian Sociology* 40 (2): 143–73. <https://doi.org/10.1177/006996670604000201>.
- Jessup, Nnette M., Tamilyn Bakas, Susan M. McLennon, and Michael T. Weaver. 2015. 'Are There Gender, Racial or Relationship Differences in Caregiver Task Difficulty, Depressive Symptoms and Life Changes among Stroke Family Caregivers?' *Brain Injury* 29 (1): 17–24. <https://doi.org/10.3109/02699052.2014.947631>.
- Jezewski, Mary Ann, and Jane Poss. 2002. 'Mexican Americans' Explanatory Model of Type 2 Diabetes'. *Western Journal of Nursing Research* 24 (8): 840.
<https://doi.org/10.1177/019394502237695>.
- Khan, Aisha. 1994. "'Juthaa" in Trinidad: Food, Pollution, and Hierarchy in a Caribbean Diaspora Community'. *American Ethnologist* 21 (2): 245–69. <https://doi-org.ezproxy.library.ubc.ca/10.1525/ae.1994.21.2.02a00020>.
- . 2001. 'Journey to the Center of the Earth: The Caribbean as Master Symbol'. *Cultural Anthropology* 16 (3): 271–302.
- . 2004. *Callaloo Nation: Metaphors of Race and Religious Identity among South Asians in Trinidad*. Durham, N.C.: Duke University Press. www.dukeupress.edu/callaloo-nation.
- Klass, Morton. 1961. *East Indians in Trinidad: A Study of Cultural Persistence*. New York: Columbia University Press.
- Kleinman, Arthur. 1978. 'Concepts and a Model for the Comparison of Medical Systems as Cultural Systems'. *Social Science & Medicine. Part B: Medical Anthropology* 12: 85–93.
[https://doi.org/10.1016/0160-7987\(78\)90014-5](https://doi.org/10.1016/0160-7987(78)90014-5).
- . 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books.
- Kowlessar, Geisha. 2011. 'Malpractice Lawsuits on the Increase'. *Trinidad and Tobago*

- Guardian*, 27 March 2011. <http://www.guardian.co.tt/article-6.2.462668.c95f76b244>.
- Kumar, Parveen, and Michael Clark. 2016. *Kumar and Clark's Clinical Medicine - 9th Edition*. Elsevier. <https://www.elsevier.com/books/kumar-and-clarks-clinical-medicine/kumar/978-0-7020-6601-6>.
- La Guerre, John. 1989. 'Sociological Impact of Changes at Caroni (1975) Ltd.' In *Future of the Caroni (1975) Ltd: A Position Document*, edited by Sanatan Dharma Maha Sabha, 35–40. Caroni, Trinidad and Tobago: Sanatan Dharma Maha Sabha.
- Lakhtakia, Ritu. 2013. 'The History of Diabetes Mellitus'. *Sultan Qaboos University Medical Journal* 13 (3): 368–70.
- Lans, Cheryl. 2006. 'Ethnomedicines Used in Trinidad and Tobago for Urinary Problems and Diabetes Mellitus'. *Journal of Ethnobiology and Ethnomedicine* 2 (1): 45. <https://doi.org/10.1186/1746-4269-2-45>.
- . 2007. 'Ethnomedicines Used in Trinidad and Tobago for Reproductive Problems'. *Journal of Ethnobiology and Ethnomedicine* 3 (1): 13. <https://doi.org/10.1186/1746-4269-3-13>.
- Latour, B., and S. Woolgar. 1986. *Laboratory Life: The Construction of Scientific Facts*. Princeton, NJ: Princeton University Press.
- Lebovitz, Harold E. 1999. 'Type 2 Diabetes: An Overview'. *Clinical Chemistry* 45 (8): 1339–45.
- Lewis, Gordon K. 1967. *The Growth of the Modern West Indies*. Ian Randle Publishers.
- Lindenbaum, Shirley, and Margaret M. Lock, eds. 1993. *Knowledge, Power, and Practice: The Anthropology of Medicine and Everyday Life*. Comparative Studies of Health Systems and Medical Care. Berkeley: University of California Press.
- Link, Bruce G., and Jo C. Phelan. 2001. 'Conceptualizing Stigma'. *Annual Review of Sociology* 27 (1): 363–85. <https://doi.org/10.1146/annurev.soc.27.1.363>.
- Littlewood, R., ed. 2007. *On Knowing and Not Knowing in the Anthropology of Medicine*. Walnut Creek, California: Left Coast Press. <http://discovery.ucl.ac.uk/43015/>.
