Charting Caregiver Movement Using a Complexity Science Framework:

An Emergent Perspective

by

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ABSTRACT

Health and healing in the United States is in a moment of deep and broad transformation. Underpinning this transformation is a shift in focus from practitioner- and system-centric perspectives to patient and family expectations and their accompanying localized narratives. Situated within this transformation are patients and families of all kinds.

This shift's interpretation lies in the converging and diverging trails of biomedicine, a patient-centric perspective of consensus between practitioner and patient, and postmodern philosophy, a break from prevailing norms and systems. Lending context is the dynamic interplay between increasing ethnic/cultural diversity, acculturation/biculturalism, and medical pluralism.

Diverse populations continue to navigate multiple health and healing paradigms, engage in the process of their integration, and use health and healing practices that run corollary to them. The way this experience is viewed, whether biomedically or philosophically, has implications for the future of healthcare.

Over this fluid interpenetration, with its vivid nuance, loom widespread health disparities. The adverse effects of static, fragmented healthcare systems unable to identify and answer diverse populations' emergent needs are acutely felt by these individuals.

Eradication of health disparities is born from insight into how these populations experience health and healing. The resulting strategy must be one that simultaneously addresses the complex intricacies of patient-centered care, permits emergence of more localized narratives, and eschews systems that are no longer effective.

It is the movement of caregivers across multiple health and healing sources, managing care for loved ones, that provides this insight and in which this project is

keenly interested. Uncovering the emergent patterns of caregivers' management of these sources reveals a rich and nuanced spectrum of realities. These realities are replete with opportunities to re-frame health and healing in ways that better reflect what these diverse populations of caregivers and care recipients need.

Engaging female Mexican American caregivers, a population whose experience is well-suited to aid in this re-frame, this project begins to provide that insight. Informed by a parent framework of Complexity Science, and balanced between biomedical and postmodern perspectives, this constructivist grounded theory secondary analysis charts these caregivers' processes and offers provocative findings and recommendations for understanding their experiences.

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PREFACE

It is pleasant at times to play the madman.

—Seneca

Chapter 1

TRANSFORMATION

The United States' healthcare is experiencing deep and broad transformation. Make no mistake—healthcare's transformation is one of exceptional complexity; its intricacies are difficult to untangle. However, one thing is certain: a profound shift is occurring. No longer focused solely on provider perspectives, care is now situated within patient and family expectations, and prevailing biomedical structures are giving way to more localized patient and family narratives.

The way in which these narratives will be interpreted and their centrality to the future of healthcare remains to be seen. Two prevailing perspectives, one emerging incrementally from a traditional biomedical view of healthcare and one emerging from a more revolutionary postmodern vision of healthcare and patient-provider roles and relationships, shape current debates.

The literature indicates that, while tightly bound to one another, these two differing perspectives may each be of utility in explaining and exploring this transformation: first, the biomedically-grounded perspective that calls this a shift toward a patient-centric view of healthcare, and second, the philosophically-grounded perspective that calls this a shift toward a postmodern view of healthcare.

The journey upon which this project now embarks will follow the converging and diverging trails of these two perspectives, and how they inform healthcare's transformation. I introduce these views at the outset with a purpose: to situate the discussion within these two very different yet sometimes similar realities. In exploring these two perspectives, it becomes clear that healthcare's transformation is a shift that is still open to interpretation: Moving toward one, the other, both, or neither paradigm may have vast implications—both positive and negative—and health and healing is at stake.

Patient-centric. When locating the conversation biomedically, healthcare's transformation appears to be a move from practitioner-centric decisions about health and healing to a more patient-centered focus. A patient-centric perspective retains the basic biomedical structures of medicine that are grounded in a tradition of western, rationalist logic.

With this retention of biomedical structures come texts about power, empowerment, majority and minority culture, the Other, and gender. Accompanying these texts is a sense of the current healthcare environment as comprised of differing types of cohesive, established, and crystallized health and healing systems from which patients may choose to select and of which practitioners must be aware. These systems are defined in relationship to biomedicine: "alternative" or "complementary" or "traditional" or "folk."

