Social Dimensions of Alzheimer’s Disease Among Caregivers in Oaxaca, Mexico

Jonathan Yahalom

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SOCIAL DIMENSIONS OF ALZHEIMER’S DISEASE
AMONG CAREGIVERS IN OAXACA, MEXICO

A Dissertation
Submitted to the McAnulty Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By
Jonathan Yahalom

May 2016
SOCIAL DIMENSIONS OF ALZHEIMER’S DISEASE
AMONG CAREGIVERS IN OAXACA, MEXICO

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Approved November 13, 2015
ABSTRACT

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May 2016

Dissertation supervised by Roger Brooke Ph.D.

This dissertation provides an analysis of the social construction of Alzheimer’s disease within Teotitlán del Valle, a rural Zapotec-speaking community in Oaxaca, Mexico. It explores how Alzheimer’s disease is locally understood, how this understanding reconfigures traditional meanings of old age, and how broader social issues are negotiated through this reconfiguration. Through 10 months of fieldwork this dissertation draws on ethnographic observations and interviews with 22 family caregivers across 9 households. This study is noteworthy for being the first known investigation in Teotitlán whose primary data was collected in the Zapotec language. Further, this dissertation integrates methods across psychology, gerontology, and anthropology, resulting in a unique interdisciplinary approach and a novel interview technique called “locally-focused interviewing.”
Results are ethnographic in nature and provide insight onto local caregivers’ experience of attending to elders with Alzheimer’s disease and other dementias. Further, these results show how caregivers’ experience is situated within multiple local discourses – different medical systems, power structures, socioeconomic parameters, norms and traditions. In so doing, this dissertation advances a number of observations. First, this dissertation leverages anthropological insights about medical pluralism – the existence of multiple medical systems in a single location – and demonstrates how Alzheimer’s disease is socially constructed via medical theories and broader social dynamics. Second, this dissertation analyzes how caregivers make decisions on behalf of dependent elders, and how these decisions are made within a medically pluralistic landscape. Although medical decisions are based on concern for elders’ wellbeing, they also invoke dynamics between local traditions and contemporary changes. Third, this dissertation traces caregivers’ daily experience as an instance of what anthropologists refer to as social suffering by attending to caregivers’ challenges, strategies, and perceptions of elders. These features disclose how the caregiving relationship is situated within a tension between local values about aging and the reality of caregiving. Lastly, this dissertation explores how and why caregivers feel responsible to care for dependent elders, and illustrates the way that the broader community is involved in shaping caregivers’ daily experience. As a whole, this dissertation contributes to the fields of psychology and medical anthropology by highlighting the social dimensions of Alzheimer’s disease and how these dimensions shape the experience of providing care for dependent elders.
For

Tommy Sage Hand

(1985 – 2012)

*Because we don't stop trying*
Acknowledgements / Agradecimientos

Seven years ago, in Northern California and on the way to wine country with my mother and stepfather, I debated whether to pursue a career in psychology. I had the option to remain at my current job, yet something seemed amiss. As we made our way through the curves of the California countryside my parents did what I will always appreciate them for – they listened and told me that they’d support me on whatever path I would come to choose. And so, months later in San Francisco I announced to my father, Aba, at our favorite restaurant that I would be moving to Pittsburgh to study for my doctorate in psychology. Soon enough we were explaining the reason for our celebration to the restaurant owner and he responded by gifting us with double magnum bottle of wine – stipulating that we could only open it together, when I returned with a degree in my hands. This dissertation marks the final step towards fulfilling that promise, and the conclusion of the conversation I’d had with my other parents even earlier. I am beyond indebted to all my parents – my mom, Aba, Glen, Sylvia and Luisa – for their understanding, support, and love. May we keep having more wine to open and more occasions to celebrate – l’chaim!

Working for my degree at Duquesne University has been a privilege. I would first like to thank Dr. Roger Brooke for having faith in my capacity to carry out this project, providing the encouragement to pursue it, and being the first person to call my attention to the importance of conducting a study on aging. Dr. Leswin Laubscher has led me by example in demonstrating what passionate scholarship looks like. I have been fortunate to call him a mentor, advocate, and friend – throughout my time in Pittsburgh and during
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I am extremely fortunate for the partnerships I forged in Oaxaca. I conducted this project as a guest scholar under Dra. Paola Sesia at Centro de Investigaciones y Estudios Superiores en Antropología Social (CIESAS). Partnering with Dra. Sesia was an honor: not only did she develop my anthropological gaze, she taught me the true, collaborative spirit of academic inquiry. Additionally, my residency at La Biblioteca de Investigación Juan de Córdova provided an inspiring space to reflect and write. I would like to thank Dr. Michael Swanton for his hospitality, enthusiasm, and guidance. También
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CHAPTER ONE

Introduction

It was August and the heavy heat pressed down on the highway. On the side stood an old woman whose wrinkled face spoke for her endurance, and whose stillness seemed to protest the oncoming rush of traffic. Her dark-gray hair fell in two tight braids over an apron, threadbare and embroidered with flowers.

I was riding in the front of a *collectivo* (one of Oaxaca’s many “shared taxis”), and I knew we were slowing to pick her up. The driver turned down the music, kept the motor running, and left me and the other passengers waiting. He approached the old woman and accompanied her to the door where I sat. And so, taking my cue to make room for another front passenger, I soon found myself sitting on top of the emergency brake – wedged between the young driver and the old woman. This was my first introduction to the dynamics of aging in Oaxaca. The *cumbia* music returned to full volume and the car pushed forward.

This Sunday morning was one of the first days of my yearlong stay in Oaxaca. I had traveled to this region of southern Mexico to conduct dissertation research on what I then could only vaguely state was on the social construction of Alzheimer’s disease. Though memorable for providing such a rich image of aging, this ride was also important for bringing me for the first time to Teotitlán del Valle (hereafter “Teotitlán” for convenience), a small Zapotec-speaking community 40-minutes away from Oaxaca City, the state capital. Many foreigners visit Teotitlán as part of the standard tourist circuit, but
on this day I was traveling to meet “Alex,” a twenty-five-year-old local with whom I had corresponded via email, months prior. Through a complicated network of associates, I was introduced to Alex because I was looking for someone to translate from Zapotec to Spanish and English. At this point I had no intention to devote my research to Teotitlán, nor any idea that Alex would become such a focal figure – a hero – to my subsequent study.

Alex greeted me at his home in his airy courtyard, with his newborn baby resting in his arms. He and his wife were in the process of dying wool and I was impressed by the bold colors that surrounded the space. Dyed skeins hung from one wall and on others were commanding tapetes (“rugs”) for which Teotitlán has earned its fame. Alex spoke to me in solid English, having spent many years in California, but I was also impressed by how he so fluidly switched to speak to his mother and wife in Zapotec, the indigenous language marked by foreign sounding tones and inflections. Through the course of this visit, Alex and I exchanged personal stories of our experiences in California (where I grew up), ate traditional chorizo with other members of his family, and eventually found time to discuss the nature of my project. I told Alex that I wanted to interview people who care for elders with Alzheimer’s disease, and that I preferred to do it in their native tongue. Alex expressed skepticism about my plans – saying he knew of no relevant cases – and so perhaps it was only due to politeness that he agreed to help.

Theoretical Background

Contrary to what most people expect when I tell them about this dissertation, my decision to devote my attention to Alzheimer’s disease was not due to personal
experience with a relative or friend, but rather to intellectual curiosity. Years ago, I began researching Alzheimer’s disease because I considered myself (and my broader culture) inept at confronting issues pertaining to death and dying. These issues appeared all but absent in the world around me, shocking exceptions rather than sober realities. I slowly began to consider not only how death seemed absent, but also how old age seemed to be something one succumbs to – instead of a life stage imbued with meaning. As historian Thomas Cole (1992) writes of the impact of this sentiment, “a culture that denies death as an integral part of life… must also deny old age as an integral part of life” (p. 141). I reasoned that studying Alzheimer’s disease would be a good way to begin my personal development and clinically challenge this dynamic.

I initially turned to neuroscience and was fascinated by statistics and technologies – all indicating how important Alzheimer’s disease is today. It is one of the more recognized illnesses in the U.S., commonly referred to as an “epidemic,” and becoming more prevalent as the population ages. It accounts for the large majority of cases pertaining to age-related forgetfulness, positing that underlying neuropathology (plaques and tangles) lead to progressive cognitive decline. While Alzheimer’s disease has been a household term since the 1980s, cases will not only rise due to population gains, but also due to the introduction of new screening technologies that can predict illness prior to the onset of symptoms.1 Encountering each of these facts was reason enough to continue studying, but I was also fascinated on a basic neurological level. For example, though

---

1 Recently the NIAH and the Alzheimer’s Association proposed significant changes from the 1984 diagnostic criteria adhered to today (Albert et al., 2011). A new “preclinical” diagnostic stage of Alzheimer’s based on the presence of biomarkers will lead to issuing diagnoses prior to the development of cognitive impairment. This diagnostic shift is intended to serve research purposes, but it will undoubtedly influence clinical practice (Carrillo et al., 2013).
plaques and tangles have been researched for over a century and believed to be the cause of clinical symptoms, they are hardly understood and researchers have continued to question whether the neuropathology we have tried to control for decades is the cause of illness at all.2

Yet for all my fascination, I soon realized that a narrow focus on neuroscience was not going to provide the type of answers I was looking for. Something seemed to be missing. I wanted to know how Alzheimer’s disease is experienced within our tendencies to fear and efforts to prevent death. As such, I knew I had to consider the actual way Alzheimer’s disease is lived, not just epidemiological and neurological models abstracted from it. Novelist Jonathan Franzen (2007) describes a similar sentiment when he writes of his own reaction to his father’s decline.

I can see my reluctance to apply the term “Alzheimer’s” to my father as a way of protecting the specificity of Earl Franzen from the generality of a nameable condition. Conditions have symptoms; symptoms point to the organic basis of everything we are. They point to the brain as meat. And, where I ought to recognize that, yes, the brain is meat, I seem instead to maintain a blind spot across which I then interpolate stories that emphasize the more soul-like aspects of the self. Seeing my afflicted father as a set of organic symptoms would … reduce our beloved personalities to finite sets of neurochemical coordinates. Who wants a story of life like that? (pp. 19-20)

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2 For a thorough review of the ambiguity surrounding the neuroscience of Alzheimer’s disease see Margaret Lock’s (2013) recent book, *The Alzheimer Conundrum*. This topic will also be reviewed in greater detail in Chapter Three.
Whatever one chooses, Franzen’s words are so powerful for reminding us that there exists an alternative story that stands apart from neuroscience itself. It is a story not about neurological failure, but the way life exists in the context of that failure. It is a story about the lived experience of Alzheimer’s disease, how persons continue to function, respond, and die within the parameters of illness.

As a student of psychology I translated this sentiment into clinical practice. Among other populations, I worked at a hospital geriatrics unit where I gained skills regarding how to assess, diagnose and therapeutically treat elders. I voraciously read, but I was most impacted by Oliver Sacks’ (1998) beautifully simple definition of disease. He writes that our understanding of disease must extend beyond brain pathology because symptoms always involve “a reaction ... to restore, to replace, to compensate for and to preserve [a person’s] identity” (p. 6). Here was a statement that at once acknowledged the devastating course of neuropathology, but also pointed to the necessity of situating neuropathology in the surrounding human world. In this way, I came to view Alzheimer’s disease as vital to study not because of an objective process that occurs in one’s brain, but more because of the way a person responds to and is viewed for having that process occur.3

In addition to my clinical training I also took an interest in social constructionism, a theory that posits that basic experiences of the world are not essential (objective facts),

3 Other writers from the phenomenological tradition further articulate this sentiment. Robert Romanyshyn (2012) argues that, although Parkinson’s disease is due to a lack of dopamine, associated behavior like the parkinsonian gait must be viewed as expressions taken by an agent that lives within this biomedical constraint. In a similar vein, Roger Brooke (2002) writes of Alzheimer’s disease that “there is always a person first, and that person is using whatever cognitive and psychological resources he or she has to understand and deal with the disintegration of a world” (p. 138). I also develop these ideas in my own work (see Yahalom, 2014).
but rather the product of a social reality. While I knew not to dispute knowledge about underlying neuropathology, I began to question why Alzheimer’s disease is so dreadful and how it has gained such popularity. Further, I wondered how the biomedical model – that is, a perspective of human life in terms of underlying biological processes – has had an impact on our experience of old age. When I refer to the social construction of Alzheimer’s disease in this study I take an approach similar to Ian Hacking’s (1986) description of “dynamic nominalism,” a concept that does not contest the existence of underlying neurological pathology, but rather points to the way that pathology and related clinical symptoms (like forgetfulness) are made meaningful because they arise within a specific social context.

Years later, I made the decision to research caregivers in another setting because I figured this would give me the best opportunity to explore the issues that fascinated me. Studying caregivers – the family members who informally provide vital care for dependent elders – would allow me to see how people conceptualize the aging process via Alzheimer’s disease, and how this conceptualization has an impact on the way aged persons exist in the social world. Conducting this research in another setting would require me to continually question basic ideas about death, dying, and illness, and help provide contrastive light on these taken-for-granted concepts from my own background. Oaxaca seemed so interesting for how it was celebrated as being a cradle of Mexico’s indigenous culture and how this population was presented as recently engaging with the broader world. This perspective was naively misinformed, but at this time I thought that Oaxaca would provide an ideal setting to study how an historically isolated group encounters ideas about senility from the biomedical tradition.
And so, with two large suitcases replete with articles and books, I arrived to Oaxaca intent on asking caregivers how their understanding of Alzheimer’s disease has impacted their relationship with dependent elders. Yet I soon realized the impossibility of this plan. As I should have known from Alex’s initial skepticism, finding cases of Alzheimer’s disease would be extremely challenging. Moreover, in order to be able to ask caregivers about Alzheimer’s disease I first needed to know what they understood by this term. Paradoxically, I had to have an answer to my question before being able to ask it. In this way, my project transformed from having a narrow focus on the meaning of Alzheimer’s disease, towards becoming an ethnography aimed at tracing forms of life in the Alzheimer-ed world. The richer and broader information I would come to gather on caregivers’ experience with Alzheimer’s disease became the substance of this dissertation.

Research Questions, Methodological Approach, and Significance

How is what we have termed Alzheimer’s disease locally understood in Oaxaca, Mexico? How does the presence of Alzheimer’s disease reconfigure local practices of caregiving for elders? And how are broader social issues negotiated through this reconfiguration?

These are the basic questions that came to guide my research, helping me move beyond assumptions about the universality of Alzheimer’s disease towards appreciating how it exists and takes on different meaning in varying social climates. These questions seemed more appropriate to my interests and population, but as such they invariably forced me to move beyond my training in geriatric psychology, towards addressing work
across disciplines. Specifically, I was led to issues in anthropology and sociology, and the way in which structures of society shape the course of human life. Without question, this project is anthropological (in a descriptive sense) – yet I consider it a work of psychology (in a theoretical sense). It is interdisciplinary and draws on multiple perspectives, but the underlying phenomenon of interest is about how individuals live – the jurisdiction of psychology – not how their lives are suggestive of broader structural features.

During 10-months of fieldwork in Teotitlán I came to interview a total of 9 households, hearing from 22 caregivers who support elders with Alzheimer’s disease and other dementias. This study is noteworthy for being the only known investigation in Teotitlán whose primary data was entirely gathered in the Zapotec language. These household interviews constitute this dissertation’s primary data, yet I engaged in numerous other ethnographic activities such as meeting individuals within and beyond the community, participating in workshops, activities, and community events, and formally studying the Zapotec language.

This dissertation employs a wide variety of tools to demonstrate the ways in which caregivers from Teotitlán draw upon local resources to understand and respond to the challenges of Alzheimer’s disease. As a whole, this research demonstrates that psychiatric diagnoses like Alzheimer’s disease cannot be understood as carrying the same meaning across time and space, but rather must be viewed through the broader context in which they exist. Scholars in medical anthropology have argued that illness is a dense signifier of social life (e.g., Gaines, 1992; Kleinman, 1980; Nichter, 2008; Pigg, 1995) and that symptoms associated with Alzheimer’s disease manifest in radically different

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4 The Duquesne University Institutional Review Board (IRB) approved the research conducted in this dissertation, including subsequent modifications to the research protocol (Protocol #2014-02-18).
ways, depending on cultural outlooks and values (e.g., Ballenger, 2006; L. Cohen, 1998; Henderson & Traphagan, 2005; Leibing, 2002). I add to these studies not only by showing how the changes that accompany elders with Alzheimer’s disease serve as a prism for understanding broader community changes, but also by taking a narrowed focus on caregiving to argue that this form of life is pivotal for negotiating those changes.

Teotitlán prides itself as a community defined by local customs, and elders are viewed as safeguarding tradition and respected on their basis of their age. Yet high rates of migration and greater engagement with capitalism have led many locals to believe these traditions are in jeopardy. Caregivers provide a unique perspective on this process because their practice lies at the juxtaposition of a duty to maintain tradition by attending to elders, and the reality of how caregivers uphold their responsibilities. This tension stands as the ethnographic background of the present study.

**Plan of the Dissertation**

In the eight chapters that follow I describe the experience of caregiving for elders with Alzheimer’s disease in Teotitlán. My approach is ethnographic not only in regards to how I collected my data, but also for how I choose to present it. In this dissertation I deliberately feature my personal story – my arrival to Oaxaca, my difficulties finding relevant participants, and my reactions when I did find them – not only for narrative purposes, but also because it is the most truthful way to present the data I came to acquire. And yet, although I have just referred to these experiences as “mine” I do not want to suggest that I was alone. The partnerships I came to form were invaluable, and I am confident that I would not be able to tell the following story without the ongoing help
I received from numerous individuals. For this reason, I specifically include Alex as a central figure in this story. Through our joint work I not only gained access to some of the most intimate dimensions of life in Teotitlán, but also established a genuine friendship that helped me better understand them. I leverage my experience with Alex as a means to unfold and tell the story of my research, from how I initially encountered and made sense of Teotitlán towards how I proceeded to acquire and analyze my data.

Following this introduction, Chapter Two is aimed towards equipping my reader with necessary information to understand what life is like in Teotitlán. While this chapter is not focused on aging per se, it introduces relevant histories, medical systems, and other facets of life that are necessary to appreciate the unique setting of my research. In the process I demonstrate how Teotitlán is at once defined by traditions that locals perceive to be changing due to engagement with broader global forces. As I come to discuss, this setting forced me to address and clarify the meaning of basic concepts like culture and how they would be mobilized in the course of this study.

Chapter Three transitions to introduce themes specific to aging. I review demographic issues and discuss how Teotitlán’s changing community structures are perceived in light of an aging population. Further, I present what I term Teotitlán’s “problem of aging” and reflect on how this problem is best appreciated through social constructionism, a theoretical perspective that posits that society produces the meaning of phenomena like aging. Finally, this chapter concludes by presenting basic information about how Alzheimer’s disease is understood on a local level, and what I needed to know in order to earnestly begin my fieldwork.
Chapter Four is focused on the ethnographic methods I used to acquire my data, as well as theoretical perspectives that account for each step of the process. I reflect on how I initially found myself reaching out to community members, and what I specifically aimed to achieve in conducting this study. I proceed to identify ethnographic challenges regarding access to the community and how my unique partnership with Alex helped me overcome them. I demonstrate how this partnership culminated in a new method of data collection that I term “locally-focused interviewing.” I discuss the nature of these interviews, and how meeting with caregivers provided a powerful lens to study the social construction of aging and caregiving. Lastly, this chapter identifies how I draw upon discourse analysis as my primary tool to understand and present research findings. I discuss reasons for viewing my data through this qualitative research approach, and conclude to summarize methodological steps of analysis.

The next four chapters are analytical in nature, aimed to present findings gathered from my interviews with caregivers. Together these chapters tell my ethnographic story — that is, how my understanding of the nature of this investigation transformed through the course of conducting research. Most broadly, these chapters illustrate how my intellectual interests regarding the adoption of biomedicine within a traditional society was less significant than the blunt realities that caregivers experience while attending to forgetful elders.

Chapters Five and Six complement each other and together illustrate Teotitlán’s medical pluralism, that is, the available medical options based on different medical systems. Chapter Five analyzes caregivers’ perceptions and etiological explanations of symptoms pertaining to Alzheimer’s disease. It makes the argument that the very
experience and meaning of age-related forgetfulness is constituted by broader social factors. Moreover, it demonstrates how caregivers’ understanding of forgetfulness is expressive of a pragmatic stance to do what is best for dependent elders.

Chapter Six continues developing themes about medical pluralism by showing how caregivers make choices regarding whom to (not) consult for professional help, and the impact of each consultation. This chapter also contextualizes the last chapter by identifying limitations in caregivers’ pragmatism – their intention to do what is best for elders – by showing how larger sociocultural factors also shape health-seeking behavior.

Chapters Seven and Eight are also theoretical twins, distinguished for their focus on the daily experience of caregiving. These chapters view all dimensions of human experience as social in nature, invoking recent work in medical anthropology on the nature of “social suffering.” Chapter Seven begins by analyzing the challenges that caregivers face, and how those challenges are experienced in light of local values and outlooks. It then turns to examine the type of relationship that caregivers have with elders, and how this relationship invokes culturally specific values. Lastly, it demonstrates how this relationship leads to strategies used by caregivers to provide care. Overall, this chapter demonstrates that there exists a tension between the local ideal of elders as respected on the basis of age and the reality of how elders are viewed through the caregiving process.

Chapter Eight addresses fundamental questions pertaining to responsibility: Why do people care, and what are the social ramifications of caring? To this end, the chapter first examines how caregiving responsibility is delegated among members of the household and specifically examines the local impact of migration. Next, the chapter
explores caregivers’ experience of responsibility by focusing on ideas about aging and death. It demonstrates how these local notions are essential towards understanding caregiving. Lastly, the chapter turns to explore how caregivers’ decisions to be responsible for forgetful elders renders caregivers into a second forgotten subject, now overlooked by the larger community.

Chapter Nine concludes with a vignette that coalesces the study’s principal findings, making a final statement about the ambivalence that surrounds aging in Teotitlán. It identifies limitations and advantages of this study, suggests ideas for future research, and reflects about what the case of Teotitlán teaches us about aging in U.S. settings.
CHAPTER TWO

The Cardinal Points of Teotitlán: A Local Introduction

The local cheese is distinctive of Oaxaca’s culinary tradition. It is produced in a single long inch-thick strip that coils to form a ball, sometimes so massive that it exceeds a foot in diameter. In local markets vendors stand behind their large globes of quesillo, waiting for a customer’s order, and then deftly unravel the round morass. Oaxaca is like its cheese, people are apt to say – so complicated that even it is tied in knots.

In this chapter my aim is to provide a brief orientation to the complex heterogeneity that is the norm of Oaxaca’s multidimensional landscape, to, figuratively speaking, securely position my reader on the Oaxacan map. To be sure, this chapter is not focused on aging per se, but is rather aimed at providing necessary information with which to appreciate and contextualize subsequent ones. What follows is divided into four “cardinal points,” a deliberate reference to Catholicism, considered essential to a preliminary understanding of Teotitlán and the broader Oaxacan world. Through the process, I tour relevant histories so my reader can ultimately obtain a feeling for “what” life is like, and from where it comes.

Geographic Heterogeneity: Local Forms of Identity

My first visit to Teotitlán brought me through some of the more exceptional parts of Oaxaca’s famed geography. Teotitlán lies within Tlacolula Valley, the eastern wing of Oaxaca’s Valles Centrales (Central Valleys), a nexus of river valleys that form a Y-
shaped alluvial plain. This land is gentle and expansive, which sharply contrasts with the state’s surroundings. In fact, Oaxaca is notorious for rugged and difficult-to-navigate mountains, making travel a treacherous affair, and the state an historically remote destination. Prior to the construction of the Pan American Highway in the 1950s, the City of Oaxaca – and the surrounding Central Valleys – were largely separated from Mexico’s broader socioeconomic landscape. Beyond Oaxaca City, most communities existed in relative isolation and developed with high degrees of autonomy. Even today, travel outside Oaxaca’s valleys is marked by serpentine roads, testing the limits of most people’s stomachs, and rendering access to many parts an arduous undertaking.

Oaxaca’s geography is crucial to an understanding of its history and present conditions. While the state’s total area is about two-thirds the size of Pennsylvania – and just fewer than 5% of Mexico’s total landmass – Oaxaca has many microclimates, and high biological and cultural diversity. It is recognized for being a biological “hotspot,” with a rich diversity of plant and animal life that have attracted researchers and tourists alike (Cummings, 2002).¹ Beyond plant and animal diversity, Oaxaca is home to sixteen indigenous groups and languages, accounting for 18% Mexico’s indigenous speaking population and making it the state with the highest proportion of indigenous language speakers (Instituto Nacional de Estadística y Geografía (INEGI), 2014). Oaxaca also features 23% of Mexico’s municipios (municipal governments), 73% of which are governed according to their own usos y costumbres (customs and traditions), further testifying to the unique and isolated communities that make up the state’s cultural landscape.

¹ Even the famed neurologist Oliver Sacks (2012) toured and wrote a book on Oaxaca’s rich fern diversity.
For all its rich diversity, Oaxaca is also one of the poorest states in Mexico (second to Chiapas), with over 60% of the state's population living in poverty and 23% meeting criteria for extreme poverty (CONEVAL, 2012). Oaxaca’s poverty is particularly striking given national statistics for Mexico, a country whose average household disposable income is less than half of the Organization for Economic Cooperation and Development (OECD) average (OECD, 2015). Oaxaca’s poverty is dually related to its geographic isolation and marginalized indigenous populations. Many communities lack basic economic infrastructure. Further, Oaxaca’s indigenous peoples have had a long history of political marginalized, which continues into the present day, rendering them on the periphery of national aims (discussed in greater detail in sections to follow).

And yet, Teotitlán is an exception to this bleak landscape. In contrast to what I knew of Oaxaca State, when I arrived that first day to meet Alex I was struck by how life seemed to be flourishing. This 5,500 resident community continues to receive federal subsidies and is designated a poor pueblo: 82% of residents meet national criteria of poverty, and 29% live in extreme poverty (SEDESOL, 2014). But Teotitlán is nevertheless different and more economically developed than surrounding neighbors. This is partly due to the production and direct sales of hand-woven tapetes (“rugs”). Close to Oaxaca City, many visit Teotitlán as part of the tourist circuit to see its colorful rugs displayed alongside major streets and to witness its centuries-old weaving process. These rugs are presented as living vestiges of Zapotec culture – incorporating motifs from ancient ruins – and celebrated as emblems of Mexico’s national history. The sale of tapetes comprises such a large portion of its local economy that it is perhaps an understatement to claim that weaving defines Teotitlán. Indeed, nearly every individual
and household I would come to encounter was involved in the weaving process, and some participants in this study even wove while being interviewed.

Figure 2.1. Rugs displayed in Teotitlán's outdoor market. (Photo by the author.)

Geography further distinguishes Teotitlán, and the community has long been considered to dwell in a sacred location. The name “Teotitlán” derives from Nahuatl (the Aztec’s language because this empire conquered Oaxaca prior to the Spaniards), and translates to mean “land of the gods,” demonstrating the importance of this landscape and location to the Aztecs. Located in the foothills of the Sierra Norte mountains, Teotitlán is situated between two small rivers and has expansive, cultivable land. Locally, Teotitlán is referred to in Zapotec as Xigie, which translates to mean “enchanted” and “below the
stones,” referring to the prominent rock located above the community and that is said to possess divine powers. This location is known as the site where the snake god *Quetzalcoatl* appeared and prophesied to the then nomadic people of Oaxaca that they should settle and give birth to Zapotec civilization (Gagnier de Mendoza, 2005, p. 23).

Figure 2.2. Zapotec temple ruins, over which the Catholic Church now stands (in the background). Also in the background stands the mountain from which Teotitlán derives its name. (Photo by the author.)

Although Teotitlán is purported to be the origin of the Zapotec people, the history of civilization in Oaxaca is more complicated. The presence of inhabitants in Oaxaca’s Central Valleys can be traced back as far as 10,000 B.C. and the region’s earliest evidence of small communities of hunters and gatherers (J. Marcus & Flannery, 1996, p.
Other communities outside of the Central Valleys existed in what is now the state of Oaxaca; yet this region’s irrigable and navigable land made it the de-facto capital of socioeconomic and political life. The most resounding contemporary image of the region’s historical stature is Monte Albán, the former capital of the Zapotec empire and one of Mesoamerica’s first cities – so celebrated by Mexican culture today that the ancient ruins appear on the $20 peso note. It is not difficult to gain a sense of Monte Albán’s historical prestige and political might: the ruins are towering and expansive, resting on a mountaintop at the center where Oaxaca’s three valleys come together, commanding a panoramic and strategic view.\(^2\)

Though there only exist fragments of information about Mesoamerican culture prior to the Spanish Conquest, what is known suggests that beliefs were shared across the region. For example the Zapotec conception of the human being was based within a larger cosmological order that incorporated ideas of equilibrium, psychosocial development, and divine rule.\(^3\) The Zapotecs distinguished between animate and

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\(^2\) Prior to the settlement of Monte Albán in 500 B.C., the Central Valleys were populated by over 85 communities (J. Marcus & Flannery, 2000, p. 367). While these communities always continued to be inhabited during Monte Albán’s sovereignty, they formed a regional alliance and coalesced power to fight against neighboring powers like the Mixtecs. This marked the birth of the Zapotec people, and Monte Albán became the religious, scientific, and political center in much of Oaxaca. By 800 A.D. Monte Albán supported a population of more than 30,000 individuals – the largest political settlement in the southern Mexican highlands – and gained power over much of what is the state of Oaxaca today (Blanton, 1978).

\(^3\) The Aztecs, who likely had an influence on Zapotec culture after their conquest of Oaxaca, believed in a world of supernatural and divine forces of dual principles – day and night, birth and death, good and evil – whose continual struggle led to cosmological harmony (Belsasso, 1969, p. 32; see also Ortiz, Davis, & McNeill, 2008, pp. 277-280). To this end, the understanding of the self was rooted in a dynamic equilibrium, captured in the Aztec term *Ixtli-in yolluitl*, which literally translates to “face-heart.” Mesoamerican cultures believed that the individual was born “faceless,” symbolically lacking a distinct self and, through moral education, developed a unique face that could be presented to the community (Padilla &
inanimate matter, the former possessing vital force that was celebrated through ritual (J. Marcus & Flannery, 1996, p. 19). With regards to health beliefs, we know in general that Mesoamerican metaphysics did not distinguish between mind and body, and so understandings of health and sickness were reflections of both mental and physical conditions, and illness often viewed as consequence of social transgression (Rubel, 1960; Somolinos d'Ardois, 1973). Though understandings of illness have certainly evolved, in chapters that follow I argue that at least vestiges of these beliefs are detectable today.

Prior to the Spanish conquest, psychiatric illnesses in Aztec cultures were conceptualized as manifesting from a general condition termed yollopoliuhqui, which translates from Nahuatl to mean “that which has left the heart” (Somolinos d'Ardois, 1976, p. 27).4 This condition referred to a type of emotional disturbance that would be similar to what today is meant by the term “losing one’s head” (Padilla & De Snyder, 1988, p. 62). There were four basic etiologies said to cause illness: pathology due to natural order, pathology due to enemy’s curses, divine punishment, and loss of self due to supernatural forces (Somolinos d'Ardois, 1973, pp. 68-70). These four etiologies were expression of broader disequilibrium of cosmic forces, and illness was a concern for the entire community (Somolinos d'Ardois, 1973, p. 25; 1976, p. 19). Treatment was provided by a trained and respected physician – tonalpouqui – who prescribed treatment

De Snyder, 1988). In contrast to Western metaphysics, Mesoamerican culture did not have a distinct notion of soul (Somolinos d’Ardois, 1973, p. 69). The closest concept was tonalli, a notion to describe the individual personality as it is constituted through dual forces of the moon and the heat of the sun (Beltrán, 1978).

4 This sentence and the larger paragraph is based on Aztec civilization. To be sure, the two are very different. Nevertheless, I include it here to discuss what little information is known about mental illness, and also because it likely bore some influence in Oaxaca, which the Aztecs later conquered prior to the arrival of the Spaniards.
according to a highly developed taxonomy of medicinal plants, exorcisms, trephination, and talk therapy in effort to reestablish equilibrium (Padilla & De Snyder, 1988, pp. 62-63).\(^5\)

The Zapotec empire of Monte Albán declined in 800 A.D., yet its influence can still be felt today.\(^6\) Alongside 15 other indigenous languages spoken in Oaxaca, Zapotec remains vibrantly alive in Oaxaca – and, apart from Spanish, it is the state’s most popular language with 450,000 speakers. In a near synonymous manner, the term “Zapotec” is also commonly used to refer to the ethnic group that derives from this history. Yet understanding Zapotec as an ethnic category is problematic and quite misleading. The state’s geography has rendered communities in such isolation that they exhibit strikingly different customs. To this end, Joseph Whitecotton (1992) argues that, although most research on Oaxaca refers to a unifying “Zapotec” ethnicity, this view is mistaken because there is no clearly bounded “Zapotec” culture. Attempts to understand different communities as Zapotec derive from 16th century Spanish chroniclers who projected their own sociocultural constructs onto indigenous populations (p. 64).

As I came to discover, this renders Teotitlán’s claim to be a traditional Zapotec community a more complicated issue. Indeed, while residents often celebrate Teotitlán as

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\(^5\) Although many features of Pre-Hispanic medicine will appear in data collected for this study, I do not suggest an essentialist reading that would posit that contemporary “traditional” medicine derives from or can be understood solely on the basis of its past. Introducing features of the cultural past helps provide greater context to this study, and prods consideration of a certain tracing of the past in the present, but should in no way be taken as my arguing that concepts have remained “the same” across time.

\(^6\) After its fall, for a 500-year period that ended with the Aztec’s conquest of Oaxaca in the 14th century, smaller empires competed for regional supremacy. Oaxaca was in a state of “balkanization” where no single power gained control, and different communities were able to develop autonomously. (J. Marcus & Flannery, 1996, p. 394).
a traditional Zapotec community – and point to their rugs as emblems of Zapotec culture – this is mainly directed towards tourists (W. W. Wood, 2008). Internally, residents maintain an identity that is based on a much more narrowed understanding – not inclusive of all Zapotec peoples across the state, but defined by the parameters of Teotitlán itself (Stephen, 2005, p. 19). This is a common feature of communities across Oaxaca. In part because of geography, identity is not constructed through broad notions like ethnicity or nationality, but rather through comunidad, a much more specific notion that points to where a person grew up.

The point is much more than an intellectual observation, and is crucial to any understanding of this study’s setting. For example, when presented with the question about “what” or “who” a person is, the people of Teotitlán first and foremost consider themselves “Teotitecos” – people from Teotitlán – prior to any other ethnic, national, or sociocultural identity. This is not a point of pride, but a critical distinction whose importance manifests in countless ways. Perhaps the most significant illustration concerns language. Although Zapotec is spoken across the state, each community has its own dialect that defines who a person is by revealing from where he or she comes. 7 Teotitecos readily distinguish their speech from the Zapotec spoken in Mitla, a neighboring community only 15-miles away, and experience serious difficulty understanding the Zapotec spoken in the surrounding mountains and other state regions. 8,9 In this way, language is a key to Teotiteco membership. Though it is not

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7 In addition to language, Teotitlán is differentiated by different legal customs, traditional dances, huipiles (loose-fitted tunics), and even sandals.
8 Teotitecos also distinguish amongst themselves according to language use. There exists a grammatical difference between members who live in the more elevated northern area of the community and those who
written and constantly evolving, residents are attentive to subtle accents and immediately
discern whether or not individuals are from Teotitlán. Language is so important because
speaking Zapotec is considered a major way to uphold local tradition. While younger
generations are bilingual and predominantly speak Spanish amongst themselves, many
elders are monolingual and the majority of social life is carried out in Zapotec.

In sum, geography is crucial towards understanding what Teotitlán is, and to
appreciate the broader Oaxacan world. Geographically separated from other
communities, Teotitlán is defined by customs that are based on the local level. This is not
the exception in Oaxaca, but the norm. It is what led Robert Taylor (1960) to claim that
Teotitlán is a “typical” Mesoamerican community – it is defined not by national or
multiregional notions of identity, but through much more narrowed criteria that ties
individuals back to the community-level. In what follows, I continue to develop this
theme and review how it developed in subsequent chapters of local history.

Civic and Religious Custom: Syncretic Layers of History

Like many of Mexico’s rural communities, Teotitlán is devoutly Catholic. People
cross themselves when in front of a religious structure or icon, attend church regularly,
and uphold religious commitments with utmost seriousness. Yet even the briefest pause
reveals complex syncretism – that is, the way in which individuals practice and live by
customs that come from multiple sources. Perhaps the most striking testimony is

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9 Challenging the claim that Oaxaca is home to 16 indigenous groups, some have even argued that the
number of different Oaxacan cultures more accurately reaches 4,000 (Ordóñez, 2000).
Teotitlán’s performance of the Danza de la Pluma (“Feather Dance”). In front of its whitewashed church whose walls incorporate stones depicting Zapotec deities and designs from ancient ruins, a group of choreographed dancers recount the story of the Spanish Conquest while wearing traditional feathered headdresses and clothing. Dancers perform for 2-8 hours per day – at times for a throng of spectators, and other times for themselves – recounting the fall of the Aztec empire and the reception of Catholic doctrine. Participation in this laborious custom is considered an honor, one of the most
prestigious religious rituals in the community (see Hernández-Díaz, 2012). This event illustrates the broader theme I now wish to describe – the way in which conquering cultures in Oaxaca did not replace pre-existing ones, but were rather adapted to fit local circumstances.

Defining the features of Zapotec culture prior to the Spanish conquest is complicated because even turning to historical origins demonstrates customs were constantly evolving. During the Monte Albán period, the Zapotec empire repeatedly encountered other communities. And, after its fall, the Aztec empire held control over the region until the arrival of the Spaniards. Hence, even before the Spanish Conquest, the Zapotecs were already accustomed to adapting to foreign influences. This renders it difficult to discern what is “properly” Zapotec apart from other cultural traditions.

Nevertheless, there exists information about Zapotec religious theology and practice. The Zapotec religion was originally animatistic, where followers recognized an overarching supreme force or principle, Coquixilla, which had no attributes, was unknowable, and had no beginning or end (J. Marcus & Flannery, 1996, p. 19; Whitecotton, 1977, p. 165). Religious practice was based on what Whitecotton (1977) calls a “quid pro quo principle” where individuals paid tribute to receive favor, and believed that ignoring divine commands would result in punishment (p. 165). In addition to believing in a supreme force, Zapotec religious practice was also based on royal ancestor worship (J. Marcus & Flannery, 1996, p. 20). Each town venerated its own

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10 However, Spanish chroniclers and some contemporary scholars claim that Zapotec religion was polytheistic. For example, Whitecotton (1977) writes that each community had a local patron deity and that Teotitlán was allotted Xaquija, the Zapotec sun god, who was prominent in the Zapotec pantheon (p. 158). J. Marcus and Flannery (1996) contest this claim, writing that “had the Spaniards [and contemporary
deceased rulers, who, after passing, were believed to become divine spirits. These ancestors were termed “old people of the clouds,” giving rise to the meaning of the word Zapotec (“people of the clouds”) – and providing what is perhaps the earliest testimony of how elders have been viewed as protecting the community by safeguarding local tradition.11, 12

Although the Spanish Conquistadors attempted to expunge local “pagan” beliefs, it is more accurate to say that they amalgamated Catholicism to fit preexisting ones. In this way, the Catholicism that Teotitecos practice today is not so much a negation of Zapotec religion, but an adaptation of one with the other. For example, whereas individuals were accustomed to worshipping ancestors from their specific communities, now many have an allotted patron saint. (Teotitlán’s is distinctively given the Son of God and Virgin Mary). Or, whereas Teotitecos historically made a short pilgrimage to the rock that was believed to be the origin of Zapotec civilization, today they go to the same place to celebrate the Day of the Holy Cross. Oaxaca’s celebration of the Day of the Dead further exhibits its rich syncretic history. While on the surface this event is tied to the Catholic Church’s All Souls’ Day, Day of the Dead is a continuation of indigenous death customs where it is believed the dead are given permission to return to earth and take part in communal life. This celebration of death is boisterous and colorful, where

11 This last point often leads to confusion. The actual word “Zapotec” derives from Nahuatl, the language of the Aztec kingdom and means “people of the zapote,” a local variety of fruit. By contrast, bènizàa, the word to refer to the Zapotec people in the Zapotec language translates to mean “people of the clouds.”

12 To this end, the extant codices that describe Pre-Hispanic medical and religious practice all point to the prestige allotted to elders. They were considered central in promoting proper religious practice and customs (see for example León-Portilla, 2012).
families unite on behalf of the deceased to provide food, mezcal, live music, and social accompaniment (see Norget, 2006; Royce, 2011).

This is not to suggest that the Spanish Conquest had little effect on local life. The arrival of the Spaniards who conquered Oaxaca in 1521 signified what Kristen Norget (2006) rightly calls “cultural rupture,” shattering and displacing dominated orders of meaning, and remaking the entire sociopolitical landscape (p. 91). While the actual conquest of Oaxaca lasted just under one week – and the Zapotecs capitulated without engaging in battle – the consequences were devastating (Murphy & Stepick, 1991, p. 16). The New World the Conquistadores brought with them what has perhaps been the region’s most devastating weapon – the introduction of measles, smallpox, typhus and other infectious diseases against which the indigenous population had no immunity. The
numbers alone are staggering, giving pause for the magnitude of losses. Whereas at the eve of the Conquest there were an estimated 350,000 indigenous people living in Oaxaca Valley, by 1568 the population dwindled to 150,000 and, by 1630 only 40,000 remained – a 90% drop in less than a 100-year period (Murphy & Stepick, 1991, p. 18).

The Spanish Conquistadores were themselves a heterogeneous group, introducing greater complexity than is often recognized into Oaxaca and Mexico’s cultural landscape. In the wake of the Spanish Inquisition (which was established in 1478 and not officially abolished until 1834), many who were prohibited from elite professions in Old Spain went to the New World. Hence, the group of Spaniards who arrived to Oaxaca (and the slaves they transported) actually was comprised of Catholic, Jewish, Muslim, and African backgrounds (Norget, 2006, p. 94).

The varied cultures and religious practices no doubt had an influence on the transmission of Catholicism in the New World. The latent diversity among the Conquistadores was evident throughout the Colonial Period, where they exhibited deep concern to distinguish “purity” among themselves and the indigenous population. Major government posts were reserved for individuals who could demonstrate “pure” (non-Jewish, -Muslim, -African, or -indigenous) Spanish origin (Guardino, 2005, pp. 19-25). And, as they were quick to distinguish among themselves, the Conquistadores also established a rigid social hierarchy: the Spanish-born peninsulares assumed roles similar to the aristocracy, the landowners were criollos (Spanish descent born in the New World), merchants were mestizos (individuals with “mixed” blood), and the indigenous

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13 Further, recent DNA evidence reveals that a large percentage of Mexico’s genotype that is considered “Spanish” is genetically Jewish (Grabman, 2009, p. 76).
populations were subordinate (Murphy & Stepick, 1991, p. 15). As I will come to discuss, today’s implicit sense of inferiority among darker-toned individuals directly stems from this history.

Nueva Antequera, as the Spaniards renamed Oaxaca City, was quickly established as the region’s socioeconomic and political center, serving a similar role as Monte Albán by integrating the various villages of the region (Guardino, 2005, pp. 19-39). Yet Antequera was slow to prosper. After hearing rumors that Antequera was the source of New World gold, and wanting to secure agricultural profits for himself, Cortes declared himself Marquez del Valle and engaged in a long battle with the Spanish Crown.15

Under colonial rule, villages like Teotitlán negotiated to maintain local control while ceding ultimate power to the Spaniards. This political situation gave rise to Oaxaca’s contemporary cargo system – what Jeffrey Cohen (2004) calls the “heart of village politics,” a lifeline for the preservation of civic-religious customs (p. 14). The cargo system is a local practice of providing free community service in exchange for citizenship.16,17 In Teotitlán today, each household is expected to provide at least one

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14 Images of this social structure can still be found today in Teotitlán’s church with a 3-part seating division; locally, it is known that these divisions correlated with social structure: the anterior ornate section was reserved for Spaniards, middle section for mestizos, and sparse rear section for the indigenous.

15 Whereas the Spanish sought to consolidate and control power in the city, Cortes succeeded to frustrate the Crown by establishing indigenous settlements on the outskirts, thereby thwarting substantial economic development. This was one of the first instances of Oaxaca’s political marginalization and represents another reason why Oaxaca continues to be on the economic periphery (Murphy & Stepick, 1991, p. 16).

16 To be sure, there are other demands placed upon citizens in Oaxacan villages: tequío is a form of voluntary labor for specific community projects; mayordomía (although rarer in Teotitlán today) is a tradition where a household sponsors a community-wide celebration.

17 The cargo system may be traced back to two principal forms of colonial governance – civic cargos and religious cofradías – introduced by the Spaniards over Oaxaca’s indigenous populations (Chance & Taylor, 1985). The first, civic cargos, was a system where select individuals held a series of increasingly
individual to carry out successive 2-year terms of unpaid service. This system is commonly believed to help preserve local customs because, first, it allots the greatest power to elders who, in their lifetimes, ascend to posts with increasing prestige. Second, it also safeguards the continual practice of civic and religious traditions by making them obligatory.

The arrival of the Spanish established more than just new governing and religious systems, but also introduced novel conceptions of illness, medical practices, and metaphysics of the self. Though the Spaniards were fascinated by the knowledge indigenous populations had accumulated of medicinal plants, they ultimately prohibited prestigious government posts. In indigenous villages these positions were typically allotted to native rulers, circulating power among privileged persons, and also preserving traditional civic order (Murphy & Stepick, 1991, p. 18). Under this system, local rulers were held responsible to comply with the encomienda system, whereby villages were subjected to serve individual colonists, leading to exploitation and forced labor of the indigenous population (W. B. Taylor, 1979, p. 14). Colonists demanded of villagers to produce specific products that were then bought at prices lower than market value, thereby “encouraging” villages to move beyond subsistence farming through economic dependency. This also fostered the type of craft specialization inherent to many of Oaxaca’s indigenous communities discussed above.

The second form of governance was established through the Catholic Church, and its introduction of cofradías (confraternities or religious corporations). After Pope Alexander VI ruled that Spain had the religious sovereignty to conquer the New World, Conquistadores were given the dual mission of both seizing land for the Spanish Crown and evangelizing indigenous populations. The Dominicans were Oaxaca’s first missionary order to arrive in 1528 (7 years after Oaxaca capitulated to the Spaniards) and Teotitlán was officially evangelized in 1580 (Gagnier de Mendoza, 2005, p. 114). The Church’s efforts were largely carried out through cofradías that were established in regional centers. Cofradías were religious institutions that collectively owned and managed land and livestock, and sponsored elaborate community-wide celebrations of patron saints. Indigenous populations were converted to Catholicism, but the decentralized organization of the cofradia system allowed Catholicism to be appropriated differently, depending on the community, and thus allowed for the stark “unorthodoxy” found in Contemporary Mexican Catholicism.

18 Technically, every married couple has to provide service. So, once a man gets married, a representative of this newly formed household must provide labor.
much of indigenous medicine because they found it threatening and heretical. The medicine brought by the Conquistadors was predominantly Greek (Galenic, to be specific) and conceptualized health and illness according to the equilibrium of four humors – fire, air, water, and earth. Treatment was based on the “principle of opposites” where deficit humors were supplemented, or ones in excess were reduced (Hernández Sáenz & Foster, 2001, p. 20). This remained the dominant medical system in Mexico until the introduction of biomedicine in the mid-19th century.

The manner by which Old World medicine was brought to Mexico had a profound impact that can still be felt today – shaping how the people I would come to interview understood and responded to illness. For example, many research participants spoke of “traditional” medicine, yet this system of medicine does not stem from indigenous (pre-Hispanic) origins, but rather from a fusion of indigenous ideas with those introduced by the Spaniards. Though complicated, this medical history is important towards understanding current life in Teotitlán.

The Spaniards transmitted medical ideas through two main conduits: elite (formal) and popular (informal) levels. On a formal level, the Spanish created a network of hospitals and a medical board (the Royal Tribunal of the Protomedicato) to issue licenses to doctors and pharmacists and to ensure practitioners properly adhered to humoral theory (Hernández Sáenz & Foster, 2001, p. 22). On an informal level, medical ideas were also transmitted via medicinas casera (“home remedies”) brought by the

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19 However, it is rumored that Cortes wrote to King Charles V not to send Spanish doctors because indigenous medics were more than competent (Hernández Sáenz & Foster, 2001, p. 22). Whether or not the anecdote is true, it reflects the highly developed medical tradition that existed prior to the Spaniard’s arrival.
Conquistadores who had their own folk conceptions of illness and medicine (Hernández Sáenz & Foster, 2001, p. 23). Folk illnesses like *mal de ojo* ("evil eye"), *susto* ("fright"), *pérdida del alma* ("soul loss"), and others were introduced to indigenous groups for the first time. Yet neither formal nor informal medicines succeeded in totally displacing indigenous medicine. Rather, they were synthesized in what Aguirre Beltrán (1992) calls a process of "acculturation," an ongoing evolution and eventual fusion between multiple systems of thought. To this end, the "traditional" medicine that exists today in Oaxaca is a product of this complicated history. Contemporary traditional healers recognize illness categories like *mal de ojo* (folk ideas introduced informally), understand illness through a humoral framework (introduced formally), and offer treatment through administering local herbs and other techniques (drawn from indigenous medical knowledge).