- Littlewood, Roland. 1988. 'From Vice to Madness: The Semantics of Naturalistic and Personalistic Understandings in Trinidadian Local Medicine'. *Social Science & Medicine* 27 (2): 129–48. [https://doi.org/10.1016/0277-9536\(88\)90322-X](https://doi.org/10.1016/0277-9536(88)90322-X).
- Lock, Margaret. 1993. 'Cultivating the Body: Anthropology and Epistemologies of Bodily

- Practice and Knowledge'. *Annual Review of Anthropology* 22 (January): 133–55.
- . 2001. 'The Tempering of Medical Anthropology: Troubling Natural Categories'. *Medical Anthropology Quarterly* 15 (4): 478–492.
<https://doi.org/10.1525/maq.2001.15.4.478>.
- Lock, Margaret M. 1993. *Encounters with Aging*. Berkeley, California: University of California Press.
- Lock, Margaret M., and Vinh-Kim Nguyen. 2010. *An Anthropology of Biomedicine*. Malden, M.A.: Wiley-Blackwell.
- Lock, Margaret, and Nancy Scheper Hughes. 1996. 'A Critical Interpretive Approach in Medical Anthropology: Rituals and Routines of Discipline and Dissent'. In *Handbook of Medical Anthropology: Contemporary Theory and Method*, edited by Carlyn Fishel Sargent and Thomas Malcom Johnson. Westport, Conn.: Greenwood Press.
- Logan, Michael H., and Warren T. Morrill. 1979. 'Humoral Medicine and Informant Variability : An Analysis of Acculturation and Cognitive Change among Guatemalan Villagers'. *Anthropos: International Review of Ethnology and Linguistics* 74 (5/6): 785–802.
- Lutfey, Karen E., and William J. Wishner. 1999. 'Beyond "Compliance" Is "Adherence": Improving the Prospect of Diabetes Care'. *Diabetes Care; Alexandria* 22 (4): 635–39.
- Lynch, Rebecca. 2016. 'The Devil Is Disorder: Bodies, Spirits and Misfortune in a Trinidadian Village'. Doctoral, UCL (University College London).
<http://discovery.ucl.ac.uk/1496020/>.
- MacDonald, Scott B. 1986. *Trinidad and Tobago: Democracy and Development in the Caribbean*. ABC-CLIO.
- Maharaj, Sandeep, Kreshma Roopnarine, Vashish Maharaj, Sushain Maharaj, Eenest Sankar, and Meera Singh. 2011. 'Impact of Chronic Disease Assistance Program on the Retail Pharmacy Sector: A Retrospective Study'. *Journal of Pharmacology and Pharmacotherapeutics* 2 (4): 244.
- Mahase, Radica. 2008. "'Plenty a Dem Run Away" – Resistance by Indian Indentured Labourers in Trinidad, 1870–1920'. *Labor History* 49 (4): 465–80.
<https://doi.org/10.1080/00236560802376946>.
- Mandelbaum, David. 1970. *Society in India*. Berkeley: University of California Press.

- <http://resolve.library.ubc.ca/cgi-bin/catsearch?bid=249086>.
- Manderson, Lenore, Marcia Inhorn, Carolyn Smith-Morris, and Arthur Kleinman. 2010. *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*. Edited by Lenore Manderson and Carolyn Smith-Morris. New Brunswick: Rutgers University Press.
<https://muse-jhu-edu.ezproxy.library.ubc.ca/book/14265/>.
- Mattingly, Cheryl. 1994. 'The Concept of Therapeutic "Emplotment"'. *Social Science & Medicine* 38 (6): 811–22. [https://doi.org/10.1016/0277-9536\(94\)90153-8](https://doi.org/10.1016/0277-9536(94)90153-8).
- . 1998a. *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Vol. 7. Cambridge, UK: Cambridge University Press.
- . 1998b. 'In Search of the Good: Narrative Reasoning in Clinical Practice'. *Medical Anthropology Quarterly*, New Series, 12 (3): 273–97.
- . 2010. *The Paradox of Hope: Journeys through a Clinical Borderland*. Berkeley: University of California Press.
- Mattingly, Cheryl, and Linda C. Garro. 2000. *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California Press.
- Mauss, Marcel. 1990. *The Gift: The Form and Reason for Exchange in Archaic Societies*. Translated by W.D. Hall. New York: Norton.
- May, Carl, Victor M. Montori, and Frances S. Mair. 2009. 'We Need Minimally Disruptive Medicine'. *BMJ* 339 (August): b2803. <https://doi.org/10.1136/bmj.b2803>.