This movement from provider to patient focus, and the texts and assumptions that underpin it, illuminates the existence of two long-standing juxtapositions. The first is the overarching conception of health and healing systems themselves as being in binary opposition to one another: those that are biomedicine and those that are not. The second is identified in patient and family expectations vis-à-vis provider perspectives, belied by the intense focus in the literature on the vital importance of navigation on the parts of both parties to arrive at consensus, as if they are destined to disagree.

The transformation of care is seen here as an emerging, empowering consideration for patient needs and wants rather than wholly based on provider expectations, with the accompanying literature demonstrating that collaboration with patients brings about better patient outcomes and lowers costs.

Postmodern. Within the patient-centric perspective, biomedical structures are retained and patient/practitioner collaboration is situated within them. In the postmodern

conversation, healthcare's transformation can be understood more philosophically, as an almost-complete break from extant care systems and perspectives.

Rather than transformation signified by a movement from practitioner-centric to patient-centric care, a postmodern perspective pushes forward an emergent understanding of care located within the experience and perception of the individual. The patient, family, and/or practitioner are situated not within extant systems but instead act and react in a relationship to one another devoid of the texts found in the patient-centric perspective and outside of the binary opposition of one system over another. This understanding seeks to avoid the limitations of prevailing structures or systems that state what care ought to be, how it is delivered and accessed, and how its worth is assessed. This perspective brings with it what we might call the reverse of the texts inherent in the biomedical perspective: how to objectively measure what is occurring in these myriad interactions in terms of health outcomes.

The transformation of care is seen here as omitting the presupposed differences in patient and practitioner perspectives that result in requisite collaboration within the patient centric paradigm. Instead, the postmodern perspective permits myriad individual stories and preferences to surface that are not found within extant systems as they are currently defined. A postmodern perspective presupposes nothing.

However, the two perspectives are not entirely discontinuous. Both take into account diverse social, political, economic, religious, and cultural factors that interact dynamically with healthcare. Both are interested in patient and family needs. Both identify the shortfalls of current systems, and both are being used to address the current state of health and healing in the United States. Both are useful in contributing to a re-envisioning of health and healing: on one hand remembering the centrality of the patient

and family experience in collaboration with the provider and on the other, cognizant of the opportunities and limitations of extant health and healing systems.

Through a lens, divided: Mexican American female caregivers. This study was situated within this broad and deep transformation of healthcare and sought to explore the tangled, compelling ways available to authentically understand and successfully incorporate patient and family narratives in the design of new healthcare delivery models.

This project examined how Mexican American female caregivers select care for their family members. It capitalized on this moment in healthcare's transformation, marked by the centrality of patient and family perspectives, and sought to witness how caregivers' processes of selection unfold within this context. Because of this focus, health and healing within this project had to be seen through the caregiver's eyes. These women and their families provided an extraordinary lens to view the process by which this selection takes place, and how these processes may be best understood in terms of the two paradigms above and activated most effectively to create delivery models that answer caregivers' needs.

Overview of Chapter 1

The remainder of Chapter 1 brings together concepts vital to understanding this project. Patient-centered care and the postmodern moment will continue to accompany us, having set the stage at the outset of this chapter and now moving us forward further into the project. I begin with an examination of patient-centered care and employ it to ascertain the current state of U.S. healthcare and current structures that undergird it from a biomedical perspective. Then, I deconstruct the current healthcare system, exploring postmodernism's utility in providing a philosophical foundation for

understanding and accessing the current state of healthcare and of patient-centered care itself.

Next, as we begin to consider the problem that this project seeks to address, I explore two issues identified by the literature as providing the context in which healthcare's transformation is occurring. The first issue is the complex interrelationship between increasing ethnic/cultural diversity, acculturation, biculturalism, and health disparities. The second issue is medical pluralism.

Following this exploration, I situate the population of interest, female Mexican American caregivers within these two issues. The fastest growing ethnic population in the United States, the Mexican American population is especially suited to inform this discussion. These individuals are considered to be bicultural due to their existence at the intersection of Mexican and American culture, and they engage frequently in multiple health and healing systems that range from biomedical to indigenous. The Mexican American female caregiver, sitting at the center of a complex web of interactions and making decisions about care, is transformed in Chapter 1 into the lens through which we are able to see what is possible in re-shaping and re-envisioning health and healing.