This all signals a larger point I wish to make about Teotitlán and Oaxaca’s broader cultural landscape. Although facets of the past may be witnessed in the present – and although Teotiteco identity is premised on maintaining local tradition – this does not suggest that culture or tradition are fixed constructs rooted in history. Religion, medicine, and government structure are neither indigenous nor foreign, but rather symbols of Mexico’s complicated syncretic history. Tradition is paradoxically not the maintenance of time-honored practices, but rather the ongoing evolution of those practices within the surrounding climate. In what follows, I continue to develop this argument by reviewing other dimensions of life in Teotitlán.
Migration: The Elasticity of Teotitlán

Migration is a defining feature of life in Teotitlán and I was often struck by how frequently individuals traveled across borders. The Zapotec word for the United States – *Stub Laad* – literally means “the other side,” testifying to the normality of crossing the national border. Indeed, the resounding presence of California within Teotitlán was salient in nearly every local interaction I’d had. For example, on a return flight to Oaxaca from California, I met a Teotiteco who was visiting for three days to attend the confirmation of a godchild. Because migration is so central to local life, in this section I focus on how it has changed what it means to identify as a Teotiteco today.

Post-independence and revolutionary ideology helps begin to contextualize Oaxaca’s large-scale migration patterns, although it is an oversimplification to simply trace the origin of one phenomenon as the consequence of the other. Paltry living

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20 In addition to national borders, I also refer to the migration from the community that occurs when individuals relocate to different domestic cities and states.

21 After Mexico gained independence in 1810, politicians were ambitious to create a nation of citizens united under the same laws, religious values, and aspiration for industrial growth. Prior to this period the Catholic Church controlled the majority of civic and public life, including the majority of the nation’s hospitals. This changed during the mid-19th century, with the federal government insisting on the separation of Church and State, taking control of religious property, including hospitals. Mexico’s independence was a period that established momentum towards the goal of socialized medicine (and marked the transition from humoral medicine to biomedicine) (Finkler, 2001b, p. 63).

Yet the drive towards economic and cultural development also fomented a national image of the indigenous “Indian” as an obstacle, in need of being appropriated within national culture. The sentiment ruptured after the Revolution of 1910 with almost obsessive preoccupation in creating a new nationalism that sought to *“mestizo-iz* the indigenous population. These ambitions perpetuated racist ideologies and exerted pressure for indigenous communities to engage in the national workforce. *Indigenismo* was a core feature of revolutionary and post-revolutionary ideology, centering on an idea of Mexican national identity that romanticized indigenous culture as the origin of Mexico, while, in so doing, creating a construct of the “Indian” as a figure of the past at odds with modernity (Lewis, 2006).
conditions and local discrimination relate to the way indigenous peoples are viewed as living “backwards” and how they are commonly excluded from the national agenda. For the past 100 years, Oaxacans have migrated, in part, to escape these conditions (Jeffrey H. Cohen, 2004, p. 93).22,23

Most often, literature on migration is presented with regard to the profound disruption it causes on economic, familial, and communal life. With half of Oaxaca’s population living in communities of less than 2,500 people (INEGI, 2014), many communities fear the real threat of becoming pueblos fantasmases (ghost towns) and are faced with the challenge of responding to what Holly Worthen (2012) calls “the presence of absence.” There is greater burden on remaining residents to uphold endangered local forms of governance and religious customs; families and communities struggle to

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22 Oaxacan migration began during the years preceding the Mexican Revolution when individuals sought refuge from fighting, and expanded during the U.S. bracero programs that welcomed Mexican migrant workers during the 1910s and again in the 1940s to satisfy labor shortages caused by both World Wars (Jeffrey H. Cohen, 2004, pp. 54-56). Teotitecos participated in both braceros but achieved greater mobility to move back-and-forth in 1986 with the U.S. Immigration Reform and Act that gave migrants the legal opportunity to have permanent residency (J. Fox & Rivera-Salgado, 2004, p. 6). Today, Teotiteco and other indigenous migrants have continued to move in pursuit of economic opportunity, giving rise to what Charles Hale (2002) calls the “extraordinary mobilization of indigenous people” (p. 485). Over 60% of Oaxacan households have at least one member living in the U.S. (Jeffrey H. Cohen, 2004, p. 6). And, despite Oaxaca’s small size and distance from the U.S. border, Oaxacan migrants account for 4% of the U.S.’s total migrant population (Jeffrey H. Cohen, 2004, p. 20).

23 Yet many of Oaxaca’s indigenous migrants continue to face discrimination once in the United States. Though my acquaintances in Teotitlán reported having positive experiences in the U.S., many migrants are unable to speak Spanish and are discriminated against by other Mexican migrants as indicated by terms like “Oaxaquitas” (“little Oaxacans”) and “Indios sucios” (“dirty Indians”) (J. Fox & Rivera-Salgado, 2004, pp. 11-12).
maintain a sense of cohesion; and local economies become dependent on remittances (Jeffrey H. Cohen, 2004, pp. 111-123).24 Furthermore, migration carries ramifications for the psychological wellbeing of those who remain and return. For example, Whitney Duncan’s (2012) study on Oaxaca’s mental health industry shows that clinical practice is flourishing, in part, as a response to the pervasiveness of migration and associated psychosocial stress.

While migration is indisputably a serious threat, studying Teotitlán proves to be so fascinating because its statistics are on par with other Oaxacan communities yet it has managed to retain socioeconomic stability. Teotitlán’s population does not appear to be dwindling and local traditions remain vibrantly alive. Nevertheless, Teotitlán is like most other Oaxacan communities – on the move. Like I learned about Alex’s personal experience in California, many of my acquaintances and friends had spent time working there, and virtually all had some members of their family currently living abroad. In this way, I came to witness what Lynn Stephen (2007) calls the “utter normality” of migration, of people living and working in discontinuous cultural space (p. 5).

Since the 1940s, many of Teotitlán’s residents have migrated and established “mini” Teotiteco communities in specific Californian cities like Santa Ana, Oxnard, and, to my surprise, Moorpark, which is just a ten-minute drive from my family’s home. Indeed, one of my most extraordinary initial experiences in Teotitlán was the ease with which I was able to converse about my own background. Having recently studied in Pittsburgh, Pennsylvania, where I had to vaguely state to friends that I grew up in a town

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24 This last point on the negative effects of remittances is controversial. Some argue that remittances improve poor economic situations.
“north of Los Angeles,” in Teotitlán I was amazed to be able to talk about specific hometown streets, shopping complexes, and other cultural markers of my childhood.

Teotitecos migrate for economic opportunity and, apart from selling textiles, a significant amount of Teotitlán’s economy derives from remittances (Stephen, 2007, p. 10). It is estimated that Oaxacan remittances make up 17% of the state’s GDP, sending 1.3 billion dollars per year (Worthen, 2012, p. 6). Beyond this, Teotiteco migrants are locally involved in other key ways: they return home for fiestas, establish links to the international textile market, and some even maintain dual professions on each side of the border.

Migration is not a one-way force, and Teotitlán is significantly impacted both by migrants leaving and returning home. This is a theme discussed by W. Warner Wood (2000, 2008) in his study on Teotitlán’s textile industry, where he argues that local features like migration entail that researchers can no longer distinguish between local versus global influences, but rather must appreciate how the global is present within the local (see also Ruiz Balzola, 2014). This is what makes migration so important to conceptualizing Teotitlán: it shifts Teotiteco culture, stretching local definitions of identity and citizenship to transcend the physical parameters of the community. Yet, by the same token, in a community where location is vital – where the Zapotec spoken in Teotitlán is distinguished from language practices just miles away – this dynamic reveals fascinating characteristics.25

25 While there exist many attempts to conceptualize migrant communities and ties to hometowns, I follow Stephen’s (2007) use of the term “transborder” to capture the way in which Teotiteco migrants cross not only state lines, but ethnic, class, cultural, and colonial ones as well. In addition to Stephen’s term, others have conceptualized migrant communities with different emphases on different features of life: transmigrants (Jeffrey H Cohen, Gijón-Cruz, Reyes-Morales, & Chick, 2003), transnational communities
Teotitecos living abroad continue to honor communal traditions such as performing the *Danza de la Pluma*, speak Zapotec with family, and bestow a sense of cultural belonging to new generations. Hence, in contrast to Murphy & Stepick (1991) who claim that Oaxacan migrants jettison traditional customs (p. 129), Teotitlán’s migrant communities are extensions for traditional practice. They have become what Michael Kearney (1995) calls “Oaxacalifornia,” a type of transnationalized space where Oaxacan migrants physically live abroad, but uphold and identify with “local” tradition. To cite but one example, many friends and acquaintances have proudly told me that, while their children have lived all their lives in California, they are fluent in Zapotec.

I deliberately feature these issues to clarify what I take culture to mean, and how Teotitlán’s ever shifting culture is not a symbol of something being lost, but a phenomenon that continues to live. At least originally, as Raymond Williams (1977) reminds us, the word “culture” was used as a noun to describe process: the culture of something, like crops, animals, or minds (p. 13). Today our definition is different. I take culture not as a set of prescriptive norms (e.g., something one must do in order to be part of the culture), but rather as an orientation people have to their social world that draws upon “shared-in-common resources” (J. A. Holstein & Gubrium, 2012, p. 163). This idea is similar to what Clifford Geertz (1973) calls the “webs” of meaning inherent to a group of people (p. 5). This does not suggest that culture is static; rather, following Michel Foucault (1972), culture is always in the making.

The cultural changes I come to analyze in this study – like local conceptions of aging, family loyalty, and responsibility – are real and substantial; but, again, this does (Kearney, 1995), dispersed community (W. W. Wood, 2008), and translocal community citizenship (J. Fox & Rivera-Salgado, 2004).
not suggest that Teotitlán is becoming any less Teotiteco. As James Clifford (1988) argues, culture it is not a romantic and timeless object that represents authenticity. Rather, it is a contested, changing, and complicated worldview that is situated “between two metanarratives: one of homogenization, the other of emergence; one of loss, the other of invention” (p. 17). Clifford’s characterization is detectable in nearly every facet of my experience in Teotitlán. For example, while the Zapotec spoken in Teotitlán is unquestionably an indigenous language, it continues to evolve and incorporate words from both Spanish and English.

More recent scholarship in anthropology has provoked us into viewing culture not as an entity positioned against alien forces, but rather as constituted by them. This is a point made by W. W. Wood (2008) in his own ethnography on Teotitlán. He argues that the Zapotec culture that is so definitive of Teotiteco textiles is not something that has survived global forces, but is rather a product of those forces. Wood turns to anthropologist Richard Wilk (2006) whom he credits with the idea. Wilk provocingly asks:

Does local culture persist despite globalization, like a nail that will not be hammered down?... Or could it be that there is something about globalization itself that produces local culture...? We have been so convinced that colonization and globalization are forces of homogenization and the domination of local cultures by modernizing and globalizing Euro-American culture that it takes a real effort to switch gears and consider this possibility… (p. 10, emphasis original)

This approach is vital in accounting for how culture in Teotitlán is situated within the broader social world. Further, it provides an account for why Teotiteco culture continues
to evolve. With this perspective, culture is not something that persists against alien forces, but rather is embedded and defined by those forces. In this way, and however much migration is perceived as a threat to local culture, migration is rather, in a paradoxical way, a defining feature of culture. This is a theme I continue to develop throughout this study, and the theoretical framework for how I conceptualize daily life in Teotitlán.

*Household and Community Structure: Local Customs in a Globalized World*

The 1994 Zapatista uprising in the Mexican state of Chiapas put indigenous issues in the spotlight of national and international politics. Deliberately scheduled to coincide with the first day of NAFTA’s implementation, the uprising signaled Mexico’s failure to *mestizo-ize* indigenous communities, and their decades of simmering anger for being marginalized at the expense of national efforts to engage the international market.

Neoliberal reforms were first introduced in Mexico during the 1980s, intended to reignite the national economy after a severe economic collapse (Haber, Klein, Maurer, & Middlebrook, 2008, pp. 66-77). And, since this period, Mexico has continued to introduce various reforms to try to reengage its economy with the broader world.

Though this history may seem abstract, it carries a direct impact on daily life in Teotitlán. Upon countless occasions I was told that life has changed primarily because people are now preoccupied about finances. “Before the corn grew easily and you could always count on having a roof under your head,” one acquaintance told me. “Now, that’s

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26 Neoliberalism is broadly understood as a *laissez-faire* capitalist approach to accommodate to the demands of global capitalism, and was viewed as an economic strategy to reposition Mexico’s role in the international market.
just not enough – people are always worried about making enough money to survive.”

Having discussed migration, in this section I now trace the effects of this history with specific focus on the evolution of the household and community structure.27

Like many other Mexican settings, notions centered on family obligation are definitive of life in Teotitlán. *Familismo* or *carnalismo* are but two concepts that point to the common experience of loyalty to one’s “blood,” a commitment to serve the larger group over concerns for oneself (Calzada, Tamis-LeMonda, & Yoshikawa, 2013; Cervantes, 2008, p. 12). The way in which human resources are collectively pooled is an important strategy to survive economic challenges. It is so common that nearly all ethnographies on Oaxaca argue that the household – and not the individual – is the primary social unit (Jeffrey H. Cohen, 2004; Murphy & Stepick, 1991; Norget, 2006).28

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27 Another significant change of this period’s economic reforms involves the healthcare sector (Haber et al., 2008, pp. 167-171). Though highly disputed, Mexico today claims to have reached universal healthcare coverage with a complicated 3-tiered insurance industry. All individuals in the formal economy are guaranteed health coverage through either the IMSS (social security for workers in the private sector) or ISSSTTE (for state workers). While these programs provide coverage for approximately half of Mexican citizens, they are not as important in serving Teotitlán because its residents are mainly a part of the informal economy. The third insurance program, enacted in 2003, is the *Seguro Popular*, designed to cover individuals not part of the formal workforce, who are more economically disadvantaged compared to the rest of the national population. Though this program has dramatically increased enrollment, critics have argued that it does not guarantee access to quality care, or ensure that healthcare services are utilized among poorer populations (Gutiérrez, 2014). Moreover, these developments were financed through legislation that simultaneously challenged indigenous communities. Much of Mexico’s neoliberal reforms worked to privatize land, end farming subsidies, and implement free trade policies – changes that placed greater pressure on indigenous communities to jettison local customs in favor of international engagement.

28 To illustrate how households are primary, in Teotitlán the onus to fulfill cargos does not fall on specific individuals so much as on the household. This also helps navigate the complicated issue of how residents living abroad are able to fulfill cargos and tequios (volunteered labor for short-term projects).
To this end, Cohen (2004) succinctly writes that “To ignore the important role of the household is to misunderstand how rural Oaxacans create their social universe” (p. 23).\(^{29}\)

This outlook is illustrated through examining household structure. Family members predominantly comprise Mexican households: nationally, 91% of households are families (of which 73% of made of nuclear families, and 27% of extended families) (INEGI, 2014, p. 33). In Teotitlán these statistics differ slightly: family members define households, but extended members more frequently occupy them. This is partly because tradition encourages extended families to live together. For example, when a man marries it is customary for his wife to re-locate to live with him and his parents. In this way, I realized early in my fieldwork that I had to re-adjust my understanding that households do not consist of single nuclear families. Many households had more than one nuclear family present, which, I was to learn, carried implications for how responsibility was allocated and members were supported.

Within Teotiteco households, age and gender are two primary classifications that define authority (Jeffrey H. Cohen, 2004, pp. 41-42; Murphy & Stepick, 1991, pp. 145-149). The eldest man of the household carries most authority, followed by next eldest adult son. Typically, men are expected to provide financial support through weaving production and sales, small-scale farming, and fulfilling cargos. In contrast, women have

\(^{29}\) Of course, being loyal to one’s family does not imply that individuals cannot act autonomously; individuals often do act independently, leave families, etc. – but these decisions nearly always occur in the implicit background of one’s obligation to the family. Moreover, as Anya Royce (2011) argues, one’s sense of obligation does not prevent individuals from crafting their own lives or fulfilling their own dreams (p. 2). Individuals see the world through the lens of their families and find personal meaning taking action to meet those needs. The point is that the family serves as a primary way to orient individuals to the world and imbue decisions with larger meaning or purpose.
traditionally lived under the authority of their husbands. A woman’s authority correlates with age so that a son’s wife is considered subservient to her mother-in-law (with whom she lives), and does chores allocated by this elder. Women are traditionally tasked with household chores, including preparing food, cleaning, and raising children. They also weave, and recently women have begun to be involved in *cargo* roles (including political posts, although this continues to be an exception) (see Stephen, 2005).

Yet however much the family is a bulwark in society, there is evidence that the strength of the traditional family unit is weakening. This is a trend across Mexico. Declining national fertility rates and delays in age of marriage mean that households now have fewer members to offer support. Further, the absence of men due to divorce, migration, and abandonment means that there exist greater women-headed households (Haber et al., 2008, pp. 165-167). For a small community like Teotitlán this trend significantly shapes daily life: whereas in 2000 there were 186 women-headed households, in 2010 these numbers dramatically increased to 280 (INEGI, 2015). In part, this trend may be traced to the broader effects of neoliberal policy and drive for capital gain: more individuals are migrating and pursuing careers outside the community, resulting in a greater number of households that are different than they were just decades prior. To be sure, family households continue to be the defining social unit – not a single individual I met lived alone or with friends. Yet in the process of conducting my fieldwork I was surprised to encounter more households that appeared piecemeal. Different members of family lived abroad for extended periods of time, and remaining

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30 Finkler (1997) has argued that Mexico’s move away from extended-family households to nuclear households leads to greater domestic violence (p. 1158).
residents came together to form a sense of community in a social setting that appeared to be subtly changing.

While appreciating the role of households is important, it does not fully account for the way in which family is locally defined. For example, when I first arrived to Teotitlán and learned about weddings, I was stunned to learn that typically only family members are invited, but that this means over a tenth of the 5,000 member community might be present. In Teotitlán and other Oaxacan communities, family networks extend beyond one’s literal bloodline and include individuals appropriated through compadrazgo networks, a type of godparenthood where a respected community member takes on financial and moral responsibility for one’s children. This dramatically expands the scope of whom one can call upon as family, and the way in which Oaxacans are able to depend on each other (see Murphy & Stepick, 1991, pp. 149-153; Norget, 2006, pp. 47-49; Sault, 1985; Stephen, 2005, pp. 49-50). Oaxacans’ extensive family networks may be confusing to an outsider, but they serve to foster greater confidence and solidarity within the community. Indeed, as Alex and I made progress in interviewing different households, one of the most baffling questions I had posed to him was who would take care of an elder if he or she should not have family support. Alex and every other Teotiteco I had questioned responded exactly the same: “Your question doesn’t make sense here.” In Teotitlán there is a common understanding that every individual exists within a larger family network, and it is inconceivable that a person would find him or herself without recourse to family support. (Of course, this simplified answer is a lot more complex, which is an issue I turn to later in the study.)
As a capitalist-based lifestyle is relatively new in Teotitlán, there exist other ways of differentiating members of the community that are not based on capital wealth. Perhaps the most significant concerns the idea captured by the Zapotec word *respeto* ("respect," deriving from the Spanish "respeto") – which played a tremendous role in how I would conduct my study. *Respeta* is a concept that refers to the amount of authority and honor a person is endowed by other members of the community. Though abstract, this concept is practiced in specific ways. Respected individuals are greeted with a distinct handshake and spoken to with different pronouns and verb conjugations. Traditionally, the amount of *respeto* given to an individual is based on age such that elders are inherently given more *respeto*. Elders are given respect on the basis of their age, accumulated life experience, and wisdom of community traditions. They are called upon to arbitrate disputes and have the last word of authority. In wedding ceremonies, for

Figure 2.5. Bus with advertisement about respect for elders in Oaxaca City. (Photo by the author.)
example, a family elder is appointed to offer advice to the newlywed couple and family. And, as I will continue to discuss throughout this study, the Zapotec word for an elder – *benguul* – literally refers to an aged person, but it is an implicit reference to the amount of respect a person has earned.\(^{31}\) That is why, when Alex and I approached households to be interviewed, he knew to first ask for permission from the *benguul*, who made decisions on behalf of the family.\(^{32}\) In addition to age, *respet* is also allotted according to number of godchildren sponsored, number and type of *cargos* the household has completed, and number of fiestas offered to the community. (Again these criteria also correlate with age.)

Yet even this local practice is evolving. A greater number of prestigious *cargos* are available without needing to spend time ascending hierarchies. And, upon countless occasions, I encountered people who talked about how younger generations fail to have respect for their elders. In this way, and like how I have come to understand what culture means, I came to see Teotitlán not as a community petrified by tradition, but one vibrantly in-motion. As Stephen (2005) so eloquently describes in her ethnography, Teotitlán is best understood as existing within a dynamic between two contrary forces, between a kin-based ideology that fosters community solidarity and a class-based ideology that emphasizes accumulation of wealth (p. 6). This is the setting that would come to define the subsequent parameters of my investigation.

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\(^{31}\) Technically, a person does not need to be an elder in order to be called a *benguul*. Every household has a *benguul* – a man that holds the highest amount of authority. However, most households are intergenerational, thus conflating the two concepts. Moreover, locals’ first association when they hear the word *benguul* is a reference to elders.

\(^{32}\) This also justifies my subsequent shorthand approach to refer to various households by citing the oldest man.
As a whole, this chapter demonstrates how Teotitlán is defined by local traditions and histories, and how these features have constantly evolved. Teotitlán proves to be a rich site for ethnographic study not because of what is being lost but rather, drawing on my understanding of culture, for how its traditions are alive in the context of change. This is not only important for appreciating local history; it is vital towards understanding the injunction to keep local practices alive. In the chapters that follow I proceed to show how elders and their caregivers serve as prisms into this process. The changes represented by elders with Alzheimer’s disease – and the way in which caregivers are dealt responsibility – provide an illustration of how local traditions continue to exist within this dynamic. To this end, I now turn to examine aging in Teotitlán and the way in which elders are perceived in light of these changes.
CHAPTER THREE

Towards Understanding Alzheimer’s Disease in Teotitlán

The greca is one of Teotitlán’s most prevalent images, celebrated in engravings on church walls, stamped on major streets, and woven in many rugs. Traced back to ancient Zapotec ruins, today it is known as an important symbol of a traditional conceptualization of life. The greca is a pattern containing five descending steps that, at its termination, rotates direction and initiates another set of steps (see Figure 3.2). Each step is said to represent a different lifecycle stage while its transformation into another greca is a symbol for death and generational continuity. Deriving from ancient Zapotec culture, the greca is heralded as a connection between past and present. Yet however much this symbol remains a part of Teotitlán’s heritage, I have already begun to show how local traditions are not fixed in the past but continuously redefined in the present. In this chapter I continue developing this theme with specific focus on aging and related disorders. I argue that these social phenomena are symbols of broader social change and, in the process, introduce relevant theoretical frameworks that will serve as the basis of my subsequent investigation.

The “Problem” of Aging in Teotitlán

At the intersection of Teotitlán’s two principal roads there exists a series of hand-painted murals depicting various public health initiatives. There are murals to promote awareness of Dengue fever, the right to receive sexual education, the dangers of domestic
violence, and, within this series, one will find a bold statement on aging. This mural’s red title announces “Seniors” [Adultos Mayores] and underneath states: “Age Doesn’t Limit the Pursuit of New Experiences” [No Hay Edad Para Sorprenderse a Uno Mismo]. In the middle there is a large illustration of a yellow pyramid with one side that specifies factors that lead to successful aging (diet, exercise, socials support, and health), and another side that lists inhibiting factors (addiction, self-neglect, lack of exercise, and poor diet). On the top of the pyramid stand two elders holding hands, providing an image of what health looks like in old age. Underneath the illustration reads: “The Problem of Old Age Isn’t Age Itself” [El Problema de la Vejez No Es la Edad].

Figure 3.1. "The Problem of Aging" mural. (Photo by the author, digitally edited by Michelle Nermon to remove telephone pole.)
Of course, by stating that age is not the cause for “the problem of old age” the mural suggests that there is a problem to be dealt with. The mural speaks to the growing problems faced by elder Teotitecos, and tries to promote an alternative vision that promises greater fulfillment, social integration, and novel experiences. While the mural certainly makes a call to action for elders to improve their lives, it also implicitly speaks to the broader Teotiteco population by offering a statement that being old is not a disability, and that elders are capable of being functional members of the community. This statement may come as a surprise. As discussed in the previous chapter, Teotitlán has traditionally valued elders precisely for their age and perceived authority of local

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Figure 3.2. Two depictions of grecas. The above image contains two patterns with grecas: the first is a photograph of Zapotec ruins in Mitla, and the second of a rug woven in Teotitlán. (Photos by the author.)
tradition. Elders are the first to be called on in weddings and other fiestas. Indeed, even the Zapotec word for elder – benguul – connotes a vision of honor and respect simply on the basis of age, much like the word “president” does.\(^{33}\) The juxtaposition aptly signifies that a major change is transpiring. Whereas elders are said to be respected precisely because they are elders, now there exists a mural to contest their discrimination. In this section I begin to analyze factors that help contextualize this change, and discuss how it introduced new problems to the Teotiteco community.

It is an often-repeated trope that elders have lost the respect traditionally given to them, but in Teotitlán there is evidence that this complaint carries tangible implications. Elders have traditionally been known as having the last word (la ultima palabra) and were thus known as being integral in presiding over local politics and community life. For example, the former political authority allotted to elders via the cargo system has been steadily undermined such that younger candidates are holding positions that were traditionally allotted to elders. Kate Young (1976) describes the case of village elders in another Oaxacan community who have lost their prestige to hold public office to members of the community that emphasize youth, accumulation of wealth, and engagement with national culture (see also Stephen, 2005, pp. 233-235). In Teotitlán Mary Gagnier de Mendoza (2005) describes public celebrations of events like Holy Thursday, and parenthetically mentions that the role traditionally prescribed to a cohort of respected elders to reenact the story of Christ was recently given to younger

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\(^{33}\) As discussed in the previous chapter, the word benguul is also used as a term to denote the head of the household. Each household – even if it consists of just newlywed couple – has a benguul holds the highest authority and respect.
community members (p. 91). Though subtle, these examples help contextualize the way in which traditional roles prescribed to elders have recently begun to erode.

A closer look at two demographic patterns helps provide initial context. The first demographic pattern concerns the overall number of elders in society, both in number and proportion of the population. Teotitlán’s percentage of elders (defined as over age 60) has risen from 8% in 1980 to 15% in 2010. This stands in contrast to the national average in 2010 where people over 60 comprised 9.1% of the total population. The overall increased proportion of elders in Mexican society is a reflection of a national demographic

transformation: whereas there are currently 9 children for every elder, in 2050 there will be an equal number of elders to children, and elders will represent one-fifth of the total population (Jackson, 2005). Mexico’s improving longevity is a result of public health campaigns initially launched during the middle of the 20th century to better control infectious diseases, meet nutritional needs, and improve medical care (Haber et al., 2008, pp. 163-171). This, coupled with lowered mortality and fertility rates, family planning campaigns, and promotion of contraceptives gave rise to a population that is quickly aging (Wong & Palloni, 2009, pp. 236-237).34

A more focused perspective of this trend within Teotitlán reveals how remarkable it is. From 1930 (when census data is first available) to 2010, Teotitlán exhibited a 133% increase in overall population, with 76% increase in youths (aged 0-19), 133% increase in

34 This trend is not exclusive to Mexico, but mirrors worldwide statistics where improving longevity rates are also equally unprecedented: by 2050 the number of older persons will exceed the number of young for the first time in world history (United Nations, 2002, p. xxviii).
adults (aged 20-59), and a disproportional 644% increase in elders (aged 60+) (see Table 3.1).\textsuperscript{35} Or, stated differently, whereas in 1930 there were 8.6 youths for every 1 elder, this

Table 3.1. The Prevalence of Elders in Teotitlán

![Prevalence of Elders in Teotitlán](image)

ratio progressively dropped such that by 2010 there were only 2 youths for every elder. Teotitlán has followed national trends regarding fertility and mortality rates, but the prevalence of migration has also contributed to the growing presence of elders who are not physically capable or cannot afford to join families living abroad. Overall, these patterns indicate that elders are significantly more prevalent than ever before in Teotitlán’s demographic history.

The second change concerns differences within the aging population itself: more people are living longer, reaching ages that were previously unimaginable. Whereas in

\textsuperscript{35} All subsequent demographic information was acquired through individual study of data provided by Mexico’s census bureau, Instituto Nacional de Estadística y Geografía (INEGI, 2005).
1921 national life expectancy was 32.9 years, by 2010 life expectancy became 74.5 years (77.4 for women and 71.7 for men) (INEGI, 2015; see also Partida-Bush, 2005). Increased longevity has also occurred in Oaxaca State, despite the fact that Oaxaca had one of the lowest life expectancy averages of 72.5 years in 2013. In Teotitlán, there were just 2 individuals who reached 80 years or more in 1930 (constituting less than 0.01% of the total population), whereas the number of “old-elders” has steadily risen such that by 2010 there were 175 individuals (comprising 3.1% of the population). These two demographic patterns suggest that Teotitlán is encountering a new experience of old age where elders are simultaneously more prevalent in society and aging longer than ever before. These changes have undoubtedly ushered in others as well. There is now greater prevalence of illness associated with old age, economic dependence, physical disability, and restrictions on community participation.

Further, while there are overall more elders in need of greater care, there are fewer younger individuals who are able to meet their needs. Lower fertility rates, improved life expectancies, and migration patterns have all contributed towards this trend, such that today Oaxacan elders not only find that they have fewer children to care from them, but they also have more family members living abroad. This observation invokes recent work in “social suffering,” a subfield of medical anthropology that views what have been considered individual experiences as inseparable from social forces (Kleinman, Das, & Lock, 1997). This approach collapses traditional dichotomies like “individual” and “collective” to show how suffering is at once collective and individual. As I will argue in more detail in subsequent chapters, the suffering of age-related disorders (including the experience of caregiving) is not just a consequence of old age,
but also a reflection of the social context in which it is situated. To this end, a recent article in *Síntesis*, a local newspaper, reports that 5-10% of all elderly patients arrive to Oaxacan hospitals because they have been abandoned and have no social support (Jiménez, 2014). Although in my fieldwork I was assured that Teotitlán is an exception and has managed to provide care for its elders, there is evidence that here, too, resources are limited. Hence, the problem of aging does not merely concern elders, but the entire Teotiteco community. It concurrently points to the different needs that arise in an aging population, and the way in which resources to respond to those needs have increasingly become strained.

*The Social Construction of Aging*

Insofar as Teotitlán faces a “problem” with elders, how is one to conceptualize its nature, assuming it has one? How can the Teotiteco community see the same cohort of individuals differently such that a campaign has been issued to curb this change? And, more importantly, how can the experience of aging in Teotitlán have changed to such a degree that arguments are now issued to claim that “Age itself is not the problem”? While demographic information helps contextualize changes, these questions pertain to the meaning of old age and, as such, numbers alone are insufficient. Drawing on the social constructivist theory (Berger & Luckmann, 1967; Hacking, 1999), Teotitlán’s problem of aging can be said to be an expression not of the demographic changes themselves, but of the way elders, their families and the broader community has responded to those changes. It concerns the meanings attributed to old age and the way in which those meanings

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36 For example, Stephen (2007) provides a brief vignette of a Teotiteco elder with gnawing anxiety about who will look after her in her old age now that her children have migrated to the U.S. (p. 310).
shape the experience of aging, both for elders and the broader community. As Carol Estes (1979) wrote over 35 years ago:

What is done for and about the elderly, as well as what we know about them, including knowledge gained from research, are products of our conceptions of aging. In an important sense, then, the major problems faced by the elderly are the ones we create for them. (p. 1)

Understanding Teotitlán’s problem of aging through this perspective helps emphasize that the local meaning, experience, and reality of age is not fixed, but rather dependent on negotiations within local culture and broader socioeconomic factors (Gubrium & Holstein, 2000). Consideration of aging as socially constructed simultaneously points attention to how meanings of growing old have been taken for granted, and also implicitly states that the current problem of aging is not a necessary outcome of present circumstances (Hacking, 1999, p. 6). In this section I seek to examine the nature of these negotiations and to further consider how their outcome shapes the reality of growing old.

To be sure, a social constructionist approach to aging is not new and many researchers have adopted this perspective for decades (see for example Carroll Estes, 1979; Gubrium, 1972). My reason for invoking a theoretical perspective that some may consider dated is not out of fidelity to theoretical history, but because it is the most relevant theory to explain the phenomena I encountered in Oaxaca. Indeed, much of current gerontological and all of anthropological work continues to be premised on social constructionism. It was first applied to study aging during the 1970s when gerontologists sought theoretical justification to respond to two dominant perspectives in the sociology of aging (e.g., see Carroll Estes, 1979; Gubrium, 1972; Harris, 1975). First,
gerontologists sought to contest Cumming and Henry’s (1961) disengagement theory
which posited that the individual and society mutually prepare for separation in
anticipation of death, such that the aging individual gradually becomes further
disengaged from society. This view not only suggested that social disengagement is
typical for elders, but that disengagement *ought* to occur during the aging process.
Although disengagement theory is no longer popular amongst contemporary
gerontologists – it perpetuates ageist stereotypes rather than ameliorates them (Butler, 1975) – many public institutions like U.S.’s Medicare and the Mexican pension system
(*70 y Más*) are founded upon it (with a rationale that the government must provide
assistance to elders who are presumed unable to provide for themselves). Later
gerontologists turned to social constructionism as a response against Rowe and Kahn’s
(1987, 1997) successful aging theory, which argued that elders are capable of aging
“successfully” – defined by avoidance of disease and disability, maintenance of physical
and mental capacity, and engagement in life. This theory was originally intended to be a
positive alternative to past gerontological theories, but it carried the concomitant burden
of establishing an ideal of aging that proved, for many, to be unattainable (M. B. Holstein

Instead of prescribing how elders ought to age, gerontologists turned to social
constructionism to describe how the aging process is inherently multifarious and
contingent upon social factors and contexts. They argued that old age is a social construct
that varies across cultures and historical periods (Achenbaum, 2005). For example,
Thomas Cole (1992) shows how, during 16th and early 17th centuries, U.S. culture extoled
aging precisely for how it highlighted fragility and dependency – features which then
were interpreted to characterize man’s ultimate relationship with God. Later, during 18th and 19th centuries, these ideals gave way to the pursuit of capitalistic enterprise, passion for material wealth, and personal autonomy. Aging increasingly became a symbol of moral failure, representing the “old world” of patriarchy and embarrassment of the limitations of self-control (p. 91).

Through social constructionism, aging and the features associated with it – senility, dependency, and physical debilitation – became understood as a relational process, not something that elders undergo irrespective of their social surroundings (Cole & Ray, 2010; Gergen, 2009). In this way social constructionism offered a means to challenge the tendency to reduce aging to an individual problem, inviting consideration of how surrounding culture was not only contextualizing the problems faced by elders, but also complicit in perpetuating them. Gerontologists have mobilized social constructionism to raise awareness about implicit ageist assumptions (Butler, 1975), to improve social policy designed for elders (Bernard & Scharf, 2007; Carroll Estes, 2001), and to inform caregiving practices to meet psychosocial needs of elders (Kitwood, 1997; Sabat & Harré, 1992).

More recently, researchers have begun to explore how contemporary biomedicine and related technological apparati have shaped our knowledge of even basic life

37 Bruno Latour (2007) has issued a strong critique on disciplines like social constructionism for presupposing the “social” as a type of material that differs from other phenomena (like aging). Latour argues that it is erroneous to posit that something like a social realm can be mobilized to explain world phenomena when it is precisely how aging exists socially that sociologists must pursue. In sum, his argument is that social constructivists are putting the horse before the cart. While I agree with Latour on epistemological grounds, I continue to reference work in social constructionism for its emphasis on different cultural lifeworlds in which phenomena like aging can transpire, and the differences between those settings. I take up this issue again in the following chapter.
processes like aging and death. Paul Rabinow’s (1996) famous essay on “biosociality” provoke us to consider how new social identities and forms of relationships are being formed on the basis of biological constructs. Further, biosociality suggests that one of the consequences of contemporary biomedicine is that the traditional boundaries between nature and culture are increasingly collapsing such that what was once considered immutable (nature) is now being operationalized and re-defined by cultural norms. In this vein, Nikolas Rose (2007) argues that “technologies of life” – i.e., biomedical practices that allow for biological and genetic intervention, “do not just cure organic disease, but change what it means to be a biological organism by making it possible to refigure – or hope to refigure – vital processes themselves” (pp. 17-18). And in a related tone, Margaret Lock (1997) argues that biological interventions that are designed to alleviate suffering actually introduce new forms by confusing basic social distinctions between life and death. This line of research further demonstrates the constituting power that culture has in shaping our experience and definition of basic life processes.

Yet to say that Teotitlán’s problem of aging is socially constructed is not to dismiss the real and acute dilemmas facing the community, elders, and their families. Nothing here negates the demographic facts presented above that demonstrate that elders in Teotitlán are living longer and are in greater number than ever before. There are greater medical conditions associated with old age, a greater number of dependents that strain household finances, and more challenges brought by demographic changes. As I will explore throughout this study, these challenges are real and at times heart wrenching. However, merely focusing on demographic facts fails to consider how they are
inextricably relational, determined by the way they are socially contextualized and imbued with meaning.38

This investigation takes a broad social constructionist view of aging to contextualize the specific way Alzheimer’s disease is shaping the reality of growing old in Teotitlán. It considers how biomedical discourse about senility – which posits that elders forget because of brain pathology – directly impacts the Teotiteco community. In the next section I turn to discuss how Alzheimer’s disease can be viewed through social constructionism, and proceed to explore specific social parameters that have shaped its local meaning.

Construction(s) of Alzheimer’s Disease

Not long after my arrival to Oaxaca I encountered on the front page of NOTICIAS, one of the state’s most circulated and respected newspapers, a headline about Alzheimer’s disease. In bold letters it announced: 20 ALZHEIMER’S CASES HAVE BEEN DETECTED [20 CASOS DE ALZHEIMER SE HAN DETECTADO] (Chavela, 2014). Although the Mexican press is known for its sensationalism, I was nevertheless struck by the way Alzheimer’s disease was portrayed as an epidemic, in language that was remarkably similar to contemporary stories on the Ebola virus. The article describes that the State of Oaxaca is proposing to follow Mexico City, which has implemented a bracelet program to locate and return the growing number of older adults that wander

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38 The alternative, viewing aging through an essentialist lens, would maintain that the problem facing Teotitlán is inherent to demographic changes themselves. This perspective is unsustainable because it is illogical to conclude that elders have begun to lose traditional attributes like respect simply because of demographic changes.
from their homes. The article explained, “Many with it [Alzheimer’s] leave their homes and go astray” [Muchas de ellas salen de sus hogares y se extravían].³⁹ It continues to illustrate the difficulty of detecting Alzheimer’s disease because symptoms are often attributable to other conditions. It states that the disease is irreversible and progressive [irreversible y progresiva] and compromises an elder’s ability to carry out basic functions. The article concludes with suggestions for treating Alzheimer’s disease, with reference to medication that can slow disease progress and manage behavioral problems, confusion, and agitation. The article also suggests modifying the home environment and “offering help to the family who suffers the most” [ofrecer apoyo a la familia que es la que sufre más].

While I had arrived to Oaxaca intent on studying Alzheimer’s disease, I was struck by nuanced differences regarding how it was represented on a local level. The people I had met who had heard of Alzheimer’s disease usually confessed to have little experience or knowledge. They suspected that this was likely due the rarity of Alzheimer’s disease in Oaxacan society. As the NOTICIAS article demonstrates, Alzheimer’s disease is gaining local public recognition, but it is still considered exceptional such that the “detection” of twenty cases has made front-page headlines. In reflecting on this and the broader content of the article, I also took note of the way Alzheimer’s disease was described primarily as a disease that impacted family and social cohesion. Yes, Alzheimer’s disease compromised memory and cognitive functions on an individual level, but the significance of these debilitations appeared in the article to have

³⁹ The Spanish original is gender-biased and uses the feminine pronoun (“ella”) to refer to individuals that have Alzheimer’s disease. This provides additional insight to how Alzheimer’s disease is represented as a disease that primarily impacts women.
more to do with the broader community and its efforts to cope. For example, the article’s emphasis on home wandering seemed to overlook the more immediate concerns I had known of Alzheimer’s disease within U.S. settings. I was accustomed to the idea that Alzheimer’s disease slowly destroys selfhood by “erasing” memory, and that these symptoms compromise one’s autonomy by increasing risk of self-injury, like leaving the stove on or getting lost while driving. Yet I soon recognized that in Oaxaca and other Mexican settings, the same concerns about selfhood carried less weight. Elders were rarely left alone and placed in circumstances that would lead to the types of dangers I had known. In this way, I came to realize that the phenomenon I had planned to study while in the United States was – in some subtle, but important manner – different from what I would come to encounter while in Mexico.

Social constructionism helps account for these differences. It provides context into the various ways Alzheimer’s disease is made meaningful across cultures, much like the way aging has carried different significances across time. Saying that Alzheimer’s disease is socially constructed suggests that what we know of it is taken for granted and that the symptoms attributed to it are not necessary outcomes of underlying pathology. For example, writers have argued that the purported loss of selfhood that is said to transpire in late-stage Alzheimer’s disease is more the consequence of social failures – neglecting to socially include the elder, treating the elder as passive, etc. – than disease processes per se (Kitwood, 1997; Sabat & Harré, 1992). Drawing on Erving Goffman’s (1961) labeling theory, research on family caregivers shows that once an elder has been diagnosed with Alzheimer’s disease, individuals are much more likely to interpret ordinary behavior as symptoms of pathology (Gubrium & Lynott, 1987). What this shows
is that the meaning, gravity, and experience of Alzheimer’s disease (both for patient and observer) involve factors beyond neuropathology. These issues are social in nature and we must begin looking in that direction to gain more insight about them.

To claim that Alzheimer’s disease is socially constructed does not negate its gravity or underlying neurology. I want to state clearly that I take the profound memory loss associated with Alzheimer’s disease to be a real phenomenon, and, moreover, that the consequences of Alzheimer’s disease do have an impact on the person, his/her ability to maintain relationships, and capacity to carry out basic functions. Furthermore, my own experience working with elders with Alzheimer’s disease and their caregivers has revealed how painful it is to witness a person as the disease progresses. Adopting a social constructionist lens does not take away from these facts. Rather, as I explain in what follows, this perspective provides greater subtlety towards understanding how those facts are constituted by specific social parameters. Of course, I am situated by these parameters as much as any other person; I cannot willingly choose to experience these symptoms differently. Yet this perspective helps reveal how Alzheimer’s disease is not, in itself, the direct cause of our experiences, and, through this exercise, social constructionism may assist to develop alternatives ways of responding to challenges.

Nevertheless, it may appear odd to claim that Alzheimer’s disease – a specific neuropathology defined by the presence of amyloid plaques and neurofibrillary tangles – can be said to manifest differently, depending on the surrounding environment. To be sure, the neuropathology associated with Alzheimer’s disease does not change so much as the interpretation of what the neuropathology signifies. My position is closest to Ian Hacking’s (1986) concept of “dynamic nominalism” which posits that kinds of people
comes into existence at the same moment as the kind of categories used to make sense of them. Hacking looks at the emergence of dissociative identity disorder and social perversion as two case examples, but his argument is perhaps stronger for Alzheimer’s disease (see Lock, 2007). Dynamic nominalism does not negate that there exist underlying neurological features regarding forgetfulness; rather, it shows how those underlying features are understood through the social process of labeling them and turning them into social objects. Moreover, Hacking’s concept points to the ways that categories – like pathological and normal aging – are not static, but subject to the way we as a society dynamically use them. To use the title of his essay, this is the process of “making up people.”

Dynamic nominalism is striking in the history of Alzheimer’s disease and the way in which, for the first half of the 20th century, it was considered an insignificant disease that affected a very small number of people. This opinion, featured in the first report that documented “Alzheimer’s disease,” extends to 1906 when German psychiatrist Alois Alzheimer studied the case of a 51-year old woman who displayed symptoms of progressive dementia, hallucinations, and delusions. Alzheimer hypothesized that the symptoms he had clinically studied were a consequence of the neuropathology he had discovered during autopsy that revealed senile plaques and twisted bundles of neurofibrillary tangles. What is so interesting about this early history is that Alzheimer

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40 These symptoms have remained the defining feature of Alzheimer’s disease and account for the progression of clinical symptoms. Amyloid plaques and neurofibrillary tangles are known to first impair subcortical regions, including the hippocampus (responsible for memory-formation), and then spread to neocortical regions. This physiological progression accounts for the course of Alzheimer’s disease symptoms: difficulty remembering new information and depression are common early symptoms; confusion, disorganized thinking and judgment, and inappropriate behavior are moderate symptoms;
was focused on this case not because of senility *per se*, but rather because senility manifested in a woman considered too young to develop it. In other words, Alzheimer believed that the original significance of his discovery was not that people grow senile, but that people younger than previously assumed could become senile. Alzheimer called these cases “atypical forms of senile dementia,” implying that there is a “typical” form of senile dementia expected to transpire among older populations (quoted in Dillman, 2000, p. 136).

The original understanding of Alzheimer’s disease as something that affects people in their fifties – and that senility was a normal feature of aging – persisted until the 1970s, with age of onset being the only distinguishing criterion. In part, this began to change through the efforts of Robert Butler (1975) who argued against “ageism” which he claimed was inherent in the idea that senility is a typical feature of aging, and with the political campaign led by Robert Katzman who was one of the strongest voices to claim that age of onset should be eliminated as a criterion because Alzheimer’s disease and senile dementia (e.g., “normal” senility among elders) were, in fact, neurologically the same entity. Katzman’s successful campaign significantly increased the number of Alzheimer’s disease cases in the general population, and challenged the assumption of inevitable cognitive decline associated with old age (P. Fox, 1989, p. 73). This argument, combined with subsequent public awareness programs led by the Alzheimer’s Disease and Related Disorders Association (now known as the Alzheimer’s Association),

difficulty with basic motor tasks (including speaking, swallowing and walking), and seizures are found at the advanced stage. Alzheimer’s disease also increases susceptibility for pneumonia and other infections, indirectly leading to death.
transformed Alzheimer’s disease into one of the most popular and devastating epidemics (for further review of this history see Ballenger, 2006). 

While Alzheimer’s disease has gained a firm foothold in U.S. political and social discourse, the common assumption that Alzheimer’s disease is caused by underlying plaques and tangles has remained a contested issue. To date, there is no research able to provide a firm clinical-pathological correlation to distinguish neuropathology associated with Alzheimer’s disease from the standard course of aging. For example, the same plaques and tangles definitive of Alzheimer’s disease are found among all aging persons, irrespective of whether or not they exhibit cognitive impairment, and it is commonly acknowledged among researchers that there is no firm correlation between clinical severity of symptoms and histological severity. Some researchers even hypothesize, in contrast to the dominant opinion that plaques and tangles are the cause of clinical

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41 This history gave rise to the popular representations surrounding Alzheimer’s disease found throughout U.S. settings today. As of 2014 it is estimated that 1 in 9 older persons suffer from Alzheimer’s disease, with the majority (82%) aged 75 or older (Hebert, Weuve, Scherr, & Evans, 2013). The prevalence of Alzheimer’s disease increases with age such that persons younger than 65 years are estimated to have a 4% risk; those between 65-74 years carry a 15% risk; people between 75-84 years carry a 44% risk; and, for those who age beyond 85 years, the risk reduces to 38% (“2014 Alzheimer’s disease facts and figures,” 2014; Hebert et al., 2013). These numbers are projected to increase in severity such that, by 2025 when the majority of baby boomers reach age 65+ years, Alzheimer’s disease is expected to be prevalent in 7.1m Americans, a 40% increase from 2010 (Hebert et al., 2013). As Lock (2013) argues the mobilization of these numbers is designed to have a political effect.

42 Even the purported objectivity of scientific investigation to reveal pathology has been called into question. Researchers have argued that scientific tools like fMRI are a form of “cultural activity” whose findings are not given things-in-themselves because they necessarily are situated within a specific culture (Choudhury, Nagel, & Slaby, 2009; Margulies, 2012).