- McCane, D. R., R. L. Hanson, M. A. Charles, L. T. H. Jacobsson, D. Dj Pettitt, P. H. Bennett, and W. C. Knowler. 1994. 'Comparison of Tests for Glycated Haemoglobin and Fasting and Two Hour Plasma Glucose Concentrations as Diagnostic Methods for Diabetes'. *BMJ* 308 (6940): 1323–28. <https://doi.org/10.1136/bmj.308.6940.1323>.
- McCollin, Debbie. 2010. 'The History of Health and Healthcare in Trinidad and Tobago 1938-1962'. Doctoral, St. Augustine, Trinidad: University of the West Indies.
- McGarvey, Stephen T. 1994. 'The Thrifty Gene Concept and Adiposity Studies in Biological Anthropology'. *The Journal of the Polynesian Society* 103 (1): 29–42.
- Mendenhall, Emily, Alicia Fernandez, Nancy Adler, and Elizabeth A. Jacobs. 2012. 'Susto, Coraje, and Abuse: Depression and Beliefs About Diabetes'. *Culture, Medicine and Psychiatry; New York* 36 (3): 480–92.

- <http://dx.doi.org.ezproxy.library.ubc.ca/10.1007/s11013-012-9267-x>.
- Mendenhall, Emily, Rebecca A. Seligman, Alicia Fernandez, and Elizabeth A. Jacobs. 2010. 'Speaking through Diabetes: Rethinking the Significance of Lay Discourses on Diabetes'. *Medical Anthropology Quarterly* 24 (2): 220–39.
- Mendenhall, Emily, and Lesley Jo Weaver. 2014. 'Reorienting Women's Health in Low- and Middle-Income Countries: The Case of Depression and Type 2 Diabetes'. *Global Health Action* 7 (1). <https://doi.org/10.3402/gha.v7.22803>.
- Mercado-Martinez, Francisco J., and Igor Martin Ramos-Herrera. 2002. 'Diabetes: The Layperson's Theories of Causality'. *Qualitative Health Research* 12 (6): 792.
- Miller, Daniel. 1997. *Capitalism: An Ethnographic Approach*. Oxford: Berg Publishers.
- . 2005. *Acknowledging Consumption*. Edited by Daniel Miller. Routledge.
- Miller, G. J., G. L. A. Beckles, G. H. Maude, and D. C. Carson. 1989. 'Ethnicity and Other Characteristics Predictive of Coronary Heart Disease in a Developing Community: Principal Results of the St James Survey, Trinidad'. *International Journal of Epidemiology* 18 (4): 808–17. <https://doi.org/10.1093/ije/18.4.808>.
- Miller, G. J., G. H. Maude, and G. L. A. Beckles. 1996. 'Incidence of Hypertension and Non-Insulin Dependent Diabetes Mellitus and Associated Risk Factors in a Rapidly Developing Caribbean Community: The St. James Survey, Trinidad'. *Journal of Epidemiology and Community Health* (1979-) 50 (5): 497–504.
- Ministry of Health. 2016. 'Ministry of Health Statistical Report 2009-2011'. Annual Statistical Report. Government of the Republic of Trinidad and Tobago.
- Mintz, Sidney W. 1986. *Sweetness and Power: The Place of Sugar in Modern History*. New York: Penguin Books.
- . 1996. 'Enduring Substances, Trying Theories: The Caribbean Region as Oikoumene'. *The Journal of the Royal Anthropological Institute* 2 (2): 289–311.
- Misra, Maria. 2003. 'Lessons of Empire: Britain and India'. *SAIS Review* 23 (2): 133–53. <https://doi.org/10.1353/sais.2003.0047>.
- Mitchell, Donald. 2005. 'Sugar in the Caribbean: Adjusting to Eroding Preferences'. World Bank Policy Research Working Paper 3802 WPS3802. Washington, DC: The World Bank.
- Mol, Annemare. 2000. 'What Diagnostic Devices Do: The Case of Blood Sugar Measurement'.

- Theoretical Medicine and Bioethics* 21 (1): 9–22.
<https://doi.org/10.1023/A:1009999119586>.
- Mol, Annemarie. 2008. *The Logic of Care : Health and the Problem of Patient Choice*. New York: Routledge. <https://doi.org/10.4324/9780203927076>.
- Montoya, Michael J. 2011. *Making the Mexican Diabetic: Race, Science, and the Genetics of Inequality*. Berkeley: University of California Press.
<https://www.ucpress.edu/book/9780520267312/making-the-mexican-diabetic>.
- Moreira, Telma, Daphne C. Hernandez, Claudia W. Scott, Rosenda Murillo, Elizabeth M. Vaughan, and Craig A. Johnston. 2017. ‘Susto, Coraje, y Fatalismo: Cultural-Bound Beliefs and the Treatment of Diabetes Among Socioeconomically Disadvantaged Hispanics’. *American Journal of Lifestyle Medicine* 12 (1): 30–33.