I continue by clarifying the rationale and significance of this project and then articulating the purpose, specific aims, and research approach. The project's research approach, constructivist grounded theory, is treated briefly here. Next, I put forth my assumptions as a researcher. Last, I provide a short list of definitions in order to provide what I perceive is my conceptual foundation regarding my understanding of health and healing systems and healing modalities. Although naming and defining are inherently violent in the constructivist mind, we can only re-shape the logico-deductive model (i.e. linear ways of arriving at conclusions based on old premises) so much (Charmaz, 2006).

Therefore, definitions of terminology are important for comprehension and they are provided at the conclusion of this chapter.

Patient-centered care. Patient=centered care is a way of viewing health and healing that is reflected in emerging policy guidelines and healthcare reform from the Institute of Medicine (IOM), (2001, 2011), the Joint Commission (2010), the Patient Centered Outcomes Research Initiative (PCORI), and the National Priorities Partnership (National Quality Forum 2008, 2010), among others.

The landmark report by the IOM, *Crossing the Quality Chasm* (2001), defined patient-centered care this way: "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (p. 40). The Institute for Patient and Family Centered Care describes this type of care as "an innovative approach to plan, deliver, and evaluate health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families" (Joint Commission, 2010, p. 92). Patient-centered care is not simply a nicety; the IOM has deemed patient-centered care an important antecedent to healthcare quality and safety (Sherwood & Barnsteiner, 2012).

According to a 2006 report by the Institute for Family Centered Care and the Institute for Healthcare Improvement with support from the Robert Wood Johnson Foundation (RWJF), the driving forces behind the shift to Patient-Centered Care are: (a) increased attention on medical errors and patient safety as a platform for advocacy, (b) greater patient access to technology and health information via the internet and the inception of the electronic medical record, which allows room for patient and family goals and expectations to be recorded, (c) a growing emphasis on health literacy, and 4. evidence-based healthcare design that is the result of widespread realization that the healthcare environment is integral to quality care (Conway et al., 2006).

A seminal article in *Health Affairs* by Epstein, Fiscella, Lesser, and Stange (2010) painstakingly detailed why patient-centered care is important: (a) it is the right thing to do (i.e. there are moral and ethical arguments for it), (b) it improves care (see Kaplan, Greenfield, & Ware, 1989; Stewart et al., 2000), (c) it improves well- being (see Epstein & Street, 2007; Street, Makoul, Arora, & Epstein, 2009), (d) it addresses health disparities (see Harris, 2010; Saha, Beach, & Cooper, 2008; Teal & Street, 2009), (e) it is of better value (i.e. it is cost effective) (see Epstein et al., 2005; Levinson, Roter, Mullooly, Dull, & Frankel, 1997). An entire issue of *Health Affairs* undertook the conversation again in February, 2013, in what the journal deemed "The New Era of Patient Engagement." The issue's content spoke both to the continued centrality of patient involvement undergirding efficacy of care in addition to the transformative quality of this new era.

Patient-centered care undergirds healthcare's transformation in two ways: via its increased engagement of consumer and family in identifying what is valued regarding care and health outcomes, and second, by taking into account diverse expectations of care. Patient-centered care is rooted in extant health and healing systems and their accompanying texts.

The postmodern moment. Witnessing the overarching biomedical structures giving way to more localized patient and family narratives, some scholars, practitioners, and philosophers asserted that the shift toward patient-centered healthcare, both in the United States and abroad, is postmodern[1] (Bakx, 1991; Figueras, 2003; Fink, 2002). As Morris (2000) put it,

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1 Notwithsanding Noam Chomsky's reference to postmodernists as fashionable people who fancy themselves philosophers, and that many have championed the end of postmodernism (see Eshelman's *Performatism* (2008), Lopez and Potter's work in critical realism (2009), and Kirby's *Digimodernism* (2009)), my dissertation research unfolding in the next chapters holds tightly to the tenets of postmodernism for reasons that will be explained below.

> Modernism . . . located the truth of illness in the doctor's story: an objectivist, scientific, biomedical account that regularly assigned medicine a heroic role in the progressive, worldwide struggle against disease . . . the postmodern narrative of illness increasingly tells the patient's story. (p. 7)[2]

This postmodern moment in healthcare rejects an overarching, static, crystallized biomedical metanarrative[3] that seeks to describe phenomena as universally experienced and instead concentrates on individual experience of phenomena within health and healing (Bakx, 1991; Fink, 2002; Fox, 1991; Morris, 2000). This shift is described as postmodern due to the current focus not on the grand metanarrative of biomedical practitioner or prevailing system as sole expert, but instead on the localized narrative[4] and patient and family experience (Egnew, 2009; Elwyn, 2004; Fox, 1991; Kleinman,2004; Larivaara, Kiuttu, & Taanila, 2001).