43 The famous “Nun Study” that examined the lifetime patterns of cognition amongst a cohort of nuns makes this point clear. Sister Mary, who had high cognitive test scores before her death at 101 also exhibited an abundance of tangles and plaques at autopsy (Snowdon, 1997).
symptoms, that they may be reparative or compensatory reactions (Glass & Arnold, 2012). The ambiguity surrounding Alzheimer’s disease is a resounding theme of Margaret Lock’s recent book The Alzheimer’s Conundrum (2013) where leading neurologists, geneticists, epidemiologists, and psychiatrists all express uncertainty about neurological substrates of Alzheimer’s disease, challenging us to “confront head-on the ontological question of what exactly is [Alzheimer’s disease]” (p. 2). Once again, my intention is not to suggest that Alzheimer’s disease is contrived, but rather to demonstrate that the interpretation of the meaning of pathology remains contested and shaped by social factors.

Though the neurological ambiguity surrounding Alzheimer’s disease is beyond the scope of this investigation, the way it has come to take on different meanings depend on the surrounding circumstances stands as this study’s theoretical foundation. Within the U.S. and other “biomedically-oriented societies,” the perceived threat of Alzheimer’s disease within the U.S. would be unintelligible in other contexts. As Atwood Gaines (1987) was the first to argue in the 1980s, the concept of Alzheimer’s disease is an explicit “Western concept” rooted in a culture that prioritizes cognition over relational capacities, physical functioning, and other dimensions of human life. To this end, Stephen Post (2000) argues that the common idea that Alzheimer’s disease is “a death

44 I invoke the term “biomedically-orientated society” to contrast Mexico (but specifically Oaxaca) with the United States, Europe, and other cultures where biomedicine has attained greater hegemony. This contrasts to Mexico and its high degree of medical pluralism (to be discussed in Chapters Five and Six). To be sure, biomedicine has always had a strong foothold in Mexico, yet it is not the only option in explaining and treating illness (see Duncan, 2012; Finkler, 2001b; Whiteford, 1995; J. C. Young & Garro, 1993). Moreover, this term also avoids implicit misconstructions caused by terms like “the west” (Mexico is a western nation), “Euro-American” (Mexico is in the Americas), and “industrialized nations” (Mexico is industrialized).
that leaves the body behind” is only intelligible within a “hypercognitive” culture that equates selfhood with cognition. In many ways, Alzheimer’s disease is so terrifying because it hits the core of what it means to be a person in U.S. society, so much that Jesse Ballenger (2006) writes that it “haunt[s] the landscape of the self-made man” (p. 9).

The question remains regarding what occurs when Alzheimer’s disease – a disease whose meaning and import is rooted in a specific culture – is introduced elsewhere. This is part of a larger phenomenon that Rüdiger Kunow (2010) calls “global aging” where biomedicine has begun to encounter, contest, and coalesce with traditional conceptualizations of old age and related conditions. Most anthropologists who take on similar issues implicitly posit that biomedicine is a hegemonic force that causes social experience to be interpreted through biomedical categories, and that this is part of an effort by the pharmaceutical industry to seek new markets. My view in this study is slightly different. Whereas biomedical hegemony has traditionally been viewed as a coercive form of domination, my sentiments better match Antonio Gramsci (1988) who articulated during the 1930s that hegemony is actually a bidirectional process between the powerful and dominated, such that the latter is an active player in shaping hegemonic views (see also Williams, 1977). This is also a conclusion drawn in Byron Good’s (2010) study of the pharmaceutical industry in Indonesia, where he argues that new conceptions and treatments of mental illness always fuse with local understandings. And in Oaxaca, Linda Hunt’s (1992) study of cancer also articulates how biomedical categories of illness co-exist with “traditional” illness categories, such that the latter continue to be relevant towards understanding the nature of etiology and treatment (see also Duncan, 2012;
These studies demonstrate that the introduction of biomedical discourse into different societies like Oaxaca is more complicated than usually assumed. Hegemony is a two-way process and biomedicine does not manifest uniformly across time and space. In the following section, I sketch preliminary information gathered on Alzheimer’s disease and its local meaning in Oaxacan settings.

*Forgetting Alzheimer’s in Teotitlán*

As already mentioned, one of the most enduring challenges to my research was that I was continually told that Alzheimer’s disease did not exist locally. Doctors, traditional healers, municipal clerks, and laypersons all told me that they had heard of Alzheimer’s disease, but believed it was non-existent in Teotitlán. Indeed, one doctor even told me that he knew of a village near the coast that had a high prevalence of Alzheimer’s disease, but could not explain why he did not know of a single local case. I came to realize that Alzheimer’s disease was believed to be nonexistent because, in part, it is locally perceived as an illness that arises in a different environment. As one acquaintance told me, “People do not have Alzheimer’s disease because they don’t need to worry about paying the rent, and other [forms of] stress experienced over there [e.g., other metropolitan settings like Oaxaca City and the U.S.].” As such, to the degree that it is known, Alzheimer’s disease is perceived as a foreign illness that resides “over there,” a psychosocial space that is perceived at odds with traditional familial and communal structure. In this way, Alzheimer’s disease is not something that merely arises due to individual pathology, but an expression of underlying social affliction. This is the topic of the current section where I sketch this local understanding, identify reasons why

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45 Traditional is in quotes to problematize this notion (see Chapter Two).
Alzheimer’s disease is believed to be so uncommon, and proceed to introduce related cross-cultural studies that help theoretically situate it. My aim is not to exhaust information concerning local representations of Alzheimer’s disease – this unfolds throughout the course of my analysis – but to equip my reader with sufficient information to appreciate what locals understood when I presented myself as a researcher interested in something called “Alzheimer’s disease.”

Before proceeding further I want to stress that the study of Alzheimer’s disease as a phenomenon situated in and shaped by local factors does not suggest local naivety or “misappropriation” of biomedicine. Surrounding culture inextricably shapes psychiatry, such that one cannot conduct a study on psychiatry without attending to surrounding sociocultural horizons (Kleinman, 1980, 1988a). As demonstrated in the contested history of Alzheimer’s disease within U.S. culture, the interpretation of what is “normal” versus “pathological” has consistently been shaped by cultural beliefs. This is not an exception in psychiatry but the norm: the implicit knowledge that we draw upon to discern illness comes from cultural perspectives, not objective frameworks. In this vein, all psychiatric systems are said to be “ethnopsychiatric,” constructed within “cultural tapestries,” that shape the definition and meaning of illness (Gaines, 1992, p. 8).

This suggests not only that meanings of Alzheimer’s disease differ across time and space, but that those meanings carry inherent clues to dynamics of the setting in which they arise (Henderson & Henderson, 2002; Henderson & Traphagan, 2005). Work on medical anthropology is critical here, as it is premised on studying how illnesses come to have meaning, and the way in which those meanings are maintained within different cultural settings (Good, 1994). This field views all medical systems as open and infinitely
malleable, such that new medical concepts are regularly introduced and medical knowledge is continually adapting to surrounding discourses (Leslie, 1980; Lock & Nichter, 2002). Leveraging these insights helps explain how psychiatric concepts like Alzheimer’s disease are taken from one setting and introduced into another.

What is known of other cultures and varying interpretations of Alzheimer’s disease confirms this approach. Lawrence Cohen’s (1998) study of Alzheimer’s disease within Indian culture shows how senility is interpreted locally through cultural anxieties about social change, and how these interpretations can overlook elders’ forgetfulness while instead focusing on other symptoms like anger that are expressive of local dynamics. Studies in Japan show how senility is viewed as a moral issue that threatens cultural expectations to remain economically productive (Traphagan, 1998), whereas in Vietnam individuals are known to express lack of concern regarding the development of symptoms in later life (Braun & Browne, 1998). In Native American populations, while forgetfulness is considered normal, concomitant psychotic symptoms are understood to be evidence of communication with the supernatural world (Henderson & Henderson, 2002). Lastly, in Brazil senile forgetfulness is distinguished from a positive capacity to forget sociocultural stress (Leibing, 2002).

Although there exist no known studies on the social construction of Alzheimer’s disease within Mexico, my initial fieldwork provided helpful insight regarding how Teotiteco culture is complicit in its local meaning. The individuals I consulted described Alzheimer’s disease not only as a rare phenomenon but also something that manifests “over there,” away from Teotitlán. Of course, from a neurological perspective Alzheimer’s disease exists whether or not people are aware of it. Yet here I adopt an
ethnographic approach and take seriously the way that Alzheimer’s disease is said to *not* exist in local settings. In this regard, and despite the fact that I eventually did find local cases, I have no reason to believe that I was being deceived or that my informants were misinformed. It was difficult to find people who had experience with Alzheimer’s disease, and tremendously more difficult to locate those individuals and families who dealt with it on a daily basis. Through greater ethnographic study I came to appreciate how Alzheimer’s disease really was rare (not in a neurological but sociological sense) and, as such, it was a disease that few people had direct exposure to.

In retrospect, there are three basic reasons why Alzheimer’s disease was so difficult to locate. The first was due to my own diagnostic confusion between my previous training in psychology and my limited understanding of local knowledge. Early in my fieldwork I assumed that my understanding of Alzheimer’s disease was standard across cultures, and that it would be possible to inquire about Alzheimer’s disease locally with mutual understanding. Yet this amounts to what Arthur Kleinman (1988b) calls a “category fallacy,” the reification of one culture’s diagnostic categories onto another (pp. 14-17). I soon became aware of local differences in how age-related forgetfulness was understood and of local psychiatric categories. Though locals certainly identified “pathological” cases of forgetfulness, people in Teotitlán also considered age-related forgetfulness normal. On numerous occasions when I spoke to elders about my project, they responded with a joke that because they tend to forget things, they should be the object of my study. It was recognized that elders have memory difficulties, and this was considered within the range of “normal.”
Yet there also existed pathological forms of forgetting. In contrast to Alzheimer’s disease, senile dementia (Spanish: demencia senil) is a diagnostic term used more frequently in Oaxaca, known as a condition where elders forget but remain capable of interacting and functioning in their environment at a basic level.\textsuperscript{46} By comparison, Alzheimer’s disease is perceived to be a severer form of forgetting where the individual is unaware of his or her surroundings, and unable to participate in social life. Consider the following excerpt taken from an interview with a family member who found out her mother had senile dementia:

Well, when they [the doctors] told us… we were worried because we didn’t know what it was. But when they explained it, we didn’t take it seriously because what the doctor said that what was serious is Alzheimer’s disease.

This local diagnostic difference helps provide one reason why Alzheimer’s disease proved to be so difficult to find: as an extreme manifestation of forgetting, Alzheimer’s disease

\textsuperscript{46} This diagnostic entity has been in use since the late 18\textsuperscript{th} century, when Mexican medicine had begun to embrace French biomedicine over humoral theory introduced by the Spaniards. Historian of Mexican medicine Germán Somolinos D’Ardois (1976), locates the first professional use of the term “dementia” to a document written on July 29\textsuperscript{th} in 1775 by three medical doctors (trained in France) who were considering the case of an old professor who had developed curious behavioral and cognitive symptoms. Although the exact symptoms are not known, what is of interest is the way the three doctors directed their attention, debated over etiology, and, in so doing, introduced a new category of illness to local medical practice. Somolinos D’Ardois (1976) writes:

What is instructive of their opinion for the medical historian interested in Mexican psychiatry … can be found [in the adjudicators’] words … [compared to] those [words] used… centuries earlier. They keep talking about sadness and melancholy, [but here] the word “dementia” [appears] and also the concept of mania. (p. 109, translation mine)

It is not clear how this term initially made an impact on local medical practice, yet today’s use of the diagnostic category demonstrates the importance of this event.
disease was reserved for the most profound cases and, as such, defined as a clinical exception.

Second, despite the relative accessibility of medical care – Teotitlán has a local medical clinic and consultations are subsidized to $20 pesos (US $1.25), plus costs for filling prescriptions – the economic parameters surrounding Alzheimer’s disease further explain its rarity. In contrast to public campaigns that promote awareness of Alzheimer’s disease in the U.S., there are scant local initiatives that seek to raise public awareness.\(^{47}\) To be sure, there are many reasons for this observation – for example, there exist more pressing medical issues like Dengue fever – but perhaps the largest reason is the local reality that there exists little industry surrounding Alzheimer’s disease. In comparison to the U.S. where a diagnosis is accompanied by options like professional nursing care and retirement homes for supporting dependent elders, in Oaxaca this industry seems to be a distant vision. (There exist two nursing homes and one psychiatric hospital that serve the entire state.) This again invokes Rabinow’s (1996) concept of “biosociality,” which was discussed above as a movement towards the commodification of vital life processes (like senility and death), and the emergence of truths that serve specific capitalistic ends. As Gibbon and Novas (2007) write, “life itself has become economically valuable” (p. 12; see also Rose, 2007). In the U.S., Alzheimer’s disease is supported by a wide spectrum of economic players (including advocacy groups, the pharmaceutical industry, nursing

\(^{47}\) Aside from newspapers, Lundbeck, an international pharmaceutical company, published the only other public document I had encountered that promoted awareness of Alzheimer’s disease. The document is titled “Caring for the Alzheimer’s Patient” [Cuidados del paciente con Enfermedad de Alzheimer]. In interesting rhetoric, it contrasts “autonomous and independent” elders from individuals with Alzheimer’s disease. “A large majority of elders are autonomous and independent and a minority demand care. This is the case of people who suffer from Alzheimer’s disease” (translation mine).
homes, geriatric specialists, research institutes, and more) that help reinforce Alzheimer’s disease as an emergent cultural truth. Each player is invested in Alzheimer’s disease and, as such, it has become more publically known. By contrast, in Oaxaca’s emerging psychiatric industry there are fewer stakeholders to produce such truths (but for an analysis of the industry's development see Duncan, 2012). Doctors are not encouraged to detect Alzheimer’s disease; there is scant age-related pharmaceutical industry; and caregiving has not been commoditized. In sum, the economic stakeholders that have helped make Alzheimer’s disease into such a publicly recognized illness within the U.S. do not exist in Oaxaca with the same influence.

Third, as hinted by my informants’ pledge that Alzheimer’s disease is something that only exists “over there,” my difficulty finding cases was due to the perception that Alzheimer’s disease is a condition associated with a different psychosocial environment. This perceived space – associated with stress that is believed to accompany “modernity” – demonstrates how local illness categories are conceptualized along psychosocial lines.48 Of the interviewed caregivers who had known about Alzheimer’s disease, most acquired their information through a public educational television channel, or through other members in the community. Through learning about their views it became evident that their understanding of Alzheimer’s disease is that it arises in more urban settings. For example, consider an excerpt from an interview with a caregiver who had lived in the U.S.

48 This is not particular to aging, and appears as a recurrent theme in Linda Hunt’s (1992) study on local representations and treatment of cancer. Oaxacans distinguish between illnesses like cancer whose causes are associated with “modernization” and illnesses like susto (“fright”), pérdida del alma (“soul loss”), and mal de ojo (“evil eye”) where “traditional” etiologies (humoral imbalances, spirit intrusion or loss, and superhuman punishment) are suspected.
Didn’t Ronald Reagan have Alzheimer’s? [In English:] The ex-president of the United States…[Continues in Zapotec:] So that’s how we heard of Alzheimer’s, and that’s how I saw what people with Alzheimer’s look like. They are sitting down, just like a thing. He [Reagan] was just sitting and staring.

Yet, as already discussed in the previous chapter, the alleged difference between local culture and what resides “over there” is a much more contested issue. Teotiteco culture has and continues to change such that what is “over there” is, in many respects, already a part of local reality (W. W. Wood, 2000). Yes, in Teotitlán individuals do not need to pay rent, and, yes, life is qualitatively slower and without other dimensions of stress associated with a “modern” lifestyle. But Teotiteco culture is not and was never isolated from broader Mexican and international discourses. The features of modernity that James Clifford (1988) articulates in an interconnected world challenge such a notion of a separate sociocultural space.

In this vein, the belief that Alzheimer’s disease resides in exterior cultures begins to take on a different meaning. It provides more information about what is occurring on a local level than what is believed to be happening outside. It reveals how Alzheimer’s disease is a symbol of the perceived difference between local and foreign lifestyles, and, as such, it stands for the looming threat of modernity over local tradition. And it shows, following Susan Sontag (2001), how illnesses are so often imbued with moral claims.

In this way and challenging Kaja Finkler’s (2001b) finding that sickness is not regarded as a private matter in Mexican culture, I found Teotiteco’s concern for privacy a central feature to my fieldwork. Alzheimer’s disease was difficult to detect because people intentionally kept quiet about it. This interpretation invokes Serge Moscovici’s
theory of social representation, which articulates how scientific information becomes commonsense, and how this transformation simultaneously serves to facilitate greater communication and social cohesion. This theory helps provide an initial explanation for how scientific ideas become a part of everyday reality and how they shape the way the world is understood. It also helps explain how Teotitecos makes use of their representation of Alzheimer’s disease as a foreign illness category in the service of protecting themselves from perceived dangers to the community (Jodelet, 1991).

Furthermore, this representation is also expressive of community dynamics and the way in which persons who do have experience with it often live in isolation. As I will explore in the chapters that follow, a consistent finding among the families interviewed is that many believed they were the only family who cared for an elder with severe forgetfulness. This adds a twist to concepts like biosociality (Rabinow, 1996) and “biological citizenship” (Rose, 2007) both of which describe the formation of identities and group cohesion based on biological conditions. With regards to Alzheimer’s disease, Lock (2007) describes biosociality as occurring through the various experiences that caregivers must go through, “draw[ing] involved families to an AD [Alzheimer’s disease] society” (Lock, 2007, p. 58). Yet instead of finding greater cohesion and sociality around Alzheimer’s disease, in Teotitlán I witnessed its bio-anti-sociality, that is, caregivers who lived on the social periphery because of its stigma.

Anthropologist Mark Nichter (2008) writes, “The ill are doubly afflicted with disease and cultural representations of their illness, and the two are mutually constitutive. Family members and caretakers are also affected by illness representations, although much less is known about them” (p. 12). Though this chapter provides preliminary
insight regarding the gap of knowledge that Nichter observes, this entire project is premised on developing a better answer. In the following chapter, I proceed to discuss how I make use of preliminary knowledge gathered about Alzheimer’s disease and explain the methods of analysis used to acquire greater depth about local caregiving practice.
CHAPTER FOUR

Methods: Ethnography, Interviews, Analysis

If, following Norman Fairclough (2013), methodology is a theory-driven process that constructs the object of research, then the specific methods used during research – the decisions one makes to acquire data, and the procedures used to analyze it – are derived from the situation where that object is located. I found myself in Teotitlán because of my interests in the social construction of aging, intending to study how recent changes construed a distinct vision of elders and established a different set of social relations. This directed my attention about where and what to look for, but it did not provide guidance about how to proceed, or explain the nature of what I would come to discover. Hence, the research methods I will describe in this chapter were not developed prior to research, but rather strategically pieced-together, adapted to meet the challenges I came to encounter. In this chapter I identify the nature of those challenges, explain how they were overcome through specific ethnographic strategies, and discuss the methods used to analyze the data I would come to acquire.

Ethnographic Challenges

From the very beginning, it was clear that Alex had his doubts about the feasibility of the project.\(^1\) In reflecting on our correspondence prior to my arrival to

\(^1\) Though it may be unconventional to so centrally feature my research assistant’s involvement, I am deliberately emphasizing his role to introduce a new level of reflexivity. As Russ Walsh (2003) notes, qualitative research has a rich tradition embracing reflexivity that “turns back upon or takes account of” the
Oaxaca, Alex later told me: “The first thing that popped up in my mind [after receiving your email] was that we weren’t… going to find anyone.” Indeed, in the previous chapter I discussed how and why Alzheimer’s disease is scarcely known in Teotitlán. I now feature Alex’s opinion to introduce his pivotal role in overcoming this and other obstacles. Through frequent conversations while walking in town, sharing meals with his family, and other moments spent reflecting on our work, I came to realize that Alex was more than a hired translator: he was a critical figure towards the acquisition and subsequent understanding of data. In this section, I introduce theoretical perspectives that research process. Acknowledging Alex’s participation in this project more truthfully reveals what was involved in acquiring its data.
help situate the nature of the challenges I faced, and begin to reflect on the way in which my partnership with Alex was central to addressing them.

Through the complicated social network I was beginning to develop in Oaxaca, Alex was recommended based on his previous work translating for a local microfinance tour company. As discussed in Chapter Two, Alex had lived in Santa Ana, California for an extended period of time but decided to return to Teotitlán to be a dancer in the Danza de la Pluma. I initially sought a research assistant because I suspected I would need help translating between Zapotec and English. The literature I had read on Teotitlán had alerted me that, though a growing number of younger individuals speak Spanish, the majority of social life is carried out in Zapotec, and that most elders experienced difficulty sustaining deep conversation in Spanish (Stephen, 2005, p. 63). I did not want to limit whom I could interview, and I also anticipated meeting with spouses of elders (whom I anticipated would likely be monolingual in Zapotec). And beyond language limitations, I also sought to partner with a translator because I wanted a connection to the community who would help me overcome cultural barriers. Being circumscribed within specific “borders” is a common dilemma in cross-cultural research; translators could help play a secondary role as a liaison to facilitate “border crossing” (Temple & Edwards, 2008).

After agreeing to help partner with me, Alex and I visited the municipality to ask for permission to conduct this study and then met with doctors at the Centro de Salud, the local health center serving Teotitlán and neighboring communities. Though given formal approval, the responses I received from each person challenged me about whether to proceed studying Alzheimer’s disease because every local denied its existence. I resolved
to continue, but instead of inquiring about Alzheimer’s disease nominally, I would look for symptoms of forgetfulness among elders. The Zapotec word *rienlá’az* translating to mean “to forget” became our catchword.\(^2\) This made sense given the reasons explained in the previous chapter (belief that Alzheimer’s disease does not exist locally, a lack of public awareness, and diagnostic differences). Moreover, I reasoned that my former training in geriatric psychology would assist me to differentiate among dementias. So, instead of following Byron Good’s (1992) recommendation to medical anthropologists to stay focused on diagnostic categories and submit them to cross-cultural research, I would first study the symptoms as they manifested locally, and then apply my psychological training to make sense of what was occurring diagnostically.\(^3\) This decision enabled me to initiate conversations with locals without confronting their skepticism. Moreover, given that Alzheimer’s disease was represented locally as a symbol of change to social order (see the previous chapter), looking for “forgetfulness” allowed me to present my interests with less cause for alarm.

Beyond the issue of whether or not Alzheimer’s disease existed, a larger challenge concerned epistemological confusion about culture and why I even wanted to conduct a study in Teotitlán. As reviewed in the previous chapter, I was inspired by writings within medical anthropology and, specifically, Gaines’ (1992) work in

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\(^2\) In Zapotec there is a distinction about what one forgets. *Rienlá’az* refers to the forgetfulness of objects, whereas *raguenlá’az* is the forgetting of a person.

\(^3\) To be sure, I am aware that differentiating between different dementias is difficult and cannot be adequately done without rigorous clinical tests. My main concern was to differentiate between progressive dementias (like Alzheimer’s disease or Lewy Body Dementia) and dementias due to injury (like vascular dementia); the former are “progressive” in the sense that they involve gradual memory loss, whereas the latter involve abrupt changes which may be recovered from. This is a critical distinction that I maintain throughout the rest of the study.
ethnopsychiatry as the systemic study of how psychiatric categories are inextricably bound within “discrete cultural systems.” According to this theory, there is no objective psychiatric discipline, and all attempts at defining mental illness are better understood as expression of the cultures in which they occur.

Yet the complexity I encountered in Teotitlán made it increasingly clear that I needed to be more precise about what I really meant by “culture,” and how I would proceed to study it. The ethnographies I had known assumed an image of the researcher as studying culture as an isolated, bounded, and systematic entity. For example, Clifford Geertz’ (1973) famous study on the Balinese cockfight showed how ethnographers have tended to view culture as “an ensemble of texts… which the anthropologist strains to read over [participants’] shoulders” (p. 452). However helpful this conception may have been in the past, it proved untenable in Teotitlán. As described in Chapter Two, Teotiteco culture is not only continuously evolving – local culture is premised and maintained in reference to what it is deemed to not be. Contrary to how we are used to thinking about it, culture is not something that persists against and despite global forces, but rather because of them (Wilk, 2006). In this vein, the prevalence of migration, engagement in the international economy, and other forms of world involvement were all blatant signals that it would be impossible to conduct a study on Teotitlán without attending to global discourse (W. W. Wood, 2000, 2008). All this required me to reconsider what I had understood about culture, leading to my recognition that Teotitlán was not a single “text” to be read in a “contained” and bounded manner, much less anything stable for which I had to find a “key” to unlock its defining nature.
The postmodern (or post-Geertzian) approach to ethnographic fieldwork attends to this reality. It sees ethnography as “perpetually displaced... a form both of dwelling and of travel in a world where the two experiences [between “local” culture and “global” forces] are less and less distinct” (Clifford, 1988, p. 9). Indeed, as Andrea Ruiz Balzola (2014) remarks on her own study of Teotitlán, “Whereas the difference in the past [in studying] the “other” was foreignness and exoticness, now the difference with the “other” consists in him [sic] resembling us and knowing us” (p. 56, translation mine). The similarities and shared experiences between my life and my Teotiteco acquaintances demonstrated how accurate this statement is. To conduct this study I could not just limit myself to ethnographic analyses of Teotitlán as a bounded site apart from broader discourse, but rather conduct a “multi-sited ethnography” that would allow me to trace connections, appropriations, and reactions to a trans-cultural phenomenon (G. E. Marcus, 1995). Hence, as it will become clearer in my discussion as to the nature of data collected, while my primary interests were in Teotitlán, I also was interested in Alzheimer’s disease as it appeared in Oaxaca City, Mexico, and international realms.

Instead of assuming culture as a “text” that is uncovered through fieldwork, the complexity I found in Teotitlán forced me to view culture as a process – that is to say, a form of life. This resonates with Bruno Latour’s (2007) recent work in sociology, which argues that it is erroneous to posit the existence of a specific thing like “culture” or “society” because it assumes that the social dimension is a known and stable concept that can be mobilized to explain other phenomena. To study Alzheimer’s disease in Teotitlán, I could not look for hidden meanings or structures – I could not say that Teotiteco culture “is” “has” or “does” something to Alzheimer’s – but rather, in the words of Martin
Packer (2010b) conduct a “regional ontology,” a map of the way phenomena like forgetfulness arise and are constituted in everyday life. This applied not only to the practice of caregiving but also, as I will soon explain, all of the places where forgetfulness is discussed and dealt with – including hospitals, traditional healers, public health events, and even my observations of Alex during the project.

The post-modern approach to ethnography not only raises awareness of the complicated notion of culture, but also puts into question my authority as researcher. What justification did I have to enter Teotitlán and conduct a study of a culture that was not mine? I worried that my interests were imperialistic, premised merely on how Teotiteco culture was different from my own. As Denzin and Lincoln (2005) state in the first page of their qualitative research textbook, research is a “way of representing the dark-skinned Other to the white world” (p. 1). Indeed, the premise of studying another culture is argued to be complicit in what Edward Said (1978) calls the “politics of othering,” the process of highlighting another’s difference by asserting responsibility to educate or civilize the people under study.\textsuperscript{4} I take these sentiments seriously, but I also did not allow them to halt my investigation. The initial observations I drew about local dimensions of aging – combined with my awareness that there existed no literature on the subject – were compelling enough reasons for me to proceed. As Ruth Behar (1996) writes about the central dilemma of qualitative research in marginalized settings, “if you can’t stop the horror, shouldn’t you at least document it?” (p. 2). Yet I proceeded with caution. My sentiment during this initial period was similarly expressed by Clifford

\textsuperscript{4} There would be no concept of culture were it not for the differences that were perceived upon the confrontation of multiple social groups. Moreover, emphasis on culture is dangerous: it reinforces ideas about difference and invents an “other” who is considered different (see Fabian, 2014).
(1988) who writes, “while ethnographic writing cannot entirely escape the reductionist use of dichotomies and essences, it can at least struggle self-consciously to avoid portraying abstract, ahistorical ‘others’” (p. 23).

As my project developed and my local partnerships deepened, my response to this dilemma moved beyond self-consciousness. While I initially knew that there was value conducting this study, inviting people to talk about their experience provided a service that the community was lacking. As I describe in the chapters that follow, the profound testimonies collected, the tears shed, and the gratitude for my attention all showed me that this project could not so easily be dismissed as imperial or voyeuristic. Moreover, I was able to justify my presence to the community through partnership with Alex. In what follows, I will describe the nature of this partnership and how it helped address additional obstacles to my research.

**Gaining Access**

Prior to my first meeting with Alex I prepared a written description of the project and basic interview questions I would likely want to address (see Appendix A). I knew that the type of work I was looking for involved more than just translating from one language to another, and that I had to educate Alex on what I was looking for and why I considered it important (Freed, 1988). We reviewed interview questions together and, to make sure Alex understood the nature of my questions, I gave him examples of possible responses that would be appropriate for each. Moreover, Alex and I had a discussion about why I found Alzheimer’s disease fascinating, how it might be shaping local meanings of growing old, and why I thought a study in Teotitlán would contribute to
cross-cultural research. Yet I did not presume to know about Teotitlán and I asked Alex about his experience with Alzheimer’s disease – he had heard of it through taking a psychology class in California, but had no personal experience – and his general perception of elders in the community. Though this was a theme we would only directly discuss towards the end of our fieldwork, I had the impression that Alex had not spent much time thinking about elders, and that this might be representative of other people his age. I realized that his involvement in the project would be a means to engage with a sector of the community that he had not really involved himself with before, and this became a way to position the project to meet his interests as well.

Alex agreed to serve as my research assistant, but, as mentioned above, he did not believe our work would be extensive. In retrospect, Alex’s doubts were not only based on his perception that Alzheimer’s disease did not locally exist, but also due to lack of confianza [confidence, trust]. Although there is no doubt I was greeted warmly when I arrived to Teotitlán, it was also evident that people extended their warmth with a certain degree of restraint. This proved to be a major obstacle throughout my research because, unlike how I was accustomed to building trust with new acquaintances in the U.S., confianza is locally established through the family and extensive compadrazo (godparent) networks, and then, more broadly, it applies to residents who know and adhere to local tradition. Confianza plays a major role in Oaxacan society such that Norget (2006) writes it is “the object of social practice” that determines on whom one can depend and with

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5 In Teotitlán, many Zapotec speakers use an abbreviated version of the Spanish word – confianz – to refer to confianza. However, relilá’áz is another Zapotec word that refers to this concept, literally translating to mean that one has a “straight heart.”
whom one speaks (p. 47). Individuals outside one’s network of *confianza* are considered strangers, people least trusted. As one family whom I had tried to speak with for three months told me, “People need time, they need *confianza*.”

This challenge represented a serious methodological issue regarding how I was able to achieve access to the community and acquire information about it. Through repeated meetings, clumsy cultural errors, and talk about similar life experiences, Alex and I developed a solid working relationship that I believe was crucial towards establishing his faith in the project and, by slow extension, the community’s trust in me. Yet I knew that access involves more than developing trust, and that I had to establish a position within the community that would foster individuals’ ability to relate to me *vis-à-vis* their experience with Alzheimer’s disease.

Typically, when researchers approach a site they are viewed in terms of social categories salient to that community (Harrington, 2003, p. 607). In this vein, there is no doubt that the mixture of warmth and restraint I was given was a result of this reality; I

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6 Although Teotitlán’s Zapotec does not feature it, other Zapotec communities make a grammatical distinction in first person plural pronouns, between “we-including-you” and “we-not-including-you.” This is yet another illustration of how much identity is formulated on the local level.

7 At the termination of our fieldwork, I interviewed Alex and asked how the community was able to develop trust in our project and myself. We were talking about how we succeeded in gaining access to our first family of participants and Alex commented:

- First, I think [I was able to approach our first family] … because … it was someone that I knew. So it was easy for me to go [to] the very first interview. And [after it, our] second interview was… [Well.] people were already talking about our interviews – that we were interviewing people. So people knew about it and they had more confidence… or [could] trust us more. And that’s when my confidence also went up, and I was able to handle more interviews. And [I] handled them better.

Though Alex was specifically referring to trust, a component of *confianza*, his statement provides greater illustration of the manner by which *confianza* extends within the community.
was initially perceived to be a consumer, like the countless other tourists who visit
Teotitlán interested in buying rugs. Challenging this perspective was not easy and took
considerable time. Through the quotidian conversations – with people in the market,
vendors on the street, and other passersby – I drew upon affiliations like shared
experiences in California, distinguished myself through my identity as a doctoral
psychology student, and expressed intent to document the community so that its needs
might better be met. (I did not profess to understand those needs, but rather desired to be
a voice speaking on behalf of the community as a researcher with attunement to
psychological issues.) This took considerable time and it is more accurate to describe it
not as a discrete stage in my fieldwork, but an ongoing effort that lasted until its
termination.

Because I did not initially know whether I would succeed in gaining access in
Teotitlán, I adopted a strategy similar to Loïc Wacquant (2011) and followed
Alzheimer’s disease wherever I suspected it might appear, tracing its circulation through
different contexts and among different social actors. I also was influenced by George
Marcus (1995) who articulates how to conduct ethnography in a multi-sited and
heterogeneous context like Teotitlán. In Oaxaca City my fieldwork involved interviews
with the director of one of the two government-sponsored casas de hogar (nursing
homes), professional and family caregivers for elders with dementia, psychologists,
psychiatrists, and other persons invested in geriatric medicine. I interviewed residents and
a curandera (traditional healer) from a different Zapotec community. I visited other
pueblos in the state and volunteered for an NGO that provides bio-psycho-social support
for elders in extreme poverty. I studied newspapers, collected informational pamphlets,
and attended a conference on geriatric medicine. Though these experiences will not be the focus of my subsequent analysis, they were significant in developing my understanding of Oaxacans’ perception of aging and Alzheimer’s disease, as illustrated in the previous chapter.

Figure 4.2. Janet Chávez Santiago teaching her Zapotec language class. On the blackboard Janet instructs students on how to say Naa naa benih Xigue which translates to mean “I am from Teotitlán.” (Photo by the author.)

Beyond issues of access, I was challenged with the decision regarding which members of the community would provide me with the best information about how Alzheimer’s disease is locally perceived. My fieldwork in Teotitlán involved meeting with 4 local doctors, 2 curanderas (traditional healers), 3 state-employed individuals who work with elders, and 1 psychologist. I also attended pláticas (see Note 9), fiestas and
public celebrations, and shared countless conversations with locals. Lastly, I formally studied the Zapotec language (the dialect spoken in Teotitlán, see Chapter Two) to better understand local customs and continue developing access to the community.

Though these activities provided a wide spectrum of the community, my project was centered on analyzing the voices of family caregivers. I made this decision prior to arriving to Oaxaca, reasoning that caregivers – the family members who live with and meet elders’ needs on a daily basis – would provide a means towards gaining an intimate vista of the aging experience. I viewed caregivers as social actors, which signifies that they are not passive recipients of medical practice – not victims to hegemony – but rather active participants in constructing its local meaning (see Gramsci, 1988; Williams, 1977). Moreover, the decision to focus on caregivers (rather than conducting a more diffuse study on the whole community) was due to recognition that I needed to find a way that Alzheimer’s disease was constituted – that is to say, the way it manifested as the intersection and mutual formation between people (i.e., caregivers) and their forms of life (i.e., providing care). This approach to ethnography comes from Martin Packer (2010a, 2010b) who argues that focus on constitution allows researchers to optimally approach qualitative research topics: in my case, how participants exist, respond, and function in the world of Alzheimer’s disease.8

Alex and I strategized about how to gain access to caregivers and eventually took a number of different approaches. Informational flyers helped publicize the project and

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8 This marks a shift from traditional conceptions of qualitative research that view data acquisition as mediated through direct interviewing on a topic of interest. As I will soon discuss, instead of directly asking participants how their culture somehow carries an effect on understandings of Alzheimer’s disease, I studied practices of caregiving to see how representations manifest locally.
provided contact information for interested persons. Partnering with local doctors and traditional healers who offered to speak to patients helped provide professional endorsement. Discussing the project with elders at pláticas (government sponsored “chats”) informed the community of elders about the project and encouraged subsequent discussion of it with their families.  

Lastly, Alex’s own networking among family members and the broader community was a major source of acquiring participants. At each of these venues, we looked for elders’ whose forgetfulness necessitated caregiving and then, through an initial informal screening to assess severity of forgetfulness, we scheduled meetings with each family. Throughout this process and, indeed, throughout my time in Oaxaca, I kept field notes about individuals I had met, various experiences, cultural facts learned, and other miscellaneous observations.

I also decided to meet with all household members because of other research that clued me to the fact that Oaxacan households – not individuals – are the primary social unit (Jeffrey H. Cohen, 2004; Murphy & Stepick, 1991; Norget, 2006). Hence, when I encountered households willing to participate in the study, I asked to meet with all members over 18-years old (for ethical issues and because I reasoned that older members were likely allotted more caregiving responsibilities). These interviews always occurred at the family’s home and we sat either in outdoor courtyards or indoors in front of altars each home has for welcoming guests. I learned that caregiving was typically not allotted to a single individual, but rather was a household responsibility divided (albeit unevenly)

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9 Pláticas (“chats”) are presentations that provide bio-psycho-social information that are required of elders if they are to receive their monthly pension through 70 y Más, the government-sponsored program designed to provide financial support to elders living in poverty.
among members. Further, I discovered that both genders across generations were intimately involved in the caregiving process.

Yet I also knew that the people I had the opportunity to meet were not the only individuals involved in caregiving. Tracing caregiving responsibility involves more than just identifying which members of the family physically provide care, but also must take into consideration what Worthen (2012) calls the “presence of absence” – in this case, the way in which migrated household members also contribute. I was aware of how caregiving is transnational in nature, circulated among family members across political borders, economies, social structures, and traditions (Baldassar, Baldock, & Wilding, 2007; Baldassar & Merla, 2013). This informed how I inquired about caregivers’ experience and household structure.

Through the course of 10-months of fieldwork in Teotitlán I interviewed a total of 22 caregivers across 9 households. Following IRB guidelines, all participants gave their written permission to participate by reading a Spanish-translated consent form or (for those who were illiterate or monolingual) have it orally summarized in Zapotec) (See Appendix B).\(^\text{10}\) These forms indicated that all identifying information would be subsequently altered to protect confidentiality. Furthermore, consent forms indicated that participants have a right to withdraw from participating at any time.

Interviews averaged 1 hour in duration, amounting to more than 10 hours of audio recording. These interviews constitute this study’s primary data and will be analyzed in the chapters that follow. While I do my best to contextualize and explain each of the voices that are featured in this study, I recognize that the size of this dataset renders the presentation of results difficult. For this reason I have crafted an “Interview Summary”

\(^{10}\) Modifications to the original IRB research protocol were made and subsequently approved.
(see Table 1) that is intended to serve as a continual reference while reading subsequent chapters. This summary contains necessary information about each household interviewed, and also provides unique “household metonyms” to help readers quickly identify which households are being discussed. Alex also helped me “rank” each household’s socioeconomic status through measuring household appearance, consumer goods, type of employment, financial remittances from relatives in the U.S., and other factors. Symptom severity was measured by me, based on caregivers’ discussion of the degree of forgetfulness, how much it impacted daily life, and related factors. All descriptions of households are designed to give an accurate vision, but information has been modified to protect confidentiality.

As seen in the Interview Summary, I interviewed 2 elders diagnosed with Alzheimer’s disease, 2 undiagnosed cases that would likely meet Alzheimer’s disease criteria, 3 cases of vascular dementia, 1 case of “senile dementia,” and 1 case of “mixed” vascular and progressive dementia.11 Henceforth, when I refer to Alzheimer’s disease I mean progressive dementia, which includes diagnosed cases of senile dementia (for the difference see Chapter Three) and undiagnosed cases of elders who progressively forget. This conflation is based on convenience, and also because I am writing to a U.S.-based audience where these cases would be labeled as Alzheimer’s disease. The decision to include vascular and mixed dementias in this study was based on methodological grounds (they help contextualize age-related forgetfulness and differentiate specific features of caregiving for elders with Alzheimer’s disease) and also on ethical grounds (I

11 Dementia rarely manifests singularly and often co-occurs with other illnesses. During my interviews I did not find a single case of uncomplicated dementia. Diabetes was the most common comorbidity. I also came across cases of osteoporosis, epilepsy, visual hallucinations, and other physical debilitations.
experienced a duty to include the testimony of individuals who so intimately shared
details of their lives).

In contrast to other known ethnographies of Teotitlán and Oaxaca, all interviews
were conducted in Zapotec. This decision was methodologically driven to ensure older
members of families were included, and also to provide an interview environment that
was more ecologically valid where participants could speak in the language used among
family and community members. This decision provided unique access into caregivers’
experience and shed greater light on cultural nuances that would otherwise be
overlooked.

Lastly, after interviewing all the caregivers we had known about in the
community, I decided to interview Alex. This decision was based, in part, as a response
to Catherine Riessman’s (2002) challenge to “do justice” in research by featuring more
than one voice. While Riessman is concerned to involve her participants in writing
research results, I take a slightly different approach by framing “my” methods as an
interpersonal endeavor that could not have been achieved independently. Here, justice
involves acknowledging that this project would not have been possible without Alex’s
commitment to it. Further, it involves bringing his voice to the fore when quoting from
interviews. This final interview further developed my ethnographic understanding of my
efforts in Teotitlán, and provided an occasion to celebrate our accomplishments.
Table 4.1: Interview Summary

<table>
<thead>
<tr>
<th>Interviewer's Name</th>
<th>Interview Setting</th>
<th>Condition</th>
<th>Time (hrs)</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Smith</td>
<td>Hospital in-law</td>
<td>12</td>
<td>20</td>
<td>None</td>
</tr>
<tr>
<td>Dr. Johnson</td>
<td>Home</td>
<td>9</td>
<td>15</td>
<td>None</td>
</tr>
<tr>
<td>Ms. Lee</td>
<td>Community Center</td>
<td>6</td>
<td>60</td>
<td>None</td>
</tr>
<tr>
<td>Mr. Brown</td>
<td>School</td>
<td>8</td>
<td>75</td>
<td>None</td>
</tr>
<tr>
<td>Mrs. Davis</td>
<td>Library</td>
<td>8</td>
<td>90</td>
<td>None</td>
</tr>
</tbody>
</table>

Note: All identifying information has been modified to protect confidentiality.
While the previous section articulated how I gained access to the Teotiteco community and whom I interviewed, this section examines specific facets of the interview process. Perhaps the most defining feature of my interviews was the fact that all were conducted in Zapotec. While advantageous for allowing me to include multiple generations of the household, this approach rendered things more challenging than I had anticipated. At once, I wanted participants to speak amongst themselves about their experiences while also having the leverage to ask them questions. Reaching this goal was an ongoing work in progress. Though I made significant efforts to educate Alex about the project prior to conducting our first interview, and although I explained to Alex each possible interview question and my reasons for asking it (see Appendix A), these measures were by no means sufficient and our mutual understanding deepened throughout our partnership. After each interview we held “debriefing sessions” where we discussed what went well and could be improved, and also addressed these issues while transcribing (discussed shortly). From the very beginning, I instructed Alex not to provide live word-for-word translation because I did not want to disrupt the flow of conversations. Instead, I asked him to summarize what participants said, enough such that I would be able to ask follow-up questions.
This approach effectively culminated in a new interview technique – what I term “locally-focused interviewing” – and helped facilitate in-group dialogue while minimizing interruptions from me. Further, this approach overcomes traditional limitations in qualitative research. In what follows I first describe these limitations, explain how locally-focused interviewing was implemented, and proceed to discuss advantages and disadvantages.

a) Theoretical Foundations

One of the biggest epistemological dilemmas in qualitative research is the way in which interviews are at once understood to arrive at the subjective or personal experience of participants, while interviews are also known to be shaped by the event of interviewing. Typically, qualitative interviews are understood to be conversations where participants express or reveal underlying thoughts that the researcher will then analyze. This understanding views language as a conduit where participants are able to “convey” or “get across” their intended meaning to the interviewer. The problem, as Packer (2010b) is apt to point out, is that this view overlooks the way that language is not a channel that directly messages subjective experience. Language is shaped by the event that situates it – the people with whom one is speaking, for example – such that we cannot maintain that it is merely a conduit to express one’s inner thoughts or experience. Rather, language is more accurately understood as a “joint production” between speakers (p. 55). In this regard and contrary to common belief, qualitative interviews are never moments when participants share their “uncontaminated” personal experiences because, once again, the things expressed are shaped by the event of interviewing. The issues
brought up by the interviewer, the topics she is interested in, and even her subtle gestures undoubtedly affect how participants respond. As Suchman and Jordan (1990) argue, the interview is “fundamentally an interactional event” which means that the things discussed do not reveal underlying or subjective data, but rather are always expressive of the interaction between participant and researcher (p. 241).12

Researchers who have acknowledged this dilemma have tended to narrow how interview data ought to be conceptualized – not as information about subjectivity, but data produced and shaped within the interview itself. The content expressed by participants during an interview is meant to express something and have an effect, to make things intelligible for the researcher. As Packer (2010b) writes, “the interviewee’s subjectivity [and what is expressed during the interview] is an effect of the... interview, not a preexisting, independent personal experience that is the content expressed in what is said” (p. 99, emphasis in original).

Yet instead of structuring the interview as an event between researcher and participant, there is another option that maximizes group dynamics, minimizes the researcher’s interaction with participants, and makes in-group discussion the data that is collected. This is the virtue of focus group interviewing, a technique that observes the dynamics of a cohort of people as they respond, contest, and negotiate responses amongst each other. Broadly defined, “A focus group study is a carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive,

12 Packer (2010b) identifies seven reasons for why interviews are different from ordinary conversations and shape the acquisition of data: the event of interviewing is scheduled, not spontaneous; it often takes place between strangers; it is not an interaction between equals; it is conducted for a third party (the research paper); interviewers adopt a “special” non-quotidian attitude; the interview is generally not about the here-and-now; it is an occasion to obtain something from the interviewee (pp. 47-50).
non-threatening environment” (Krueger, 2009, p. 2). Traditionally, focus groups have been used to poll a group of individuals about their perceptions and attitudes towards consumer products, and are more commonly utilized in marketing research (Cox, Higginbotham, & Burton, 1976; Merton, Lowenthal, & Kendall, 1990).

Focus group interviewing is also a powerful way to elicit opinions within a group, and witness the way in which meaning is interpersonally negotiated. Put in this way, focus groups offer an alternative to the epistemological limitations of qualitative interviewing. While the things discussed during interviews are always constitutive of the interview event – and shaped by individuals present – focus groups provide access to study the construction of meaning within a cohort of peers, rather than studying the construction of meaning between participant and researcher. Of course, the researcher unavoidably has influence on the direction, content, and manner by which things are discussed, but in comparison to the dyadic researcher-participant interview design, focus groups minimize the researcher’s influence to allow for in-group discussion.

b) Technical Implementation

Leveraging my partnership with Alex alongside these insights led to a new interview method that I call “locally-focused interviewing.” This term carries a double-significance of the term “focused,” standing at once for methods drawn from focus group interviews, and also focus on dialogue among members of the community. In this section I proceed to discuss how locally-focused interviewing was implemented based on these two components.
The first component draws on interview techniques from focus group literature regarding how to maximize group discussion (Carey & Smith, 1994). To this end, I developed a set of open-ended interview questions that were to be discussed among caregivers, and tried to elicit contrasting or divergent opinions (see Appendix A). Participants were asked to provide concrete examples of when, why, and how events occurred; this encouraged participants to not just describe facts, but to share stories of their personal experience. With those members who were not as vocal, we inquired about their opinion regarding what other participants had said. I also followed Greg Myers (1998) who views the moderator’s role as avoiding closure within group discussion, and so Alex positioned me as an obvious outsider to the community who needed to have things explained. While this raised greater awareness of me in the group discussion, utilizing me as an audience or “buffer” helped organize the conversation and also provided a platform through which participants could express disagreement.

The second component centered on Alex and his ability to carry out group discussion. This component implements what is considered “local” about this interview technique, fostering conversation amongst locals within a given community and minimizing intervention from foreign individuals. Though this was developed throughout the course of our partnership, Alex gradually assumed the principal role in conducting interviews. He waited for me to ask basic questions, and then held in-depth conversations with each family member about their opinions. Through ongoing training, Alex developed insight regarding when to ask probing follow-up questions – asking for clarification, questioning why a decision was made, or requesting more detail regarding
how things are experienced – and then briefly summarized answers to me to maintain the flow of the conversation.\textsuperscript{13}

Alex’s role as group moderator was central to implement this new approach. At once, Alex was a facilitator of the conversation and a member of the community. He spoke in Zapotec from within the community while making content intelligible to me, the individual whom everyone knew was from outside. Drawing on literature that demonstrates group interviews are useful in studying socially marginalized populations (Madriz, 1998), this novel approach further helped to strengthen my access to the community by deemphasizing my role and instead trying to foster conversation among participants. As I will illustrate throughout the remaining chapters, this design enabled me to study in-group dynamics of the community – not only among household members, but also between the household and Alex.