<https://doi.org/10.1177/1559827617736506>.
- Morrock, Richard. 1973. ‘Heritage of Strife: The Effects of Colonialist “Divide and Rule” Strategy upon the Colonized Peoples’. *Science & Society* 37 (2): 129–51.
- Munasinghe, Viranjini. 1997. ‘Culture Creators and Culture Bearers: The Interface Between Race and Ethnicity in Trinidad’. *Transforming Anthropology* 6 (1-2): 72–86.
<https://doi.org/10.1525/tran.1997.6.1-2.72>.
- . 2001. *Callaloo or Tossed Salad? East Indians and the Cultural Politics of Identity in Trinidad*. Ithaca, N.Y: Cornell University Press.
- Nayak, Shivananda B, Valendrea Rahming, Yudestri Raghunanan, Chandani Raghoonath, Adriel Rahman, Dillon Rajh, Sherry Rambadan, and Nandini Ramdass. 2016. ‘Prevalence of Diabetes, Obesity and Dyslipidaemia in Persons within High and Low Income Groups Living in North and South Trinidad’. *Journal of Clinical and Diagnostic Research : JCDR* 10 (5): IC08-IC13. <https://doi.org/10.7860/JCDR/2016/18154.7875>.
- Nevadomsky, J. 1980. ‘Abandoning the Retentionist Model: Family and Marriage Change among the East Indians in Rural Trinidad’. *International Journal of Sociology of the Family* 10 (December): 181–98.
- Nevadomsky, Joseph. 1982. ‘Changing Conceptions of Family Regulation among the Hindu East Indians in Rural Trinidad’. *Anthropological Quarterly* 55 (4): 189–98.
<https://doi.org/10.2307/3317148>.

- . 1983. 'Economic Organisation, Social Mobility and Changing Social Status in Rural Trinidad'. *Ethnology* 22 (1): 63–79.
- Niehoff, Arthur, and Juanita Niehoff. 1960. *East Indians in the West Indies*. Milwaukee Public Museum Publications in Anthropology, no. 6. Milwaukee.
- Novak, Marta, Istvan Mucsi, Connie M. Rhee, Elani Streja, Jun L. Lu, Kamyar Kalantar-Zadeh, Miklos Z. Molnar, and Csaba P. Kovesdy. 2016. 'Increased Risk of Incident Chronic Kidney Disease, Cardiovascular Disease, and Mortality in Patients With Diabetes With Comorbid Depression'. *Diabetes Care* 39 (11): 1940–47. <https://doi.org/10.2337/dc16-0048>.
- Oldroyd, John, M. Banerjee, A. Heald, and K. Cruickshank. 2005. 'Diabetes and Ethnic Minorities'. *Postgraduate Medical Journal* 81 (958): 486–490.
- Packard, Randall M. 2016. *A History of Global Health: Interventions into the Lives of Other Peoples*. Baltimore: Johns Hopkins University Press.
<https://jhupbooks.press.jhu.edu/content/history-global-health>.
- Pal, Amar Nath. 1996. 'The Sacred Cow in India : A Reappraisal'. *Indian Anthropologist* 26 (2): 53–62.
- Palmer, Donald W., and Carlisle A. Pemberton. 2007. 'An Estimation of the Efficient Size of Sugarcane Enterprises for Farmers in Trinidad'. *Farm and Business - The Journal of the Caribbean Agro-Economic Society* Volume 07 (Number 1).
<https://ideas.repec.org/a/ags/fabtho/36807.html>.
- Palmer, Steven. 2006. "'The demon that turned into worms': the translation of public health in the British Caribbean, 1914-1920". *História, Ciências, Saúde--Manguinhos* 13 (3): 571–89.
- . 2010. *Launching Global Health: The Caribbean Odyssey of the Rockefeller Foundation*. Conversations In Medicine And Society. Ann Arbor, Mich.: University of Michigan Press.
- Palmié, Stephan. 2006. 'Creolization and Its Discontents'. *Annual Review of Anthropology* 35 (September): 433–56.
- Pan American Health Organization. 2012. 'Health in the Americas, 2012 Edition Country Volume: Trinidad and Tobago.' United Nations Department of Economic and Social

- Affairs, Population Division.
- Pels, Peter. 1997. 'The Anthropology of Colonialism: Culture, History, and the Emergence of Western Governmentality'. *Annual Review of Anthropology* 26: 163–83.
- Perry, John. 1969. 'A History of the East Indian Indentured Plantation Worker in Trinidad'. Louisiana, USA: Louisiana State University and Agricultural & Mechanical College. https://digitalcommons.lsu.edu/gradschool_disstheses/1612.
- Phillips, Daphne. 1994. 'Decentralization and Marginalization in Health Care in Trinidad and Tobago'. In *19th Annual Conference of the Caribbean Studies Association*. Merida, Yucatan, Mexico.
- Pickering, Andrew. 1995. *The Mangle of Practice: Time, Agency, and Science*. Chicago: University of Chicago Press. <https://www.press.uchicago.edu/ucp/books/book/chicago/M/bo3642386.html>.
- Pinto Pereira, Lexley M., Avery Hinds, Issa Ali, Ravita Gooding, Michelle Ragbir, Kavita Samaroo, and Shivananda B. Nayak. 2009. 'Do Current Standards of Primary Care of Diabetes Meet with Guideline Recommendations in Trinidad, West Indies?' *Primary Care Diabetes* 3 (2): 91–96. <https://doi.org/10.1016/j.pcd.2009.03.003>.
- Poon-King, T., M.V. Henry, and F. Rampersad. 1968. 'Prevalence and Natural History of Diabetes in Trinidad'. *The Lancet* 291 (7535): 155–60. [https://doi.org/10.1016/S0140-6736\(68\)92559-2](https://doi.org/10.1016/S0140-6736(68)92559-2).
- Poss, Jane, and Mary Ann Jezewski. 2002. 'The Role and Meaning of Susto in Mexican Americans' Explanatory Model of Type 2 Diabetes'. *Medical Anthropology Quarterly* 16 (3): 360–77.
- Price, Richard. 2001. 'The Miracle of Creolization: A Retrospective'. *NWIG: New West Indian Guide / Nieuwe West-Indische Gids* 75 (1/2): 35–64.
- Prorok, Carolyn. 1987. 'Hindu Temples in Trinidad: A Cultural Geography of Religious Structures and Ethnic Identity.' Louisiana State University. https://digitalcommons.lsu.edu/gradschool_disstheses/72.
- . 1991. 'Evolution of the Hindu Temple in Trinidad'. *Caribbean Geography* 3: 73–93.
- . 2015a. 'The Diasporic Hindu Home Temple'. In *The Changing World Religion Map*, edited by S.D. Brunn. New York: Springer.

- . 2015b. 'The Materiality of Diasporic Identity: Hindu Temples in Trinidad and Malaysia'. In *Indian Diaspora: Socio-Cultural and Religious Worlds*, edited by Pratap Kumar, 252–79. Leiden, The Netherlands: Brill.
<https://brill.com/view/book/edcoll/9789004288065/B9789004288065-s014.xml>.
- Pyke, D. A., and G. H. Wattley. 1962. 'Diabetes in Trinidad'. *The West Indian Medical Journal* 11 (March): 22–26.
- Ramdath, D Dan, Debbie G Hilaire, Kimlyn D Cheong, and Sangita Sharma. 2011. 'Dietary Intake among Adults in Trinidad and Tobago and Development of a Quantitative Food Frequency Questionnaire to Highlight Nutritional Needs for Lifestyle Interventions'. *International Journal Of Food Sciences And Nutrition* 62 (6): 636–41.
<https://doi.org/10.3109/09637486.2011.572545>.
- Ramnarine, Tina Karina. 1996. "'Indian" Music in the Diaspora: Case Studies of "Chutney" in Trinidad and in London'. *British Journal of Ethnomusicology* 5: 133–53.
- Ramsaran, Dave. 2013. 'The "Myth" of Development: The Case of Trinidad and Tobago'. In *Caribbean Sovereignty, Development and Democracy in an Age of Globalization*, edited by Linden Lewis. Routledge Advances in International Relations and Global Politics. New York, NY: Routledge.
- Reddock, Rhoda. 1999. 'Jahaji Bhai: The Emergence of a Dougla Poetics in Trinidad and Tobago'. *Identities* 5 (4): 569–601. <https://doi.org/10.1080/1070289X.1999.9962630>.
- . 2014. 'Radical Caribbean Social Thought: Race, Class Identity and the Postcolonial Nation'. *Current Sociology* 62 (4): 493–511. <https://doi.org/10.1177/0011392114524507>.
- Richardson, Bonham C. 1975. 'Livelihood in Rural Trinidad in 1900'. *Annals of the Association of American Geographers* 65 (2): 240–51.