\textit{c) Advantages and Disadvantages}

This approach also involved certain methodological and epistemological limitations. Methodologically, it required that Alex assume leadership as a primary investigator when he was not trained in interviewing techniques. It was risky for endowing Alex with power to either direct the conversation in a way I considered unproductive or not follow-up on themes that would have been of interest to me. To be

\textsuperscript{13} Though there were certainly times when I felt Alex was missing my point, I came to realize that the way he interpreted my questions and how my questions were discussed with family members was perhaps more valuable to my study than having my questions directly answered. For example, whereas I initially wanted to know whether an elder’s forgetfulness signified a personality change, Alex inquired whether forgetfulness caused limitations to the work the elder was able to perform. This reminded me that my conception of personhood is different from the local emphasis on productivity.
sure, Alex’s development as interviewer was an ongoing work in progress and we together attained better proficiency through the course of our interviews.

Epistemologically, conducting interviews in a group setting also entailed that the nature of my data could only provide insight on group dynamics. It overlooked personal (private) dimensions of caregiving, experiences that caregivers might have been embarrassed or pressured from others to not voice.

To this last point, one of the most salient dimensions that is absent in the following chapters is a thorough discussion of gender. This is especially surprising given what has earlier been stated about local gender norms (see Chapter Two): women are socially tasked with domestic responsibilities whereas men carry public (economic and civic) roles. Caregiving is indisputably a domestic responsibility, and yet talk about gender seemed largely absent in my interview data. In retrospect, it is likely that issues about gender – how it shapes the allocation of responsibility, how one subsection of the population interviewed (women) are disproportionately allocated more responsibility, and how gender challenges traditional roles – are a central feature of caregiving. Yet gender is not mentioned because my analysis is limited to the actual discourse I came to gather about caregiving (see the following section). In this case, it is probable that conducting group interviews foreclosed this opportunity. Women likely felt uncomfortable addressing gender dynamics with men present, both represented by their spouses, children, elders, but also by Alex and me.

Nevertheless, in the course of conducting our interviews, I came to appreciate how advantageous my approach was. The fact that caregiving is overlooked in Teotitlán (to be explored in Chapter Eight) rendered these interviews a unique event. Alex was
carrying out conversations with caregivers about their experience – a dimension of the community he had not encountered before. Conversely, caregivers were explaining and making known their experience to a representative of the community who had typically overlooked their situation. In this unique setting I was able to witness the social production of the meaning of caregiving – not between participants and researcher, but among participants and a community representative.

Ethnography in Transcription: A Note on Discourse

After each interview Alex and I met to translate and transcribe audio recordings, typically before moving on to the next. This provided another opportunity to reflect on how to improve our technique. We met at his home or mine, in front of two computers – one for him to control the audio, and another for me to transcribe. This process was arduous and sometimes amounted to more than 10-hours spent transcribing for every one hour of recording. Yet it was profoundly informative. Often, Alex encountered a word or concept that had no equivalent translation. He either tried to find a phrase using a combination of Spanish and English words or, more often, paused to explain concepts that were too difficult to capture in a single phrase. For example, one participant used the Zapotec word *anim*, which roughly translates to “soul.” Alex explained that this translation is only approximate because it is used specifically to describe a soul of the deceased. (The Zapotec word *garlieng* is used to describe the soul of a living person.) Through recurrent instances like this I continued to develop my knowledge of local culture. Transcribing not only gave me a chance to unpack what occurred during interviews – to witness the powerful way caregiving was discussed by family members
and with Alex – but it also provided an opportunity to further question a member of the community about the broader significance of the data I was gathering.

The resulting transcripts produced a rich set of texts that constitute this project’s primary unit of analysis. I view these data (and all other supplementary data collected in the course of my fieldwork) as “discourse,” referencing a specific theoretical tradition that studies language and, more broadly, social practices. This conceptualization invokes a tradition initiated by Foucault (1972) to describe discourse’s constitutive power in the social world. While summarizing Foucault’s work is beyond the scope of this investigation, it is important to demonstrate how I leveraged this theory to make sense of my data.

For Foucault, discourse refers beyond the things said in language to include the broader system of historically situated “practices” that construct subjects within regimes of power. Discourse is not a social object, but rather what constitutes social objects within an historical and cultural frame. In this vein, I do not conceptualize discourse as text-based but rather a broader set of social and institutional fields. Moreover, focus on discourse means that I do not attend to what is often believed to lie behind it – namely, thoughts, feelings, and other sorts of presupposed mental states. As Kendall and Wickham (1998) state, “We cannot go beyond [the] discursive ‘surface’ to a ‘deeper inside’ of ‘thought’: the surface is all there is” (p. 37). This is not to deny that mental states co-occur when things are spoken, but rather that the things spoken constitute the best material available for analysis. By the same token, this definition of discourse also means I cannot reference an order that exists beyond discourse because there is no such transcending space (Kendall & Wickham, 1998, pp. 38-39). According to Foucault, all
things are constituted in, and shaped by, discourse. This helps provide a theoretical foundation for the social construction of aging described in the previous chapter: of course the body ages independently of discourse, but this theory reminds us that the body is always positioned in a discursive realm – a set of cultural practices – that constitutes how aging is made meaningful.

Following this understanding, to speak of discourse is to refer to three interrelated features: it is action-oriented in that it achieves a specific effect (Austin, 1975); it is constituted within the discursive event (following and responding to prior discourse, situated within local norms, etc.) (Packer, 2010b); and it is an act of construction (it is constructed from surrounding discourse, and constructive of the world) (Potter, 2003). Thus, sensitivity to discourse implies not just talk endorsed by participants, but institutional structures, power relations, and the way in which my participants and the meanings of aging they endorse are constituted and engaged with broader discursive practices. As I will soon show, this means that while my analysis is focused on texts from interviews, it also references the larger discursive realms observed through the course of my fieldwork.

While this definition of discourse helps to make sense of the nature of my data, it does not explain how I proceed to analyze it. This proves to be a more complicated issue because, as Linda McMullen (2011) points out, discourse analysis is a nonspecific term that does not denote any single research method. There exist a variety of analytic approaches that draw on Foucault’s notion of discourse to achieve different methodological ends. Instead of arguing for one over others, in this project I strategically piece together elements from different methods to optimally address my research needs.
From Potter and Wetherell (1987) I learn to identify not only patterns found in discourse, but also divergences that provide insight into how and why differences exist (pp. 168-169). Their work helps navigate the complicated dataset acquired in this project, studying caregivers of elders diagnosed with Alzheimer’s disease, those non-diagnosed, and those with other dementias. Kendall and Wickham (1998) are instructive in encouraging me to adopt a perspective that helps identify contingencies (historical factors that situate the occurrence of discourse) and also eschew the search for hidden meaning (pp. 5-20). This approach helps draw my attention to local medical history and see it as having constitutive power in local biomedical practice, as well as other sociocultural histories that shape discursive events. Moscovici (2000, 2008), although not traditionally considered a discourse analyst, helps explain the psychosocial process regarding how scientific ideas are appropriated in a culture, and the way in which those ideas become commonsense. Further, his work reveals how representations are not just ways of seeing the world, but that they also facilitate social cohesion. In a similar vein, Reiner Keller’s (2011) application of discourse to social constructionism (Berger & Luckmann, 1967) provides a theoretical platform for studying how knowledge is institutionalized and regularized through social discursive practices. Lastly, Fairclough (2013) encourages “transdisciplinary” work, with specific attention to the dialectical relations between text-based discourse and other institutional structures. This approach helps me understand how notions like Alzheimer’s disease are introduced to local culture as part of a larger movement of the medical industry and neoliberalism. Moreover, it highlights the utility of engaging with other disciplines (anthropology, sociology, economics, and history).
**Methodological Steps of Analysis**

In what follows I identify the specific steps taken to analyze data. This approach is a combination of techniques drawn from other studies and adaptations to the parameters of my own.

The first step of analysis involved collecting all research data. This included 9 transcribed interviews with caregiving households in Teotitlán, 1 concluding interview with Alex, 3 interviews with professional caregivers (i.e., nurses) in Oaxaca, 1 interview with a family caregiver in Oaxaca, notes from meetings with various locals (doctors, traditional healers, and more), consent forms given to participants, newspapers, pamphlets, photos and field notes taken throughout my fieldwork. Knowing that my primary interest concerned the interviews with caregivers in Teotitlán, my focus was principally directed towards this dataset. I read and re-read each of the 9 household transcripts indiscriminately, without having any aim other than to gain deeper familiarity with each interview. I also referenced other data acquired apart from these interviews. I intentionally let this process occur over a 2-week period, wanting to slowly reflect on and develop a preliminary orientation with the data.

Next, I began coding which, as Potter and Wetherell (1987) argue, is distinct from actually analyzing data. Coding is the first step to categorize information, a method of using shorthand single or short-worded references that point to specific sections of discourse (Saldaña, 2012). In the margin of my transcripts I wrote codes like “Doctors: Why Consult” or “Caregiving Challenge: Lost Companionship.” (For a list of the codes

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14 Coding is different from looking for the frequency of occurrences of specific statements. Frequency may be an important factor to consider, but a code may still be valuable if it only occurs once (Potter & Wetherell, 1987, p. 167).
developed see Appendix C.) These codes were not developed prior, but rather written during and in response to my reading. While some codes were only used once, the majority of them were used across transcripts. Coding represented my first attempt at making sense of the data while drawing on my understanding of its nature as discourse—wondering what participants were trying to communicate to others (including me), how it is expressive of a larger sociocultural horizon, how it is constructive of a specific way of understanding forgetfulness and the caregiving experience, how talk of biomedical concepts is situated within multiple medical systems, etc.

Drawing on focus group literature, I also adopted analytic methods defined by Kidd and Parshall (2000) that suggest both the individual and the group be considered the primary unit of analysis. To this end, I studied the way in which participants (including Alex and myself) interacted with each other, how meaning was collectively formulated, and also the points at which individuals disagreed, acquiesced, or abstained from participating. For example, some participants within the same household were more vocal than others, and I wanted to be sure to note whether their responses occurred due to prompting, or occurred spontaneously in the group dialogue.

After coding I developed a set of common themes that arose from inter-related codes that resonated across interviews, while also being attentive to exceptions. This is a strategy advocated by L. A. Wood and Kroger (2000) who write, “the overall goal of analysis… requires the identification and interpretation of patterns of discourse” (p. 95). Hence, I use these themes as a means to further analyze data and address different, divergent moments of discourse that manifested. These themes grouped together different
codes under a common idea. So, for example, as I had developed numerous codes that pertained to visits to medical doctors, I created a theme that was simply called “Doctors.”

I succeeded in studying different codes and themes within and across interviews through creating an interactive computer spreadsheet. I input over 400 excerpts of text categorized by code, theme, and household, and was quickly able to selectively navigate and compare data across multiple interviews. This spreadsheet was my primary way to access data, yet I also returned to original transcripts for greater context.

During this time I also studied relevant literature to develop my knowledge of the themes gathered through analysis, paying specific attention to how these themes engaged, challenged, and supported existing literature. I continued to work with Alex and other local informants, who clarified information about local culture and further explained each theme. Once I felt I had sufficient understanding of themes, I then returned to the transcripts to ensure their reliability, checking to see how well each theme was consistent with the broad pattern of discourse across interviews, and also accounted for smaller segments.

While these efforts were directed towards presence – that is, physical data acquired from interviews – my analysis also involved a study of what invariably was absent. This includes migrant household members that live abroad, but more importantly concerns what is not and cannot be put under the analytic microscope. This refers to my relationship with Alex, my impressions in meeting with each caregiver, and my overall experience conducting an ethnography in Teotitlán. It refers to the space of the unspoken, of research material that is not material at all, but rather casts a shadow over all my data and reading of it. To be sure, this type of data played an equally central role in my
analysis. It constituted the lens through which I was to read my interviews, and it also provided a sense of personal accountability to how I would come to present it. In this way, my approach to writing the following chapters of analysis was not simply to aggregate codes and themes, but to present them in such a way that they were congruent with my experience in acquiring them. As I will come to show, this involves how I perceived caregiving to represent Teotitecos’ devotion to elders – an act of love – and how I understood what my participants expressed as being situated in that light.

**Presentation of Analysis: Structure and Strategy**

The following analytical chapters adopt a structure that I concluded would be most intelligible to readers. I divide my analysis into four chapters – comprising two theoretical pairs that first explore the experience of being situated within multiple medical systems, and then unpack the daily experience of caregiving. Each chapter contains distinct themes that articulate different dimensions of my data, referring to others when needed. This linear approach seemed the best option to present results, although it will be obvious that each theme (and chapter) is interrelated and informs analysis of others. For this reason I encourage readers to review the Table of Contents. This will help develop a better orientation and understanding of why some issues are not elaborated, though they might be briefly mentioned.

All chapters integrate data across all interviews, but each begins with a brief vignette that is simultaneously intended to illustrate the topic of the chapter, provide a detailed picture of select households, and tell the ethnographic story of my fieldwork. This is a story about my intellectual development conducting this research and,
specifically, how my initial interest about biomedical knowledge regarding Alzheimer’s disease proved to be less important as I began to encounter the ordinary details of caregiving. While I recognize that it is unconventional to highlight my own development as researcher, I consider this lesson vital in articulating the significance of my findings.

As I start each chapter with a vignette of a specific household, I also introduce and contextualize all other households when they are invoked. New voices from other households are introduced with a brief ethnographic sketch to contextualize data throughout the four chapters. Afterwards, I subsequently refer to households through metonyms that are unique (see “Interview Summary,” Table 1). For example, I distinguish one household as being “the successful tortilla makers” from another household that was unique for attending to an elder with severe epilepsy. This approach allows for households to be introduced when appropriate and avoids front-loading readers with too much information. I reason that this is the most optimal way to engage readers while maintaining analytic rigor.

Further, my strategy to highlight four households at the beginning of each chapter (and not all nine in a separate chapter) was due to my recognition that I could not possibly do justice to every household while providing the level of detail I felt my readers needed to appreciate caregiving in Teotitlán. I reasoned that the alternative, writing a separate chapter that would introduce each household, would be burdensome and repetitive. Of course, this decision ultimately means that there is much about my data that remains unexplored and unsaid. But I consider this an inevitable feature of qualitative research – a form of inquiry that at once attends to the complexity of human experience
while also acknowledging that the nature of its complexity ultimately means human experience cannot be fully concretized. With this in mind, I now turn to my analysis.
CHAPTER FIVE

The Pluralism of Forgetfulness: Symptoms and Etiologies

Setting the tone for our fieldwork, Alex and I approached our first household with tact only a local would know. Though guests do not typically schedule visits in advance, Teotitecos arrive to other homes quietly so as to not cause disturbance. Alex tapped on our first household’s metal door in such a muted succession of knocks that I initially wondered if anyone would hear our call. We waited for minutes and I had already abandoned my hope when, sure enough, the door opened. A man in his mid-forties appeared and Alex briefly announced the reason for our visit by asking about the forgetful elder, and inquired whether his family was willing to be interviewed. To my surprise the man stepped back to open the door and gestured our welcome. We entered an expansive courtyard partly paved and the rest of compacted dirt, with overgrown fruit trees, clucking chickens, and two small looms for weaving rugs. Alberto, whom I call the man that greeted us, entered the house and returned with two plastic chairs that he arranged with others in a circle. He called upon his wife, Beatrice, a woman in her early-forties who was doing household chores, and his sister, Cecilia, in her mid-fifties who had been weaving. And it was like this – sitting in a circle beside Alex who explained our visit in Zapotec – that my first interview took place.

Alberto and Cecelia lived in different homes on the same property with their respective families, and jointly cared for their widowed mother. Like most of my interviews, I did not meet with this elder, their mother who would be the focus of our
conversation. I wanted to respect their privacy, and I was also aware that the elder was too vulnerable. Hence it was from Alberto and his family that I learned that they had been aware of their mother’s forgetfulness for years, and that she was recently diagnosed with senile dementia. As discussed in Chapter Three, senile dementia is a local illness category that refers to mild age-related forgetfulness. It stands in contrast to the severe mental and physical inactivity known of Alzheimer’s disease. As naïve as it may sound, I remember thinking that this was not a “real” case of Alzheimer’s disease because the elder was not diagnosed with it by a doctor. At this early stage in my fieldwork I was determined to find families who were told by doctors that elders were forgetting due to Alzheimer’s disease, focusing on how that diagnosis impacted caregiving practice. Now, I realize that my difficulty finding diagnosed cases was instructive in itself. As I will subsequently show, it shed light on how Alzheimer’s disease and age-related forgetfulness are understood in locally specific ways.

My early experience with Alberto and his family introduced me to the immense challenge of conducting interviews and the complex theoretical landscape in which they occurred, two primary themes that would become the foundation of my analysis. First, conducting this interview highlighted the obvious yet taken-for-granted fact that asking a caregiver to describe his or her experience is akin to asking a pointed question about the most intimate dimensions of a person’s life. To this end, I take stock in Arthur Kleinman’s (2008) observation that “caregiving is a foundational component of moral experience… [that is best understood as] an existential quality of what it is to be a human being” (p. 23). In the four chapters of analysis that follow, I illustrate what this moral experience looks like and what it means to be human in Teotitlán. Though it is
unfashionable to theorize about love, I argue alongside Kleinman that this is precisely the heart of caregiving practice. Each theme I come to analyze is meant to point towards this larger phenomenon – despite recognition that it is impossible to fully succeed. I am aware that all of the specific dimensions of caregiving – that is, all of the following sections and chapters – are but fragmented parts of this larger gestalt.

Second, my interview with Alberto and his family also called my attention to the varied ways Alzheimer’s disease (and age-related forgetfulness) is conceptualized via a medically pluralistic landscape. Drawing upon traditional and biomedical understandings, Alberto and every other caregiver I interviewed demonstrated that their ideas about aging are not homogenous, but rather profoundly complex and contested. Medical pluralism points to the idea that different medical traditions can coexist in the same setting. In Teotitlán, biomedicine and traditional medicine stand side-by-side as alternatives, supplements, and mutual influences.¹ To be sure, the existence of multiple medical systems is not the exception but the norm across cultural contexts (Leslie, 1980; Lock & Nichter, 2002; Pigg, 1995). Yet the manner by which these two systems interact – and the way in which they constitute my participants’ daily lives – is essential to understanding this project’s data.

Medical pluralism is the theoretical groundwork of this chapter and the next, which together serve to illustrate the complex ways that multiple medical systems interact and color the experience of attending to Alzheimer’s disease. I seek to show how caregivers’ ideas and practices exist at the juncture between two medical systems, and,

¹ To be sure, in addition to traditional and allopathic medicine, Oaxaca is also home to homeopathic medicine (see Finkler, 2001b; Hunt, 1992; Whiteford, 1995). My decision to not include it in the following analysis was based on the fact that homeopathy did not surface during any of my interviews.
more generally, how these medical systems are perceived with regard to broader social changes. This branch of anthropology is credited to Charles Leslie (1980) who, by demonstrating the existence of multiple medical systems in most societies, argued that traditional medicine continues to be relevant and that biomedicine is rarely hegemonic (see also Good, 2010). More recently, as Lock and Nichter (2002) articulate, research in medical pluralism has revealed the vast range of medical practices that exist across and within the same cultures. It also provides a perspective to examine how traditional medical systems have responded to biomedicine, creating an alternative medical viewpoint to “modern” medicine’s association with industrialization, capitalization, and other forms of engagement with non-traditional global forces (Comaroff, 1981).

In this chapter I review how caregivers provide unique insight into medical pluralism by showing the way that laypersons navigate between and augment from Teotitlán’s diverse medical landscape. Illness is not viewed from a traditional or biomedical perspective, but as a synthesis of the two. Further, following Kleinman (1997) who urges ethnographers to consider “what is at stake” in medical practice (pp. 97-100), I seek to demonstrate that views about forgetfulness represent Teotitlán’s ever-shifting community structure, perceived as threatened in the face of its engagement with the broader capitalist world (see Chapter Two). In this way, the various understandings caregivers have of forgetfulness do not merely concern one medical framework versus another, but point towards an issue that highlights the very integrity of filial piety, local tradition, and communal solidarity.

This chapter progresses sequentially, from the basic symptoms of forgetfulness towards how those symptoms are interpreted via local medical knowledge. The first
section of this chapter outlines elders’ symptoms, the features of forgetfulness to which caregivers are attentive. I demonstrate how these symptoms are indicative of Teotitecos’ broader understanding of the social world. The second section reviews etiological understandings (e.g., how people explain and make sense of illness). I show how etiologies are not rooted within one medical system versus another, but rather involve complex fusion of each. In the process, I demonstrate how these understandings open up new possibilities for action.

Symptoms: The Spectrum of Forgetfulness

Through the course of my interviews I had the opportunity to meet with caregivers of elders in different stages of what would be called Alzheimer’s disease – that is, a spectrum ranging from those elders’ whose forgetfulness almost seemed benign, to a type of forgetfulness that was unquestionably pathological. In what follows I proceed to sketch this spectrum and discuss how each phase is expressive of caregivers’ experience of the social world.

Early-stage elders were often discussed in terms of forgetting ordinary events. As Alberto and his family represented early-to-mid-stage symptom severity, I first consider another household and so turn to Luis and Laura, a married couple in their mid-forties. These individuals provide care for Laura’s mother, an elder in her mid-seventies who was recently widowed and deemed in need of help managing household affairs. Luis and

2 The following section is focused on symptoms of progressive forgetfulness known in cases of Alzheimer’s disease. Vascular dementia is not considered here because the onset of symptoms is so abrupt that including these cases would distort the spectrum under consideration. See Note 5 for an illustration of the different ways caregivers experience the suddenness inherent to vascular dementia.
Laura recently moved in to live with this elder, and our interview took place in their new home. At one point, I asked them to describe what sort of things they notice Laura’s mother to forget and I was particularly struck by their lighthearted tone.

Luis: She often forgets her bag.

Laura: [laughs] Her money.

Luis: For example, when she wakes up – when she gets out of her room – she’ll get her bag ready and [she’ll] leave it at the entrance, and she goes back to her room. And then she starts asking where her bag is. And that kind of surprises us, because it happens so often.

The levity of this exchange is perhaps best explained by Luis and Laura’s lack of concern. Laura laughs at her husband’s observation, but then supplements it with her own. Here, forgetting appears benign, ordinary, a simple instance of inattentiveness that most individuals can relate to. The elder’s forgetfulness poses no major hindrance to family functioning and can easily be overlooked. But there is more. Luis curiously says that the elder’s forgetfulness nevertheless strikes him as strange. He is surprised about the frequency with which his mother-in-law forgets, the number of times she is confused about where her belongings are. Indeed, my very arrival to this household occurred because Alex and I had learned about Laura’s mother from other members of the community. Luis and Laura had told people about their experience – further indicating that they found this behavior “surprising.” In this way, minor forgetfulness is something caregivers are attentive to, but nevertheless a condition they minimize.
Moving along from the most benign detection of forgetfulness to a case that presents with slightly greater severity, I return to my first interview with Alberto, Beatrice, and Cecilia. Much like Luis and Laura, these caregivers continued to describe forgetfulness without concern.

Alberto: When she forgets we don’t pay much attention to it, and we feel it’s normal because when we get together again she gets back to normal. But when Cecilia goes away, even if she is only doing chores, she always is asking, “Where did she go?” even though she was told where Cecilia went… But, but – to truly forget – she doesn’t really forget.

Here, forgetfulness is described as something more severe than the typical misplacement of objects. Alberto’s mother has difficulty recalling events that structure daily activities. She asks where individuals have gone, signifying that her experience of the world is more disintegrated. Yet Alberto continues to minimize the impact of his mother’s forgetfulness. He normalizes it by observing that she can remember at other times, and he contrasts her symptoms with a more severe or “true” manifestation (although at this point it is unclear what “true” forgetting amounts to). Like Luis and Laura featured above, Alberto says that forgetfulness is not something that he and his family are attentive to.

I want to pause and consider how curious this statement is. At once, Alberto and his family talk about an experience while saying that it is something they overlook. One way of understanding this is through the nature of discourse and the way in which talk about forgetfulness shapes caregivers’ experience of it. As I noted in Chapter Four, my understanding of discourse is premised on the idea that talk is constructive of the world, changing how things are viewed and how persons behave (Potter & Wetherell, 1987, p.
33). Here, caregivers’ talk about forgetfulness as something that is normal changes their worldview; it constructs a perspective that at once acknowledges symptoms while simultaneously minimizing their importance. It follows, then, that caregivers’ behavior is founded on their understanding of forgetfulness as benign.

My intention in presenting this spectrum of forgetfulness is not to prove a broader point about discourse. Rather, I aim to show how discourse about forgetfulness impacts its meaning across levels of severity. This is a point about the social construction of aging and, compared to U.S. settings, how age-related forgetfulness means something different in Teotitlán. I want to move beyond the idea that forgetfulness is an objective symptom that signifies the same thing across time and space in order to show how it means something different, depending on one’s broader social horizon.

To this end, I turn to consider Sergio, an unmarried man in his early-thirties who cared for his demented father with the help of his married brother, Manuel in his mid-forties, and their mother, Linda, in her mid-to-late sixties. Unlike most other households I interviewed, I detected no looms for weaving and learned that this household had established a successful tortilla business. They were wealthier than most families, and their immaculate courtyard and concrete (non-adobe) walls stood in contrast to many other houses I had visited. I asked these participants to describe instances when they noticed the elder forgets. Though the symptoms they experienced were more severe, I was surprised by the remarkable similarity of their demeanor compared to the households featured above.

Sergio: One time I was coming back home and he [my father] asked me, “Who’s your dad?” [Family laughs in unison.]
Linda: Oh, last year one of my daughters came back home and when she arrived to the house she was very happy. And then my husband asked her, “Who are you?” And my daughter told him, “I’m your daughter.” And he said that he didn’t believe her, and he laughed. So he forgets. Even now he confuses his children. He will switch their names and he would call Sergio “Manuel,” and Manuel “Sergio.” And he always confuses them.

Forgetfulness here means more than just misplacement of objects or ordinary events. It involves difficulty remembering basic information. Family members are forgotten, names are confused, and there is a more serious threat to the elder’s coherence of the life around him. What is interesting is not the fact that memory problems can be more severe, but rather that caregivers’ responses are so similar despite different levels of severity. Sergio and his family continue to laugh – like the excerpts featured above – and thus illustrate that this perspective is maintained even when basic family exchanges appear more jeopardized. Again, this illustrates the constructive power of discourse, highlighting how talk about the normalcy of forgetfulness shapes one’s experience of it.

Although appealing to discourse helps explain how caregivers are able to experience forgetfulness as normal, it does not explain why they do it. This is to say, merely observing that something is a function of discourse does not go far enough to explain the reason for why speech manifests the way it does. This question is especially pertinent to a U.S. audience, where age-related forgetfulness is noted with such hyper-acuity and alarm. By contrast, I came to realize that Teotitecos’ view of forgetfulness as normal is not incomprehensible at all. In the most general sense, the majority of social interactions are premised on overlooking peculiarities in order to establish a sense of
common understanding. With speech, for example, we tend to find meaning in what other people say despite the ambiguity, irrationality, and opaqueness that surround language. In the words of Donald Davidson (1984), we maintain a principle of charity, an assumption that other people are rational agents and that it is our responsibility as listener to decipher the meaning they seek to convey.3

Yet the fact that even caregivers who deal with more severe symptoms view forgetfulness as normal moves this idea beyond a general statement about the nature of language towards an observation specific to Teotitlán. Why do caregivers like Sergio, Manuel, and Linda, the successful tortilla makers, state that their father’s inability to recall members of the family is normal when it so clearly is not? Although there are many ways to account for this stance, the most compelling reason is found by questioning what is “at stake” if they do not uphold it (Kleinman, 1997, pp. 97-100). At stake is not only Sergio and Manuel’s relationship with their father (and Linda’s relationship to her husband), but more broadly their view of family and social cohesion, respect towards elders, and local tradition. The ideal of a unified family is vital in a context like Teotitlán where family structure is changing so rapidly, where customs like living with one’s parents are compromised in the wake of capitalism and migration, and where elders are perceived as losing the authority that tradition prescribes. A unified family hits the core of what it means to be a Teotiteco today. Hence, for caregivers like Sergio, Manuel, and Linda, claiming that forgetfulness is normal is not due to pure human instinct (as would be suggested by merely appealing to Davidson’s principle), but something one wants to

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3 Davidson states that this idea is indebted to philosopher W.V. Quine. I refer to it as Davidson’s principle because I was not able to trace this source and because Davidson is often credited for it.
affirm because of what is considered to be threatened. It is a means to maintain family relationships, to continue viewing elders as they have always been viewed.

Though this observation appeared valid throughout my fieldwork, it proved untenable in the most severe case. Carlos, an elder in his mid-seventies, lived with his son, Francisco, a prominent resident in his early-fifties, Francisco’s wife, Martha, in her mid-forties, and their adult children. Together, they cared for Carlos’ wife who was diagnosed with Alzheimer’s disease but more accurately would be described as meeting late-stage disease criteria. In addition to the unique fact that this elder was diagnosed with Alzheimer’s disease (I found only one other case) this interview was memorable for the amount of time I spent trying to arrange it. As I will describe in Chapter Seven, it took months for Carlos and his family to develop enough confianza to meet with me. After learning about the severity of the elder’s condition, I better appreciated why they were resistant. Although I was accustomed to asking my participants to describe symptoms of forgetfulness, here it seemed inappropriate to even use the word “forgetful.” The following excerpt illustrates how confused I initially was regarding the severity of this case.

Carlos: Now, she’s completely forgotten everything. She eats, sleeps, sometimes, but sometimes she doesn’t [even] sleep. But that’s how it started – it slowly started. Until she completely lost her memory.

…

Jon [to Alex]: OK [so] what is she forgetting?

Alex [to Jon]: No [you don’t understand], she completely forgets everything.

Jon: She forgets everything? Does she know their names?
Alex: Does she remember you, all of you?

Carlos: She doesn’t remember us.

Like the mid-stage case, Carlos’ description shows how the elder has forgotten members of the family. But this interview provides a more general sense of the spectrum of forgetfulness, illustrating the slow development of symptoms. Now, Carlos states that his wife’s memory is “completely lost.” (My brief exchange with Alex is further testimony of the serious nature of the elder’s forgetfulness: Alex has to bluntly state to me that this case is pivotally different from others we had encountered.)

Compared to other caregivers, Carlos does not laugh or attempt to normalize his wife’s forgetfulness. The gravity of his description is profound. Here, Carlos’ use of the world “completely” points to how his wife not only fails to recollect information, but no longer functions on a basic cognitive level. (It perhaps sheds light on what Alberto meant above when he compared his mother’s perceived benign forgetfulness with ‘true forgetting.’) Members of the family are not recognized, memories are not recalled, and

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4 Of further interest is the remarkable similarity this interview holds with descriptions of caregivers featured above. In Carlos’ reflection on earlier stages of his wife’s illness, he and his family also described how symptoms were initially perceived as innocuous. They discussed the first instance they detected something was amiss.

Marta: The way it started was that she started to forget what she was going to buy at the market, or she would forget her purse.

Carlos: Or she sometimes forgot what she bought at the market.

Marta: And that’s how it started. And it gradually progressed. Or sometimes if she’s doing something all of a sudden she’s doing something else. That’s how it started.

Through the 6-years that have transpired, Carlos and his family have witnessed the worsening of symptoms. Though it is uncertain what precisely led him to believe that his wife had a disease, it is clear that he and his family are aware that symptoms are slowly progressing.
even speech (discussed at a later part of the interview) is totally compromised. The charity with which caregivers are known to view forgetful elders is no longer tenable. Through this household we gain insight into the limitations of how forgetfulness is minimized and family relations perceived to proceed as normal.

Taken as a whole, each of the caregivers featured above illustrates a moment along the spectrum of progressive forgetfulness. On one hand, this spectrum is congruent

5 It is instructive to compare cases that feature a sudden onset of symptoms (cases of vascular dementia). Here, forgetfulness is abrupt and typically was not described as worsening. These cases are representative of the narrative told by Sophia, a mid-sixties caregiver who lives alone with her husband who has recently experienced a series of debilitating strokes.

Sophia: Well, I don’t know, it all happened all of a sudden… And I didn’t [initially] pay attention to it… And then that Sunday, as I was waking him up and told him, “We should get ready to go to church,” and he said, “OK.” And when he got up, he went out of the room. And then he came back in, and went out again. And I asked myself, “What’s wrong with him?” And he kept going in, and going out, going in, and going out of the room. And I asked him, “What’s wrong with you? What’s wrong? – Are you forgetting something? Did you forget something?” And he said, “Yes, but I don’t remember what I’m looking for.”

All of the caregivers who cared for elders with vascular dementia described stories like this, focusing on a specific moment when they realized something had abruptly changed. At first, Sophia states that she tried to ignore symptoms but the sudden onset of changes forces her to confront what has happened. The contrast between Sophia’s story and caregivers of progressive dementia shows how the latter are able to overlook forgetfulness and continue functioning for extended periods of time.

Moreover, in these cases forgetfulness is perceived to improve, rather than gradually worsen. Consider Juanita, a curandera (traditional healer) and wife in her mid-sixties who cares for her husband with vascular dementia. Juanita expressed hope that seemed all but absent with caregivers for elders with Alzheimer’s disease.

Juanita: He’s starting to remember. I think he will gradually remember. The doctor’s said it might take from 2-3 years until he remembers everything. And that’s how long the treatment will take… [And] since I’m the caregiver, I want him to get better. I want him to overcome his symptoms. And I always thought that he would get better, and I would make him get better. We have to go forward. There’s no retreat.
with how Alzheimer’s disease is classified according to early-, mid-, and late-stage symptoms in the U.S. and other settings. That is to say, in Teotitlán age-related forgetfulness aligns with what we know about Alzheimer’s disease and other forms of progressive dementia: memory problems become more problematic with time. On the other hand, this spectrum highlights location-specific understandings of forgetfulness. Compared to a setting where early signs of forgetfulness are considered a grave forecast, in Teotitlán forgetfulness is minimized and considered normal. This process occurs in light of broader social changes to the Teotiteco community. Nevertheless, and despite the fact that forgetfulness is perceived as benign, elders are still viewed as having changed. Their behavior is different, their ability to contribute to household chores is impacted, and many also had other concomitant illnesses (see Chapter Four, Note 12). In the following section I review how caregivers perceive the nature of this change. I take up the question of etiology to further explore how age-related forgetfulness is understood.

Etiology

In this section I move beyond discussing how caregivers are (in)attentive to forgetfulness towards how forgetfulness is understood to arise. To this end, I return to my interview with Alberto and his family, the first household I had the opportunity to meet. At a decisive point during the middle of our conversation I encountered a curious story about another elder that was known to forget. While learning about other cases was

In comparison to the way that time provides a reason to be hopeful for caregivers like Juanita, among caregivers like Carlos who live with elders in late stages of Alzheimer’s disease, time is a threat, a vision of how conditions are expected worsen. (Interestingly, this threat is not found among early- and mid-stages – presumably because of caregivers’ perception that forgetting is still a normal course of aging.)
interesting in itself, I was more taken by how this other family understood the nature of forgetfulness. At this point in our interview Alex takes the initiative to ask Alberto and his family about how the other elder was cared for. The answer we received was a powerful illustration of how understandings of illness are constituted within multiple medical systems.

Alex: What do you think – would a doctor have helped [this other elder] or not have helped?

Beatrice: I don’t know… because he [the other elder] did go to the doctor once and when the doctor said he had that [Alzheimer’s] disease, the relatives did not believe it, that he was lying. And they [the family] believed this happened to him because once he went to the mountains and he fell asleep there, that’s what they said, right? That’s why that happened.

Alberto [interrupts]: Bialan [“soul loss”; Spanish: pérdida del alma], he forgot where he put his donkey.

Alex [to Jon]: They said that they [the other family] went to the doctors but they didn’t believe that he was diagnosed with Alzheimer’s.

What is so striking in the this excerpt is that the doctor’s diagnosis of Alzheimer’s disease is contested through the family’s understanding of bialan, a traditional illness category. At once, the family visits a doctor – a representative of biomedicine – while also entertaining and ultimately deciding upon a traditional understanding of illness. This brief exchange introduced me to the complex ways that age-related forgetfulness is understood through varying medical perspectives, highlighting the pluralism I would find
throughout my other interviews. It illustrates how etiological understandings are not predictable but rather draw on multiple theories from different medical systems.

Kaja Finkler (2001b) writes of her study in Mexico that “to know the cause of a sickness is to make sense of one’s suffering… [Etiologies] furnish a window to people’s ideologies, morality, social interaction, and relations to themselves, their bodies, and their environment” (p. 31). Indeed, the various etiological understandings I found among caregivers provide a similar prism onto social life. Throughout this section I will show how caregivers’ explanations of forgetfulness draw upon locally prevalent ideas about illness while they illustrate caregivers’ attempts to respond to them. Moreover, caregivers’ talk about etiology demonstrates how individuals creatively make use of the eclectic medical models that are part of their surrounding landscape. To this last point, I came to realize that it did not make sense to divide or oppose traditional medicine from biomedicine. From the perspective of caregivers, both were relevant and useful to explain symptoms, and each tradition was adapted to make sense of forgetfulness (see Nichter, 2008, p. 76).

In what follows I present a list of etiological beliefs endorsed by caregivers and consider how etiologies impact caregivers’ relationships with elders. My broad argument is that each of the following etiological beliefs opens a space for caregivers to become

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6 In contrast to the prevalent idea that caregivers are indifferent to etiology, this explains why I found them regularly engaged in such theorizing. Throughout my interviews I found instances of family members reflecting, debating, and contradicting explanations about why elders forget. This dissonance does not render etiology unimportant; on the contrary, drawing on focus group literature (Carey & Smith, 1994), it provides a perspective into the way the meaning of forgetfulness is understood locally and how it is a product of negotiation.
agents of action, that is, individuals capable of attending to and caring for elders whom they know to be increasingly debilitated.

a) Soul Loss and Fright

I return to the excerpt featured immediately above. Alberto, Beatrice, and Cecilia are discussing the only other elder they know in the community with a condition similar to their mother. This elder has since passed away, but the relevance to the family is still apparent such that it appears spontaneously in their dialogue. The other family decides to consult a doctor and receives a diagnosis of Alzheimer’s disease. The family encounters the doctor’s diagnosis, refuses to believe it, and instead maintains a traditional explanation – Bialan. When Alex and I encountered this word while transcribing, he stopped the recording and had a puzzled look on his face. “They’re talking about something that has no real translation,” he told me. We spent minutes – and then subsequent days – hashing out the meaning of this illness category, whom it affects, and its treatment.

In Teotitlán bialan [“soul loss,” Spanish: pérdida del alma] occurs when an individual is abruptly taken away from a place – or experiences a shock or trauma – and subsequently becomes irritable. Typically associated with vulnerable individuals (children and older adults), the affected person is said to have lost his or her soul.7,8 It is a

7 The Zapotec expression used, biang anim (“soul loss”), further sheds light on what exactly is lost – it is the soul that departs from the deceased (in comparison to garlieng, which refers to the soul of living persons).

8 While soul loss is presented as a “traditional illness category” the concept more accurately illustrates how traditional ideas fuse with non-traditional ones. As discussed in Chapter Two, Mesoamerican Pre-Hispanic culture did not believe in the “soul,” but rather tonalli, a conception of the self that was based upon
condition where the person is physically alive, but in some subtle way, is different and no longer him or her self. In the story told by Alberto and his family, the elder was in the field letting his livestock graze and, after being shocked due to an unknown cause, forgets where he put his donkey. He returns home impatient, forgetful, and no longer the same person. These symptoms are understood as having a telos, directing the affected person to return to the place where his or her soul was lost in order to be reacquainted with it.9

Though bialan only appeared once in my interviews, another illness category, xhibi [Spanish: susto, “fright” or “fear”], appeared more often. The idea behind susto is that a sudden shock or traumatic event causes part of the self to leave the body. Susto has been researched in Teotitlán (Fitzsimmons, 1972) and is more widely recognized as an illness category across Latino cultures (Rubel, 1960).10 Locally, susto and soul loss are treated as two separate illness categories, but they are conceptually related. Susto (a shock) is understood to be one of the causes of soul loss – though not all cases of susto cause soul loss, and there are also other circumstances (like spirit intrusion) where a person may lose his or her soul.

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9 It would be interesting to compare the symptoms known of post-traumatic stress disorder with bialan, and specifically to examine the role of flashbacks as a symptom that invites a person back to the event and location of his or her trauma.

10 Susto is also included in the DSM-5 (2013) as a “cultural concept of distress.”
I further learned about traditional ideas like *susto* through my interview with Sergio, Manuel, and Linda, the owners of the successful *tortilla* business. At this moment of our conversation, Alex and I asked about possible reasons to make sense of why the elder forgets.

Linda: He used to forget when he was younger, and also there was this thing that happened to him in the mountains.

Sergio: I don’t think that has anything to do with it.

Manuel: But the majority of people forget stuff anyway. But him, he probably had something when he was younger.

Alex: What happened to him in the mountain? Did something happen?

Linda: Yes, there was this thing that happened to him when he was younger. Because they used to have cattle in the mountain. So he went by himself to herd the cattle. And he realized there were two dogs chasing him. Then, as he was running, he entered into an unknown place. It looked to him as if he was running through mud. He made it running through the mud, but then he got stuck. So he stopped and started walking back. And then he saw an enormous person. And then he realized it was the devil. It had horns. And then he got scared and didn’t know how to escape.

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Alex: Do you think that something to do with his forgetfulness?

Linda: That I don’t know, I don’t know.
Beyond illustrating how traditional illness categories are still relevant, this exchange provides insight into how past incidents of susto are used to explain forgetfulness in the present.\textsuperscript{11} Linda recalls an event she knows happened to her husband decades ago. She cites this incident to speculate on a possible cause of her husband’s current forgetfulness, implying that these past injuries may have resurfaced to cause her husband to forget. This makes sense, given how she believes her husband suffered from forgetfulness immediately after experiencing susto. But Linda ultimately states that she does not know

\textsuperscript{11} In contrast to the way susto is used to explain progressive forgetfulness by means of an incident in the distant past, caregivers of elders with vascular (sudden onset) dementia theorized about susto as something that occurred more recently. To this end I turn to consider Mario, his wife, Isabelle, and his mother, Graciela. This household was one of the poorest I visited in Teotitlán, illustrating local wealth disparities. They made such a strong impression on me for their humility, expressing sincere gratitude despite their difficulties. At one point during this interview they poignantly discussed the night when they believed the elder experienced susto and how this was a cause for his abrupt onset of symptoms.

Isabelle: It was in the middle of the night.

Mario: “Something appeared,” he said. But he didn’t tell us what it was. It was shocking for him, because when he left he was fine. But when he returned, he was in a stupor [Zapotec: quedrualaśaldian, literally: “he’s not there”].

Isabelle: He then told us that he saw an animal, a very hairy animal, a big animal. [Whispers:] That’s what he thought he saw. And he said that he was very frightened. I don’t remember exactly if he said that the animal attacked him, or if it just stood in front of him.

Mario: That happened the very first time.

Isabelle: That’s why we think that that caused what he has now.

In this excerpt Mario and his family continue to use susto as a means to explain their elder’s forgetfulness, but their story is more recent, and points to the moment when character changes were noticed. Technically, this understanding points to a different local illness category, mal de hora (“bad hour”), which involves local belief that there are specific hours during the night where individuals are vulnerable to spirit intrusion. Mario’s father goes to the restroom during this hour and returns disheveled. He is no longer the same person. Though this story is different than the one Linda tells, it involves a similar shock to the agent. Mario’s father is asustado (he “has” susto). The difference between these two instances of susto makes sense given the difference between symptoms appearing through the course of time.
if this explanation is valid. After introducing the idea, her son, Sergio, contests the idea, while Manuel, her other son, states he is undecided. Though Linda’s suggestion is left as a tentative hypothesis, it nevertheless illustrates the broader point that ideas about susto are locally accepted reasons to explain age-related forgetfulness.

My turn to these traditional conceptions of illness is not to suggest an essentialized reading of Teotitlán. It would be foolhardy to argue that concepts like bialan and susto involve the same undiluted Pre-Hispanic metaphysics. Indeed, the fact that locals draw parallels between bialan and pérdida del alma (“soul loss”) shows the evolution of traditional ideas. (There existed no notion of “soul” in traditional Zapotec culture; see Note 7). Hence, instead of suggesting that bialan somehow represents a “pure” traditional understanding of forgetfulness, I present it to suggest a more nuanced point regarding medical pluralism. Etiologies cannot be viewed as purely traditional or biomedical, but rather a mode of understanding that is constituted by the mutual existence of multiple medical systems. In this way, a traditional understanding of soul loss is leveraged to explain age-related forgetfulness, a purportedly new, “modern” illness. I believe this helps demonstrate how traditional ideas continue to have relevance as new, biomedical ones are introduced – while avoiding the claim that traditional medical ideas somehow contest or eclipse new ones.\(^{12}\) Though this is a subtle point, I consider it

\(^{12}\) Moreover, it illustrates Foucault’s (1972) point that surface knowledge remains influenced and shaped by underlying depth knowledge. The surface knowledge – what Foucault calls connaissance – are forms of knowledge applied and consciously known by individuals. Illness categories like bialan and susto are examples; so too is Alzheimer’s disease. Surface knowledge is a type of knowledge that can be true or false, and is consciously known and applied to the world. Calling it surface knowledge is not diminutive; it only implies that there is some constituting factor beneath. Depth knowledge – what Foucault calls savoir – is that factor. It is an overall worldview, a set of practices that does not represent a single object of knowledge, but a general perspective that informs understanding of the world. Of course, my use of the
important because it avoids the type of essentialist arguments that view settings like Teotitlán as living apart from or resisting “modern” medical ideas.

I also feature this etiology for how it illustrates my argument that etiological understandings open a space for action. The family described by Alberto who challenged the doctor’s diagnosis likely also heard from the doctor that there is no treatment for Alzheimer’s disease, that there exists nothing to reverse, arrest, or mitigate symptoms. This is a current fact about Alzheimer’s disease, including in the U.S. (see Chapter Three). Yet beyond limitations in the U.S., Teotitlán has no industry (like nursing homes) designed to help support families impacted by Alzheimer’s disease. Hence, if the family had accepted the doctor’s diagnosis, they would have been left with few options to care for the elder. Their belief in soul loss thus opens up a new possibility to do something, to seek medical treatment from specialists apart from biomedicine.

This moves beyond an understanding of etiology as mere theoretical explanation. Now, etiology is understood as a type of explanation that constructs a vision of the world based on desired action. In this case, etiologies are explanations premised on hope. Further, they demonstrate how Alzheimer’s disease is not only constructed of a social world, but also constructive of the world caregivers want to live in. This is a world where action is possible, where forgetfulness does not signify an end but rather a different horizon of options. Much like Moscovici’s (2008) description of how representations form, in part, to maintain social cohesion, etiologies are ways to continue engaging with

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terms “surface” and “depth” knowledge is taken from Ian Hacking (1998, pp. 198-199). To further clarify his appropriation of Foucault, Hacking compares these two forms of knowledge to Noam Chomsky’s depth and surface grammar: depth grammar is the underlying basic structure that founds the grammatical rules inherent to surface grammar.
elders, to respond and to treat illness. In what follows, I continue to develop this argument by showing how other etiologies are equally oriented towards taking action and providing care.

\[b) \text{Rumination and Depression}\]

In addition to the idea that fright can cause forgetfulness, caregivers also talked about more subtle behaviors noticed of elders like their sadness, rumination, and social withdrawal – observations that would otherwise be considered instances of depression.\(^{13}\)

To begin to introduce how caregivers understand depression as a cause of forgetfulness, I return to my interview with Carlos and his family, the household I devoted months to try to interview. Recall that Carlos’ wife was diagnosed with Alzheimer’s disease and represented the most severe case I had encountered. At one point, Carlos and his family discussed how they believed the elder’s earlier battle with diabetes contributed to her forgetfulness. To make sense of this logic I needed to appreciate that depression is locally viewed as a mediating cause of forgetfulness.

Carlos: Well, since she’s diabetic, what we think caused it… She had one of her fingers amputated… It got infected so it had to be amputated. That’s when she started to ruminate [Zapotec original: *riquielá’áz*; literally: “to think a lot from the

\(^{13}\) To be sure, depression is not only a Western construct, but also a psychological condition known prior to the Spanish Conquest (Belsasso, 1969, p. 32). My reference to depression is meant to point towards what the DSM-5 terms an “idiom of distress” – that is, ordinary talk about feeling sad – although depression may also meet diagnostic criteria as well.
That’s what we think caused it. That’s why it started gradually. She couldn’t handle all that rumination.

[Later in the interview]

Francisco: She liked to work a lot and when this happened she considered herself useless. And she would just sit down. She didn’t like doing it [not being active].

Carlos: And that was something she valued throughout her life. So she considered herself a useless person.

Francisco: So all of this contributed to her forgetfulness.