- Risch, Neil, Esteban Burchard, Elad Ziv, and Hua Tang. 2002. 'Categorization of Humans in Biomedical Research: Genes, Race and Disease'. *Genome Biology* 3 (7): comment2007.1. <https://doi.org/10.1186/gb-2002-3-7-comment2007>.
- Roberts, Elizabeth F. S. 2015. 'Food Is Love: And so, What Then?' *BioSocieties; London* 10 (2): 247–52. <http://dx.doi.org.ezproxy.library.ubc.ca/10.1057/biosoc.2015.18>.
- Rock, Melanie. 2005. 'Classifying Diabetes; or, Commensurating Bodies of Unequal Experience'. *Public Culture* 17 (3): 467–86. <https://doi.org/10.1215/08992363-17-3-467>.

- Roopnarinesingh, Nira, Nancyellen Brennan, Claude Khan, Paul W. Ladenson, Felicia Hill-Briggs, and Rita Rastogi Kalyani. 2015. 'Barriers to Optimal Diabetes Care in Trinidad and Tobago: A Health Care Professionals' Perspective'. *BMC Health Services Research* 15 (1): 396. <https://doi.org/10.1186/s12913-015-1066-y>.
- Root, Michael. 2001. 'The Problem of Race in Medicine'. *Philosophy of the Social Sciences* 31 (1): 20–39. <https://doi.org/10.1177/004839310103100102>.
- Rosenberger, Nancy. 1994. 'Encounters with Aging: Mythologies of Menopause in Japan and North America. By Margaret Lock. Berkeley: University of California Press, 1993. Xliv, 439 Pp'. *The Journal of Asian Studies* 53 (4): 1271–72. <https://doi.org/10.2307/2059282>.
- Roy, Tapash, and Cathy E. Lloyd. 2012. 'Epidemiology of Depression and Diabetes: A Systematic Review'. *Journal of Affective Disorders, Dialogue on Diabetes and Depression: Dealing with the double burden of co-morbidity. A selection of papers produced by the Dialogue on Diabetes and Depression*, 142 (October): S8–21. [https://doi.org/10.1016/S0165-0327\(12\)70004-6](https://doi.org/10.1016/S0165-0327(12)70004-6).
- Sav, Adem, Michelle A. King, Jennifer A. Whitty, Elizabeth Kendall, Sara S. McMillan, Fiona Kelly, Beth Hunter, and Amanda J. Wheeler. 2013. 'Burden of Treatment for Chronic Illness: A Concept Analysis and Review of the Literature'. *Health Expectations* 18 (3): 312–24. <https://doi.org/10.1111/hex.12046>.
- Sav, Adem, Sara S. McMillan, Fiona Kelly, Elizabeth Kendall, Jennifer A. Whitty, Michelle A. King, and Amanda J. Wheeler. 2013. 'Treatment Burden among People with Chronic Illness: What Are Consumer Health Organizations Saying?' *Chronic Illness* 9 (3): 220–32. <https://doi.org/10.1177/1742395312463411>.
- Schauer, Philip R., Deepak L. Bhatt, John P. Kirwan, Kathy Wolski, Ali Aminian, Stacy A. Brethauer, Sankar D. Navaneethan, et al. 2017. 'Bariatric Surgery versus Intensive Medical Therapy for Diabetes — 5-Year Outcomes'. *New England Journal of Medicine* 376 (7): 641–51. <https://doi.org/10.1056/NEJMoa1600869>.
- Schneider, T. 1972. 'Diabetes through the Ages: A Salute to Insulin'. *South African Medical Journal* 46 (38): 1394–1400.
- Schwartz, Barton M. 1965. 'Patterns of East Indian Family Organization in Trinidad'. *Caribbean Studies* 5 (1): 23–36.

- . 1967. 'Differential Socio-Religious Adaptation'. *Social and Economic Studies* 16 (3): 237–48.
- Scott, David. 2004a. 'Modernity That Predated the Modern: Sidney Mintz's Caribbean'. *History Workshop Journal* 58 (1): 191–210.
- . 2004b. *Conscripts of Modernity: The Tragedy of Colonial Enlightenment*. Durham: Duke University Press. <https://doi.org/10.1215/9780822386186>.
- Smith, Raymond T. 1996. *The Matrifocal Family: Power, Pluralism and Politics*. New York, NY: Routledge.
- Smith-Morris, Carolyn. 2006. *Diabetes among the Pima: Stories of Survival*. Tucson: University of Arizona Press.
- Spence, John. 1978. 'Report of Committee to Consider the Rationalisation of the Sugar Industry, Volumes I and II'. University of the West Indies, Alma Jordan Library, St. Augustine, Republic of Trinidad and Tobago.
- Stewart, Charles, ed. 2007. *Creolization: History, Ethnography, Theory*. Walnut Creek, CA: Left Coast Press.
- Stimson, Gerry. 1974. 'Obeying Doctor's Orders: A View from the Other Side'. *Social Science & Medicine* 8: 97–104.
- Strauss, Claudia, and Naomi Quinn. 1997. *A Cognitive Theory of Cultural Meaning*. Publications of the Society for Psychological Anthropology 9. Cambridge, UK ; New York: Cambridge University Press.
- Sutton, David. 2001. *Remembrance of Repasts: An Anthropology of Food and Memory*. 1st ed. Materializing Culture. Oxford: Berg Publishers.
<https://www.bloomsbury.com/uk/remembrance-of-repasts-9781859734742/>.
- Trostle, James A., W. Allen Hauser, and Ida S. Susser. 1983. 'The Logic of Noncompliance: Management of Epilepsy from the Patient's Point of View'. *Culture, Medicine and Psychiatry* 7 (1): 35–56. <https://doi.org/10.1007/BF00249998>.
- Trouillot, Michel-Rolph. 2002. 'Culture on the Edges: Caribbean Creolization in Historical Context'. In *From the Margins*, by Nicholas B. Dirks, Talal Asad, Irene Silverblatt, and Paul A. Silverstein, edited by Brian Keith Axel, 189–210. Durham: Duke University Press. <https://doi.org/10.1215/9780822383345-007>.

- Vaag, A. A., L. G. Grunnet, G. P. Arora, and C. Brøns. 2012. 'The Thrifty Phenotype Hypothesis Revisited'. *Diabetologia* 55 (8): 2085–88. <https://doi.org/10.1007/s00125-012-2589-y>.
- Vertovec, Steven. 1992. *Hindu Trinidad: Religion, Ethnicity and Socio-Economic Change*. Macmillan Academic and Professional.
- . 1997. 'Three Meanings of "Diaspora," Exemplified among South Asian Religions'. *Diaspora: A Journal of Transnational Studies* 6 (3): 277–99. <https://doi.org/10.1353/dsp.1997.0010>.
- . 2011. 'The Cultural Politics of Nation and Migration'. *Annual Review of Anthropology* 40: 241–56.
- Vlassoff, Carol. 2007. 'Gender Differences in Determinants and Consequences of Health and Illness'. *Journal of Health, Population, and Nutrition* 25 (1): 47–61.
- Wade, Peter. 2004. 'Human Nature and Race'. *Anthropological Theory* 4 (2): 157–72. <https://doi.org/10.1177/1463499604042812>.
- Walston, Jeremy, Kristi Silver, Clifton Bogardus, William Knowler, Francesco Celi, Sharon Austin, Brian Manning, Donny Strosberg, Michael P. Stern, Nina Raben et al. 1995. 'Time of Onset of Non-Insulin-Dependent Diabetes Mellitus and Genetic Variation in the B3-Adrenergic–Receptor Gene'. *New England Journal of Medicine* 333: 343–47. <https://doi.org/10.1056/NEJM199508103330603>.
- Weaver, Lesley Jo, and Emily Mendenhall. 2014. 'Applying Syndemics and Chronicity: Interpretations from Studies of Poverty, Depression, and Diabetes'. *Medical Anthropology* 33 (2): 92.
- Weedon, Chris. 1997. *Feminist Practice & Poststructuralist Theory*. 2nd ed. Oxford, UK ; Cambridge, MA: Blackwell Publishers.
- Wehling, Peter. 2011. 'The "Technoscientization" of Medicine and Its Limits: Technoscientific Identities, Biosocialities, and Rare Disease Patient Organizations'. *Poiesis & Praxis* 8: 67–82. <https://doi.org/10.1007/s10202-011-0100-3>.
- Welch, Winston, Wayne Frederick, Karl Theodore, Martin De Gannes, Adesh Sirjusingh, Valerie Alleyne-Rawlins, and Albert Persaud. 2016. 'Review of the Levels of Health Care Delivery by the Regional Health Authorities'. Committee to Review the Levels of Health Care Delivery by the Regional Health Authorities and to Rationalise the System

- of Public Sector Doctors in Private Practice Report 1. Government of the Republic of Trinidad and Tobago. Parliament of the Republic of Trinidad and Tobago.
- Welch, Winston, and Adesh Sirjusingh. 2017. 'Second Report of the Committee to Review the Levels of Health Care Delivery by the Regional Health Authorities and to Rationalise the System of Public Sector Doctors in Private Practice'. 1B. Government of the Republic of Trinidad and Tobago. Parliament of the Republic of Trinidad and Tobago.