Initially confused by their explanation, I came to realize that Carlos and his family were assuming the following logic: having diabetes led to the elder’s finger amputation, limiting her ability to work, which then caused her to become depressed and, ultimately, forgetful. Though there exists a lot of rich material in this excerpt, I want to focus on the moment in their logic where they assume depression is the direct cause of forgetfulness.14 One way to make sense of this logic is to again recall that not working undermines one’s sense of identity (discussed in Chapter Two, and again in Chapter Seven). Being debilitated, the elder is socially unmoored, and so becomes alienated, withdrawn, and, ultimately, forgetful.15

14 This understanding is an inversion of common beliefs held in the U.S. where depression is viewed as a comorbid symptom of Alzheimer’s disease. However, it is interesting to note that there is evidence that history of depression is known to be associated with increased risk of Alzheimer’s disease (Ownby, Crocco, Acevedo, John, & Loewenstein, 2006).

15 This perhaps contextualizes research on the epidemiology of depression in Mexican settings. Slone et al. (2006) found that, while the prevalence of depression in Mexico was lower than that known in the U.S., its symptomology was different. Mexican symptoms of depression were primarily somatic in nature, involving
What is so interesting about this understanding is that, in addition to the way that caregivers endorsed this etiology, elders were also reported to cite it. This was most salient during my interview with Pablo and Vanessa, the only other household with a diagnosed case of Alzheimer’s disease. In addition to being memorable for the elder’s diagnosis, Pablo and Vanessa made a strong impression on me due to the fact that they were caregivers for an elder not in their immediate family (discussed in greater detail in Chapter Eight.) As Alex knew that I was interested in understanding participants’ etiological beliefs, he took the initiative in raising the following question.

Alex: What do you think? Why is she forgetting? What do you think is causing it?

Vanessa: When I talk to her I ask why she forgets… Well, what she says is that it is probably because she thinks about a lot of things that happened throughout her life. What happened to them [the elder and her deceased husband] when they lived here [in Teotitlán]. And that’s what has affected her the most. A lot of thinking. That’s when she says that she forgets.

Pablo: And also because her husband passed away, and he was buried there [in Mexico City] – they weren’t able to bring him back, because they weren’t able to pay the expenses to have the funeral in town. That’s what affected her the most…

Vanessa: There was a time when she would cry in her room, she would even scream. And that’s something that also affected her.

fewer cognitive features like worthlessness and guilt. In my interviews, the feelings of worthlessness and rumination described by caregivers of their elders suggests how cognitive features of depression can be experienced with greater force, such that they explain forgetfulness.
This excerpt reads remarkably similar to Carlos’ and his family, with the only difference being the cause of the depression. Here, we get better understanding that any reason for social withdrawal – a major loss like being widowed, or physical disability like an amputation – can lead to depression, which then causes forgetfulness. In this case, the elder’s husband has died and, more recently, she has had other setbacks in her social life.

Appealing to depression as a cause of forgetfulness shows how adverse life circumstances – what Finkler (1997, 2001b) calls “life’s lesions” – become inscribed on the body and expressed through illness. Focusing on these circumstances helps caregivers make sense of elders’ symptoms, attributing the cause of forgetfulness to something they can understand. But it also does something more. It provides for a common language – a means to engage – between caregivers and forgetful elders.16 Through Vanessa’s excerpt above, we see how understanding forgetfulness via depression establishes a common understanding, and a way to engage with the elder. And, because depression is something caregivers can attempt to ameliorate, etiology is again shown to be a form of action, a means to engage forgetful elders.

c) Stress

Related to depression, stress is another etiological understanding that applies existential meaning to forgetfulness. I highlight stress as a separate category because of the way it is locally perceived as a different cause of illness to depression, and also

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16 This provides greater context for findings on Mexican-American caregivers that attribute the onset of behavior change as a result of personality and stress, rather than dementia itself (Apesoa-Varano, Barker, & Hinton, 2012, p. 278).
because of the common way stress is used to explain forgetfulness. Indeed, as I already mentioned in Chapter Three and will continue to discuss below, Alzheimer’s disease is widely believed by locals not to exist in Teotitlán because of the relative absence of stress. Following this logic, caregivers continue to adhere to this understanding as they explain the cause of forgetfulness – now claiming that elders forget because they experience stress. To this end, I return to my interview with Luis and Laura, the caregivers I discussed earlier as representing the most benign case of forgetfulness. Recall that these caregivers now live in the home of Laura’s mother because she is viewed incompetent to be alone. At this point in the interview Luis and Laura are reflecting on the changes they have observed and their understanding of why they have transpired.

    Luis: Seven years ago my father-in-law passed away. And since then, we’ve noticed that she’s been forgetting.

    Laura: And since then we’ve been having little problems with her, which often leads to her forgetfulness. And ever since, we haven’t had a good relationship. She doesn’t like anything – everything I do, she says is wrong. And the conclusion I come to is that my dad’s death caused this. That’s what I think. But I don’t know if it’s a lot of stress due to the death of my dad. And also for that reason we came to live with her because we don’t want her to stress more.

Implicitly, Laura is drawing a distinction between the depression her mother experienced from the death of her husband, and her mother’s concomitant stress as a widow. Like depression, stress is an understanding of illness that allows caregivers to establish a sense of connection. Caregivers can inquire if elders are feeling stressed, which then fosters
dialogue. Stress explains forgetfulness because it provides an understanding of why the elder has changed – why he or she appears absent minded, irritable, and different than before. Yet, in comparison to depression, this etiological understanding focuses on environmental factors that currently plague a person. These factors can be removed, minimized, or assumed by other individuals.\(^{17}\) Again, this understanding opens up a set of possible actions for caregivers to take.

\textit{d) Forgetfulness as Standard Aging}

I now turn to aging as an explanation itself. Many caregivers explained forgetfulness via aging, citing the lifecycle as a sufficient reason for why elders are known to forget.\(^{18}\) This further explains how caregivers were earlier discussed as viewing forgetfulness as normal and non-problematic. As an etiological understanding, this perspective holds that it is normal to forget and that aged persons tend to forget more.

Surprisingly, however, even caregivers who dealt with elders with mid-level symptoms endorsed this opinion. To this end I return to my interview with Manuel, Sergio, and Linda, the successful \textit{tortilla} makers who cared for an elder that had difficulty identifying family members. At this point in the interview the family was

\(^{17}\) Though caregivers were attentive to how elders appeared angry, caregivers did not cite it as a reason for why elders forget. This may be just due to my limited dataset, but it diverges from research that shows how expressed anger is perceived as sickness-producing (Finkler, 1997, p. 1148). It is interesting to note that, in contrast to the way that pent-up or repressed anger is understood be a causal factor of illness in the U.S., in Mexican settings it is the expression of anger that results in sickness (Hunt, 1992, p. 310).

\(^{18}\) Much effort is directed towards combating this opinion within the U.S. For example, in the first pages of \textit{The 36-Hour Day} (2011), the most popular guide written for dementia caregivers, the authors explicitly state that "severe memory loss is \textit{never} a normal part of growing older" (p. 7, emphasis original). As I have discussed, this debate stood as the foreground of whether Alzheimer’s disease constituted an actual disease at the time of its discovery (see Chapter Three).
discussing their understanding of the elder’s condition, and Alex then posed the following question directly.

Alex: Do you think he has some sort of illness?

Manuel: It could be due to a sort of illness, or it could also be due to his age.

That’s what I think; it might be because of his age.

Manuel entertains the idea that his father’s forgetfulness is an illness (an idea Alex introduces), but he then concludes that a better interpretation is that age is the cause.

Manuel’s hesitancy – his willingness to consider Alex’s suggestion, but then conclude that forgetfulness “might be” due to aging – is also telling. Though he has an intuition about the cause of his father’s condition, he concedes that he ultimately does not know.

This illustrates how etiological understandings are tentatively held, and sheds better insight onto the way that caregivers simultaneously hold multiple ideas about illness at the same time. Nevertheless, despite the tentative way Manuel endorses this etiology, I discovered this same understanding across many interviews, in all but the most severe cases of forgetfulness.

Understanding forgetfulness as caused by aging presupposes certain ideas about the aging process in general. Though the structure of interviews did not afford the opportunity to discuss local understandings of the lifecycle, I did encounter occasional statements that hinted towards a more sophisticated explanation. To this end I return to my interview with Luis and Laura, the caregivers recently discussed who began caring

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19 Moscovici’s (2000) discussion of “cognitive polyphasia” is particularly relevant here for the way it accounts for how the same individuals are able to maintain multiple understandings from epistemologically different (and conflicting) perspectives (p. 241).
for and living with Laura’s mother to minimize her stress. At one point in the interview, Luis shared how he considers forgetfulness to also be a natural part of aging, and then, as if on second thought, explains why he understands this to occur.

Luis: What I think is that it’s a disease that happens to elders only. Because most of the elders forget things anyway due to their old age. And I think it’s because they’ve used a lot of their brain.

Like other caregivers I interviewed, Luis observes that most elders seem to forget things so he concludes that forgetfulness is a natural part of aging. Yet in the process Luis makes a curious observation about how elders are known to ‘use up their brain.’ Here, Luis seems to be implicitly positing a hypothesis that individuals are endowed with a limited amount of resources, and that aging represents the progressive depletion of those resources. This invokes a common belief in Oaxaca about the lifecycle as a continual process of desiccation. According to local knowledge, individuals are born with a certain amount of wet attributes that eventually become used and dried (Royce, 2011, pp. 12-14). In this regard, forgetfulness is understood as a symptom of deficiency, of one’s wet resources turning dry. This is what Luis appears to hint towards in his suspicion that elders have “used up” their mental resources.

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20 The idea of mental faculties as dependent on finite wet resources has a long history that extends to ancient Greek medical theory. Galen hypothesized that the lifecycle is determined by a process of perpetual drying: the infant is endowed with moisture, compared to the old person who is dried out (see Cole, 1992, p. 8). Considering how Spanish Conquistadores introduced Galenic medicine to Mexico, it is not surprising that these two concepts are so similar across time and space. I should also add that, elsewhere in Mexico, J. C. Young and Garro (1993) present a related understanding of the lifecycle based on the concept of fuerza (literally, “force” or “strength”) that eventually becomes used as the individual ages (p. 46).
This understanding is another instance that demonstrates how etiology discloses a realm of action for caregivers to take. Adopting this idea leads to greater empathy towards elders, awareness among caregivers that they, too, will grow old and may become forgetful. Interestingly, however, this explanation contrasts with how representations of illness are typically thought to be based upon an “other-same” dichotomy. People with illness are typically viewed as “other,” having a condition that the agent, as member of a purportedly healthy cohort, does not possess – in other words, illness is commonly viewed as a marker of social difference (Jodelet, 1991). Yet here, by comparison, viewing forgetfulness as due to aging facilitates greater identification with elders. It normalizes age-related forgetfulness by observing that it is a condition every person is liable to develop. In so doing, this etiology fosters greater interpersonal, familial, and social cohesion. Once again, this demonstrates how etiology involves more than a theoretical explanation of illness, but a way to live with and respond to it.

*e) Feigning Forgetfulness*

In comparison to the above etiologies, caregivers from specific households also suggested that the elder may be pretending and that forgetfulness might not need to be explained any further.21 This understanding is essentially a statement that the elder uses forgetfulness as an excuse to carry out unwanted behavior. Not surprisingly, the only caregivers to endorse this etiology were those that experienced difficulties trying to

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21 Additional etiologies used to account for age-related forgetfulness were 1) physical injury to the brain (golpes) and 2) poor diet. I do not feature these in the above discussion because they were exclusively used by caregivers to explain vascular (not progressive) dementia. The only exception was Sergio, Manuel, and Linda, the successful tortilla makers, who considered a past injury to the elder’s brain as a possible cause to his forgetfulness.
control elders’ disruptive behavior. For example, Sergio, Manuel, and Linda, the successful *tortilla* makers, discussed how disobedient and disruptive the elder’s behavior has been. At one point during the interview they questioned whether the elder’s deceptiveness might better explain his forgetfulness.

Manuel: Yes, he is always doing stuff that he is not supposed to. But… I think about the way he is … He is very tricky. And I think that’s a mentality he has always had. So that’s what I don’t understand, if he uses it [his forgetfulness] for his own gain… [H]e is very tricky, very tricky. And I say this because I know him. And he has been like this for a long time. So that’s why I can’t understand if he really forgets or [if he is] just tricky. So I don’t know – it’s on him if he’s lying to us, or if it’s true what’s happening to him.

Here, Manuel debates whether his father is deceiving him and his family, but he ultimately leaves the issue unsettled. He recalls his father’s behavior in the past, and is observant of his defiance in the present. Yet he nevertheless states that “it’s on him [the elder] if he’s lying to us.” If the elder were lying, then Manuel and his family would be deceived. Implied in this logic is a statement about how Manuel does not wholeheartedly endorse this explanation. (How else would Manuel be deceived if he already believed the elder was pretending?) What this shows is that, while Manuel is aware of the possibility that he is being deceived, he ultimately chooses not to believe his father is feigning symptoms.

I only encountered this perspective in one other interview – with Luis and Laura, the couple who recently moved to live with Laura’s mother – and their relationship with the elder was also marked by discord. And, in a similar vein, Luis and Laura discussed
this etiology as a possibility, but one that they did not wholeheartedly endorse. Together, these cases provide an interesting perspective on how I have been discussing etiology as having constructive social power. Etiologies render caregivers as active agents, individuals capable of responding to the symptoms they observe. Understanding elders as pretending to forget does not contradict this argument, but rather sheds light on how caregivers are implicitly aware of the power of their explanations. As Manuel illustrates, caregivers entertain but then put aside this understanding because they recognize that the reasons they adopt to explain forgetfulness carry tangible consequences for their relationships with elders.

**Conclusion**

I return to my interview with Alberto, Beatrice, and Cecilia, the first caregivers I had the opportunity to meet. As I continue to discuss in subsequent chapters, this interview was a powerful vista onto caregiving experiences, practices, and decisions. But above all these dimensions, this interview – like every other interview I would eventually conduct – was instructive for teaching me that caregiving refers to a set of experiences that cannot be concretized. This comes close to Kleinman’s (2008) observation that caregiving hits the core of what it means to be human. It points towards caregivers’ love for elders, their ultimate concern that problems will abate and their families will remain firm. This was implicit in every moment of my interview with Alberto and his family, but I believe it was especially salient towards the end. As we were beginning to wrap-up our discussion, it occurred to me to inquire whether Alex and I had missed asking about any topics that were central to their experience. Alberto said that we had not, that he and his
family were content with how we had discussed their mother. But he then asked me if I knew of any available medication that would arrest his mother’s forgetfulness. Coming from the same individual who stated that he viewed forgetfulness as unproblematic and normal, this question was more than surprising.

Upon further reflection, I came to appreciate that Alberto’s question was not expression of his “conversion” towards biomedicine, nor a new understanding of forgetfulness as an illness. Rather, it was an expression of what was salient throughout the interview – his concern for his mother, and his willingness to consider whatever would be useful for her wellbeing. This illustrates a theme that underlies this entire chapter – namely, that caregivers’ ideas about illness from Teotitlán’s pluralistic landscape are not rooted in allegiance to one medical system versus another, but based on pragmatism, a desire to do what is best.

As a whole this chapter not only illustrates that age-related forgetfulness is socially constructed by surrounding discourse, but that it is also constructive of the world caregivers want to live in. In this way, social constructionism provides a way to account for caregivers’ experience with and responses to forgetfulness, not resignation to it. Social constructionism shows how desire interacts with and shapes the surrounding world. This point comes from two sub-arguments made in this chapter. First, this chapter reveals how the meaning of forgetfulness can significantly vary depending on surrounding discourse. Though forgetfulness is an observable (“objective”) symptom, the way it is talked about has a constructive effect on how it is perceived and understood. Forgetfulness among elders is considered normal by caregivers, a perception that is maintained until late stages of illness. Further, it is possible that this perspective assists in
challenging larger social changes in Teotitlán, to preserve familial and social cohesion.

Second, this chapter demonstrates how etiological explanations are not rooted in one specific medical system versus another, but draw upon popular ideas of both traditional and biomedical systems. These ideas are not just a means to theorize about forgetfulness, but more importantly disclose a realm where caregivers can take action. In this way, caregivers are not passive subjects to medical theory, but are actively involved in leveraging the theory(ies) that best serve their pragmatic concerns for elders’ wellbeing.

In the chapter that follows I continue to develop the theme of how caregivers take action by focusing on their decisions to seek medical help.
I continued to experience difficulty finding diagnosed cases of Alzheimer’s disease. Months into my fieldwork I arrived to a fourth household and I was confident I had stumbled on my aspired case. After meeting him at his front door, Sergio, the unmarried man in his mid-thirties earlier mentioned from the successful tortilla family business owners, described things about his father that were telltale symptoms of Alzheimer’s disease. The elder was known to initially forget seemingly minor things, but now he often failed to recollect who his children were. He wandered aimlessly through the streets and has tried to board buses. And he seemed angrier, at times even violent. After briefly explaining to Sergio that we are looking to interview people who take care of elders like his father, Sergio directed us through his courtyard to the altar room, an indoor space every Teotiteco home has for worship and welcoming guests. Adorned with religious icons, candles, and photographs of deceased relatives, Alex and I waited for Sergio to call upon other members of his family. I noticed a degree of wealth definitive of this household, compared to the ones I had visited prior. We sat in sturdy wooden chairs, as opposed to plastic ones. There were no looms for weaving – evidence of the family’s success in their business. And the walls were finished in plaster and paint, giving me the general feeling of being further removed from the campo (“farmland”). A few moments later Sergio reemerged with his mother, Linda, in her late-sixties, whom he lived with.
because he was unmarried. And, after, Manuel arrived, Sergio’s older brother in his mid-forties, married, and living in the adjacent house on the same plot of land.

Despite my belief that Sergio’s father had Alzheimer’s disease I not only discovered that he did not receive this diagnosis, but he hadn’t received any diagnosis. I learned that Sergio’s family never consulted a doctor, *curandera*, or any other person for medical help. I was beyond confused. Given the severity of the problems they faced and their relative affluence, how could this family not have asked for help? In the following excerpt my unmasked confusion speaks for itself. At this point in our interview I decided to ask if Sergio and his family had even considered visiting a traditional healer – trying to identify *someone* whom they thought might help.

Manuel: Well, I personally do not believe in that type of thing. I only believe in the power of God. What I do is pray for him. Since *curanderas*, at least for us, they’re not useful.

Alex [to Jon]: They don’t believe in *curanderas*.

Jon: Please explain to them that I don’t understand – because their experience is so difficult, taking care of him. But they’re not going to any expert, for [the elder’s] health. I don’t understand why.

Alex [to Jon]: They explained first of all because, regarding the doctor, he [the elder] doesn’t want to go. And regarding the *curanderas*, they don’t believe…

Like so many other instances, I turned to Alex for explanation about the “hows” and “whys” of the phenomena we encountered – here, why this family has chosen to forgo all medical help (from whichever medical tradition) and how they cope without it. Alex
summarizes the family’s position that, first, it is against the elder’s wishes to visit a doctor and, second, not visiting a curandera is a matter of belief. Their strategy is to pray to God that their situation will improve. And so, this interview presented me with yet another reason for why finding a diagnosed case of Alzheimer’s disease would be an ongoing challenge – beyond the fact that there are many different ways for medics to describe and name what I would call Alzheimer’s disease, many families choose not to even consult doctors when caregiving proved to be difficult.

I deliberately feature this family and their decision to forgo medical help to introduce the topic of medical consultations, what Charles Nuckolls (1991) aptly calls “deciding how to decide,” and the way such decisions involve deeply complicated and often contradictory rationales. More broadly, this is what medical anthropologists refer to as “health- [or help-] seeking behavior” (Kleinman, 1980, p. 20; Nichter, 1978). Adapting Kleinman’s three-tiered framework (1980), in Teotitlán I view health-seeking behavior as occurring within the following overlapping sectors: the popular sector involves home remedies; the folk sector is comprised of curanderas (traditional healers who possess specialized spiritual and local knowledge); and the professional sector consists of medical doctors, nurses, and other specialists whose practice is locally sanctioned and legitimized (p. 50).¹ As my interview with Manuel and his family demonstrated, individuals may leverage none, although more often I found caregivers choose among one type of healer over another.

Building on the last chapter that demonstrated how forgetfulness is not perceived as problematic, here I raise the question regarding what brings families to consult

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¹ I refer to curanderas in the feminine form because all practicing folk healers in Teotitlán were women. Yet there exist many male curanderos throughout Oaxaca, Mexico, and Latin America.
specialists when elders manifest symptoms. Specifically, in the sections that follow I inquire why caregivers consult doctors, curanderas, or neither, how they make their choice among alternatives, and the impact of each.

In many ways, this chapter is intended to complement, complicate, and limit the argument I previously made. Whereas in the last chapter I argued that caregivers’ understanding of forgetfulness is a pragmatically based stance that opens up alternatives for action, in this chapter I argue that this alone is insufficient to appreciate how caregivers are constituted within Teotitlán’s medically pluralistic landscape. Before, I showed how caregivers endorse multiple etiologies that transcend epistemological boundaries, but here I show how caregivers’ decisions about whom to (not) consult is based on other factors that go beyond their relationships with elders. Following my appropriation of Fairclough (2013) and the idea that discourse is inexorable from power, my thesis in this chapter is that broader discursive realms of power, politics, economics, and social influence are essential to appreciate health-seeking behavior in Teotitlán.² These realms shape the parameters of how individuals navigate local medical options, establishing the boundaries of the pragmatism previously described.³

² This challenges Pigg’s notion of “harmonious pluralism” where she writes that “many kinds of healing are not seen as different systems… [Rather] [t]hey merely constitute what is understood to be an open set of locally available options” (p. 23).
³ I recognize that this stance renders me in the minority of research in medical anthropology. Most anthropologists – especially those who have focused on Mexico – take a position similar to Finkler (2001a) who argues that Mexicans do not distinguish between different types of healers because their concern is a pragmatic choice to access the best medicine (p. 132). This sounds very close to my argument in the last chapter. But there I focused on caregivers’ relationships with elders and here I discuss how caregivers make medical decisions. The pragmatism that I identified before appears more limited in the health-seeking behavior I will come to analyze here.
**Biomedical Options**

Allopathic doctors are known locally and respected individuals who have specialized knowledge to cure illness. The Zapotec reference to doctor, *benih ni resiak*, literally means “a person who cures.” As this traditional phrase suggests, doctors have been present in Teotitlán for centuries, embedded in extended histories of conquest, colonialism and, as I will come to argue, contemporary power. From the time of the Conquest, the Spaniards introduced European-trained *médicos* whose practice was based on classical Greek humoral medical theory. As discussed in Chapter Two, these practitioners and other Conquistadores challenged and eventually subverted indigenous medical practice, leading to the eventual collapse of Pre-Hispanic medicine (Somolinos d’Ardois, 1976; Treviño, 2001, p. 54). Nevertheless, New World physicians began to selectively incorporate humoral medicine with parts of what remained of local knowledge of medicinal plants, leading to a *mestizo* (“mixed”) medical practice that flourished until the introduction of biomedicine (Hernández Sáenz & Foster, 2001, pp. 19-25). This persisted until the early 19th Century when French-based biomedicine arrived to Mexico, leading to two lasting consequences for medical practice. First, it introduced a perspective that continues to be definitive of biomedicine today, distinguishing between objective (biological) and subjective (psychological) symptoms of illness, and training the physician about how to interpret underlying biological causes. Second, this initiated yet another displacement of indigenous knowledge, solidifying what are now the defining features of “traditional” medicine. As I will subsequently describe, the theory and practices employed by *curanderas* are the result of a combination of local knowledge of
medicinal plants, Pre-Hispanic notions of the self, and concepts like humoral imbalances introduced by the Conquistadors.

In the immediate sections that follow I continue to trace how biomedicine is embedded within larger structures of power. Whereas indigenous (or traditional) medicines have been historically delegitimized through ruling dominations, I now analyze how biomedical practice continues to be embedded through government programs, standardized medical procedures, and economic parameters. To be sure, this analysis is limited to age-related forgetfulness. But this focus serves as a prism to study health-seeking behavior in a pluralistic landscape, and how biomedicine is perceived and utilized by individuals. To this end, I first consider what circumstances lead persons to consult a physician with the underlying question regarding how and why biomedicine is perceived to be useful.

\textit{a) Consulting Doctors}

Given that doctors are known locally to treat illness, it is interesting to consider the question regarding why caregivers consult doctors when elders begin to forget. In other words, what are doctors perceived as curing when forgetfulness is perceived to be normal? Literature on health-seeking behavior among Latin Americans demonstrates that the severity of symptoms impacts how, when, and why people visit doctors (Larkey, Hecht, Miller, & Alatorre, 2001). In this section I contribute to this finding by showing that the severity of symptoms matters, but the more important factor is the type of symptom. In light of how caregivers perceive forgetfulness to be normal, I demonstrate how other symptoms not related to forgetfulness constitute the main reason to seek
medical help, and how medical consultations are circumscribed within larger regimes of power.

I return to my interview with Alberto, Beatrice, and Cecilia, the first household I had the opportunity to interview. Recall that Alberto’s mother was diagnosed with senile dementia. While this diagnosis was interesting in itself, I was also curious about why Alberto and his family consulted a doctor when they perceived his mother’s forgetfulness as normal.

Beatrice: It was because of the pain in her feet, and her knees, her waist, and she would always complain about her pain. Everything happened gradually. It first started with her feet, then she used a cane. And then the cane wasn’t able to support her weight anymore, so she used a walker. And then we thought that the pain was probably in her knee. And then we took her to the doctor and he told us that she had severe osteoporosis. And he said that she needed a study, but the study she needed was for her whole body [including her brain]. So then they realized that she had it [referring to senile dementia]. And they asked her some questions. According to the answer of the questions, they also diagnosed the illness she has [senile dementia].

There are a number of interesting features to this excerpt. In congruence with the fact that the majority of caregivers view forgetfulness as non-problematic, Alberto and his family do not visit doctors because of forgetfulness. Instead, they initially visit a doctor because of the elder’s pain. At first tolerable, the elder’s pain increasingly grew more acute such that at a decisive point they decided to seek medical help. It was the moment they suspected that the elder’s pain was located in her knee – pain with a hypothesized
physical origin – they made the decision to seek help. This line of reasoning illustrates a preliminary reason for why doctors are considered useful – they cure pain that has a physical origin.¹ But, in the process of visiting the doctor to treat her knee, the consultation ends with an answer to a question they had not raised. It was through visiting a doctor for somatic pain that the family learns about senile dementia, an illness wholly different from her presenting problem.

Whereas Alberto and his family consulted a doctor because of physical pain, caregivers also consult doctors due to knowledge about other, non-visible symptoms that do not involve pain at all. To this end I return to my interview with Pablo and Vanessa, the caregivers that surprised me for their devotion to an elder with Alzheimer’s disease who is not in their immediate family. Again, Alex and I inquired about why they decided to consult a doctor and how they discovered that the elder had Alzheimer’s disease.

Vanessa: Because of her high blood pressure, that’s why we took her… That’s when they asked her [if she was taking her medication]. And at that time I already knew that she wasn’t taking the medication anymore… And so when I took her to the clinic, she told the doctor that she was still taking her medicine. That’s when they [the doctors] realized that she forgets. And that’s when they told me that there is this disease, that’s called this [Alzheimer’s disease], and perhaps that’s what she has.

¹ This resonates with prior research that shows how other Mexican indigenous communities perceive doctors as treating physical, not mental or spiritual ailments (Ayora-Diaz, 1998).
This excerpt again demonstrates that forgetfulness is not caregivers’ reason to seek medical help. Vanessa’s description mirrors much of what Beatrice says – even how the diagnosis pertaining to forgetfulness is discovered accidentally. But here Vanessa reveals that there exist other non-visible symptoms that lead caregivers to seek help. Previous awareness about high blood pressure – and Vanessa’s knowledge that medical doctors are the appropriate individuals to treat this condition – led to their visit.

Surprisingly, the observation that caregivers visit doctors for reasons other than forgetfulness holds even for late-stage cases. To this end I return to my interview with Carlos, his adult son, Francisco, and family, the household I had devoted months to interview. Recall that this elder represented the gravest case of Alzheimer’s disease I had encountered. I inquired about what initially brought them to seek medical help.

Francisco: Well, she started to forget very often. And consequently her behavior wasn’t normal anymore… What depressed her the most was that she lost a finger. [And] due to that situation, it started to get worse... So we took her to a neurologist [because of the depression]… Yes, he is the one that diagnosed her with Alzheimer’s, or senile dementia.

Here, Francisco and his family are attentive of forgetfulness – they know that the elder has begun to forget in a concerning, not “normal” way – but their decision to visit a doctor is still not due to forgetfulness per se. They visit a neurologist for the elder’s depression and, again, it is through this encounter that they learn that the elder has Alzheimer’s disease.\textsuperscript{5} What is interesting here is that while depression is the reason why

\textsuperscript{5} There are reasons that Francisco and his family visit a neurologist and not a standard medical doctor, but to protect their confidentiality I am intentionally omitting this facet of their story. For the same reason,
Carlos’ family sought medical help, it is a symptom that would not traditionally be
thought to fall within the domain of standard medicine. At once this illustrates how
medical doctors are considered relevant for other non-physical symptoms (beyond pain).

What is so remarkable about all of the above excerpts is that no caregiver knew
anything about age-related memory diseases, nor did they consider visiting a doctor to
assess memory, but elders nevertheless end up being diagnosed with an illness
concerning it. In a setting where doctors are not the only individuals known to cure
illness, one must pause and consider the vast power this shows them to have. In addition
to treating pain, doctors are consulted through routine, to make sure that medical
conditions individuals cannot independently detect – things like high blood pressure,
diabetes, or depression – are not present. Moreover, for many elders in Teotitlán, this is
not a personal choice one makes, but something solidified by government policy: the
government-sponsored program, 70 y Más, gives elders a pension on the condition that
they biannually visit doctors and attend bimonthly pláticas (informational workshops). In
so doing, the state legitimizes and transforms one medical system over others, illustrating

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Francisco equates senile dementia with Alzheimer’s disease. This appears to stand in contrast to the way I argued in Chapter Three that senile dementia is considered a different disease category. To be sure, I still believe this distinction is locally valid. Francisco knows that he is speaking to me, a U.S. researcher who is accustomed to understanding milder cases of senile dementia under the broader diagnosis of Alzheimer’s disease.

6 Families also visit doctors upon the recommendation of curanderas. Though I will discuss below how a minority of families turn to traditional medicine, some who did recounted instances when they were referred to a medical doctor. As will be discussed in subsequent pages, these recommendations occurred in response to more traumatic injuries like a stroke. Curanderas were reported to be effective treating the elder, but also recognizing that there were some facets to the condition that were biomedical in nature, beyond the scope of their practice.
how power relations shape healing in local contexts (Connor, 2001, p. 4; see also Rose, 2007).

Figure 6.1. *Plática* [informational community meeting]. Domingo Gutierrez Mendoza, the local organizer of Teotitlán’s 70 y Más, leads a workshop to elders about nutrition. (Photo by the author.)

It is not my intention to criticize biomedical practice or mourn government-sponsored policy. In my personal opinion these programs are commendable by providing much needed support for a cohort of marginalized individuals. Yet from an ethnographic perspective, it is extraordinary to witness how these programs are constituted within larger regimes of power, and how that power culminates in introducing new concepts of disease. This at once demonstrates the regularity of medical consultation – what Foucault (2003) calls the “politics of health” – and the way biomedical information about non-observable and non-painful conditions like diabetes and Alzheimer’s disease are circulated. Moreover, it illustrates limitations in explaining health-seeking behavior as solely motivated by pragmatism for what is best for elders. The decision to seek medical
help is, in part, motivated by caregivers’ pragmatism, by a wholehearted concern to ensure elders’ wellbeing. Yet I have begun to demonstrate how it is also constituted within broader power structures that dictate with whom and how consultations occur. In the sections that follow, I continue to develop this argument by reviewing how individuals navigate and seek help within other corners of the medical landscape.

\textit{b) Consulting Medical Specialists}

The excerpts featured above all describe caregivers’ first consultation with doctors. But what do caregivers do after? To whom are they referred, and why? In this section I briefly want to consider how caregivers make decisions after their first medical consultation. This question engages with literature on the pathways to dementia diagnosis, and the way in which culture is found to play a role in health-seeking behavior (Hinton, Franz, & Friend, 2004). Though appealing to a broad notion like culture can be useful, this does not go far enough to account for how people make medical decisions after having met with a general doctor. In what follows I briefly illustrate how caregivers consult with medical specialists and, by so doing, illustrate how health-seeking behavior is best understood as the junction between caregivers’ pragmatism and structural constraints.

When caregivers consult doctors, they are given a tentative diagnosis that they are told can only be confirmed through subsequent consultation with a specialist. This was a consistent finding across all the households I interviewed who had met with a doctor. To orient my discussion about how caregivers encounter and respond to this reality I introduce Juanita, a woman in her early-sixties who cared for her husband that recently
experienced a series of debilitating strokes. In addition to learning about her moving experience, my interview with Juanita was memorable because she also happened to be a *curandera*. Nevertheless, and despite her faith in traditional medicine, Juanita consulted a doctor, and then a medical specialist to help her husband recover.

Juanita: So our general doctor wasn’t able to find out what was wrong with him. That’s why he sent us to a neurologist. And the neurologist explained that a vein that’s in the forehead ruptured. And the blood clot, and that’s what affected his eyes. So the prescription he gave is to dissolve the clotted blood to get better.

Juanita’s experience is representative of a majority of other caregivers who consulted a doctor, and then learned that elders must be brought to a specialist to be sure of their diagnoses. At once, this illustrates caregivers’ awareness of the limitations of general doctors, and their shrewdness of the broader medical system. They are aware (or become aware) that general doctors are the first level of triage, and that there exist different specialists to consult depending on the first doctor’s recommendation.

However much this is similar to what is known in U.S. settings, observing post-consultation behavior is interesting when one considers Teotitlán’s medical landscape. There exist other available medical options – and this is especially true for caregivers like Juanita (a *curandera*) who have faith in traditional medicine. Hence, it is significant that, when an expert from one medical system expresses uncertainty, caregivers continue to go upstream within that same system. Having made contact with a physician, caregivers appear to pursue recommendations with the hope that they will find a solution that works. This last point is helpful in further developing a theme from the previous chapter – namely, caregivers are pragmatic in the sense that they strive to gain more information
and treatment for elders, and are willing to continue consulting specialists to achieve this end.

While caregivers know that medical specialists have greater diagnostic insight, there also exist structural limitations that bar access to specialists. Referral to a specialist means that caregivers must travel with elders outside Teotitlán to Oaxaca City (not far in terms of distance, but a difficulty for those without access to transportation or face limited financial resources). Other limitations like finances also pose barriers. This was a major hurdle for Pablo and Vanessa, the caregivers who made an impression on me for taking care of an elder not in their immediate family. Recall that this elder was one of the two elders diagnosed with Alzheimer’s disease. To this end, at one point in the interview Pablo and Vanessa were describing their experience in the medical system.

Pablo: They [general doctors at the community clinic] told us that if we took her to a specialist, we could be certain. But …we’re doing the best we can. And to take her to a specialist is more expensive …

[Later in the interview]

Alex: What do you think a special doctor will do?

Pablo: Well first of all, we’ll get our questions answered, and what probability … I hope that he will tell us the truth, whether it’s really because of her age that she cannot get better, and if it’s going to get worse until the day she passes away. Or will there be a way to save her if you have money. Those are the questions I want answered. But I’m hoping to have money in the near future… Even if I don’t buy the medication, but at least get my questions answered.
This excerpt is noteworthy for how it sheds light onto the way specialized doctors are perceived, and the type of services they are thought to provide. Though Pablo and his family cannot afford it, they speculate on the way specialists can provide more definitive answers than their general doctors. They wonder about the expected course of the elder’s illness, and suspect that there may be available medications to treat her. These speculations provide greater insight into health-seeking behavior once initial contact with doctors is made, and, again, caregivers’ determination to find what works. Yet I feature this excerpt to also introduce the way that caregivers are limited in pursuing follow-up consultations with specialists. Though Pablo suspects that specialists might help, and although Pablo personally wants to consult one, he and his family decide to not visit because of financial limitations. This further illustrates my argument about health-seeking behavior: though motivated by pragmatic concern for what is best, is also constituted by broader structural parameters.

c) Not Consulting Doctors

I return to consider Sergio and his family, the successful tortilla makers presented at the beginning of this chapter. Recall that this family made a strong impression on me because they chose not to consult any medical specialist, despite symptom severity and economic comfort to afford it. In fact, this household was not unique, and I encountered another family of caregivers (Luis and Laura, the caregivers who moved in with Laura’s mother who exhibited milder symptoms) who similarly decided to forgo medical consultation altogether. This brings me to the question about when not to consult doctors. Relevant literature focuses on sociocultural determinants, and, specifically, how
involvement among family members leads to increased delays of help-seeking behavior (e.g., Lin, Inui, Kleinman, & Womack, 1982). My findings do not contradict this observation, but provide greater detail on the nature of family structure, local representations of aging, and why these together delay (or inhibit) help-seeking behavior.

In this brief section I broadly argue that a common belief that aging is concomitant with illness (and that forgetfulness is normal) leads to a mutually shared opinion that consulting doctors is senseless.

To begin, I further explore Sergio and his family’s reason for not seeking medical help. Although this topic was discussed at numerous junctures, at one point Sergio and his family explained why they decided not to consult a doctor.

Linda: No, he hasn’t been diagnosed with anything because he doesn’t want to go.

Sergio: He doesn’t want to go to the doctor. And even if he were to go, if they were to prescribe any medications, he would just take it all at once. So I don’t see how there’s a point to take him to the doctor since he won’t take his medications the way he’s supposed to.

There is a type of simplicity in this response that I find remarkable. Despite the fact that Sergio’s father cannot recall his name, despite the behavioral problems he and his family face, and despite the fact that they know conditions are worsening, Sergio and his family decide not consult a doctor. Their reason is simple: the elder does not want to go. Even if caregivers wanted to consult one, they overlook their own desires in order to honor what elders want. While this decision may appear to be a negation of caregiving responsibilities, there is also good reason to understand it as a mechanism that upholds them. In light of how I have discussed Teotiteco family structure (see Chapter Two),
research on Latino elders shows that social and familial support is more important to their sense of wellbeing than medical attention (Beyene, Becker, & Mayen, 2002). Hence, by respecting elders’ wishes not to visit a doctor, caregivers are perceived as attending to them in a pivotal way. Sergio and his family highlight how listening to elders and demonstrating respect is central to caregiving responsibilities, and, in some instances, eclipsing their own inclinations to seek professional help.

To further illustrate this point, I return to my interview with Alberto and his family, the first caregivers I interviewed where the elder was diagnosed with senile dementia. Although these caregivers had consulted a general doctor – recall that this consultation occurred because of the requirements of the government-sponsored pension program – their decision not to consult a medical specialist further illustrates how doctors are considered irrelevant because the problems elders face are understood as a standard feature of aging.

Alberto: If we took her to a specialist, they might help, but she says that that’s the way she’s decided to end her life. When we tell her to visit the doctor she answers, “There’s no need for me to go to the doctor – I’m old.”

Alberto’s statement is noteworthy for a number of reasons. He speculates that a medical specialist might be able help, but nevertheless he and his family choose to not consult one. This casts an interesting light on the pragmatism I observed in the previous chapter. Whereas earlier I argued that caregivers assume a stance that opens up possibilities for action to provide for elders, here Alberto demonstrates an instance where he deliberately

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7 I also recognize that this may be an instance of collusion. Sergio’s fidelity to his father’s opinion makes sense given his desire to minimize the significance of forgetfulness. It colludes with a desire to continue life as normal, to believe that his father’s memory lapses are no reason for concern.
decides to not take action. As Alberto explains, this decision is made in light of his mother’s resounding statement, “I’m old.” It is a conviction that forgetfulness is a natural feature of aging, and also that it is a natural signifier of one’s death. Doctors are for treating illness when it is not supposed to happen, but the aging process is one where illness is expected. This is an opinion held by elders and, through inference, their caregivers. Hence, another reason not to visit a doctor concerns representations of aging and the way in which it is believed that illness inescapably accompanies this part of the lifecycle.

These two excerpts are representative of other caregivers who decided to not consult medical specialists or any physician whatsoever. At once they demonstrate how local understandings of aging and central values about the family shape health-seeking behavior. As I have argued throughout the above sections, there is more involved in one’s decision to seek medical care than just simple pragmatism to do what is best. Notions about caregiving vary across time and space, and in Teotitlán I have shown that such behavior is premised on locally defined outlooks and structural parameters. In what follows I continue to discuss health-seeking behavior by now turning to examine the impact that consultations have on caregiving households.

d) The Impact of Biomedical Consultations

As I have begun to explore, the most obvious impact medical consultations have on caregivers is the way in which consultations transform “normal” forgetfulness into a diagnosed biomedical disease. This is a clear instance of what Carroll Estes and Binney (1989) term the “biomedicalization of aging,” a process whereby perceived normal
physical and mental decline is placed under the domain and control of biomedicine.\(^8\) All of the caregivers who consulted doctors made their decisions on the basis of previously known biomedical illness categories. Yet, in the process, they were introduced to a new illness category – senile dementia, or Alzheimer’s disease – thereby expanding the power and scope of biomedical domain. This finding, implicit throughout the previous pages, is monumental with regards to how the perception of elders is changing in Teotitlán. Following Duncan (2012) who observes how Oaxacan mental health professionals go beyond the provision of treatment to actively foment local culture change, my findings demonstrate how doctors, nurses, and other stakeholders in biomedicine are equally integral to a type of “cultural change” – initiating not only a change in scope of biomedical practice, but a more fundamental reconstruction in how the aging process is understood.\(^9\)

Because I assume this point has been sufficiently illustrated, in the subsequent paragraphs I discuss more subtle effects concomitant to medical consultations. Specifically, I discuss the impact of learning that an elder’s memory difficulties are not normal, but a recognized biomedical illness. This touches on the question that initially compelled me to conduct a study in Teotitlán – that is, do medical diagnoses hurt or heal

\(^8\) It also touches on what Kitwood (1997) calls the “Alzheimerization of dementia,” the way in which symptoms of dementia are increasingly viewed through notions about Alzheimer’s disease (p. 22).

\(^9\) To be sure, my very interest in forgetfulness as a psychologist-in-training contributed to this phenomenon. I knew very well that one cannot conduct ethnographic research without having an impact, and I am confident that my project was no exception. While I am aware of epistemological problems (investigating a local setting that my very investigation changes), I do not believe I caused harm. Moreover, as I have argued throughout this project, Teotitlán is not an island, but actively engaged with the surrounding global social, economic, and political world. I view my involvement as a researcher as another instance of this reality.
families as they face challenges associated with aging? Those who believe that diagnoses help families have defended their arguments through attribution theory, a perspective that views diagnoses like Alzheimer’s disease as allowing families to decrease blame of the elder, develop greater patience, and increased sympathy (see Wadley & Haley, 2001; Weiner, 1993). In contrast, others appeal to Erving Goffman’s (1961) labeling theory that views diagnoses as leading to negative consequences that stigmatize and shame the diagnosed person (see Kitwood, 1997; Sabat & Harré, 1992).

My data neither supports nor negates either theory, but rather demonstrates how complicated and multifaceted this debate is. To this end I feature one excerpt that illustrates and condenses relevant data on this theme. I return to my interview with Pablo and Vanessa, the caregivers who impressed me for attending to the elder not in their immediate family. They provide a good perspective on the impact of diagnosis because the elders’ symptoms were not as severe as compared to other cases, and they recently learned from a physician that the elder suffered from Alzheimer’s disease. Again, Alex takes the lead in asking about the impact of diagnosis.

Alex: Has your point of view changed towards her?

Vanessa: … It has changed. And it made me think that they’re probably right, she might not get better…

Pablo: And that causes us to worry more about her. Because we see her and we know and we understand that she has an illness. And so there is more to worry about, and we think about what’s going to happen in the future. Because she could get worse. And we think about the future, and how much worse it could get.

…
Vanessa: Well it has definitely changed because we don’t see her the same way we used to see her. And now I treat her differently. So it doesn’t get worse. And when I hold her hand I tell her to behave and that she’s not acting in an appropriate way. And she calms down.

Pablo and Vanessa explain a number of different consequences of their knowledge that their elder forgets due to a disease. First, they clearly state that they no longer view the elder in the same way. In Pablo’s very succinct words, he and his wife “understand that she [the elder] has an illness.” Implicitly, understanding that the elder has an illness means that the things that irritated Pablo and Vanessa – things like being blamed for lost objects, repeated arguments, etc. – are beyond the elder’s control. This exempts the elder from being responsible: if she cannot remember what she has done, then she is less responsible for her actions.

Second, Pablo and Vanessa’s excerpt illustrates how diagnosis has shifted their anticipation of the future. Whereas Pablo and Vanessa previously viewed the difficulty they had had with their elder as circumstantial (as a consequence of unwanted behavior that could be changed), they now recognize it as a situation that will not resolve itself. They wonder about time, the course of illness, and worry about how much worse the elder’s condition will become. This demonstrates how diagnoses change caregivers’ temporal perspective of their world. Instead of time serving as a hopeful symbol of recovery, it now becomes a threat of the deterioration to come.

Third, this excerpt also provides information about how diagnosis modifies caregiving strategy. Though this theme will be explored in more detail in the following chapter, here I want to point towards how learning that an elder suffers from an illness
leads, in this case, to greater patience and self-restraint. Anticipating that the elder’s condition can worsen, Vanessa takes steps “so that it doesn’t get worse.” She avoids arguments because she knows that they make the elder more agitated and forgetful. She recognizes that it is beyond the elder to repair family conflicts. Vanessa takes responsibility by reminding herself to be calm, to hold the elder’s hand, and to explain things carefully.

Of course, I recognize that my data is too limited to significantly weigh in on the debate between attribution and labeling theories. While Pablo and Vanessa’s new perspective of the elder as ill minimizes blame, it also challenges their belief that the elder can change her behavior. Re-invoking a theme from last chapter, diagnosis gives them less impetus to uphold a charitable view of the elder as a coherent, meaningful individual, and, by so doing, undermines the elder’s sense of dignity and personhood (see Kitwood, 1997, pp. 46-68). But then again, taking a more positive view, diagnosis also involves a different type of respect based on a new vision of the elder. It is one where the elder is a symbol of vulnerability, of one’s responsibility to remain patient and calm. The point is that diagnosis enacts both positive and negative consequences, and that the two cannot easily be separated. This highlights the complicated nature of the debate between attribution and labeling theory. In what follows, I leave this issue aside by tracing other dimensions of medical consultation, now turning to consider how caregivers make decisions regarding traditional medicine.
Traditional Medical Options

Earlier I wrote that traditional medicine does not originate from a pure Pre-Hispanic origin, but rather represents the syncretic history of indigenous medicine combined with humoral theory hypothesized to originate from the Spaniards, and other ideas introduced from abroad. This syncretic system became formalized into a distinct medical practice that was called “traditional” medicine. The most known practitioner today is the curandera, widely recognized as an expert with specialized knowledge (Ortiz et al., 2008; Treviño, 2001; J. C. Young & Garro, 1993). Whereas doctors practice within Kleinman’s (1980) professional sector, curanderas operate in the folk sector.11,12

Yet however much curanderas are often described as general folk practitioners in other Mexican settings, in Teotitlán they are perceived with much more specificity. The Zapotec word for curandera – benih ni rusiak xibih – translates as “person who cures susto [fright].” This means that, at least nominally, curanderas are not perceived as medical practitioners in a general sense, but as having expertise in a very specified arena. Curanderas are individuals who possess specialized knowledge about local plants and

10 As discussed in Chapter Two, “other ideas” refers to those concepts of illness brought from Jewish and Muslim Conquistadores, as well as African slaves. The Spanish Conquistadores were a heterogeneous group that cannot be understood as introducing a single homogenous set of medical practices.

11 My adherence to the term “folk” is not diminutive but rather meant to point to the common ways of acquiring knowledge. Gaines’ (1992) use of “folk” psychiatry is an example (p. 5). Or, in a similar vein, Norget’s (2006) use of the term “popular” refers to the ambivalent and contradictory beliefs inherent to a laypersons (p. 16). Like Norget, my use of the term “folk” refers to a perspective distinct from elites. Folk knowledge is common, widely dispersed, and part of the everyday culture. Indeed, as discussed in Chapter Two, the very practice of curanderas originates not directly from Pre-Hispanic roots, but from the Spanish Conquest and the way indigenous medicine was delegitimized.

12 Curanderas do not typically rely on medical practice as a primary means of income. Most have other professions and practice traditional medicine on the side.
herbs, and use this knowledge for the treatment of susto. They administer teas and
provide other traditional interventions (incantations, limpias [spiritual cleansings], eggs,
and more). Nevertheless, despite the specificity that curanderas’ title suggests, their
practice is supple and wide-ranging. I have heard of curanderas being consulted for mal
de ojo (“evil eye”), mal de hora (“bad hour”), pérdida del alma (“soul loss”), spirit
possession, divination and other reasons.13

In what follows I seek to address how curanderas are consulted with regards to
age-related forgetfulness. Like how biomedicine is understood to exist within larger
socioeconomic parameters, I argue that traditional medicine is constituted with regards to
contemporary regimes of power. In this vein, traditional medicine cannot merely be
understood by reference merely to tradition, but rather with regards to how concepts
about tradition engage with circumstances of the present. As Valentina Napolitano (2002)
writes of her own study on pluralism in Mexico, “Complementary [i.e., traditional]
medicines are part of a postmodern condition, [this] practice … indicates an emergent

13 I initially found this to be contradictory. I reasoned that either susto was viewed as the cause of all these
other illnesses, or there was profuse inconstancy in the profession. As my fieldwork developed I learned to
not resolve this dilemma. I came to realize that traditional medical practice operates on a different logic
than my own, with greater suppleness than I was accustomed to given the specialization I had known of
medical practice in the U.S.