- Whitmarsh, Ian. 2009. 'Hyperdiagnostics: Postcolonial Utopics of Race-Based Biomedicine'. *Medical Anthropology* 28 (3): 285–315. <https://doi.org/10.1080/01459740903073554>.
- WHO. 1985. 'Diabetes Mellitus: Report of a WHO Study Group'. World Health Organization Technical Report Series 727. Geneva: World Health Organization.
- . 1999. 'Definition, Diagnosis and Classification of Diabetes Mellitus and Its Complications: Report of a WHO Consultation. Part 1: Diagnosis and Classification of Diabetes Mellitus'. Department of Noncommunicable Disease Surveillance WHO/NCD/NCS/99.2. Geneva: World Health Organization.
- . 2016. 'World Health Organization - Diabetes Country Profiles, 2016'. Geneva: World Health Organization. http://www.who.int/diabetes/country-profiles/tto_en.pdf.
- Wiedman, Dennis. 2010. 'Globalizing the Chronicities of Modernity: Diabetes and the Metabolic Syndrome'. In *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*, edited by Lenore Manderson and Carolyn Smith-Morris, 38–53. New Brunswick: Rutgers University Press.
- Wikan, Unni. 1990. *Managing Turbulent Hearts: A Balinese Formula for Living*. Chicago: University of Chicago Press.
- Wilk, R. R. 1999. "'Real Belizean Food": Building Local Identity in the Transnational Caribbean'. *American Anthropologist* 101 (2): 244.
- Wilks, R., C. Rotimi, F. Bennett, N. McFarlane-Anderson, J. S. Kaufman, S. G. Anderson, R. S. Cooper, J. K. Cruickshank, and T. Forrester. 1999. 'Diabetes in the Caribbean: Results of a Population Survey from Spanish Town, Jamaica'. *Diabetic Medicine: A Journal of the British Diabetic Association* 16 (10): 875–83.
- Williams, David R. 1994. 'The Concept of Race in Health Services Research: 1966 to 1990'. *Health Services Research* 29 (3): 261–74.

- Wilson, Marisa, and Vishala Parmasad. 2014. 'Political Economies of Sugar: Views from a Former Sugar Industry.' In *Dietary Sugars and Health: From Biology to Policy*, edited by Michael Goran, Luc Tappy, and Kim-Anne Lê, 13–26. Abingdon: Taylor & Francis.
- Wong, Wesley. 1976. 'Some Folk Medicinal Plants from Trinidad.' *Economic Botany* 30: 103–42.
- Wright, H. B., and B. Taylor. 1958. 'The Incidence of Diabetes in a Sample of the Adult Population in South Trinidad'. *The West Indian Medical Journal* 7 (2): 123–33.
- Yates-Doerr, Emily. 2015. *Weight of Obesity: Hunger and Global Health in Postwar Guatemala*. Berkeley: The University of California Press.
<http://california.universitypressscholarship.com/ezproxy.library.ubc.ca/view/10.1525/california/9780520286818.001.0001/upso-9780520286818>.
- Young, Robert. 2001. *Postcolonialism: An Historical Introduction*. Oxford, UK ; Malden, Mass: Blackwell Publishers.
- Zhang, Bing, Zeyuan Deng, Yao Tang, Peter X. Chen, Ronghua Liu, D. Dan Ramdath, Qiang Liu, Marta Hernandez, and Rong Tsao. 2014. 'Effect of Domestic Cooking on Carotenoids, Tocopherols, Fatty Acids, Phenolics, and Antioxidant Activities of Lentils (Lens Culinaris)'. *Journal of Agricultural and Food Chemistry* 62 (52): 12585–94.
<https://doi.org/10.1021/jf504181r>.
- Zhang, Ping, Xinzhi Zhang, Jonathan Brown, Dorte Vistisen, Richard Sicree, Jonathan Shaw, and Gregory Nichols. 2010. 'Global Healthcare Expenditure on Diabetes for 2010 and 2030'. *Diabetes Research and Clinical Practice* 82 (3): 293–301.
- Zola, Irving Kenneth. 1972. 'Medicine as an Institution of Social Control'. *The Sociological Review* 20 (4): 487–504. <https://doi.org/10.1111/j.1467-954X.1972.tb00220.x>.
- . 1981. 'Structural Constraints in the Doctor-Patient Relationship: The Case of Non-Compliance'. In *The Relevance of Social Science for Medicine*, edited by Leon Eisenberg and Arthur Kleinman, 241–52. Culture, Illness, and Healing. Dordrecht: Springer Netherlands. https://doi.org/10.1007/978-94-009-8379-3_11.