I came to appreciate this suppleness during my interview with Juanita, the curandera who was
also a caregiver for her husband with vascular dementia. In the following excerpt, Alex asks for
clarification about why she treats her husband with an herb known for susto with regards to his
forgetfulness.

Alex: Why are you using a plant for susto? Did something scare him?
Juanita: Not necessarily. It’s a general medication, and it’s very medicinal. And because it has a
lot of natural ingredients. And the way I prepare it is, I add other medicinal plants.

This brief passage illustrates the way that traditional medicine is leveraged to treat other conditions beyond
susto.
phenomenon that re-inscribes tradition into modernity” (p. 105). In what follows, I consider the re-inscription of local tradition by continuing to ask why caregivers do (not) consult *curanderas*, and the impact this has on the caregiving family.

*a) Consulting Curanderas*

In this section I seek to address the question about how *curanderas* are consulted for age-related forgetfulness. While I believe this question carries relevance in Teotitlán it immediately poses problems because none of the households with elders who experienced progressive dementia turned to *curanderas* for help. This makes sense given how many caregivers discovered by accident that elders had a memory disorder, and also how age-related forgetfulness is considered normal. Nevertheless, other caregivers who treated elders with sudden-onset (vascular) dementia did consult *curanderas*. I feature their experience into this analysis because they provide further insight into health-seeking behavior within Teotitlán’s pluralistic landscape. In this section I argue that consulting a *curandera* is a personal choice that is based on belief in traditional medicine and etiological understanding of illness.¹⁴

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¹⁴ Because this analysis is limited to data gathered through the course of my interviews with caregivers, I do not discuss how *curanderas* respond to conditions like *pérdida del alma* (“soul loss”) because no participants had that experience. However, though discussions with other members of the community I learned that this condition is also treated in specific ways. Either relying on past knowledge or consulting a *curandera*, a layperson – who shares a close relationship with the person affected by soul loss – first fills up a jug with water. Then the person blows bubbles into the water through a reed while walking through public streets and the setting where the loss occurred, calling the name of the afflicted person, and invoking back his or her lost soul. Interestingly, the afflicted person does not need to know that this is being done on his or her behalf in order for it to be effective.
To this end, I introduce Mario, a caregiver in his early-forties, his wife, Isabelle, in her mid-thirties, and his mother, Graciela, in her mid-seventies. Like other households I had interviewed, these individuals assembled together to provide support for Mario’s father who recently had a severe stroke. In addition to describing the hardship in witnessing his father’s disability through acts like helping him defecate, Sergio and his family also struck me for their humility. Their gratitude and composure for what life did afford them was remarkable, especially given the fact that they were one of the poorest households I had visited. I was engaged throughout the interview, but I was particularly struck by Graciela’s description of what occurred when she realized an abrupt change in her husband, and how she first turned to a curandera for help.

Graciela: What happened is that I didn’t know that he went to the restroom... But that night when I saw him [return], he was holding his pants. And he was wearing his sweater inside out. I asked him “What’s wrong?” He was just staring in one place. He didn’t talk. I asked him, “What happened?” And I didn’t call my son [Mario] because I didn’t want to worry him. So he wouldn’t hurt himself as well [by the suspected cause of illness, an evil spirit]. So I went to Francisco [Mario’s brother’s] house, and I called Francisco and told him that there’s something wrong with his dad. And he asked me, “What’s wrong?” And I told him that he just stares at one thing, and I don’t know what it is. And he came running – holding a bag of eggs, about four of them, four eggs… And so he [Francisco] rubbed the egg on him, on his whole body. And he said, “We’re going to take these [the eggs] to the curandera.” It was around 4:00 in the morning. Or was it at 5:00? So they [Francisco and Mario] went...
[Later in the Interview]

Graciela: She [the curandera] told us, “I don’t know what happened to him – I think someone changed him [Zapotec original: bachada-lán; literally, “to change him”]. I think someone changed his heart or something.” And she said that she did not know what happened – when she was treating him he was still healthy. And we don’t know why that happened. We still can’t understand what happened to him.

[Later in the interview]

Alex: Why did you take him to a cuandera?

Mario: We took him to the curandera because that’s our first choice before taking him to a doctor. However, afterwards we went to the doctor because she told us to take him to the doctor. And we took him to the curandera because it was susto.

Alex [to Jon]: Because he was scared of something and the belief they have here is that if someone is scared of something you first go to a curandera. And that’s why they took him there first. After that they took him to a doctor.

This powerful excerpt contains a wealth of information about consulting traditional healers. First, as Alex explains to me, a foreigner to the community, in Mexico there are different illness categories and how one understands the nature of illness determines whom one will consult first (see also Higgins, 1975, p. 35; Hunt, 1992; Napolitano, 2002; Whiteford, 1995; J. C. Young & Garro, 1993). In this case, Mario and his family suspected that the abrupt change in symptoms was due to susto (“fright”) and so called
upon a *curandera* for help.\(^\text{15}\) At a very surface level, this demonstrates how *curanderas* are called upon because they are perceived to treat a certain category of illness that physicians cannot. *Curanderas* treat spiritual attacks that are considered beyond physical bodily concerns (Ayora-Diaz, 1998, p. 166). This shows how different medical systems are distinguished not only because of varying medical practices, but also because there exist different categories of illness.

Yet there is more to be gleaned from this excerpt. First, it illustrates the connection between popular and folk sectors of medicine. Graciela’s son does what he can based on popular medical knowledge, and then turns to a specialist whom he believes is better prepared to respond. Francisco rubs eggs on his father’s body, acting on local belief that this practice draws out negative energy (see Hunt, 1992, p. 49; Rubel, 1960, pp. 800-801). This provides greater insight into health-seeking behavior by providing an instance of popular medical practice that occurs immediately after an elder is perceived to have turned ill. Second, Graciela and her family not only demonstrate a division among medical specialists, they express preference for *curanderas* over doctors.\(^\text{16}\) Mario states traditional medicine is his first point of contact. Why? One reason could be that Mario’s household was the poorest interviewed for this study. Poor households are known to rely on traditional medicines with greater dependency than wealthier ones (Van Gameren, 2010, p. 55). Yet while economic status may help explain this case, it cannot fully

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\(^{15}\) More specifically, the elder was believed to fall ill because he went outside during a *mal hora* (“bad hour).” In Teotitlán it is believed that there exist certain hours during the night when spirits (or the devil) may attack. People wear shawls on their head and also try to avoid being out during these hours. Although this appears to be a different illness category from *susto*, the fright it causes leads family to the similar forms of treatment (see also Norget, 2006, p. 74).

\(^{16}\) This complicates Finkler’s (2001b) generalization that Mexicans uniformly resort to biomedicine as an initial treatment option (p. 4).
explain caregiver preference of traditional medicine since I encountered another household, better economically positioned, who also preferred to first consult *curanderas*. Moreover, there are instances where *curanderas* charge as much or more than biomedical doctors.

As such, another idea I want to advance is that one’s turn to traditional medicine is an act of adhering to local tradition. As I will continue to explore in subsequent pages, consulting *curanderas* is a matter of belief. Mario and his family believe in *susto* and the power of *curanderas* to treat certain conditions related to it. They believe in an etiology that is not recognized by biomedicine, and so they seek traditional remedies. Belief is the lynchpin of traditional help-seeking behavior, but it is also expressive of viewing the world though a traditional (non-biomedical) perspective. In the section that follows I consider caregivers’ reasons for *not* visiting a *curandera*, and how this further illustrates the central role that belief plays in traditional health-seeking behavior.

*b) Not Consulting Curanderas*

Consistent with reasons about why caregivers do not consult doctors, caregivers also do not consult *curanderas* because of their view of the normalness of forgetfulness and adherence to elder’s will. In this section I do repeat that theme, but instead focus on how not consulting a *curandera* is also due to one’s lack of belief in traditional medicine. At once I intend to further illustrate how utilizing traditional medicine is a matter of belief, and provide greater illustration about what is at stake in claiming one believes in this facet of local tradition.
To this end, I return to my interview with Pablo and Vanessa, the caregivers who attend to an elder remarkably not in their immediate family. Recall that they had discovered that the elder had Alzheimer’s disease upon a required medical check-up. Prior to visiting the doctor, Pablo and Vanessa recognized that she was forgetting but did not consider it an illness. I wondered whether after this visit they had considered consulting a curandera.

Alex: Have you visited a curandera or a natural healer?

Vanessa: No we didn’t.

Pablo: To be honest…

Vanessa: He doesn’t believe in that.

…

Alex: Why?

Pablo: The way I see it is that her illness doesn’t… have a cure with a natural remedy. So it needs a specialized doctor.

There are two things to be noted in this exchange. First, like the caregivers above, the decision to consult a curandera is based on belief, which Pablo and Vanessa profess to not have. They do not believe in curanderas because they do not believe in susto as an illness category. Over and over, among different caregivers and across households I encountered the same statement: people do not visit curanderas as a matter of belief. A related second point seemed to follow – caregivers implicitly state that they do believe in the biomedicine. Pablo’s statement suggests that because a physician detected the elder’s
illness, it concerns biomedicine. This brings up a previous point about how the
difference between traditional and biomedicine is, in part, based on different etiological
categories that caregivers believe in.

To further illustrate how caregivers do (not) believe in traditional medicine I
return to my interview with Carlos and his family, the household that took months to
interview. Recall that this household introduced me to another diagnosed case of
Alzheimer’s disease and was the gravest case I had encountered. After learning that this
household did not consult a curandera Alex and I inquired about their decision. Carlos,
the husband whose wife had dementia, is the first to respond.

Carlos: I’m not very into natural medicines. And the way we live nowadays,
natural medicine worked before. But also it killed a lot of people. And also a lot
of people lived because of it. And when it works, it works slowly. Compared to
the doctor’s [medicine], it’s quicker. That’s why I’m not really into natural
medicine.

Francisco: No we’re not into it.

…

Alex: He [Jon] is saying that we’ve encountered other families who told us that
people forget because of pérdida del alma [“soul loss”]. Do you think this is the
case?

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17 This pertains to the hope Pablo was shown to express in pages above regarding his statements on
specialized doctors. He has not visited one, but he imagines that specialists can better diagnose elders’
forgetfulness, and provide effective medication. Interestingly, while traditional medicine is denied on the
basis of its perceived futility, biomedicine is maintained despite Pablo’s lack of experience of it.
Francisco: No, that’s not the case. Because if it were the case we would have visited a natural healer. But this is not the case.

…

Alex: Why?

Francisco: We don’t really believe in that.

Like the first excerpt, here is another statement that one does not consult *curanderas* due to lack of belief. Yet Carlos’ comments add greater nuance to this finding. For Carlos, it is not the case that traditional medicine is absolutely ineffective. He clearly states that he knows traditional medicine can be effective (although he also states it can cause harm). But his comments are not merely about medical efficacy; they point towards a broader idea to explain why he does not utilize traditional medicine. Life has changed. The circumstances of living in Teotitlán are different such that traditional medicine and traditional illness categories no longer seem relevant. This is what I believe Francisco was saying when he speculates about the circumstances under which he would consider visiting a *curandera*. If he happened to believe that his mother’s forgetfulness was due to *pérdida del alma* (or a related traditional illness category), then he would have sought appropriate help. But he does not. Hence, *curanderas* are relevant for treating traditional illnesses, but it is only that those illnesses are no longer believed to exist.

It is not my intention to point out contradictions in my participants’ logic. I believe that most decisions are rife with logical inconsistencies and that these are expressive of the underlying natural complexity of the world. Hence, in these instances, I view inconsistencies as moments of tension, a vista onto the way that individuals are drawn towards two simultaneous directions. For this reason, I find caregivers’ professed
disbelief in traditional medicine interesting given the prevalence of traditional (non-biomedical) ideas about illness (e.g., the way that Francisco understands rumination as the cause of his mother’s late-stage Alzheimer’s disease). As explored in the previous chapter, non-biomedical theories about illness are inherent in every etiological understanding. Yet the majority of caregivers stop short of endorsing a traditional illness category (like susto or pérdida del alma). Why? Perhaps one reason is to be explained through the logic of local belief. Like Francisco stated, if he believed, he would go. There is a commitment implied in this statement, and for this reason he does not believe.

Though there are certainly other ways to interpret Francisco’s statement, one reasonable conclusion is that it sheds light on the way traditional medicine is viewed locally as inferior. There were many times during my fieldwork when I was told by acquaintances that they did not believe in traditional medicine only to later find out that they had recently consulted a curandera for specific illnesses. People seemed to experience stigma, embarrassment, and shame for engaging with traditional medicine. Just like traditional medicine has been marginalized since the Spanish Conquest, today it is similarly positioned as inferior. But now it stands in contrast to biomedicine and the way the latter is viewed as an organizing symbol of modernity. Again, I do not intend to critique biomedicine but rather to point attention to how one’s avoidance of traditional medicine is embedded within broader power structures (visible in many instances, like the federal government’s insurance programs and its requirement for elders to seek

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18 I am aware that these two medical systems are very different in nature. Pre-Hispanic medicine is distinct from contemporary “traditional” (or “indigenous”) medicine. As discussed above, contemporary traditional medicine was influenced and in a large extent was shaped by Spaniards. My overall point is that during both periods there existed two competing medical systems where one was legitimized at the expense of another.
medical attention via its pension program). In the process, traditional medicine becomes a symbol of backwardness, highlighting the tension between traditional identity and national (or “modern”) ways of living. Hence, it is not just lack of belief that accounts for caregivers’ underutilization of traditional medicine, but the way that broader power structures constitute what one believes.

c) The Impact of Traditional Medical Consultations

If, as I have argued, the decision to (not) consult a curandera is constituted within broader notions of progress, then the impact of these consultations must be perceived as a juncture of tension between “modernity” and tradition. In this section I aim to briefly account for this process. To be sure, to speak of “impact” points towards a different phenomenon than what I earlier had in mind when I described consultations with an allopathic physician. Unlike caregivers who consulted physicians and discovered a disease pertaining to memory, consulting a curandera draws upon shared understandings of illness. There are few surprises in traditional medicine. Yet it is also for this reason that I inquire about impact, questioning what traditional consultations perform for caregiving households. In what follows I continue discussing how traditional medicine is constituted by broader power structures, now specifically focusing on how one’s engagement with curanderas is a symbolic act that affirms local tradition.

To this end I return to my interview with Mario, Isabelle, and Graciela, the caregivers who illustrated their preference for traditional medicine and struck me for their humility. Recall that they called upon a curandera the night they noticed the elder abruptly turn ill – what they understood as the result of being victim to the “bad hour.” In
what follows Isabelle discusses how the elder is treated, and her understanding of how treatment pertains to tradition.

Isabelle: What the *curandera* uses are materials from the earth like water, rocks, fire, and everything that belongs to the earth. And that’s how they work – just like our ancestors used to work… [And so] she prescribed a natural medicine – she prepared some herbs for him to drink, and she left us some herbs to make drinks for him. And he was cleaned [Spanish original: *limpia*] with an egg, and we were told to throw away the egg very far [because it contained dangerous energy].

This brief description not only provides insight into traditional medical treatment, but also about the way that it is understood to serve as a bridge between past and present. Curiously, Isabelle does not state that the *curandera* was quick to provide a cure – she says the opposite, namely, that the *curandera*’s treatment took a considerable amount of time. Yet her description is nevertheless positive. She describes how *curanderas* use past remedies, “just like our ancestors.” This is not just a description of traditional medicine, but also a justification of it. She and her family turn to traditional medicine *because* it is part of tradition, because it is a locally known approach.

But, by the same token, caregivers’ affirmation of traditional medicine is also constituted within biomedicine’s larger presence. There would be nothing to affirm or justify if biomedicine were not an alternative, if it were not a more available option. In this vein, tradition is not something passively upheld, but rather something perceived to be contested, opposed, and threatened by “modern” alternatives. Caregivers’ decision to use a *curandera* is a protest against these alternatives. It is an affirmative statement of
tradition in the wake context of broader change. In this way, the impact of traditional medicine involves not only recovery from illness, but also recovery of local tradition.

**Conclusion**

I return to consider my interview with Sergio, Manuel, and Linda, the caregivers I presented at the beginning of this chapter who decided not to seek any medical assistance whatsoever. The perplexity that marked my experience with these caregivers now seems better accounted for. Discussing their decisions to decline all available medical support, Sergio and his family reminded me how consultation is a matter of choice within Teotitlán’s pluralistic landscape. In comparison to the previous chapter where I outlined caregivers’ pragmatic stance, here I demonstrate how caregivers do not indiscriminately try any form of medicine, but rather make deliberate choices among medical options. If Sergio had considered his father’s forgetfulness an illness pertaining to his physical body, he would have visited a doctor. And if he had believed in susto or natural medicine, he would have turned to a curandera. The point of this chapter is to illustrate how health-seeking behavior like Sergio’s draws upon broader dimensions power, economics, and social influence – dimensions that shape how individuals respond to elders’ forgetfulness. These dimensions are the constitutive factors for how caregivers’ pragmatic concerns to do what it is best for elders are carried out.

This chapter has advanced two underlying arguments regarding health-seeking behavior in Teotitlán’s pluralistic setting. First, consulting a doctor for age-related forgetfulness occurs within an institutionalized regime of power. Caregivers do not consider seeking medical help for age-related forgetfulness, but rather, through different
avenues, and thus find themselves within the biomedical system. This transforms what forgetfulness means, and how caregivers come to make decisions to respond to forgetfulness itself. Second, caregivers’ decisions to consult a *curandera* are a matter of belief in traditional medicine. These beliefs are based on viewing the world through a traditional perspective, a stance imbued with significance in the context of perceived changes to the community. Overall, I argue that caregivers’ pragmatic concern to do what is best for elders is important, but that health-seeking behavior is constituted within a broader regime of power.

These two points are illustrative of an underlying theme developed throughout the course of this chapter – namely, that the choice whether or not to visit a *curandera*, doctor, or neither is part of a larger dynamic involving how Teotitecos’ local traditions are perceived to be changing and advancing towards “modernity.” In this way, the medical pluralism I have attempted to document during these two chapters involves more than a set of medical options. In the words of Pigg (1995), medical pluralism more fundamentally represents “an arena for the negotiation of social difference” (p. 19). This is a difference not only marked by the distinction between healers and caregivers, but also among the Teotiteco community whose members embrace different elements of their own traditions. It is a negotiation of what it means to uphold tradition in the context of contemporary change, and how various individuals experience that pledge differently. In what follows, I leave aside the issue of medical pluralism to apply greater focus to the lived experience of this negotiation. I turn to study how caregivers uphold and implement their responsibilities, how this impacts relationships with elders, and how these relationships further highlight the perceived strain of traditio
CHAPTER SEVEN

The Experience of Caregiving: Challenges, Perceptions, and Strategies

As already mentioned in previous chapters, my interview with Francisco and his family, a prominent resident in his early-fifties, was a long endeavor. Alex and I met Francisco early in my fieldwork, having approached him because of his involvement with Teotitlán’s municipio (local government). I was looking for cases of Alzheimer’s disease, and I was still unaware of just how difficult they would be to find. Francisco told us that he knew of none, but generously offered to help recruit participants, should he encounter any. Through the following months Francisco and I had kept in touch, but my attention was largely directed in other more productive directions. Then, to my surprise, upon visiting Francisco at his home one day, he shared that his seventy-year-old mother might be pertinent. She showed signs of severe forgetfulness and was diagnosed with Alzheimer’s disease. I was stunned. After months of being told Alzheimer’s disease does not exist in Teotitlán – by people like Francisco – I had found a case. Only one problem remained. Francisco was not interested in being interviewed. He politely brushed me off, saying that the decision was not his to make, but his father’s. Each time I saw Francisco he told me he would speak to his father, but this response, I knew, was more courtesy than commitment.

I finally found myself sitting beside Alex, Francisco, and his family in their courtyard after months of visiting their home, talking about my project, and sharing why I considered it important. Francisco and I had established a strong relationship and I
believe that by this time his family had developed enough confianza to share the intimate details of their lives. During the morning of this interview, I waited nervously in what was the most affluent household I had visited. I admired rugs for sale displayed on courtyard walls, some of the finest I had seen. Carlos, Francisco’s father in his mid-seventies, appeared, and I gave him the pastries I had grown into the habit of bringing from Oaxaca City, to thank households for their time. Next arrived Martha, Francisco’s wife in her mid-forties, and finally Jorge, their son in his early-twenties. Like the other interviews I had led, we sat together in a circle. Alex and I introduced the project to the family and explained that I would like to learn about the details of caring for this elder.

However much I was determined to interview this first known case of Alzheimer’s disease in Teotitlán, once I came to conduct this interview my intellectual interests about the impact of diagnosis quickly shattered. Even months into my fieldwork I sought to find diagnosed cases of Alzheimer’s disease, believing that these households would provide a type of insight that would carry my understanding beyond other interviews I had conducted. I believed that diagnosing age-related forgetfulness would somehow carry tangible implications to family life. Yet upon hearing about the everyday details of this household’s experience, I realized that what matters is not a technical distinction between diagnostic categories – or the way that forgetfulness is explained via biomedicine – but rather the ordinary tasks required of caregivers and the way those tasks render family relationships in a new light.

Interviewing Francisco’s family was a profound reminder of this lesson, for it represented the most extreme case of forgetfulness I would encounter during my fieldwork. Carlos described his wife as cognitively lost, no longer able to maintain
conversations and carry out basic functions. He and his family shared the harsh details of their daily experience – helping his wife defecate, shower, hydrate, and eat – reminding me that caregiving is a serious commitment that significantly alters how families operate as a cohesive unit. This is the topic of the present chapter, where I seek to outline how individuals experience the act of providing care.

Performing tasks for dependent elders is commonly described in the literature on caregiving, leading to the observation that fundamental changes are a standard experience in this stage of family life (e.g., Hargrave & Anderson, 2013; Mace & Rabins, 2011; Schulz, 2000). Carlos takes care that his wife eats; Francisco ensures his mother has bathed; and Jorge knows to monitor his grandmother to ensure her physical safety. Though Carlos and his family were by no means exceptional in this regard, their experience – and hesitancy to talk about it – highlighted what is, perhaps, the most definitive feature of caregiving. It is challenging. These challenges are everyday and often relentless, placing emotional demands on caregivers that become other instances of suffering. Not only do elders suffer due to their illness, but their caregivers also suffer by struggling to cope with new responsibilities. Most often, this experience is referred to as “caregiver burden,” depression, and anxiety (see Drinka, Smith, & Drinka, 1987; Mahoney, Regan, Katona, & Livingston, 2005; Schulz & Williamson, 1991).

Yet whereas most caregiving literature is framed in terms of caregiving challenges and techniques to better cope, my research led me to recognize that such attempts are inadequate so long as they overlook social dimensions. For example, Monin and Schulz (2009) rightly suggest that family caregivers experience suffering not only because of the physical demands of their roles, but also because they are dealing with
central issues pertaining to the lives of their loved ones. These authors introduce the idea of “emotional contagion,” that is, a process whereby caregivers experience suffering because they are exposed to the suffering of another person, not merely because of the physical demands of their labor. They argue that psychological support aimed to address the interpersonal realm of caregiving experience is critical to meeting their needs. Arguments like this are vital in moving beyond an idea of caregiving as merely a realm of physical adversities. Caregiving is rightly interpersonal in nature, premised on the relationships shared between caregivers and dependent elders. Yet an interpersonal perspective of caregiving is, in itself, insufficient. It overlooks the social dimension – that is, the fact that caregivers’ experiences do not manifest in a vacuum, but rather exist within a larger set of normative standards, expectations, and traditions. In the following two chapters I seek to outline this context, how this broader social horizon is the constitutive factor for caregivers’ daily lives.

Whereas in the last two chapters I focused on medical pluralism, in this chapter and the next I turn to focus on the day-to-day experience of caregiving, what it looks like, and how one operates in the world as caregiver. While the phenomenological tradition refers to this set of concepts as “lived experience,” in what follows I assume a theoretical framework that attends to experience as constituted within and shaped by broader social factors.\(^1\) I turn to recent anthropological work on “social suffering” which, as discussed

\(^1\) The term “lived experience” has been a philosophical tenet in the phenomenological tradition since Dilthey (1996), and is traced through Husserl (2008), Merleau-Ponty (1962) and appears in nearly all contemporary work. It refers to the prereflective dimensions of human existence – what it is like to live through something (van Manen, 2004). As such, this concept is not inconsistent with my turn to anthropology’s concept of “social suffering,” but I choose the later because it applies greater emphasis to the social factors that constitute experience.
in Chapter Three, points to how human experience is fundamentally social in nature, and how this observation collapses traditional dichotomies between the collective and individual, political and familial, medical and psychological (Kleinman et al., 1997). This term is meant to emphasize that individual experience – right down to physical pain – is inescapably woven within a social fabric. Pain is not just a physiological response to a physical stressor, but is fundamentally constituted by social factors – economic parameters, political regimes, cultural values, and more.

While it may seem exaggerated to refer to caregiving as an instance of suffering, I deliberately choose this term to highlight how caregiving is inherently painful and difficult. Adding the term “social” illustrates that experience cannot be understood without attending to the way one’s community is complicit in its shaping – that is to say, the way caregiving is socially constructed. Hence, the suffering that caregivers like Carlos experience is not just due to his wife’s medical issue. It is an individual, familial, and social issue that crosses traditional boundaries of how we tend to conceptualize experience.

In this chapter I specifically focus on the challenges endured by caregivers and their strategies to manage them. I analyze these issues because they provide a vista onto caregiving experience, highlighting how caregivers live and operate on a daily level. My thesis is that caregiving reveals a tension between the ideal of the elder as benguul – respected on the basis of his/her age and perceived authority – and the reality of how elders are viewed through the caregiving process. This chapter is divided into three sections. First, I examine the daily challenges caregivers face, and argue that these challenges cannot adequately be understood without attending to the broader social
horizon. Second, I discuss how challenges lead to a specific type of relationship with elders, a type of “role reversal” that must be appreciated with attentiveness to cultural values. Third, I conclude to analyze caregiving strategies and how they shed light on the way that both elders and caregivers are socially constituted within the caregiving relationship.

Caregiving Challenges

One of the most striking features of my interview with Carlos and his family was the bluntness with which they described their experience. In a commanding-yet-soft voice, Carlos cited numerous reasons why caring for his wife was challenging. I was struck by the severity of this wife’s symptoms, the way in which Carlos described having a partner that was alive but near-cognitively dead. I believe Alex was similarly affected, because at one point he asked Carlos what made caregiving most difficult.

Alex: What do you think is the most difficult part of taking care of her?

Carlos: The hardest – the hardest part – is to take her to the restroom. That’s the hardest part. When she eats, it’s not that difficult. But when she has to go to the restroom it is. And also when she needs to take a bath. Those are the two hardest parts about taking care of her. Because she is not aware that she is taking a bath. She’s not aware, [really].

Carlos’ biggest challenge is taking his wife to the restroom to defecate, urinate, and bathe. Absent to the world around her, Carlos knows his wife is no longer fully aware of his efforts. In this excerpt and so many others, Carlos provides an illustration of what caregiving is like – the harsh details of his experience – and what about them render
things so challenging. In many ways, the relationship that this elder once supported as wife, mother, and grandmother has begun to disintegrate.

“Caregiving… for dementia draws you into an enmeshed relationship,” says Kleinman of his own experience with his wife. “You begin to lose the self of your own self, because you’re constantly entering [another’s] space to do things for them” (Religion & Ethics NewsWeekly, 2011). Much like Kleinman, Carlos and many of the other caregivers I interviewed described how their relationships changed as a result of assuming new responsibilities. To analyze this change I now consider caregiving challenges – that is, the specific features of caregivers’ daily experiences that are difficult to endure. Understanding what makes caregiving challenging helps shed greater light onto caregivers’ experiences, and also how caregivers form relationships with elders. My argument is that caregivers perceive things to be challenging within a specific set of values and beliefs, and that these factors are essential to understand caregiving experience. Studying how these factors contextualize caregiving provides a vista onto the social construction of caregiving and, by extension, the construction of the meaning of aging as situated within the caregiving relationship.

\[a\) Intra-Family Strife\]

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2 Yet I should state from the outset that while this section is focused on challenges, I do not want to suggest that caregivers are simply obliged to meet them. Caregivers provide support to elders, but they also receive. Returning to Kleinman, I take stock when he remarks that, in caregiving “your own humanness deepens as you engage the humanness of someone else” (Religion & Ethics NewsWeekly, 2011). Hence, when I discuss caregiving challenges I refer to those consequences that are a part of the commitment one has decided to make. Caregiving is a practice one elects to uphold, in part, because of the profound moral experience it occasions (see also Norris, Pratt, & Kuiack, 2003, p. 340). (In the following chapter I take this issue up more directly.)
One of the most common challenges cited throughout my interviews is that living with a forgetful elder often leads to household conflicts. Caregivers said that they are frequently blamed for lost objects, targets of elders’ anger, and perceived as the reason for elders’ depression. To this end, I return to my interview with Luis and Laura, the caregivers who recently decided to move in with Laura’s widowed mother because she was judged incompetent to live alone. They show how caregivers experience elders’ seemingly minor accusations as serious challenges. Recall that Laura’s mother exhibits early-stage symptoms like forgetting minor objects. Below, Laura describes how the onset of these symptoms has become a daily challenge.

Alex: Does it affect you that she [your mother] forgets those little things?

Laura: Oh, of course it affects me… Because she’s always blaming me that I hide things from her. And she’s always sure that I’m the one that hides it from her. I don’t know why she can’t think to ask me in a polite manner where her purse is – because there’s a way you can ask someone in a respectful way. Like, “Have you seen my bag, by any chance?” But what she does [is] she’s always pointing her finger at me and is sure that I’m the one that took it. And I think that’s something

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3 While many caregivers stated that they did not view forgetfulness as problematic (see Chapter Five), they commonly described it as the cause for the frequent instances of fighting they encountered. One way to account for this apparent paradox is to note that caregivers view forgetfulness as normal and, as a consequence, attributed blame to the elders’ personality, not their illness. This resonates with studies on Mexican-American families who similarly attribute caregiving difficulties as due to personality changes (Drumond-Andrade, 2012, p. 188).

4 Although I assume that the stress of caregiving also leads to conflicts among caregivers themselves (that is, among the caregiving family apart from the elder), there is no data to support this in my interviews. One reason is likely due to the nature in which I conducted my interviews. Meeting with the entire household served methodological purposes of seeing how meaning is negotiated, but it also limited the extent to which participants could discuss how other members of the family impact caregiving.
that always gets me angry. And we start arguing. And I have a lot of things to do
instead of hiding her bags. So I don’t have time to do that. And I tell her that,

“I’m tired of you treating me this way.” And this is an everyday problem.

The manner by which Laura conveys the relentlessness of her mother’s accusations is
telling. Laura’s use of words and phrases like “always,” “everyday,” and “I’m tired”
helps convey how these instances have come to be definitive of her daily experience. Her
mother’s accusations obstruct her from carrying out other chores and, more distressing,
Laura gets angry. This is a point I will continue to make throughout the subsequent pages
on caregiving challenges: it is not their objective content, but rather their implications and
larger perceived meaning that makes things challenging. That is why Laura does not
experience accusations against her as distressing per se. Rather, her distress comes from
the way these accusations test her patience and put her relationship with her mother in
jeopardy. In a context where family cohesion and respect for elders is paramount – where
individual identity is premised on how one contributes to the larger social unit – one
could understand household strife as a dense signifier of social disorder. It undermines
who a person is by virtue of relationships shared with others. It is a gradual threat to
one’s sense of self, an erosion of the stability one has gained from looking up to an elder
as benguul. Laura’s excerpt is but one among many instances of intra-family strife – but
each of the other examples occurs in the same light. To avoid belaboring the point, I
proceed to discuss other challenges.
b) Wandering

Elders’ tendency to wander is another challenge that caregivers frequently cited. Many said that elders often attempted to leave home with little direction or purpose, jeopardizing their physical safety and causing household alarm. To provide one illustration I return to my interview with Sergio, Mario, and Linda, the successful tortilla makers whose elder has gradually faced difficulty recognizing family members. Through this interview and many others I came to see how wandering is a daily challenge definitive of their experience.

Linda: [H]e’s always watching when people are coming to the house. Since there are a lot of people that come to the house, so sometimes they don’t lock the door properly and that’s when he takes advantage of it, and he gets out. He’s always sneaky to be able to get out of the house when people come and go. And when it’s locked he always forces it to open. And we tell him that it’s locked but he doesn’t listen and he forces it open.

Similar to how Laura was shown to experience arguments with her mother as ceaseless, in this excerpt Linda describes the ongoing challenge of her husband attempting to leave home. Wandering is a threat given Linda’s awareness that her husband could be physically injured. He lacks awareness about his surroundings and would have difficulty returning home. But it is also a challenge with regards to how it renders their relationship. The challenge is two-fold. While it is first a challenge to ensure the elder’s physical safety, it is also a challenge to have him comply with his family’s demand. To this last point, although the elder does not directly make accusations against the family, his behavior nevertheless leads to intra-family conflicts. There emerges a division among the
family, a rift in their unity: whereas caregivers seek to ensure elders’ safety, elders belie their efforts by continuing to wander. This shows how, in addition to intra-family conflicts, caregiving challenges also lead to a perspective of elders that stands in contrast to them having the last word. Compared to how elders are normatively expected to safeguard tradition and command respect, now they are seen as a liability against their own wellbeing.

c) Human Necessities: Defecating, Hygiene, and Eating

The above examples illustrate how caregiving challenges symbolize tensions regarding how elders are perceived to introduce household conflict. Yet there exists another set of challenges obvious in more severe cases, but also detectable in more mild ones. Challenges pertaining to human necessities – like Carlos described in taking his wife to the restroom – continue to change caregivers’ relationships with elders, but in different ways. They force caregivers to assume a new set of auxiliary responsibilities on behalf of the elder that further signify relationship changes. Because so many caregivers in addition to Carlos cited challenges related to human necessities, I feature other voices to reflect on this theme. To this end, I turn to my interview with Mario, Isabelle, and Graciela, the caregivers who impressed me for their humility while being faced with such astringent life circumstances. Recall that these caregivers attended to Mario’s father, who recently had a stroke and was understood as suffering from a case of susto. Mario and his wife provided more detail on their experience.

Mario: And now that he’s in this state, we have to change his soiled pants – I have to change it. [Because] he’s not able to go to the restroom.
Alex: Can he sit [on the toilet]? 

Mario: Oh yes he can sit. 

Isabelle: Yes he can sit. But he [whispers:] can’t do his necessities. 

Mario: He does it at anytime.

Like Carlos, Mario’s statement points to the harsh reality that his father cannot control his bowels and must be attended to. It is difficult for him to acknowledge, and embarrassing for his wife, Isabelle (who later whispers). Even Alex asks for further clarification, wanting to know to what degree Mario’s father is affected and how serious their responsibilities are. I take interest in Alex’s question, and the way in which it expresses surprise at the gravity of the situation. Alex has difficulty imagining these responsibilities and how far astray they appear from what he knows of the ideal of elders. Here the elder has not only lost symbolic authority, he appears to have lost command of his own body. In response, Mario and Isabelle express shame in describing their experience. They feed off each other’s words, appearing taciturn and reluctant. They know that the challenges they face are unusual and difficult for others to imagine, that their experience stands in such contrast to the normative vision of elders.

The challenge of taking an elder to the restroom is qualitatively different than other challenges presented above. It is an instance of how caregivers are required to become involved in a dimension of elders’ lives that was previously viewed as private. This comes close to what Kleinman describes of “caregiving enmeshment,” when “your own subjectivity becomes part of their subjectivity; their subjectivity is part of you” (Religion & Ethics NewsWeekly, 2011). The boundary that had separated individuals
becomes blurred, leading to greater fusion between caregivers and elders. Yet enmeshment and dependency do not signify the same thing across time and space. In contrast to U.S. settings where autonomy is prioritized, in Teotitlán enmeshment invokes local values regarding how elders have the last word and how they inherently are given respect. Enmeshment requires caregivers to view elders in a different light.

To further illustrate this point I return to my interview with Sergio, Manuel, and Linda, the successful tortilla makers. These caregivers similarly talked about challenges pertaining to human necessities, but the comparatively mild nature of their challenges raised my attention to how these difficulties are experienced with regard to local values. At one point Linda, the forgetful elder’s wife, discussed her experience helping her husband eat and maintain good hygiene.

Linda: That’s another problem. We can’t get him to eat. He’s often forced to eat something. And also to have him wash his hands – If we’re eating, he just doesn’t want to do it. As well as when he uses the restroom. We have a hard time to [get him to] wash his hands before he returns to the table. Sometimes we force him, sometimes we just don’t...

Linda’s awareness that her husband is not eating or washing his hands is itself a physical concern that jeopardizes his health. So, she forces him or, at times, gives up. But either decision signifies her awareness that her husband is no longer capable of maintaining the

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5 To further articulate the distinction, in the U.S. becoming dependent is often perceived as a loss to one’s dignity, a perception based on how autonomy is so valued. By contrast, in Teotitlán all family members are considered dependent on one another, perceived as jointly contributing to the household. The dependency occasioned by not being able to meet human necessities is an illustration of the gradual loss of authority of the leader of the household, the elder as benguul – not loss of the dignity as an autonomous agent.
habits that previously marked his good health (or local practices to promote others’ health). In the process, Linda comes to hold a relationship qualitatively different than before, a relationship no longer centered on her husband’s authority, but rather one where her husband is recognized as needing auxiliary help. This is the experiential challenge for all caregivers who must assist with human necessities. They are challenging not due their objective content – not due to an inherent idea of personal hygiene – but rather for how such ideas exist within a broader world that imbues them with meaning. In this way, challenges related to human necessities are difficult not only for their frequency or coarseness, but more fundamentally for the perceived symbolism of change. They are illustrations of how caregivers take responsibility for a set of activities that were previously considered private, individual matters.

\[d)\] **Anticipating Loss**

While many caregivers cited strife, wandering, and human necessities as being central challenges, this alone does not explain why their experience is so laden with emotion. I now want to consider the obvious yet previously unstated point that caregiving challenges are premised on a single, more encompassing one – that is, the fact that caregivers are challenged by their anticipation of loss. At stake is the aging process itself, the reality that elders who are increasingly dependent will soon perish. This is how I understand Carlos – from the household that took months to interview – when he described his relationship with his wife. In the following excerpt Carlos responds and challenges his family who earlier said that they did not notice changes regarding how they viewed the elder after the onset of her symptoms.
Carlos: I saw it very differently, and it was difficult. Because we always worked together. And since we were in the rug business, she’s the one that helped me to wash and dye the yarn. So we did everything together. But when she started to forget, it was very difficult for me. Because there was no one else that could help me … It’s difficult in many ways. For everything and in everything. Because there’s no one to help me work and no one cooks. Because after all wives are very integral… So I see myself as a useless person when it comes to cooking. Because I can’t do anything in that realm. That’s why I see this as very difficult.

Carlos’ statement provides insight onto gender divisions and local conceptions of marriage, but I want to focus on the more encompassing point about how he and his wife formed a partnership to mutually provide and care for each other.\(^6\) The progressive dissolution of their partnership is what Carlos is forced to recognize. It is a challenge centered on the ongoing losses they have endured together, and the final one he anticipates witnessing alone. It is about feeling “useless” both because of how domestic responsibilities are traditionally allotted, and also because he is forced to imagine a life without his wife, a life where he anticipates being existentially unmoored. Like the other challenges he and other caregivers cited, this is a daily recurrence. But it is more. Carlos describes it in curious but heartfelt terms – “for everything and in everything” – that is, he experiences it for every reason, and during every moment. This challenge is not only unique to Carlos, but is found among all caregivers as they recognize that forgetfulness

\(^6\) However, regarding Carlos’ comments on gender, this excerpt is also interesting for its illustration of how caregiving may compromise local gender roles. Not only is Carlos anticipating loss in the future, but he is currently experiencing loss of his male identity.
and debility are tokens for the aging process itself. It is a challenge that appears to eclipse other challenges, despite how subtle it is and how harsh others may be.

Though I apply greater focus on local ideas about death and dying in the following chapter, here I want to briefly address how the challenge of anticipating loss is also constituted within a specific cultural landscape. As discussed in Chapter Three, most anthropologists recognize that death is not an objective biological event, but an experience whose meaning varies widely from one context to another. For example, Lock’s (1997) cross-cultural study of different definitions of death across U.S. and Japan demonstrates how underlying values generate vastly different responses to death and dying. In Oaxaca, death is not considered a sudden event that separates the living from the dead, but rather an ongoing social process that is part of everyday experience. To this end, in her study of Oaxacan death customs Norget (2006) describes how the quality of one’s life is inseparably linked to practices aimed towards treating the dead properly (see also Royce, 2011). How one anticipates and provides for another’s death carries immense weight in the local consciousness. Persons are expected to respect the infirm and provide a space to allow others to die in peace – and it is believed that if this is not provided, the deceased will return to haunt the community of living. This belief adds an additional challenge for individuals who experience difficulty avoiding household conflict. It highlights how the anticipation of death carries different meaning and, more generally, how caregiving challenges are again woven in a broader cultural fabric.

As a whole, my purpose in enumerating caregiving challenges is, first, to illustrate the daily experience of caregiving and, second, to highlight how this experience leads to new ways of perceiving elders. From intra-family fighting to wandering to meeting basic
human necessities, challenges alter how elders are viewed and socially positioned in relationships. Interpersonal boundaries become blurred, and seemingly distant realities about mortality now seem more immanent. All these challenges are situated within a broader context that imbues them with meaning. These challenges invoke local tradition, revealing a tension between the ideal and reality. In retrospect, perhaps this begins to explain Carlos and his family’s initial reluctance to be interviewed. Though I still believe it was a matter of confianza, I now realize that their suspicion was not only about me, but rather whether they felt prepared to discuss the harsh details of their lives. It was about how family affairs have so profoundly changed. In what follows I proceed to discuss the nature of this change, and conclude with how it informs caregiving practice.

*The Perception of Elders: Local Functions of Role Reversal*

The challenges briefly outlined above are, in one way or another, definitive of all my encounters with caregivers. They paint a picture of a reality that is as stark as it is bitter, harsh as it is relentless. Caregiving is challenging precisely because it requires individuals to take on responsibilities that symbolize fundamental changes to relationships – changes in who cares for whom, gender roles, parental roles, and more. But how exactly do these changes modify caregivers’ perception of dependent elders? Whereas in the last section I began to show how challenges lead to a vision of elders that stands in contrast to tradition, in this section I go further to analyze the precise nature of that change and how it informs caregivers’ relationship with them. In what follows I describe how caregivers are prone to view elders by comparing them to children, and how this perspective must be understood through attentiveness to local culture. While
comparing elders to children may appear to denigrate elders, it ultimately serves a positive function by mitigating the challenges presented above. Nevertheless, I demonstrate that this perspective puts in tension the local ideal of the elder as benguul and a new image of the elder based on caregiving experience.

a) Theoretical Background

Comparing dependent elders to children is a well-researched phenomenon captured by the notion of “role reversal.” This idea points to the hypothesized change that occurs when spouses, adult children, grandchildren, and other relatives become “parents” to elders who are no longer able to support themselves. It comes from an article written by Arthur Rautman (1962) that describes how the autonomy that once distinguished parents from their children slowly becomes blurred and eventually “reversed” in the aging process. Though dated, role reversal continues to be featured in much of contemporary literature on caregiving and has become a taken-for-granted description. For example, in The 36 Hour Day (2011), what many consider the most useful handbook on dementia caregiving, Mace and Rabins invoke a distinction between responsibilities and roles (pp. 195-199). Responsibilities are the jobs assigned to family members. Responsibilities may or may not change, and their inherent malleability shows how they are not determinative of the way the individual is viewed. By contrast, roles are the ways

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7 Rautman’s notion is based on psychoanalytic theory, postulating that the envy and resentment that characterizes children’s relationships with their parents eventually becomes fulfilled through the aging process. Adult children consequently experience shame by having their fantasies come true.

8 Also endorsing this view, Richard Schulz (2000), in his caregiving handbook, describes role reversal as a common experience of caregiving, yet one that has the potential to cause resentment and anger towards the dependent elder, threatening to compromise provision of care (p. 41).
people are seen and understood within the family. Individuals carry specific roles that are created and solidified by family interaction. Whereas cooking dinner is a responsibility, being a voice of authority is a role. The point is that role changes are more difficult to accept and adjust to. Hence, according to this view, the challenges I presented in the previous section signal more than changes to what one is responsible for, but a fundamental shift in identity. They reconfigure who a person is in relation to the demented elder.

b) Local Prevalence

Although I will soon discuss why this concept is problematic, I first want to illustrate its prevalence across households. Caregivers did not discuss role reversal in technical terms, yet they often described how the caregiving relationship is like parenting and, further, that the recipients of their care (elders) were like children. Consider the following description offered by Juanita, the curandera who cares for her husband with vascular dementia. Like what so many other caregivers experience, Juanita’s husband cannot bathe and experiences difficulty performing other basic functions. Here, in the process of explaining the challenges she faces, Juanita also comes to describe her husband in a language strikingly congruent with role reversal.

Juanita: The same thing happens when he goes to bathe. We have to get him ready, get his water ready, just like a child. We have to have his clothes ready, his towel, and we have to monitor him while showering so he doesn’t wet his towel or clothes. And we also have to watch when he dresses, especially when he puts his shoes on, because he tends to put them on wrong. (Emphasis mine.)
In this excerpt, Juanita describes her responsibility of bathing and monitoring her husband – echoing similar descriptions about challenges related to human necessities – but further says that these activities render her husband “like a child.” As she would ensure that children bathe properly, Juanita here states that she takes the same precautions with her husband. Caregiving, she suggests, is like parenting. But there is something more to be said here. Juanita is not only describing the presence of new responsibilities associated with parenting; she is saying that she has, in a metaphorical sense, become a parent. Like my argument in the previous section, Juanita’s responsibilities are symbolic of a new way of relating to her husband, a reminder that she cannot maintain the same relationship they shared prior.

In a similar vein, I return to my interview with Sergio, Manuel, and Linda, the successful tortilla makers who cared for an elder that could not remember names of individuals in his immediate family. Recall that these caregivers also experienced the elder as “tricky” for continuously misbehaving and disrupting household peace. At one point in the interview Alex takes the initiative to inquire how their challenges have occasioned a broader shift in their view of the elder.

Alex: But how about you – this is a personal question – how do you see him? Do you still look at him as your dad?

Manuel: Well, right now I see him more like a child rather than my dad.

Sergio: Me too. I see him as a child. Because sometimes he gets me pretty angry. Because sometimes I tell him to do something very gently but he just doesn’t do it.
Linda: A few days ago we were making *maize* [taking corn off the husk] and I got distracted just for a second. [Then] I realized he was throwing the husk at me. Or he would just walk on the corn. And also he would always mix the *maize*, the good ones with the bad ones.

In this excerpt Alex prompts Manuel to consider how he views the elder, which leads Manuel and his brother to respond that they similarly view him as a child. They argue that this perspective is justified by how their father provokes arguments and is disobedient. Moreover, they proceed to express how viewing him as a child is related to how they no longer view him as the same member of the family. Yes, he is nominally their father, but his behavior is unrecognizable, and he appears to be a different person – a child.\(^9\)

These are but two excerpts of a finding that I encountered in nearly all of my interviews. Given the variability across households I studied, the different severity of symptoms caregivers treated, and the divergent opinions among members within the same households, it is extraordinary how prevalent this perspective was. Without prompting it, viewing elders as children was endorsed in both harmonious and discordant households, among adult children, spouses, and other family members.\(^{10,11}\)

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\(^9\) Equally interesting is how Linda, the elder’s wife, does not go on to contest her sons’ perspective. She provides an anecdote to justify their remarks, but also does not go so far as to explicitly agree with them. Though this is only one instance, it may suggest that perceiving elders as children is difficult, a conclusion one draws reluctantly, and only after other understandings are exhausted.

\(^{10}\) By “harmonious” and “discordant” households I respectively refer to households that reported arguing among members, and households that did not.

\(^{11}\) Only two exceptions existed. The first was Carlos’ family, the household that I devoted months to interview and presented the severest case of Alzheimer’s disease. Perhaps the severity of his wife’s condition – and the way obedience is no longer an issue – explains why he and his family do not view the
c) Theoretical Tension

Despite how often role reversal was discussed during my interviews – and its popularity in U.S. caregiving literature – there exists a branch within gerontology that critiques its validity and usefulness. The critique stands on two grounds. First, gerontologists argue that role reversal is an inaccurate way to describe the caregiving relationship. This perspective equates caregiving with parenting when, in fact, adult children know that the recipients of their care – their parents – are not children at all. As Mildred Seltzer (1990) writes, “children remain children to their parents all their lives” (p. 9). To this end, critics argue that this concept is inaccurate because it does not account for the phenomenon of caregiving: caring for a dependent elder presages increasing dependency, whereas with children one anticipates increasing independence (Brody, 1990). Second, gerontologists argue that role reversal is destructive to the caregiving relationship. It maintains ageist assumptions by depreciating elders as children, foreclosing respect and denying the possibility of reciprocated familial relationships (Brody, 1990).

My intention in this study is not to argue whether something should be occurring in Teotitlán, but to describe what is actually happening and explain its consequences. In this regard, the prevalence of this finding demonstrates that the perspective of elders as children does, to a large degree, apply to local caregiving experience. This perspective

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elder as a child. The second exception was in my interview with Luis and Laura, the caregivers who recently moved in to live with Laura’s mother who showed signs of mild forgetfulness. While they did not explicitly say Laura’s mother was like a child, at one point Laura said, while discussing their frequent arguments, that while Laura continues to view her mother as a mother, she is not sure about how her own mother views her. Quoting Laura, “I think she’s the one who has forgotten who is her daughter.”
puts the local understanding of the elder as *benguul* into tension, undermining the reasons for why elders command respect.

Of course, caregivers know that elders are not actually children, and they also do not negate that elders remain their husbands, wives, fathers, mothers, etc. For this reason, I follow Hargrave and Anderson (2013) who make a distinction between “classic role reversal,” which they rightly argue robs elders of their adult status, and what I term “metaphorical role reversal,” a description of elders made by comparing them to children (p. 17-18). The latter position does not state that elders *are* children, but says they are *like* them. It is a metaphor in Lakoff and Johnson’s (1980) use of the term, a means to orient oneself to a new situation by reference to another more familiar one.

*d) Local Functions*

Given my understanding of discourse, I understand caregivers’ comments about elders being like children as, again, an act of construction – both constructed from surrounding discourse and constructive of the world (see Chapter Four). In part, caregivers compare elders to children because of their own parenting experiences. Many adult caregivers are in what gerontologists call the “sandwich generation,” responsible for caring not only for dependent elders but also for dependent children (Brody, 1985; Miller, 1981). They know what caring for children is like, and thus compare caregiving to it. But their talk about elders as children is also constructive – it creates a relationship with elders that would be different without such talk. Here, the constructive effect of discourse is not just something done by one person, but an interpersonal process performed between and among different members of the household to form a consensus
about how to understand and respond to elders. In other words, caregivers’ talk about elders being like children carries real consequences. It is an attempt to work through the tension between local ideal of old age and the reality of caregiving, an attempt to arrive at a perspective of elders that equips caregivers with an orientation about how to understand and respond to their challenges.

These consequences can be mapped in two ways. First, I view this perspective as a mechanism for caregivers to prepare for anticipated loss, a recognition that dementia is a process that will continue to intensify until the moment of an elder’s death. As such, viewing elders as children is a coping mechanism, a way for caregivers to begin confronting the harshness of loss as it progressively unfolds (McWilliams, 2011, pp. 100-150). To illustrate this point, I introduce another caregiving household. Francisca, a woman in her early-sixties, and Dominga, her niece in her early-thirties, jointly cared for one of the more tragic cases I had encountered. In addition to their poverty, Francisca and Dominga were challenged by the severity of the elder’s health. Over the course of years the elder has progressively exhibited greater memory difficulties, had a series of strokes, and also suffered from severe epileptic fits. Their description of the elder was tragic, but I was especially struck by one moment when Dominga described how she views her uncle as a child.

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12 This is but one example of why I view conducting group interviews so advantageous – it maximizes group discussion and provides an opportunity to see how meaning is negotiated among individuals (Carey & Smith, 1994; Myers, 1998).

13 This local function is compared to U.S. settings where comparisons of demented elders to children add greater stress to caregivers and denigrates their relationships with elders. This is perhaps one reason why there exists such strong domestic effort to challenge this perspective.
Dominga: I can’t say that I look at him in the same way I used to look at him. I look at him now as a kid. Like if he was a person that is there, but not there. Am I making sense? That’s the way we look at him. We only look at a body. But he is not there.

Dominga’s statement is powerful description of how she views her uncle as a child, and how this perception is a symbol for her loss. Like other caregivers, she is quick to say that she views her uncle differently since the onset of his symptoms. This perspective allows Dominga to distinguish between his body and his personhood; his personhood has progressively departed, while his body remains.14 Despite not being dead, Dominga shows how this perspective orients her perspective to see the elder as if he already were. Of course, Dominga knows her uncle is still alive, but what this perspective helps achieve is acknowledgement and preparation for the reality she anticipates encountering.

There is also a second function that caregivers achieve by viewing elders as children. It helps caregivers understand that elders are not intentionally being difficult, and that they are not deliberately causing strife. This helps lighten the burden of caregiving. To illustrate this point, I return to my interview with Pablo and Vanessa, the caregivers who impressed me for their decision to assume responsibility for an elder not in their immediate family. At one point, Pablo described the nature of the challenges he and his family faced as caregivers, and how they needed to develop a better way to cope.

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14 As discussed prior, the distinction between two different types of souls helps shed further light on how the dying process is locally understood. Dominga’s comments could perhaps be understood as a chronologically reversed instance of the dying process. Here, Dominga appears to suggest that her uncle’s anim (the soul that departs when one dies) has already separated from his body, while garlieng (the soul one has while living) keeps him physically alive.
Pablo: I told them [my wife and children] that she is no longer an adult. We will consider her more like a child. She would be doing this and that, or pulling this and that, or switching the place of things that belong to us. Her mentality is no longer the mentality of a person in good health. Just like us, we think before we act, and she does everything she’s not supposed to.

Here, Pablo explicitly states how viewing the elder as a child is a strategy he and his family have adopted. To justify it, he contrasts the elder’s state of mind to his own – he is capable of thinking prior to acting – and he realizes that this is what marks the elder as different. He concludes that she is like a child. But it is through this realization that Pablo is able to manage the challenges of caregiving differently. He knows the elder is not capable of acting otherwise, and he also knows it is futile to try to educate her to change. If the elder is like a child, then Pablo must learn to be patient (a strategy discussed in the following section).

Yet there is more to be said here. While this understanding is intelligible in other contexts, it specifically concerns local beliefs where children are considered to possess a spiritual nature fundamentally different than adults. Children are perceived to lack awareness of the world, limited in having a basic understanding of their actions. This is not a statement about moral development, but a metaphysical declaration about the nature of the soul. For example, compared to deceased adults who are believed to be required to repent for their sins in purgatory, when children die they are believed to be *angelitos* (lit. little angels) and permitted direct access to heaven (Norget, 2006, pp. 118-121).15 They

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15 To further illustrate this point, in contrast to the melancholic music that accompanies pallbearers at funerals of deceased adults, when children die the music is bright and upbeat. Relatives are expected to be
are exempt because they are not capable of sinning; they lack awareness to have had behaved differently. In this way, one would have reason to draw the broad conclusion that caregivers’ view of elders as children is not diminutive, but rather a way to pardon and experience elders with greater patience.

In contrast to the pernicious effects role reversal is said to have in U.S. settings, my data provides preliminary evidence that viewing elders as children may serve a positive function. This hypothesis posits that role reversal in Teotitlán is neither destructive nor invalid, but a common perspective that helps families confront the challenges of caregiving. Moreover, while role reversal highlights the tension between local ideal of old age and the reality of caregiving, it may also help caregivers reach a resolution. Though many of the arguments against role reversal in U.S. settings are well directed, my findings suggest that they do not apply in Teotitlán. Here, role reversal is not a threat to the elder’s autonomy, or a way to disparage elders, but a means to improve caregiving practice and, ultimately, may help foster social cohesion. In the section that follows I discuss how this perspective informs caregivers’ strategies to deal with those challenges.

Caregiving Strategies

As I have begun to hypothesize, role reversal may contribute towards reducing the intensity of challenges caregivers face, in this section I proceed to discuss the specific way caregiving practice is implemented. Here, I analyze caregivers’ strategies aimed to respond to the challenges presented above, and question how those strategies operate cheerful because of knowledge that children have direct access to heaven. Nevertheless, I have come across more than one family who experienced the death of the child with a profound sense of loss.
within their relationships with elders. By “strategies” I mean the interventions, techniques, and other forms of action taken by caregivers toward the mollification of challenges and provision of care for elders. Enumerating strategies provides a more comprehensive picture of the daily experience of caregiving, and also sheds greater light on the relationship between caregiver and elder.\textsuperscript{16} My argument in this section is two-fold. First, I seek to show how role reversal establishes a justification for various strategies caregivers use. Second, however, I argue that these strategies culminate in a vision of the elder that is at odds with tradition, the ideal that elders are respected on the basis of age.

\textbf{a) Patience}

One of the most common strategies endorsed by caregivers is their attempt to be patient with elders and the challenges that they bring. Though patience is not typically considered a form of behavior, caregivers demonstrated how it translates into specific action. I could provide an excerpt from every interview, but I choose to highlight my encounter with Pablo and Vanessa, the caregivers who impressed me by assuming responsibility for an elder not in their immediate family. At one point during the interview Pablo provided a rich illustration of how patience is a central strategy in helping his household overcome caregiving challenges.

Pablo: Well, what we try to do is ignore whatever she says. Just like we said, if she’s arguing about something, we’ll always agree with her. I’m the one that’s

\textsuperscript{16} To elaborate this last point, my focus on caregiving strategies is another way to study constitution, that is, the mutual formation between people and their forms of life (see Chapter Four). The caregiver is borne out of the practice of providing care, as is the dependent elder who is the recipient of this activity.
always telling her [my wife] to agree with whatever she says, since she’s the one that takes care of her most of the time. Also because she [my wife] gets stressed very quickly. With me, I try to calm down first and agree to anything she’s saying. And she [the elder] calms down a lot quicker [by my] agreeing with her.

The first observation to draw from Pablo’s comments is contextual. His patience arises in response to challenges. Like so many other caregivers, Pablo says that the elder provokes arguments about misplaced objects. And, it is during these moments – the instance when Pablo experiences his patience to be most compromised – that Pablo reminds himself to be more patient. Patience helps establish a frame of mind to better provide for elders, to overlook things like household strife so that elders’ needs continue to be met. The reminder to be patient also extends beyond the elder to include how one must be patient to maintain ideas about family unity and, as I have begun to speculate, to remember and abide by local values. Yet there is an inherent paradox in this picture: while caregivers maintain local values through patience, their patience also undermines values by overlooking elders’ perceived authority. This is a consequence of how caregiving has changed roles, and the perception of elders as children. In Pablo and Vanessa’s case, patience leads them to abstain from arguments, to ignore and be complacent with the elder. But this, in effect, removes them from being conversational partners. Pablo’s description of how the elder attempts to engage with him via arguments is interesting for how patience leads Pablo to be passive. He agrees to the elder’s demands and complaints; he says that she is right. Hence, patience helps caregivers overlook challenges, yet it creates tension with regard to central values.
b) Confinement & Monitoring

In addition to patience, I also found that caregivers commonly strategize to lock-up and monitor elders. This collective decision is in response to the challenge of elders who are prone to wander, and also due to other forms of disruptive behavior. This was a salient theme during my interview with Sergio, Manuel, and Linda, the successful tortilla makers. Recall that this family described the elder as being “tricky” and they were challenged on a daily level about how to minimize his disruptive behavior.

Sergio: I think that it’s easier – or what makes it less stressful – is when we lock him up. Even though when we lock him up he touches everything that’s in the room and he digs around. And whatever he finds interesting in the room he will dig in, and touches everything he knows he’s not supposed to. But at least he’s safe there, and I know where he is.

There is an obvious simplicity to Sergio’s strategy: as caregiving is challenging because elders are prone to wander, one solution is to prevent them from wandering by confining them to one place. This is helpful when caregivers are at home, but more so when they must leave to go to the market or do other activities outside. It helps ensure elders’ safety and mollify caregivers’ stress. Caregivers do not need to worry about elders wandering in the streets and the consequences that might arise.\(^1\) This strategy also helps address other

\(^1\) At a different moment in the interview Sergio offered greater clarification about why he and his family have adopted this strategy.

Manuel: That’s what worries us. That’s why we try to lock him, and not let him out – Because it’s very dangerous for him to get in a cab or a bus and get lost somewhere. And sometimes we get the worst thoughts, and that’s something very dangerous, I think. And he can probably go get in a cab and go somewhere, but the thing is he probably won’t make it back. Just like what happened in
challenges by monitoring elders to ensure that they do not cause problems at home. It is a strategy premised on suspicion that elders are liable risks against themselves, and capable of creating household problems. Even if elders are not specifically known to wander, I found that every household closely monitored elders to help manage their behavior. Once again, this establishes further tension between the reality of caregiving and the role tradition prescribes.

Upon preparing to write this section I considered stating that there exists a new meaning of how elders have the last word, now because caregiving strategies lead families to abstain from responding. The reasons for caregiving that are based on respect and love seem to be undermined by caregiving practice. Yet such a sentiment is not only too harsh, it is also incomplete. Caregivers may strategize not to respond to elders – to lock-up, monitor, and have patience – but they also assume other strategies that function toward engaging them. Hence, instead of concluding that caregiving somehow paradoxically undermines itself, in what follows I introduce how caregivers adopt another set of strategies with different and complementary effects.

\textit{c) Engagement: Conversation and Activity}

Whereas I concluded that the above strategies serve to minimize caregiver stress at the expense of distancing elders, here I aim to show how caregivers also adopt other efforts that carry the opposite function – to engage elders through conversation and activity. This set of strategies is poised in response to the perception of elders as inactive, inattentive, and having difficulty maintaining former relationships. To illustrate this point

\text{Tijuana [an incident when the elder wandered, discussed earlier in the interview]. That’s why we always watch him, to make sure he doesn’t go out, and that’s the biggest risk in his condition.}
I return to my first interview with Alberto, Beatrice, and Cecilia, the first caregivers I interviewed who represented the diagnosed case of senile dementia. Like many other caregivers, this household described efforts to try to engage the elder, and helped provide insight onto why they view this set of activities as important.

Alberto: We try to motivate her every time we walk by and we see her sleeping. We joke around with her. And she jokes back, and we tell her not to sleep too much. “Are you feeling OK?” “Are you sitting OK?” “Would you like to move to a shady place?” Or, “Are you tired?”

Beatrice: We also ask her if she wants to lie down to rest. “Would you like to eat a fruit, or drink some water?” We try to chat with her.

Yes, inquiring about unmet needs helps caregivers know whether they are upholding their responsibilities; but it more importantly serves to form greater dialogue with elders when they seem distant. Alberto’s statement begins with a simple summary to describe his behavior. He says his efforts are aimed to motivate the elder. He does so when the elder is sleeping, and more generally when she appears to be disengaged. Motivation may appear to be a curious way for Alberto to justify his jokes and inquires about unmet needs. But it makes sense given his understanding of forgetfulness as caused by depression and inactivity (see Chapter Four). In this way, attempting to engage elders is a mechanism aimed at arresting illness itself.

Hence, whereas the strategies outlined above were shown to reduce caregiving burden by disengaging elders, there also exists another set of strategies aimed to involve them more. This strategy was not an exception but the norm; it was found in every interview, across levels of severity and among the same caregivers who described efforts
to disengage elders. Yet how could such disparate strategies coexist? A preliminary explanation is that different strategies arise depending on the challenges caregivers face. The first type – disengaging the elder – occurs in problematic circumstances. Caregivers do not want to argue with elders and want to avoid physical injuries, so caregivers do what they can to minimize these challenges. The second type – engaging with elders – not only occurs during moments of harmony, but more importantly when symptoms of forgetfulness seem to be worsening. As elders appear more withdrawn, disengaged, and absent from household activities, caregivers take action to bring them back.

This last point is best illustrated by examining severe cases. While these caregivers face greater limitations in getting elders to be physically active, they continue to try to engage with elders in other ways. To this end I return to my interview with Carlos, his adult son Francisco, and family, the household featured at the beginning of this chapter. Recall that this elder has lost her ability to communicate and has forgotten how to carry out basic behaviors. Doing this interview gave me the opportunity to witness how caregivers strategize to engage with elders who are unable to respond to their efforts. Like other households who dealt with milder stages of forgetfulness, Carlos and his family continued to try to engage the elder – but here, it was evident that this strategy was directly aimed at moderating forgetfulness itself.

Francisco: For example, when we all get together, we invite her to join us, so she’s able to participate with us. And we see the change – she becomes more content.

... 

Alex: Is it difficult sometimes?
Francisco: Not really, to the contrary, she likes it. Because when she’s alone that’s when she seems more depressed. But when we’re all together and she hears us talking she participates.

Carlos: Even if she is saying something completely off-topic…

Francisco: She laughs.

Carlos: She likes to be among us. We can see that she’s happy.

While this excerpt could be read in a similar way to Alberto’s comments above, it is more remarkable when one considers the circumstances this household faces. Carlos’ wife can hardly talk (when she does he recognizes it is off-topic), fails to recollect basic facts like where she is located, and has difficulty carrying out basic motor tasks. Nevertheless, he and his family optimistically report that they continue engaging the elder in conversation. The elder has trouble verbally responding, but her behavioral gestures signal to Carlos and his family that she enjoys their efforts. She appears more active, and they notice she is happier. And, because she is happy, Carlos and his family believe that she is less forgetful. While this draws on etiological understandings, it also demonstrates how caregivers continue to try to engage elders, however debilitated they may become. It highlights caregivers’ concern to continue doing what is best for elders – despite the challenges faced and the difficulties encountered.

These efforts reveal what is, perhaps, the heart of caregiving practice: caregiving strategies are not just directed towards minimizing burden or distress, maintaining family harmony, or upholding shared ideas about tradition. More fundamentally, strategies are also centered on love. While I recognize that writing about love is inherently problematic
– it reifies a set of concepts from my background onto another setting – it is impossible to analyze caregivers’ efforts to engage elders without taking it into consideration. Love is different across time and space, but it seems apparent that among the caregivers I interviewed love means doing what is best for elders because of one’s deep concern for their wellbeing. Love means engaging elders when they cannot participate; it means speaking to elders when they cannot respond; and it means taking efforts to arrest the progression of illness when illness already seems to have already won.

As a whole, this presentation of caregiving strategies – the way that caregivers assume behavior that both engages and disengages elders – illustrates how caregiving is not a one-dimensional practice with a single objective, but rather draws on multiple objectives that supplement and support each other. Caregivers simultaneously seek to minimize disruptions to household unity, ensure that elders’ needs are met, and take action to serve elders’ health. Each strategy draws on local values about what is important, but each also illustrates how the same values are put in tension through caregiving practice. In the process, elders and caregivers are constituted in different ways. Elders are simultaneously distanced and brought closer with other members of the household, while caregivers struggle with how the same dynamic foretells the ultimate distance – death – that they know will come. This renders both caregivers and elders in a different light; it changes who they are by virtue of being constituted within caregiving practice.

Conclusion

This chapter has advanced a number of points regarding the local experience of caregiving. First, by describing the challenges faced by caregivers, I demonstrate how
caregivers are led to acknowledge fundamental changes to the relationships they share with elders. Second, this acknowledgement culminates in a different vision of elders – one that compares them to children. As I have begun to hypothesize, this vision appears not to be diminutive, but rather may serve as a useful strategy to cope with caregiving challenges. Third, I analyze caregiving strategies and how their diverse natures provide information on the way elders and caregivers are constituted within the caregiving relationship.

As a whole, this chapter offers a detailed sketch of the daily experience of caregiving. It adopts a perspective of caregiving that is inseparable from the broader social context, illustrating details of caregiving experience and how it is constituted by site-specific (social) factors. It moves beyond traditional literature on caregiving as a form of physiological and interpersonal suffering, showing how suffering is inherently social. While this last point has only begun to be defended, in the next chapter I will continue developing the idea that caregiving experience is not merely constituted by the encounter between adults and demented elders, but rather produced within a specific cultural setting that maintains locally defined ideals concerning the individual, elder, family, community, and tradition. This chapter demonstrates how caregiving practice is based upon those ideals, and how caregiving may symbolize their perceived jeopardy.

This point is not an intellectual, but a moral issue. It involves how people understand, live with, and support each other. It centers on local meanings of love, what it means to give one’s love, and how one anticipates losing love through the dying process. These hit the heart of human experience. This may be why, considering their
initial reluctance to be interviewed, Carlos and his family ended our discussion with a sincere expression of gratitude.

Carlos: I would like to wish you – since you’re investigating this – I hope that you can find a cure for other elders. I hope so because it’s very difficult for the elder. Well, elders forget, so that really doesn’t matter [and impact them]. Even if they’ve passed away it won’t hurt them anymore. However, the caregivers are the ones that have a hard time… Because not all elders have families that will have patience for them. And there are other elders that don’t have relatives, or anyone. And those people that don’t have anyone, that’s very difficult. They live like animals. I’m sure that’s the way some people live. And there are people that only live two in a house. And those people can’t do anything. So I’m wishing the best for you. And [I think] this is a good investigation. And hopefully…

Alex: Thank you very much.

Alex [to Jon]: He said that he thinks that there are no questions you missed. asking. However, he is wishing you good luck on your investigation and hoping that you might find a medicine or …

Jon: Gracias.

Francisco: Or psychological help for relatives.

Carlos and Francisco express hope not only for a medical solution, but also, in more modest terms, for a better way to live, to manage the challenges of caregiving. It is a hope to respond differently, and it is a hope to better live with the tensions discussed above.

Earlier I wrote that the interview is an occasion for households to acknowledge
relationship changes. Carlos’ gratitude also suggests that our interview served another purpose. It helped him and his family process their experience, to feel understood outside of their home. Further, it gave them a chance to appreciate their family and compare it to situations where they imagine elders could be less fortunate. This is the theme I turn to in the following chapter, where I explicitly take up the question concerning why caregivers uphold their responsibility, and what social ramifications this decision entails.
CHAPTER EIGHT

The Experience of Responsibility: The Second Forgotten Subject

Toward the end of our fieldwork I asked Alex if he was willing to be interviewed. As described in Chapter Four, I made this decision to better feature his voice in my analysis, to do justice to his contribution to the project. So, sitting across a table at a restaurant while waiting for our food, Alex and I reflected on our experience and the various households we had the opportunity to research. Then, at one point, I asked Alex what he found most surprising about the project. He immediately mentioned Pablo and Vanessa.

Jon: Why was that [interview] so surprising to you?

Alex: Because I *did* think there were good people in town – But I never imagined that there were people able to take care of someone who didn’t [even] have a relationship [with the elder].

Jon: Yeah…

Alex: … For instance, if I have an uncle or aunt who doesn’t have children [him or herself], then I would have the duty to take care of them. But in this case, they [Pablo and Vanessa] have completely no relationship to the elder.

My sentiments were similar. As discussed earlier, Pablo and Vanessa were caregivers for an elder in her late-seventies with mid-stage symptoms of forgetfulness. Originally, I approached this household with anticipation because, after months of fieldwork, it was
the only other diagnosed case of Alzheimer’s disease I had encountered. Yet from this interview I learned more about the act of caregiving than an intellectual lesson about diagnosis. It put into focus the theme of responsibility – the way it is distributed, why individuals feel it, and how complex and far-ranging it extends. As Alex stated, neither he nor Pablo nor Vanessa felt that the elder was a part of the family. Technically, she was, but it was complicated: the elder was the widow of Vanessa’s father’s deceased brother. No matter how extensive family networks are in Teotitlán, this was by far the largest stretch of family ties I had encountered.

Alex and I first approached this household not knowing what to expect. We had heard about an elder with Alzheimer’s disease but we were confused about which household actually cared for her. When we finally met Pablo, a man in his early-forties, I was immediately struck by his cheerful appearance. In comparison to many other participants who warmed up to me through the course of the interview, Pablo took no time demonstrating his hospitality. He invited us into his courtyard and I was again struck by socioeconomic disparities across the homes I had the opportunity to visit. Here I encountered unfinished concrete and adobe walls, few adornments, and a loom for weaving. Pablo called upon Vanessa, his wife in her late-thirties, equally warm but visibly over-worked. Together we gathered seats in a shady side of their courtyard while Alex took the lead to provide an explanation about the purpose of our visit.

I had been regularly told that in Teotitlán elders do not have to worry about becoming dependent because there always exists family to care for them. Pablo and Vanessa shed new light onto this statement. They raised my attention to how responsibility is not merely based on notions like reciprocity or filial piety, but on local
traditions much more difficult to define. Indeed, although there exist traditional words to refer to “responsibility,” *responsabl*, a Spanish cognate, is the Zapotec word used most frequently.¹ This is but one linguistic illustration of the much more diffuse way that Teotitlán continues to evolve. Local words and traditions are in such flux that one cannot assume to know what notions like responsibility mean. Clarifying this topic is the purpose of the present chapter. While in the previous I analyzed caregiving perceptions, practices, and relationships, in this final chapter of analysis I take on three fundamental questions about caregiving experience – How is responsibility distributed? Why do people feel responsible? And what are the social consequences of making this choice?

This chapter is meant to complement the previous by providing greater insight into the experience of caregiving. Again, I view this experience as an instance of social suffering, something that must be conceptualized from a multidisciplinary framework. The experience of caregiving resides within local and global, social and economic, political and cultural parameters. Each of these is not only understood as a contextualizing factor, but also for giving rise to caregiving experience – explaining why caregivers suffer (see Kleinman, 2010; Kleinman et al., 1997).

What follows is divided in three sections. The first reviews how responsibility is distributed among family members with specific attention to migration and the

¹ There also exist two non-Spanish Zapotec cognates to refer to responsibility, yet these are rarely known among younger generations. *Zagunilá àz* is an adjective used to describe a person who is dependable, attentive to others, and responsible. Deriving from the word Zapotec word for “heart,” *là’áz*, this adjective is a part of the group of Zapotec words that describe inner convictions (e.g., *relilá àz* means to have faith, *rikielá àz* means to worry, *redxulá àz* means to enjoy). The second Zapotec word to describe responsibility is *naux* and translates to mean “to look after or care for someone.” For example, elders are heard saying “¿Tu naia nai?” (“Who will care for me?”). Alex and the majority of participants used neither word, and referred to responsibility through the Spanish cognate.
circulation of care across national borders. The second takes up the question regarding why people decide to feel responsible – that is, what reasons individuals have to uphold responsibility. This section focuses on cultural orientations, and how this site-specific factor is essential towards understanding responsibility in Teotitlán. Lastly, I conclude to discuss the ramifications of responsibility, that is, what occurs after a person has made the decision to become a caregiver. I argue that this decision renders caregivers into a second forgotten subject, now forgotten by the community whose traditions they uphold.

Delegation of Responsibility: The Parameters of Migration

My interview with Pablo and Vanessa made such a strong impression for demonstrating how caregiving responsibility extends beyond one’s immediate family and is rather constituted within broader social parameters. This was a theme discussed throughout the interview – partly due to my own confusion about why these caregivers decided to assume responsibility, and also because this decision cast such a large shadow over their daily lives. At one point, upon hearing about their difficulties and doubts, Alex and I came to directly ask why they decided to uphold their responsibility.

Pablo: Why? Because we’re… doing an obra de caridad [Spanish original: “act of charity”] by having her in the house. She doesn’t belong to us… She was kicked out where she is supposed to live, which is with my uncle next door. Because they are los responsables [Spanish original: “the ones supposed to take care of her” because they are the closest relatives she has]. But they [the elder’s closest family in Teotitlán] kicked her out on the street, and she didn’t have anywhere to go. So they came to ask us for a favor… if we could take care of her
and have her in our house. So we felt really bad to leave her out on the street [because] she could have been homeless. So we decided to have her in our house.

While Pablo does not say it here, the elder had spent the majority of her life away from Teotitlán in Mexico City. She had maintained family ties while away, yet she returned in her old age to a community that hardly recognized her. Pablo and Vanessa help introduce the theme of migration and how living away from the Teotiteco community immediately concerns caregiving practice.

Further, this case is also instructive for revealing how responsibility is allocated among family members. Here, through witnessing how responsibility is perceived to fail – how the elder’s most immediate family has refused care – we obtain a more general statement about how it is designed to work. Responsibility is normatively prescribed to one’s immediate family relatives, which explains why a disproportionate number of caregivers are direct family members (see “Interview Summary,” Chapter Four). In Pablo and Vanessa’s case, the elder is a widow, has no living children, and so could only call upon her extended family. Though these individuals initially cared for her, their offer was eventually rescinded due to frustration with caregiving. And so Pablo and Vanessa – two individuals that are not directly related to the elder – decided to take on the responsibility.

The story is astonishing. So many people upon so many occasions told me that elders do not need to worry about who will take care of them – and here was an elder on the brink of homelessness, saved only because of another’s goodwill.² Hence, in contrast to the maxim that an elder’s closest family assumes responsibility, my interview with

² Although I later learned that there are no actual homeless people in Teotitlán (and that the threat was really about not having a dependable home in which to reside), it was in stark contrast to the way responsibility was typically discussed.
Pablo and Vanessa taught me that responsibility is a much more complicated issue than is typically recognized.

This section traces one dimension of responsibility’s complicated nature. Though I had the opportunity to collect rich information about a variety of dimensions of responsibility, the sections that follow are specifically focused on migration. I keep this focus because migration provides another illustration of my argument about the social dimension of caregiving, of how broader social parameters constitute caregiving practice. Moreover, migration so clearly illustrates why caregiving responsibility is much more complicated than it is typically assumed. In what follows, I discuss how responsibility is circulated across borders and how it is assigned when migrants return home.

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Further, other data gathered on the division of responsibility were inconclusive. For example, while gender, age and marital status all certainly influence the allocation of responsibility, my interviews involved all types of persons and demonstrated that no single factor is determinative of who will assume it. Yet in itself, these inclusive results contrast with research literature that describes how female members disproportionately hold caregiving responsibility in Hispanic households (Ayalon & Huyck, 2002; Henderson & Guitierrez-Mayka, 1992). Further, they shed contrastive light on local customs that dictate that women are traditionally assigned domestic responsibilities, while men are expected to uphold economic ones (see Chapter Two). Though limited, my data suggests a more complicated view. Both genders across generations were involved in caregiving practice. However, as earlier excerpts have indicated, women do carry a disproportionate burden in domestic responsibilities, including provision of care for elders.

In addition to my limited data set, perhaps it is also difficult to make conclusions about gender because of the way data was acquired. While I asked about which individual was the primary caregiver, conducting my interviews in a group setting may have silenced the perspective of women who carried out those responsibilities. If this is true, then this casts further light on the gendered dynamics of caregiving: women carry out responsibilities but may not be socially recognized for it.
a) Caregiving Across Borders

Tracing caregiving responsibility involves more than just identifying which members of the family uphold it, but also must take into consideration what Worthen (2012) calls the “presence of absence,” that is, the way in which non-present individuals (migrants) also contribute. Like many other Oaxacan communities, Teotitlán’s high rate of migration ultimately means that families are disjointed as individuals live across city, state, and national borders. Stephen’s (2007) concept of “transborder lives” points to the lived experience of these circumstances; Teotiteco identity is now stretched and transcends traditional boundaries. In this section I show how caregiving is situated within this reality. I analyze the division of responsibility across borders to demonstrate how caregiving must be perceived as a multi-sited practice.

Recent work on “transnational family caregiving” is noteworthy in this regard for the way it demonstrates how care is circulated among family members across political regimes, economies, social structures, and traditions (Baldassar et al., 2007; Baldassar & Merla, 2013). Here, care is not only defined by hands-on embodied work, but also involves economic, moral, and social support that can be exchanged across borders.

To this end, I consider how care is circulated beyond Teotitlán, especially given the resounding finding that all interviewed households had at least one member living in the U.S. Though I initially made the assumption that caregiving was inherently more difficult due to migration, participants noted that their ability to care is, in part, facilitated by the remittances they receive from family living abroad. Below, Juanita, the curandera who cares for her husband with vascular dementia, illustrated this point in discussing her sons, all of whom resided in the U.S.
Juanita: It does affect me, but it has to be so, it is necessary [Spanish original: *necesidad*. Although if they were here, they would be helping me…

Alex [to Jon]: It would be very helpful if they were here, she said. However… it’s because they have… to succeed, that’s why she assumes the responsibility.

…

Alex: How do they help now that they’re not living here?

Juanita: They help me economically and by sending us clothes.

This excerpt illustrates many features of caregiving in a setting marked by migration. First, it provides insight onto the way migration is perceived locally, the way it is seen as a necessity and something that both Juanita, Alex and the rest of my interviewees take as a given. Family members need to succeed; they need to take economic opportunities when they arise. Second, Juanita states that her sons would be physically involved in caregiving *if* they were living in Teotitlán. This introduces the obvious point that the individuals who uphold primary caregiving responsibilities are the ones who remain and have not migrated. It shows how responsibility is circulated by default among the individuals who have chosen not to migrate. Nevertheless, Juanita says that her family divides responsibility across borders. While her sons provide economic support and other necessities like clothing, Juanita takes on embodied responsibility by attending to her husband on a daily basis. This last point illustrates how migration is at least partly conducive to caregiving itself. It results in the distribution of necessary materials to allow other persons to provide care at home.

This is the scene that Baldassar and Merla (2013) intend to describe in their notion of “transnational caregiving.” They use this concept to demonstrate how
physically distant family members have a continued presence in local life via remittances. In this vein, they argue that “not all caregiving has to be embodied or proximate in order to qualify as care” (p. 12). Many of the other caregivers I interviewed not only echoed similar sentiments, but also stated that this type of support was essential to devote their time towards this end. This helps illustrate how migration is conducive to caregiving responsibility, and also how responsibility must be conceptualized with attunement to broader social structures. In what follows, I now consider migrants who return to Teotitlán and how this occasion provides further insight onto the distribution of responsibility.

b) Responsibility upon Reunification

In addition to the way responsibility is delegated across borders, many migrants also uphold responsibility once they return to Teotitlán. As I described in Chapter Two, I was often struck by how permeable borders are for the many Teotitecos who return home to fulfill cargos, attend fiestas, or to be present for other occasions. Again, this was mentioned throughout my interviews and I introduce but one example to illustrate this broader point. The following excerpt is taken from my interview with Graciela, Mario, and Isabelle, the caregivers who impressed me for their capacity to speak of their difficulties with such humility. Recall that this family was responsible for an elder who recently had a debilitating stroke. Through the course of the interview, Alex and I learned

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4 Conversely, by contributing economic support, migrant family members are able to directly contribute to the family and ensure elders are adequately cared for. This facilitated migrants’ sense of local involvement, transcending borders that separated them (see Bryceson & Vuorela, 2003).
that one of their sons lived in the U.S. but has recently returned home. I wondered how
his return has shaped the way the family now operates.

   Graciela: Yes, one of my sons often goes to the States, but he’s here now. He
   hasn’t been able to go back because he has a cargo. So I don’t think he will go
   back anytime soon.

   Mario: And [when he returns home] he brings stuff for us.

   ...  

   Mario: Well, [now that] he’s here he comes to visit him [the elder]… For
   example, when we go out to a fiesta and, if he chooses not to go, he comes to take
   care of him.

Like other caregivers, Mario and his family describe the material benefits of having a
family member live abroad. But they also make the rather obvious point that when
migrants return to Teotitlán their remote contributions transform into embodied ones.
Graciela says that her son’s return brings her relief, and Mario says that he and his family
can temporarily leave home and have a break from their responsibilities. In this way,
returned migrants help distribute responsibility more evenly, and help give a much-
needed break for those individuals that have not migrated.5

   In part, literature on transnational family caregiving is premised on dispelling the
idea that transnational families are suffering and unable to provide sufficient care for
dependents. Writers acknowledge that caregiving responsibility is often distributed

5 Nevertheless, this excerpt demonstrates that migrants do not return for this purpose. Despite the fact that
Graciela and her family benefit from her son’s return, Graciela acknowledges that her son did not actually
return to help give care. Rather, he returned to fulfill a cargo and only because of this decision has he taken
on caregiving. Migrants return home and help when they can, but they do not return home in order to help.
unequally, but they challenge the idea that “proximity is essential” by applying greater focus on the way care is exchanged transnationally (Baldassar & Merla, 2013, pp. 12-13). While I am sympathetic to how transnational families experience stigma, I also strive to present an accurate view of caregiving as it exists in Teotitlán. Caregiving “works” in the context of Teotitlán’s migratory patterns – remaining family members are able to pull together sufficient resources to provide for elders, and migrants significantly help – but this does not entail that migration is a non-issue. Indeed, the very fact that caregivers are relieved when migrants return home testifies to caregivers’ experience of being overworked and strained due to limited human resources. In this vein, I argue that migration intensifies the responsibility felt among family members who remain home. The fact that some members have migrated means that the remaining members of the household must carry a greater share of responsibility. These circumstances significantly shape how responsibility is circulated and one’s experience having assumed it.

As a whole, this section takes a close look at migration to illustrate the broader point about how responsibility is distributed within complicated, multi-sited parameters. With regards to migration, it accounts for both positive and negative aspects of the transnational distribution of care. On the one hand, and in support of current literature, caregiving does not just refer to embodied action, but also involves a set of contributions that are provided remotely, across borders. Remittances may help other members provide care, and family visits can provide relief to caregivers who regularly assume responsibility. On the other hand, migration may also poses major challenges – it very

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6 As discussed in Chapter Three, human resources are further constrained by population trends (historically low fertility rates and higher life expectancies), as well as more women entering the work force (see Herrera, Angel, Venegas, & Angel, 2012).
clearly limits who is left available to provide care. Together, these factors provide another example of what medical anthropologists mean when they write about social suffering – in order to adequately capture the complexity of experiences like caregiving, one must approach experience from an equally complex framework. Here, caregiving transcends borders and occurs within different geographic, political, and economic dimensions. In what follows I continue to develop this argument by now turning to explore caregivers’ personal reasons for feeling responsible.

*The Call of Responsibility – Or, Why Care?*

Reasons for caregiving may seem self-evident, but I hope I have begun to challenge this view. Not only is responsibility complex and multi-sited, I now aim to show how it also draws upon values that vary from one location to another. To this end, in this section I take on the very simple question – Why do caregivers experience responsibility to care? This question addresses the lynchpin of caregiving practice, inquiring about one’s personal justifications for taking on responsibility at all.

Traditional literature on caregiving approaches this question from various vantage points. In his handbook on dementia caregiving Schulz (2000) discusses the importance of responsibility and identifies egoistic, altruistic, and social norms as the various reasons for why individuals feel responsible (pp. 33-38). His discussion of social norms is most relevant to my interests, presented as a contextualizing factor for why caregivers feel accountable to provide care. Social norms are shared expectations and standards for relationships, and Schulz rightly observes that these differ across culture and context. In Oaxaca, where the household is known as the primary social unit, one’s sense of
responsibility is first directed to this end. Here cultural norms are based around shared values like *familismo*, crystalizing one’s sense of obligation, loyalty, and sacrifice for the good of the family (Behnke et al., 2008; Calzada et al., 2013; Cervantes, 2008). With regards to caregiving for dementia, *familismo* has been studied to show how individuals make decisions about institutionalization (Gaugler, Kane, Kane, & Newcomer, 2006), how it is a factor leading to caregiver distress (Robinson Shurgot & Knight, 2005), and how it modifies family members’ perceptions of available social support (Gelman, 2012).

These studies are important and help situate data; yet they do not sufficiently provide an answer to my question. As my interview with Pablo and Vanessa illustrates, appealing to cultural notions like *familismo* does not fully explain why caregivers have reasons to care (since Pablo and Vanessa experience responsibility for an elder not in their family). Further, explaining responsibility through this notion does not account for why caregivers devote attention to *this* dimension of family life over others. Simply put, why do individuals feel responsible to care for elders, given all the other persons and things that demand care in one’s family? This question highlights how taking a broad cultural approach overlooks the way that caregiving is, in itself, personally fulfilling. Most literature on *familismo* tends to suggest that persons sacrifice their own desires for the larger good, whereas my experience helped me consider how caregiving is a responsibility that persons find meaningful and want to uphold.⁷

What appears lacking is a focus on the way one feels called to responsibility, a more detailed analysis of why caregivers experience a sense of obligation when they

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⁷ Of course, I do not mean to suggest that family members are not socially pressured to become caregivers. My point is that, within a setting where family members are expected to become caregivers, this is something individuals prefer to do.
specifically encounter dependent elders. This is my task in this section. I trace how a broad understanding about responsibility for the family is played out in the specific case of old age dependency. To this end, this section is divided into two parts, each intended to capture two fundamental features about the how the scene of dementia occasions another’s sense of responsibility. I first examine local understandings of old age and, next, turn to local understandings of death. Both are shown to constitute caregivers’ responsibility and both illustrate my broader argument about how responsibility is constituted within social factors unique to Teotitlán.

a) Visions of the Elder

As described at various junctures, the notion of the benguul refers to how elders are respected on the basis of their age and accumulated life experience. In this way, respect is a main reason for other persons to be concerned about elders’ wellbeing, accounting for part of caregivers’ sense of responsibility. Yet as I have explored this theme throughout previous chapters, I now turn to other features about old age that lead caregivers to feel responsible. In what follows I review how elders are viewed in regards to their relationships with other persons, contributions to family life, and role in the community. Each of these site-specific visions constitutes caregivers’ experience of responsibility and also highlights how responsibility draws upon local values.

To begin, I return to my interview with Carlos, Francisco and his family, the household I tried to interview for months. Recall that this family represented the most extreme case of Alzheimer’s disease I had encountered, and that their daily experience was a stark reminder of how heavy caregiving responsibility can be. To acquire better
understanding of their responsibility I inquired about why they do not solicit professional help – and, specifically, why they do not consider nursing homes (recall that there exist two outside Teotitlán in Oaxaca City). Their response brought into focus a multifaceted vision of old age and how it justifies their sense of responsibility.

Carlos: Well, to begin, in Oaxaca nursing homes are very new. Secondly, the custom that we guide ourselves by [is that] until the person has passed away, that’s when you are no longer relatives. For instance, she’s my wife. So until she dies that’s when she is no longer my wife. That’s a custom. It is shameful if you take your relative to a nursing home. And also [your] conscience would not be in peace. At least on my part, I would not be in peace if I were to take her there. Because I don’t know how she would be treated. Even though she’s like that, she is cared for here – by all of us.

Alex: How about you?

Francisco: No I wouldn’t do that [take my mother to a nursing home]. And also like he [my father] said, because of our customs, that’s just not possible. And it’s not viewed well by the community, if you were to take an elder to a nursing home.

Carlos: And also your conscience wouldn’t be in peace.

Francisco: And also because we’ve spent so much time with her, it would be difficult to do it.

Alex: So is this part of our culture?

Francisco: Yes it is.
Carlos: That’s the way it is.

There is so much to this dialogue but I first take interest in Alex’s concluding question to Carlos and Francisco about whether these views are definitive of their – including his own – culture. On the one hand, I read Alex as asking on my behalf, as translating local ideas that he knows may not be obvious to an outsider. On the other hand, there is remarkable curiosity in his question, one that may express his own uncertainty about local traditions. Alex has not had the experience of caring for a dependent elder. And, despite how Francisco and Carlos discuss their own sense of responsibility with such conviction, Alex appears surprised. This may have to do with the complexity of their reasons. Carlos’ concluding statement – “that’s the way it is” – is a deceptively simple summary of why he and his family experience responsibility. It is an illustration of how responsibility is experienced unreflectively and how even locals may be confused about its nature.

Nevertheless, in the course of their response, Carlos and his son Francisco provide a wealth of information about their experience of responsibility and how local understandings about old age constitute it. First, in response to my question about nursing homes, Carlos makes the obvious point that nursing homes are new and that viewing care as a commodity is not part of local thinking. Professional caregiving contrasts with local notions about what it means to have an elder in one’s family. Simply put, having an elder in your family means that you have someone to take care of. This is illustrated in Carlos’ statement about his wife being a family member until her death, and his implication that her membership entails responsibility for her. Hence, the very definition of family – and
the way in which Carlos continues to view his wife as a part of his family – presupposes obligation to other members.

Second, Carlos and Francisco state that they lack faith in and personally dislike the idea of professional caregiving. They doubt that a caregiver would be able to provide for the elder as well as they do. And they express desire for what is best for her. These statements contain an underlying logic that, as I understand it, goes as follows: the individual best suited to provide care for an elder is the one that cares for her the most – and, because Carlos and Francisco want what is best, they consider themselves responsible. Care for an elder is something that cannot be bought because it is a manifestation of love. Moreover, it is an expression of something caregivers personally want. In Francisco’s words, he personally desires to care for his mother because he knows that he would regret losing time should someone else assume his responsibility. He understands that his mother is old and her death is imminent. And he concludes that he wants to make the most of the time that remains.

Lastly, Carlos and Francisco cite how community-shared ideas about old age translate into their personal experience of responsibility. They imagine that their failure to uphold responsibilities would be perceived by others as a larger failure of upholding traditions about how to properly treat elders. They imagine being judged, shamed, and not only experience loss in their own relationship with the elder, but also with their broader social world.

Together, the reasons Carlos and Francisco cite for feeling responsible draw on implicit understandings of elders and demonstrate what is at stake locally in failing to uphold responsibility. My point in identifying these facets is to illustrate that, first, being
responsible is a direct consequence of how elders are viewed and, second, that responsibility is personally meaningful. Though their reasons refer to shared ideas about aging and family life, their reasons for upholding it occur on a personal level. Caregivers want to be responsible, and want that elders are properly cared for. In this way, assuming caregiving responsibility is not an instance of self-sacrifice (as would be suggested by appealing to a broad notion like familismo). Rather, it is a choice one makes because it is personally fulfilling.

Yet there exist other important reasons that account for caregivers’ responsibility that go beyond reference to family. These are important not only to provide a more complete picture of responsibility, but also to account for caregivers like Pablo and Vanessa who decide to assume responsibility despite the elder not being in their family. When I questioned Pablo and Vanessa about this topic, they rather vaguely explained that they felt empathy for the elder and so decided to assume responsibility. Though this was helpful, their explanation did not go far enough in elucidating why they made their decision.

Other caregivers provided further clarification. From these interviews I learned that caregivers also experience responsibility based on their perception of age-related dependency and their anticipation of growing old themselves. In this way, elders are a vision of one’s own susceptibility to the aging process, a reminder that everyone grows old and will be in need of care. To illustrate this point I return to my interview with Mario, his wife, Isabelle, and his mother, Graciela, the caregivers who impressed me for their humility. Recall that this family vividly described cleaning the elder’s soiled pants, and attending to other basic human necessities. Again curious about the weight of their
responsibilities, I inquired about what reasons they had to continue to persevere. Mario’s wife, Isabelle, responds on behalf of her husband (who found some issues too emotionally difficult to address himself).

Isabelle: I think I understand what you mean. OK, so what he tells me is that “We will all get to be old. And my dad is getting old that way. So I have to take care of him. I have to take care of him to the best of my ability.” He accepts the situation.

Isabelle’s summary that Mario “accepts the situation” does not just refer to the elder’s dependency, but his view of the aging process itself. It is recognition that all people grow old if they live long enough. And it is recognition that Mario will likely experience a condition similar to his father’s – old, unable to work, and in need of care. This helps mollify the burden of caregiving and it also constitutes another reason to feel responsible. Just like Mario would want to be cared for in his future dependency, he identifies and feels responsible for the person who experiences it now. He expresses a hope, a vision of the future where there will be someone like him to assume responsibility for himself in old age.  

This introduces another answer for why caregivers feel responsible: viewing elders as dependent fosters compassion, empathy and investment in their wellbeing. Further, it explains how caregivers experience responsibility apart from appealing to notions about family. It demonstrates that responsibility for elders invokes more diffuse

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8 This is what gerontologists refer to as the “generational contract,” where one generation invests care in another with the implicit expectation that they will be cared for when needed. Though Mario and other caregivers expressed uncertainty whether such contracts will be fulfilled – that is, whether future generations will care for them – this situation is not unique to Teotitlán but across cultural spaces and epochs, even found in the Hebrew Bible (see Bengtson & Achenbaum, 1993).
feelings about social security. And, going back to the case of Pablo and Vanessa, it helps explain how caregivers experience responsibility despite it not manifesting in the narrow scope of one’s family.

My larger purpose in this presentation is to review how caregivers’ perception of elders constitutes caregiving responsibility. Both facets of their vision – based on how elders are seen within their families and how elders invoke personal reminders of future dependency – illustrate the way that caregivers are summoned on an individual level. Further, this section demonstrates that responsibility is not an act of self-negation or sacrifice, but something one finds personally meaningful in carrying out. This moves the discussion of caregiving responsibility beyond broad cultural notions like familismo, towards appreciating how cultural notions are upheld because they are personally rewarding. Responsibility does not occur simply because one must prioritize elders or family unity – because it is normatively prescribed – but rather because it is something individuals want to assume. In what follows I continue to develop this argument by now turning to consider local understandings of death and how they represent additional reasons to be responsible.

b) Visions of the Dead

There also exist other reasons to feel responsible that do not involve how elders are perceived with regards their old age, but rather how they invoke local understandings of death. For example, Carlos’ twice-repeated statement of having a bad conscience was about the idea of admitting his wife to a nursing home, but it also hinted at local ideas about his personal future once she passes. Carlos does not want to regret overlooking his
responsibility as a husband, a feeling that he believes would plague him well after his wife’s passing. This is the theme I now wish to explore in this section, focusing on how caregivers’ anticipation and understanding of death is another constitutive factor for their experience of responsibility. Although I assume it to be common for individuals across different cultural settings to have regrets after the death of a loved one, in what follows I illustrate how these sentiments draw upon locally defined ideas about death and dying.

And again, although these reasons are social in nature, they summon caregivers on an individual level.

Many other caregivers cite future regret as a reason for their experience of responsibility, but it is still not clear why they would regret and what weight it would bear on their future lives. While U.S. readers are prone to understand regret as an instance of personal guilt – that they would have unsettled feelings and thoughts – my data encourages me to further examine why caregivers specifically worry about death. As I have described at various points, Oaxacans’ beliefs about death contrast with those held in the U.S. Instead of marking the end of relationships, in Oaxaca death is known to initiate a new type of relationship, invoking new social responsibilities, commitments, and interpersonal connections. Living people are expected to carry out regular actions on behalf of the dead, demonstrating that the dead have not been forgotten and remain integral to family life. For example, each home has an altar for worshipping deceased persons, and individuals are expected to visit family gravesites. This is because the dead are viewed as active members of the community who demand ongoing respect. As Norget (2006) writes in her study on Oaxacan death customs, “life and death are not viewed as mutually exclusive ontological states. Death is not experienced as an event that
introduces discontinuity and disruption... [Rather,] the dead are understood to return frequently to the domain of the living” (pp. 115-116; see also Royce, 2011). This belief serves as an additional reason for why caregivers experience responsibility.

Figure 8.1. Funeral procession. (Photo by the author.)

To illustrate this point I return to my interview with Francisca and Dominga, the sister and niece who struck me for their experience of caring for an elder with dementia and severe epileptic fits. At one point during this interview Francisca brought up a recent interaction she had had with the elder and how she spoke to him as if he were already
dead. Her summary of this event is a powerful illustration of how local beliefs about death constitute her sense of responsibility.

Francisca: And like I told him [the elder], for instance yesterday, I was talking to him [whispers:], “I believe that you realize now that you’re not with us anymore. I don’t know what you feel, or where you are, or where you feel you are. Or, I don’t know what you feel about where you are” (— since he always says that when he dreams he is on a path, and that he is leaving, or going away). “So I ask you for just one little thing, José, if you pass away in this condition [when unconscious],” I told him, “it will not be our fault. And you know that we have taken care of you the best we can. I did not despise you,” I told him. “I never left you alone in any festivity or party, I never left you hungry. Even when you were healthy, or now that you are sick, but at the moment that you’re going to receive God’s will [Zapotec original: dixhchey “God’s gift of death,” but also a “gift” in general], go freely and peacefully. I don’t want you to return and bother us. Because there are people that, when they die in this way, return and bother their relatives. I assume you have lived a good life, please forget everything you’ve been through, or anything that happened to you.” That’s what I told him.

This excerpt, perhaps one of the most poignant descriptions of a caregiver’s exchange with a dependent elder, reveals how anticipation and beliefs about death lead to feelings of responsibility. It touches on the suffering Francisca knows her brother is experiencing, the worry she personally carries, and broader cultural ideas about death. She views the elder in the process of dying, speaks to him as half-dead, and begs him to leave the family in peace. Though the dead are always known to return to the community of the
living, Francisca illustrates how the dead are also capable of haunting and burdening it. The deceased are known to haunt families because, first, they did not have a good life and also because they did not die peacefully. So Francisca tries to mitigate this risk, to remind the elder that he has had a good life and that she and Dominga have done everything in their power to provide for him after he fell ill. These efforts illustrate another reason for how and why caregivers experience responsibility. In part, it is a means to protect themselves and their families, an effort to allow the community of the living to proceed in peace.

Figure 8.2. Home altar with offerings during Day of the Dead. (Photo by Michelle Nermon used with permission.)

Norget (2006) concludes her study on Oaxacan death customs by noting that “death does not threaten [local] social order, so much as provide an occasion to revitalize it” (p. 114). It encourages living persons to live in harmony and to behave in a manner that honors the deceased. My research confirms and furthers this observation by showing
how even the anticipation of death revitalizes moral behavior. Caregivers feel responsible to provide for dependent elders, in part, because of anticipated posthumous relationships. In this way, caregiving is not only situated in the temporal present, but the future – not only by needs of the living, but also by visions of the dead.

As a whole, this section has reviewed why caregivers feel responsible for elders based on local beliefs about aging and death. Moving beyond broad notions about *familismo*, this section demonstrates how caregivers experience locally specific reasons to attend to dependent elders and why upholding them is personally fulfilling. It attests to the social nature of responsibility – it is social in nature, but personal in experience. Lastly, this section demonstrates the importance of studying caregiving with attentiveness to local beliefs. Being attentive to local understandings about old age and death are essential in appreciating caregivers’ experience as responsible subjects. In what follows, I conclude my analysis of responsibility by now examining how caregivers’ lives are affected after having assumed it.

*Consequences of Responsibility: The Forgotten Subject of Caregiving*

Since Chapter Seven I have attempted to illustrate how caregiving experience is inextricably woven within a broader social fabric. Caregiving challenges and strategies are ones that directly concern local understandings of what it means to grow old, family obligation, and social cohesion. And, in this chapter I have shown that caregivers’ experience of responsibility – both the way it is distributed and one’s decision to assume it – far exceed perspectives that appeal to family, personal, and cultural factors. My overall point is that responsibility cannot be merely reduced to any single factor – it is all
of them. This perspective invokes what anthropologists have recently argued about the social nature of suffering. Though suffering is experienced on a personal level, it is constituted within a broad array of systemic factors, spanning from local customs to transnational realities. People would not suffer in the same way were it not for these conditions.

Moving this analysis further, I now conclude to demonstrate how caregivers’ decision to uphold their responsibility begets another instance of social suffering. I examine the way that, once one decides to be responsible, caregivers become further removed from social life. In part, this concerns the rich library of studies on caregiver burden, and how caregivers are known to experience higher levels of anxiety, depression, and other psychological issues. Caregiving handbooks are premised on this observation, written to provide techniques on how to provide care while minimizing personal distress (e.g., Mace & Rabins, 2011; Schulz, 2000). Yet these approaches offer general tips that overlook specific circumstances. They do not take into consideration how caregivers’ surrounding communities are complicit in the very difficulties they face. To address this deficiency I now explore how caregivers are specifically distressed in Teotitlán, and how their distress is constituted by specific social circumstances.

This topic returns me to an observation made in Chapter Three about what I then called the bio-anti-sociality of Alzheimer’s disease. Challenging other researchers who

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9 With regards to cross-cultural research, it is widely discussed that Latino and other non-white caregivers tend to experience less symptoms of depression and stress compared to Caucasian cohorts (Connell & Gibson, 1997; yet for an exception see: Harwood et al., 1998). Although investigation of specific psychological issues was beyond the scope of this study, the content and nature of my interviews provided greater insight on this theme. What follows is not an inventory of psychological issues, but rather an illustration of how those issues – broadly conceived as instances of caregiver suffering – arise in a social setting.
claim that caregivers are drawn into new forms of relationships through their identification with Alzheimer’s disease (Lock, 2007; Rabinow, 1996), I argued that stigma and local understandings in Teotitlán render caregivers on the social periphery. Now, I illustrate how caregivers directly experience this reality. In what follows I first present an analysis of how caregivers lack social support, then I discuss how caregivers believe they and their families are topics of local gossip, and lastly I consider how the interview process was, in itself, an indication of the social understanding that caregivers lack. My overall point is that the suffering caregivers experience is not due to their involvement with elders *per se*, but also concerns broader social dynamics. Caregiving experience is best understood as an instance of social suffering.

*a) Caregivers as Forgotten by the Community*

At various points of this analysis I have attempted to account for how caregivers feel isolated due to the challenge of being stuck at home. In this section I briefly explore how this experience is also due to their disappointment in not being remembered by visitors. I call these instances of “responsibility breakdown” because in communities like Teotitlán it is one’s responsibility to visit immediate and extended family. To provide an initial illustration I return to Mario, Isabelle, and Graciela, the humble caregivers who described bitter daily experiences like attending to the elder’s soiled pants. While so much of this interview was spent unpacking their difficulties, at one point Alex had the intuition to ask if they felt lonely.

Alex: I understand that taking care of an elder is very difficult. Do you think you are lonely as you are taking care of your dad?
Mario: Yes, and I have brothers – but they only come every now and then. And there are days that they don’t come. It’s very seldom when they come.

What is interesting in this excerpt is that Alex’s question about whether Mario feels lonely as a caregiver is not only affirmed, it is also explained by the fact that close family members do not come to visit. Though Mario has brothers who live in Teotitlán, they do not live with their father and do not care for him. Mario, his wife and mother are alone in upholding responsibility. This illustrates how caregivers’ experience of being confined at home carries a second meaning: they are also isolated because few people come to visit.

Loneliness also involves lapses in visits made by extended family. Recall that in Teotitlán the definition of family is broad due to *compadrazgo* (god-parenthood) networks. This has traditionally been understood as serving to increase the amount of people one can call upon for help. Godparents are expected to support godchildren as they grow up; and, for their part, when godchildren become adults they are expected to reciprocate by looking after godparents. Yet during my interviews I encountered numerous instances where these expectations were not upheld. To illustrate but one example I return to my interview with Sergio, Manuel, and Linda, the successful *tortilla* makers who described their care for an elder that was beginning to forget members in the family. At one point Alex and I inquired about how their larger family network participated.

Alex: For instance, if you have godchildren… do they come and visit?

Linda: Mmmm [no].
Sergio and Manuel: No.

Jon: Why?

Alex: Do you know why?

Manuel: Well, that I can’t say anything about that, since each person has their own way of doing things. And they can’t be obligated to come.

Linda: Well, they do come on important festivities.

Alex: But come just to visit him, do they do that?

Linda: No they don’t come.

As Manuel states that home visits are meaningful because one is not obligated to make them, their omission is reason for his disappointment. This is further illustrated by Alex’s asking whether extended family members visit out of their own will – “just to visit” – which he knows they are expected to do. Privately, after conducting this interview and at so many other moments during our fieldwork Alex commented that individuals were not doing what they ought to do, that they were neglecting their responsibility as family. Although there also existed other households whose families did visit, I encountered enough instances to lead me to conclude that this experience was common and further explained caregivers’ isolation. This illustrates how responsibility renders caregivers on the social periphery. In what follows I continue to trace this experience by now turning to explore how caregivers’ sensitivity to other peoples’ actions further explains their isolation.
b) Caregivers as Topics of Gossip

Despite the fact that caregivers experience difficulty leaving home, many also justified their isolation by noting they were the topic of local gossip. Like most small communities, news travels quickly in Teotitlán and members are prone to talking about one another.\textsuperscript{10} The Zapotec phrase for speaking gossip – \textit{natu dambul} – further sheds light by literally referring to a person who parades through the streets while clanging on a tambourine to announce community events. In Teotitlán gossip is not something one can easily ignore, but rather molds who one is and how one experiences the surrounding social world.\textsuperscript{11}

Despite their commitment to elders’ wellbeing, many caregivers believed that the community was gossiping about their own negligence. For example, caregivers expressed awareness about members of the community who questioned whether the elder was actually ill, or if the elder’s observable decline had more to do with family mistreatment. To begin to illustrate caregivers’ attunement to gossip I return to my interview with Francisco and Dominga, the caregivers who attend to the elder with dementia and severe epileptic fits. At one point they came to state that the stress they experience in caregiving has intensified because of awareness that the community is negatively talking about them.

\textsuperscript{10} For example, I have been told that the public market is locally known not only as a site to purchase household goods, but also for its social function. It is \textit{puros chismes} [Spanish: “pure gossip”), many people have jokingly told me.

\textsuperscript{11} Though she does not directly analyze the local presence of gossip, in her study on Teotitlán Stephen (2005) mentions its prevalence at various moments. For example, at one telling point she features the story of a woman weaver who became the subject of community gossip, eventually ruining her planned marriage (p. 315). Vignettes like this further help illustrate gossip’s prevalence and strength.
Francisca: And now, what happens to him, which wouldn’t have happened before [his illness]... If he were to go out, he would get scared… He would scream… He runs. And that happened [before] so many times. [So] we locked him up. But, God forgive me, you know how our relatives are, so they say, “Perhaps it’s not true that he is ill.”

This interview highlighted how local perceptions of illness directly impact caregivers’ experience. As the elder is less visible from community affairs, people (including Francisca’s own family) have begun to question if illness actually explains his absence, or whether Francisca and her niece are more to blame. Moreover, since many people believe that conditions like Alzheimer’s disease do not exist in Teotitlán, explanations that center on this reason carry little weight. So, the community tries to find other plausible reasons to explain elders’ absences – and, in so doing, people gossip.

I do not intend to suggest that every caregiver is the topic of local gossip; to be clear, not every caregiver endorsed this experience. Yet insofar as I seek to describe how caregiving is an instance of social suffering, my aim is to show how community acts like gossip can represent a major reason for their distress. Further, enough caregivers cited this experience that it merits being presented here.

To continue illustrating this point I return to my interview with Sergio, Manuel and Linda, the successful tortilla makers who were described above as being disappointed in not receiving extended family visitors. While these caregivers continued to bring the elder in public, they nevertheless believed that the community was gossiping about them.
Sergio: When people see him walking out [on the street], they probably think we don’t properly take care of him.

Manuel: Sometimes people criticize elders, or their relatives that [don’t] take care of them. For instance, him, when he goes out – and since he doesn’t like to shower – people might say that we don’t take care of him properly.

Sergio: I’ve even talked to people his age, and I talk to them and tell them about him… And in the end they often tell us that we’re the ones that are not taking care of him properly.

Manuel: The way people view elders is determined by how they think their children are taking care of them.

Linda: I tell him to change his clothes.

Manuel: And a lot of people criticize us, the way we take care of him. Because that’s the way it seems from the outside. We’re the ones that do not take care of him the way we’re supposed to. And that’s the way people in town are. They don’t know what’s really going on. And everything that’s happening inside they can’t see. And sometimes we [the community] tend to criticize, and we don’t understand how things really are.

This excerpt is powerful for a number of reasons, illustrating how important one’s perspective is in order to make sense of surrounding circumstances. The outward appearance of elders – their disheveled appearance or absence from community life – means two different things, depending on what one knows about the elder’s condition. For caregivers, it is evidence of the ongoing challenges that elders present, yet for the
larger community it is suggestive of family mistreatment. In this way, Manuel’s succinct statement – “everything that’s happening inside they can’t see” – at once testifies to internal household affairs, and also points towards his personal experience and struggles. It illustrates his isolation, the way in which his larger community simply does not understand his commitment.12

Of course, people gossip because they are concerned that elders are well treated – that the elder remains seen and treated as the benguul – and that families are upholding their responsibilities. But gossip creates a division among the community. Caregivers are excluded from the social group, perceived as being different (other) than the larger community that upholds local tradition. In the process of identifying caregivers as different, the larger community is solidified by comparing itself to something it is not. Denise Jodelet’s (1991) study of the social representations of illness is perhaps the most relevant to this observation. Though specifically about the mentally ill, it provides a broad picture of how shared ideas about illness carry a social function. According to Jodelet, perceptions of illness affirm one’s own social identity by contrast to another’s perceived difference. My data on gossip complicates this view. Among the caregivers I interviewed, the other is not the individual who appears disheveled and different (i.e., the ill person); rather, the other is the individual considered responsible for causing perceived differences (i.e., the caregiver). Caregivers are the other, cast aside due to their perceived mistreatment and negligence of shared values. In this process, social cohesion occurs

12 Moreover, this excerpt is interesting for the way Manuel and his family tries to manage Alex and my own opinion about the elder’s mistreatment. Linda asserts that she does uphold the responsibilities that people gossip about: she tells her husband to change his clothes and later her family descriptively illustrates other acts of care. Caregivers fear how community members view them, and their efforts to manage others’ impressions are indicative of gossip’s impact.
through affirming tradition, respect, and proper treatment of elders – but is premised on caregivers’ exclusion. Group identity is not solidified in contrast to another predefined group (like the ill), but rather based on a division within the same.

Although it is beyond the scope of my investigation to identify the way in which caregiving leads to specific psychological difficulties, the prevalence of gossip and the infrequency of family visits both illustrate how caregivers experience isolation and concomitant distress. I have argued that these are not only due to the demands of caregiving *per se*, but more importantly concern social dynamics. In this way, the suffering caregivers experience is an instance of social suffering. At once, gossip serves to undermine the responsibility caregivers have assumed, while it also discourages caregivers from sharing their experience in the community. Moreover, it better explains caregivers’ own reluctance to speak to me, and their conviction that other people do not – and could not – understand the responsibility they have decided to uphold. In the final part to this section I consider how my experience conducting interviews provides further insight on this point.

c) *The Interview as Occasion to be Heard*

The actual interview event was also testimony to caregivers’ isolation. In previous pages I discussed how, despite initial reluctance to participate in my study, many caregivers ended their interview with appreciation. In what follows I continue to develop this theme, with intent to highlight how caregivers’ perception of the interview as a positive experience is an expression of the social contact they lack.
This impression was one I had from the very beginning of my fieldwork, but at
different moments it became more pronounced with the various people I had met.
Perhaps the most poignant moment occurred when I witnessed Alex’s empathic response
during my interview with Sophia, a caregiver in her mid-sixties.\(^{13}\) When I met Sophia I
learned that her husband recently had a series of strokes that rendered him all but
incapacitated. He could hardly speak, he had difficulty carrying out basic tasks, and his
personality had abruptly transformed. Beyond these hardships, meeting with Sophia was
also memorable because all her children lived in the U.S. and she cared for her husband
alone. Her loneliness was palpable, and throughout the interview Alex and I were moved
by Sophia’s emotionally laden responses. For example, consider Alex’s words of comfort
when Sophia began to weep. At this point of the interview Sophia stopped talking and the
interview abruptly grew thick in emotion.

Alex: Don’t feel bad that you’re crying – it’s good that you’re crying. That’s one
of the reasons that we’re here. It helps people to cry.

Jon: Tell her that I know it’s really difficult, and I really appreciate that she’s able
to talk to us about it.

Alex: He is thanking you that you’re giving us the privilege to interview you. And
like I said, this is a good way to help people get out their feelings. Because
sometimes we close ourselves up, or there are people – like our own relatives –
who don’t understand us. If you are sharing [your feelings] with someone, they
[might not] listen to you. They will always have something [else] to say. [But] we

\(^{13}\) I am reintroducing Sophia because she was only mentioned earlier in a footnote. See Chapter Five, Note 6.
won’t say anything to you. All we are saying is listening. And it will help because you’re getting out everything you have inside.

What I find so moving about this exchange is not only that Sophia is crying, but the way in which Alex, a member of her larger community, arrives to her comfort. There were many moments like this, instances that I came to identify under the code “Alex as Therapist,” where Alex takes the initiative to comfort and respond to participants’ distress. In this excerpt, Alex goes beyond translating my words to compose his own. He expresses his understanding of the project and its purpose in the community. As he sees it, we have been visiting caregivers to alleviate their emotional pain, to let them express themselves and feel understood. Our approach is to simply listen, to not talk back, to not criticize, and cease minimizing caregivers’ experience. It is to give Sophia and other caregivers what Alex knows they lack – a sense of being cared for themselves. In Alex’s own words, “All we are saying is listening.”

Though I initially considered ending this interview because it appeared to cause Sophia distress, I quickly realized that her crying was not a request to stop talking, but an expression of gratitude to be invited to it. The interview gave Sophia an opportunity to express what she had not shared prior. It was an occasion for her to be heard. This was apparent throughout our discussion, but it was most obvious towards the end. Sophia reflected on how this moment was exceptional to her experience as a caregiver, and how much she needed to be heard by her broader community.

Sophia: Well the way I see it is that, now that you [Alex] brought him [Jon], it personally helps me. For example, those questions he asked, it helped me to get everything out. It’s just like when you’re talking to someone and getting
everything you have inside out. After that you’re more relaxed. And I will not be weak. That’s the way I experienced it. That’s the way I experienced it, because I need someone to talk to. I need to talk so I can relax my mind. It’s helping me because no one has come and asked me how I am doing. [For example,] “How are you doing with him?” – [just] someone that would sympathize with me, or someone that could just give me a word of hope. And that’s something that would comfort me. For instance, now that you came, that itself comforted me.

Alex: That’s really good to hear.

Sophia: You are welcome [to come back here] and thank you for everything, and all the questions you asked. And you have left me happy… After all, I think God sent you. I don’t know how, but there’s a reason why you came. Things don’t happen – there’s always a reason why things happen. God always sends someone to give hope and strength… It’s my hope for me to get through this hard time, and to relieve my soul. And right now the questions you asked, I gladly answered them. For instance, when I go somewhere, I like to talk, and I like to share my thoughts. And I believe that that relieves my mind and helps me be happy because I don’t like being sad. Because if I get depressed or if something happens to me I will probably die before him [laughs]. That’s why I thank you.

Sophia’s gratitude is only understandable in the context of the larger isolation she faces. The interview was an exception to her broader experience, to a world of isolation she inherited after taking on her responsibility. In Sophia’s words, being invited to speak is a way to “relieve [her] mind,” a means to recuperate her personal fortitude. I do not want to suggest that the relief Sophia experience is simple, nor to suggest that talking serves the
same psychological function across cultures. Yet I do believe that talk is an undeniable medium of social exchange and, in this way, its rarity in Sophia’s life testifies to the isolation she and many other caregivers endure. In a similar vein, most of my interviews appeared to offer relief to caregivers, an occasion for them to be heard. This was evident in the sweets participants and I shared after turning off my recorder, the invitations they made for me to return, and subsequent affectionate encounters we’d had on the street.

I make this point not to celebrate what I did for caregivers, but rather to show how the effects of my research reveal what they lack. Caregivers’ positive reactions to being interviewed were personally my most powerful experiences because they highlighted my own role in their daily lives. These are lives steeped in the difficulty of caregiving and the pain of being a part of a community. These are lives not merely defined by what occurs at home, but also for what materializes outside.

As a whole, this section accounts for other reasons that caregivers suffer that extend beyond their actual experience with elders, due to their (lack of) involvement with the community. Their isolation, burden and distress are all constituted by larger social dynamics – and inattentiveness to this dimension amounts to overlooking the core of caregiving experience. As others have observed about the social construction of aging, this analysis demonstrates that caregivers’ problems are – at least partly – constructed by the broader community.

Conclusion

I return to my interview with Pablo and Vanessa, still impressed by the responsibility they have shouldered. Through the course of this chapter their
responsibility for an elder not in their family is more intelligible, and their experience
upholding it is more transparent. Yet I am still struck by this interview and the manner by
which I arrived to their home. Like other households, it took months to come across
Pablo and Vanessa, to trace how far one’s sense of responsibility extends and to
encounter what everyone confidently told me did not exist – diagnosed cases of
Alzheimer’s disease. And yet, for all my initial fascination about diagnosis I learned that
this topic mattered very little. What proved to be important to caregivers was not some
technical distinction between illnesses, but rather the things they faced on a daily level. In
this way, I came to realize that my ethnographic challenges were not about access to a
population, but issues about caregiving itself. My challenges were testimony to
caregivers’ own – to their isolation, to their being misunderstood, and to the way in
which other social factors color their daily commitments. The overall point is that these
features illustrate that caregiving is not narrowly defined by dyadic relationships;
caregiving is situated within a wider social realm. Caregiving must be understood
through attentiveness to socioeconomic, transnational, and cultural parameters. These are
among the central factors of caregivers’ experience, for why they suffer.

This chapter has argued that caregiving is social in nature by analyzing three
facets of caregiving responsibility. First, it demonstrates that responsibility is a
multifaceted phenomenon that circulates across transnational borders. It is situated within
broader social dynamics than is typically appreciated, and these broad factors directly
shape caregiving experience. Second, this chapter analyzes local reasons for why
caregivers experience responsibility with specific reference to elders. This again
advances how responsibility is social in nature – how it draws upon shared values – and
why caregiving must be studied with attentiveness to this realm. Last, this chapter concludes by revealing how caregivers’ decision to uphold responsibility begets another instance of suffering. In taking responsibility for elders who forget, caregivers become forgotten by their broader community. This highlights how caregivers’ experience – their suffering – is inextricable from surrounding social circumstances. As a whole, each of these points draws on multiple frameworks and together demonstrates how caregiving is social in nature. It illustrates that caregiving is not merely a dyadic practice that involves care of elders, but is constituted and shaped by one’s broader community.

Attentiveness to the social dimensions of caregiving puts into focus how responsibility is a symbol of local dynamics in Teotitlán. It shows how local traditions are negotiated and upheld in the context of broader cultural change regarding engagement with capitalism and migration. In this way, caregiving experience fosters lessons about who a person is in regards to local values. It highlights what is at stake about taking care of elders and why this responsibility is viewed as important. This was the ultimate lesson I drew from meeting with Pablo and Vanessa. Towards the end of our interview I inquired whether they knew of other elders with similar conditions. Predictably, they did not, but their answer was unquestionably more profound than the question I had raised.

Pablo: Well, on my behalf, I haven’t met anyone or heard of anyone. And unfortunately my mother died at a very young age and my dad passed away at the age of 60 or 65, so I didn’t know anyone with that illness. And now that we are the ones taking care of her, it’s difficult. But I’m also taking it as a thing to learn from. And I’m sacrificing myself. And like I said, it’s a big experience and I’m understanding what taking care of an elder is like… And whenever someone
might need advice I’ll be able to give it. I’ll be able to say what taking care of an elder is like. This is pretty much like going to school.

Much like going to school, Pablo states that caregiving has taught him about something that is being forgotten by his broader community. He has learned more about local tradition and what is at stake in its maintenance. He has learned why looking after an elder is important and how this local norm may be eroding. In the process, Pablo has developed life experiences that set him apart from neighbors. He is now able to offer advice, much like elders are sought for theirs. In this way, caregiving has rendered Pablo into a new type of benguul, into a person distinguished by his or her accumulated wisdom. The major difference is that few people recognize him for it. One day, perhaps, people will call upon him. He will be able to speak about the importance of elders, the inherent tension of upholding local traditions and, as I have described throughout this dissertation, the experience of giving one’s love.
CHAPTER NINE

Concluding Remarks

Every year, after the somberness of Easter and before the torrential rains of summer, the people of Teotitlán assemble for a five-day fiesta. Brass bands parade through the streets, costumed dancers cavort, and different households across the community unite. Although popularly referred to as carnival, this event is also known for a more specific name, La Danza de Los Viejos (“The Dance of the Elders”).¹ As I prepare to conclude, I can think of no better image to coalesce the themes developed in previous chapters.

In fact, in this Danza, elders are not the main actors, but rather it is a group of individuals meant to represent elders. With greyed whiskers and sunken eyes, each afternoon two young men don wooden masks to conceal their identities. These viejitos (“affectionate elders”) begin slowly, by limping over wooden canes and lumbering through the streets.² The elders’ wives – also men in costume – shriek in laughter as a throng of people with a brass band follows, heading towards the municipal building.³

These viejitos represent ancestors who have returned to the community to offer advice. They possess local knowledge that is otherwise unspoken; they know what has

¹ There also exists a Zapotec word, dguul, which literally means “elders,” but in this context also refers to the fiesta of elders.
² Viejitos is a diminutive of the word viejo. Although literally translated to mean “little elder” many Spanish words in diminuitive form do not literally refer to size, but rather express affection.
³ For more detail on the event see Gagnier de Mendoza (2005) who provides the only known published description of this event in Teotitlán. While the Danza de los Viejos is part of local tradition, it is more popularly known to be celebrated in the Mexican state of Michoacán (see Hellier, 2001).
occurred behind private doors. The viejitos and their wives first meet with the municipal president in his office. In a setting where respect is paramount – where one does not criticize authorities – what occurs is exceptional. In private and later in public, the viejitos identify shortcomings, embezzlements, and even illicit affairs. They tell the president what he has done wrong and what the community is missing. And, after each critique,

![Image](image.jpg)

Figure 9.1. La Danza de los Viejos. (Photo by the author.)

gossip, or joke, the viejitos’ wives erupt in cackled laughter that echoes through the streets. Anyone is target to their gossip and, during the community dance that follows, the elders slowly turn their attention to the broader group of spectators. Their ribald jokes and quick criticisms are contagious. Their caricature of old age is uproarious.
And yet, for all its levity and despite all the fun, this rendition provides a more profound image of what old age means in Teotitlán. It is an image where elders’ authority is matched with farce, where the *benguul* as a bastion of tradition becomes a spectacle of entertainment. Of course, locals know that this is a staged affair. But the fact that this provides such occasion for laughter – that the *viejitos* can so captivatingly create so much entertainment – demonstrates that the traditional black-and-white picture of the *benguul* is actually cast in more shades of color. This is the spectrum through which elders are seen in Teotitlán, the ambivalence experienced by a community at once anchored by tradition and adrift in the proceedings of reality.

*Summary of the Dissertation*

This dissertation puts into focus this underlying ambivalence, revealing how caregivers uphold local traditions – all while situated in a broader social world where tradition continually evolves. It calls attention to the way that elders are cared for on the basis of their local authority, and also how that authority is now being redefined. And it demonstrates how local traditions are being negotiated through the caregiving process.

As I conclude this study I am struck by the intricacy of this perspective compared to what I had anticipated upon first arriving to Teotitlán. Whereas I had originally come with the green intention to quickly assess how residents understood Alzheimer’s disease, the challenges I encountered required me to slow down and instead take a detailed inventory of the surrounding social landscape. I needed to know more about Alzheimer’s disease – what locals understood and why cases were so hard to locate – before I could inquire about it. In a metaphorical sense, I had to learn to speak by listening. Though the
process was more arduous, the results were richer. They culminate in revealing dimensions of caregiving that exceed my original question, theoretical and psychological issues that I could not have predicted encountering.

This dissertation strategically adopts theories and approaches across disciplines and culminates in a new research method – what I term “locally-focused interviewing” – to overcome epistemological and methodological difficulties. The final results are ethnographic in nature, a detailed sketch of caregiving as a form of life, an inventory of the experience of living in an Alzheimer-ed world. Most generally, this sketch reveals how caregiving is situated within multiple local discourses – different medical systems, power structures, socioeconomic parameters, norms and traditions. It provides an account of the social construction of Alzheimer’s disease. It is not only constructed within current social circumstances, but also constructive of the world in which caregivers aspire to live. This is a normative world characterized by upholding values about intra-family harmony, social cohesion, and maintenance of local tradition. It is a world that is perceived to be quickly changing, and a world that is put into question through the realities caregivers encounter. Moreover, this dissertation also sheds light onto the daily experience of caregiving. It demonstrates that caregiving is situated within broader social dynamics – that caregiving is social in nature – and how these dynamics are essential towards understanding the constitution of caregivers and dependent elders. Lastly, it demonstrates how the decision to care for forgetful elders leads to broader social consequences. It renders caregivers into a second forgotten subject, now forgotten by the larger community.
Research Limitations

Yet however rich I take these results to be, they are also limited. Conducting locally-focused interviews was advantageous because it provided insight onto how the meaning of caregiving is socially constructed. Yet this approach also foreclosed meeting with caregivers individually and soliciting their private opinions. The data acquired in this study was produced in the context of other people – family members – and this undoubtedly had an affect on caregivers’ comfort discussing certain experiences. For example, no caregivers mentioned family distress. I do not assume this theme was not broached because of its absence in the household, but rather because of caregivers’ discomfort addressing it. Similarly, talk about gender was absent in my data and I take this finding not to suggest that gender is irrelevant, but rather that it is such a salient issue that caregivers experience discomfort addressing it among their spouses, elders, husbands, and also with Alex and me.

Second, my own presence as a U.S. researcher who was not part of the community also likely had an impact on data. At many times I suspected that caregivers were trying to make a specific impression on me, garnering their responses to appear in a perspective they prefer to be seen. To be sure, this is an inevitable feature of all interviews, a consequence of the fact that the interview is a “joint production” between participant and researcher, and recognition that both parties contribute to shape what comes to be discussed (Packer, 2010b, p. 55).

The data presented in this study must be read with these limitations in mind. Nevertheless, these research findings continue to be expressive of actual caregiving practice – at the very least, they provide insight into how caregivers operate as a unit in
the presence of an outsider to their community, how caregivers want to be viewed by outsiders, and how they experience this viewpoint to be lacking in their community. Each of these represents a facet of local caregiving experience, but none are taken to represent caregiving irrespective of context.

**Directions for Future Research**

To assess if caregivers’ would endorse different opinions in a private setting a future study is recommended to follow this one. This additional study would continue to posit that the household is the primary social unit, but now specifically focus on how the individual caregiver navigates and talks about social setting. Multiple caregivers from the same household would be individually interviewed, and the researcher would then compare and contrast data from individual caregivers within the same and across households. Because this design would be aimed to invite caregivers to discuss facets of their experience that may be difficult to broach in front of others, this study would not partner with a local (who may contribute to participant discomfort), but instead be led by a researcher competent in Zapotec or only investigate Spanish-speaking caregivers.

Further, to fully account for the experience of caregiving in Teotitlán one must also look outside, beyond the physical parameters of the community to other locations where Teotitecos continue upholding local tradition. While this study has considered the impact of migration, it could go further to explore how caregiving occurs transnationally. This invokes work on “transnational family caregiving” and how care is circulated among family members across political regimes, economies, social structures, and traditions (Baldassar et al., 2007; Baldassar & Merla, 2013). Though this was explored among
caregivers in Teotitlán, a follow-up study is recommended to go beyond the physical parameters of the community. This study would be multi-sited by design and trace family life across borders. It would investigate how satellite members of a family understand, contribute, and cope with the immediate demands of caregiving.

Cross-Cultural Significance: Clinical and Social Lessons

Nevertheless, the results of this dissertation already carry relevance beyond Teotitlán and speak directly to U.S. audiences. First, this study provides lessons for the fields of clinical psychology and psychiatry. Demonstrating the social construction of Alzheimer’s disease in a specific cultural setting issues a reminder not only about the importance of attending to culture in clinical practice – that one must be cautious not to impose one’s own view about age-related conditions when working across cultures – but also the way that our culture shapes what clinical practice attends to. This study supports past work in disciplines like ethnopsychiatry and demonstrates that practices that purport to treat “abnormal” conditions are premised on cultural outlooks about what normal is taken to be (see Gaines, 1992).

This lesson is perhaps more valuable than ever today. In the wake of recent advancements in the detection of biomarkers and the push for pre-clinical diagnosis, we have tended to overlook the fact that the objects that exist under the microscope are inescapably interpreted by an eye steeped in a specific cultural outlook. This urges us to reconsider our efforts to detect Alzheimer’s disease prior to the onset of clinical symptoms and to question the utility of these efforts. Further, this study urges us to consider how these efforts must be read with regards to our own cultural horizon – our
values, hopes, and anxieties – and not simply an objective reading of neuropathology.

Psychiatry and psychology are cultural practices, even as these disciplines transition to be founded upon empirical science.

Further, this dissertation sheds light on two broad features of our cultural outlook – how we tend to define human life and our blind spot about illness. To the first point, this dissertation illustrates how our own experiences of Alzheimer’s disease – our alarm, our battles, and our agony – are reactions that are borne from and expressive of a very specific cultural outlook. As Jesse Ballenger (2006) writes, “Dementia can be seen as one of the emblematic diseases of our times, just as hysteria was in the Victorian era” (p. 153). And, just like hysteria is only intelligible by reference to a climate where expression of desire was anathema, we see how our experiences of dementia are constituted in present cultural values. Doing so highlights our implicit definition of the good life. We see that what appears to make life meaningful is our sense of self-control, self-creation, and autonomy – the very features that are threatened by Alzheimer’s disease and finalized by death. And, doing so raises awareness about how the ever-growing group of people who cannot uphold these values – the people with dementia and other dependencies – are cast on the moral periphery. This is why Stephen Post (2000) calls Alzheimer’s disease “a moral challenge.” It is a challenge not because we still appear to be floundering in the development of medicines for the future, but rather because we are excluding the ill from living with dignity and respect in the present.

This study also reveals our blind spot. We tend to view illness as an aberration to life, and old age as the foreclosure of it. But this stance overlooks how these experiences are in themselves meaningful. It overlooks how we are able to spiritually and morally
grow, despite the limitations of illness and the finality of death. As historian Thomas Cole aptly points out, we tend to respond to the anxieties of growing old via a “psychologically primitive strategy” of splitting images of a “good” old age of health and autonomy, apart from a “bad” old age of sickness and dependency (p. 230). The caregivers featured in this study demonstrate not only the impossibility of this stance, but also provide an alternative. Despite their ambivalence and despite their challenges, caregivers demonstrate that illness and old age are not aberrations to life, but are rather inextricable features of it. Further, they demonstrate that genuine recognition of this fact can lead to real existential meaning – in their case, a way to engage with who one is by supporting from where one comes.

Local Significance

As the caregivers featured in this study provide reason to reflect on our culture, they also stand as moral voices for their own. In a context where old age is viewed with ambivalence, where the authority of experience is met with the comedy of farce, caregivers are pivotal figures that cast clarity within a sea of doubt. Kleinman and Hanna (2008) write that caregivers are best understood as antiheroes, persons who do not engage in physical combat to change the world, but rather have an effect through subtly perturbing it. Indeed, the caregivers I had the opportunity to meet in Teotitlán exhibited similar attributes. They not only put into focus the subtle changes occurring to local meanings of aging, but more importantly highlight the impetus to take ownership of it. Teotiteco caregivers are antiheroes by reminding their community about what is at stake

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4 Further, these authors argue that caregiving supplements biomedicine and its inattentiveness to psychological and spiritual needs.
in the context of its ambivalence – of the importance of maintaining social cohesion via local traditions – and why neighbors ought to follow suit. They demonstrate why the forgetful ought not be forgotten, and the broader social injuries that occur when they are.

As a researcher who is not from Teotitlán I recognize that it would be unfit to conclude with my own statements about the local impact of this project. For this reason I turn to Alex and consider how his involvement has impacted him. This was a theme we had discussed throughout our fieldwork, but it was most salient towards the end. At a restaurant I had chosen to celebrate our partnership, Alex and I again began to reflect on the course of our work. We recalled challenges that we had faced and surprises we had encountered. We remembered the gratitude that caregivers expressed, despite some having been so reluctant to talk. And, it was in this setting that I took out my audio recorder for the last time. Alex had helped me document others’ voices so well, and so I explained that I wanted to also feature his own. Inspired by our conversation, I now invite Alex to have the final words.

Alex: It’s very different the way I see [things now]… There are some people that need a lot of help, and I didn’t realize that people needed [that much] help.

Jon: Why do you think you didn’t realize it before?

Alex: Probably because I [spent so much time with] people who didn’t [need] much help… So, I was in this little bubble where everything was good around me. But now… my point of view [has] changed.

Jon: So how do you think it has changed?
Alex: Well, first of all, now that we’ve finished interviewing and we met a lot of people, now I would like to help those people. And not just old people, but also other people … with [other] needs.

Jon: Why do you think this whole experience made you want to do that?

Alex: Because [I saw] the way they lived… And that’s something that [sparked] in me … a desire to help… [Now] I would like to help, and with nothing in exchange. Just do it as a part of me, as a part of my life.
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APPENDIX A:

Interview Questions Prepared for Alex

Background Questions:

– Introduce everyone present: What is your relationship to the elder?
– Please tell me about the elder both about his/her personality and condition.
– What is his/her diagnosis? (If there are multiple diagnoses, we want to hear about them all.)
– What is your understanding of the elder’s forgetfulness?
– Why does the elder tend to forget? (What caused it?)
– Considering the elder’s forgetfulness, what will happen in the future?
– What are the main symptoms that the elder exhibits?
– What exactly does the elder forget? And what does the elder not forget?
– Has the elder’s personality changed?
– Is the elder still the same person? (Why/why not?)

Questions about Caregiving

– Who is the primary caregiver? What are the responsibilities of this role?
– Do you feel alone in your responsibility?
– Does one family or multiple families live here? And, how does the family work together to provide support?
– How does your community provide support?
– How has migration impacted caregiving?
What are other reasons for why caregiving is challenging?

What are your strategies for managing the challenges?

How has the elder’s condition impacted your life as caregiver?

Questions about Encounters with Doctors:

- Why did you initially see a doctor? What problems led you to visit the doctor?
- Where did you go? Whom did you consult?
- Please tell me about the moment you learned the elder had an illness.
- When the elder was diagnosed, what was the process? (Was it through referral to a clinic, diagnosed during annual check-up, etc.?)
- Did you suspect something was wrong before? (What made you seek medical help?)
- Were there other experts you consulted first? (Was the doctor the first or last person you went for help? Why?)
- What did you learn from the doctor that you didn't already know?
- After visiting the doctor, how has your understanding of the elder changed?
  How has your approach to caregiving changed?

Questions about Understanding Before Meeting with Doctors

- How did you learn about the Alzheimer’s disease, and what do you know about it?
- Do you remember growing up with elders with a similar condition? What was that like? How were they cared for?
Questions about Support from Non-Doctors

- Have you visited a *curandera* (or any other medical specialist) for the elder’s forgetfulness? What did s/he do?
- Considering the elder’s disease, what are the limits of doctors?
- Considering the elder’s disease, what are the limits of *curanderas*?

Other Questions

- How do you think elders are viewed in your society? Has there been a change?
- Do you know other people in the community with a similar condition?
APPENDIX B:

Consent Form

The form displayed below was textually translated into Spanish and orally translated into Zapotec to obtain consent to participate in this study. Participants were also given a copy of this form for their own personal record, with the researcher’s contact information should they want to be in touch.

DUQUESNE UNIVERSITY
600 FORBES AVENUE ♦ PITTSBURGH, PA 15282

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE: Social Dimensions of Alzheimer’s Disease Among Indigenous Caregivers in Oaxaca, Mexico

INVESTIGATOR: Jonathan Yahalom, M.A.

ADVISOR: Dr. Roger Brooke

Advisor's Department of School
Department of Psychology
Duquesne University
544 College Hall
500 Forbes Ave
Pittsburgh, Pennsylvania 15219
USA

Advisor’s Phone Number 001 412 396 6563

SOURCE OF SUPPORT: This study is being performed as partial fulfillment of the requirements for the doctoral degree in Clinical Psychology at Duquesne University.
PURPOSE: You are being asked to participate in a research project that seeks to investigate the experience of caring for Alzheimer’s patients. In participating in this study, you are asked to participate in an interview for approximately 60-90 minutes. Our discussion will be recorded on an audio recording device.

Your interview will be transcribed and analyzed, with all identifying information removed. Results will be published in a final dissertation, and may be shared in academic conferences and journals.

RISKS AND BENEFITS: Although this interview is intended to be a friendly discussion, you may feel discomfort talking about your experience caregiving. If so, you are free to withdraw from the conversation at any time. Overall, there are no risks greater than those encountered in everyday life. Your participation will contribute towards understanding specific cultural needs when treating Alzheimer’s disease.

COMPENSATION: You will not be compensated for participating in this study.

CONFIDENTIALITY: Your name (or any related individuals) will never appear on any survey or research instruments. Further, no identity disclosed in any other part of the research. The consent form and any materials containing identifying information will be stored in a locked file. Audiotapes and transcriptions will not contain any identifying information. They will be stored in a locked file in the researcher's home. All materials will be destroyed within two years of completion of the research.

RIGHT TO WITHDRAW: You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time, for any reason.

SUMMARY OF RESULTS: A summary of the results of this research will be supplied to you, at no cost, upon request.

VOLUNTARY CONSENT: I have read the above statements and understand what is being requested of me. I also understand
that my participation is voluntary and that I am free
to withdraw my consent at any time, for any reason.
On these terms, I certify that I am willing to
participate in this research project.

I understand that should I have any further
questions about my participation in this study, I
may call Dr. Roger Brooke at (412) 396-6563 and
Dr. Linda Goodfellow, Chair of the Duquesne
University Institutional Review Board at 001 412
396 6326.

________________________________________
Participant's Signature                     Date

________________________________________
Researcher’s Signature                     Date
APPENDIX C:
List of Codes

The following list of codes was developed through the course of reading (and re-reading) the 9 household interviews with 22 caregivers in Teotitlán.

Doctors: Multiple Medical Experts (traditional. & allopathic)
Doctors: Money Spent
Doctors: Visiting
Doctors: Not Visiting
Doctors: Engaging in Advice/Explanations
Doctors: Not Engaging in Advice/Explanations
Doctors: Why Consult

Interventions - Doctor - Helpful
Interventions - Doctor - Not Helpful
Interventions - Doctor - Against Elders' Will
Interventions - Specialist Doctor

Curanderas: Visiting
Curanderas: Not Believing

Interventions - Curanderas - Helpful
Interventions - Curanderas - Not Helpful
Interventions - Curanderas - Against Elders' Will
Interventions - Prayer

Pluralism: First Consultation - Whom
Symptoms: Forgetting
Symptoms: As Problematic
Symptoms: As Non-Problematic
Symptoms: Normal Forgetting
Symptoms: Passing Out
Symptoms: Not Working
Symptoms: Pain
Symptoms: Mentally Absent
Symptoms: Off-Topic Speech
Symptoms: Blaming Others (Lost Objects)
Symptoms: Depressed

Course of Symptoms: Detection of Abnormality
Course of Symptoms: History of Symptoms
Course of Symptoms: Expectations of Illness

Etiology: Age
Etiology: *Pérdida del Alma*
Etiology: *Mal Hora*
Etiology: *Susto*
Etiology: Stress
Etiology: Depression
Etiology: Thinking A Lot
Etiology: Inactivity
Etiology: Brain Failure
Etiology: What the Doctor Explained
Etiology: Self-Will
Etiology: Contagion
Etiology: Diet
Etiology: *Golpe* (head injury)
Etiology: Emotional Repression
Etiology: Elder as Pretending
Etiology: Vaccine

Comorbidities: Osteoporosis
Comorbidities: Diabetes
Comorbidities: Hallucinations
Comorbidities: Body Problems/Physical Pain

Obtaining Info about Alzheimer’s: By Accident
Obtaining Info about Alzheimer’s: Intentionally
Obtaining Info about Alzheimer’s: Impact of Info
Obtaining Info about Alzheimer’s: No Impact of Info
Obtaining Info about Alzheimer’s: Follow-up studies
Obtaining Info about Alzheimer’s: No Follow-up studies

Representations about Alzheimer’s: Info from Community
Representations about Alzheimer’s: Info from Media
Representations about Alzheimer’s: Prior Knowledge
Representations about Alzheimer’s: As Severe

Other Forgetful Elders: General
Other Forgetful Elders: Why Now?
Other Forgetful Elders: New/Modern Disease

Responsibility: Primary Caregiver (General comments)
Responsibility: Primary Caregiver Justification
Responsibility: Family (General comments)
Responsibility: Family Justification
Responsibility: Community Support
Responsibility: No Community Support
Responsibility: Migration (General)
Responsibility: Migration Finances
Responsibility: Migration Visiting
Responsibility: Government Programs
Responsibility: General Comments
Responsibility: Breakdown
Responsibility: Accepting Illness (Stoicism)

Forgotten Caregiver: Lonely
Forgotten Caregiver: Stuck
Forgotten Caregiver: Gossip

Caregiving Challenges: Restroom
Caregiving Challenges: Physical
Caregiving Challenges: Not a Challenge
Caregiving Challenges: Finances
Caregiving Challenges: Testing Patience
Caregiving Challenges: Sanitation
Caregiving Challenges: Relief (of Abuse)
Caregiving Challenges: Hindrance to work/life
Caregiving Challenges: Provoking Arguments
Caregiving Challenges: Lost Companionship

Caregiving Strategy: Patience/Maintain Peace
Caregiving Strategy: Engaging in Conversation
Caregiving Strategy: Remind Positive Memories
Caregiving Strategy: Lock-up
Caregiving Strategy: Keep Occupied/Active
Caregiving Strategy: Monitor

Perception of Elder: Before Illness as Angry
Perception of Elder: Angry/Aggressive
Perception of Elder: Tricky
Perception of Elder: Wanderer
Perception of Elder: Looking for Lost Objects
Perception of Elder: Depressed
Perception of Elder: Like a Child
Perception of Elder: Like a child - Not Responsible
Perception of Elder: Not a Person/Not Alive
Perception of Elder: As Same Person
Perception of Elder: Meriting Respect
Perception of Elder: Meriting Empathy
Perception of Elder: Lost Respect
Perception of Relationship with Elder

Misc.: Reflection on Memory
Misc.: Elders' Perspective of Themselves in Community
Misc.: Perspective of Elders in Community
Misc.: Perspective of Me/Project
Misc.: Alex as Therapist
Misc.: Other Illness Representations: Nerves
Misc.: In-Family Fighting