Identifying healthcare's "postmodern moment" may seem to imply a break with biomedicine/modernism and thus a linear progression of history toward something "post-modern," implying that there are future philosophical paradigms down the road. However, for the purposes of this research, describing healthcare as "postmodern" is simply to say that it is (once again) embracing and celebrating diversity and contestation in its search for improved safety, quality, and care delivery.

A postmodern perspective undergirds U.S. healthcare reform in two ways: the research shows there is now a "a multiplicity of theoretical standpoints in healthcare"

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[2] There are those who fear the implications of widespread adoption of a postmodernism perspective in healthcare, particularly for its contextual nature and its rumored disregard for facts, research, and observable phenomena. See *The Sokal Affair,* (http://www.physics.nyu.edu/ faculty/sokal/), a hoax in which a physicist from New York University published a gibberish article in one of the most prominent cultural studies journals in the country, *Social Text,* as an example. This article garnered the physicist national attention and conversation around the prank, and its implications continue. See also the February 1, 2008 editorial in *Advanced Nursing Practice.* Postmodernism's utility in understanding health and healing systems, as well as the limitations of its perspective, are discussed further in Chapter 2.
[3] Lyotard (1984) defines postmodernism itself as "incredulity toward metanarratives." See also Foucault (1976).
[4] See Lyotard (1979), *les pétits recits.*

(Peters, 2001, p. 7) and questions the prevailing biomedical perspective, comprised of linear systems and categories, that may indeed be beginning to fall away.

Problem

Despite the widespread edification of patient-centered care and its liberating corollary, the postmodern perspective, all is not well.

Patient-centered care remains an abstraction still being defined and operationalized. Documents such as the IOM's *Crossing the Quality Chasm* (2001) and *Unequal Treatment* (2002) and PCORI's *Principles of Patient Centered Research* serve as evidence to the continued codification and development of criteria for recognizing patient-centered care and the utility of its corollary, the postmodern perspective.

The increased engagement of consumers championed by the transformation of US healthcare has illuminated two issues central to the success of the patient-centered movement itself that are in desperate need of examination: (a) the complexity of increasing ethnic/cultural diversity, acculturation, and biculturalism (U.S. Census Bureau, 2000b, 2002) and the imbroglio of these phenomena in widespread health disparities in diverse populations and (b) the dynamic and fluid medical pluralism that prevails in these diverse populations, about which little is known.

These two issues are important to examine jointly because they provide the current context in which healthcare's transformation is occurring. In the next sections I chart my way through the current context, moving down through the first issue— increasing ethnic and cultural diversity, acculturation and biculturalism, and health disparities, and the second issue—medical pluralism—respectively.

Increasing ethnic and cultural diversity. The demographics of the United States are changing drastically. The census report, *Overview of Race and Hispanic Origin: 2010,* reports that of all groups in the U.S., Hispanic and Asian populations grew

fastest in the first decade of the 21st century. Although non-Hispanic White is still

recorded numerically as the largest race and ethnic group in the United States, this

population is growing at the slowest rate. The Asian population grew faster than any

other race group between 2000 and 2010 and accounted for the second-largest numeric

change, gaining the most in its share of the total United States population, moving from

approximately 4% of the population in 2000 to 5% in 2010. Hispanic populations,

however, accounted for the largest numeric change, with more than one-half of the

27.3 million increase in the total U.S. population due to a rise in the Hispanic population;

in 2010, Hispanics counted for 16% of the total U.S. population of 308.7 million (U.S.

Census Bureau, 2010).

Acculturation and biculturalism. With this increasing diversity, ever-larger

numbers of individuals and their families are negotiating a simultaneous existence within

their respective birth cultures and the host or mainstream culture. Each of these cultures

informs individuals' thoughts, feelings and behavior at different times and in different

amounts (Luna, Ringberg, & Peracchio, 2008; Ramirez-Esparza, Gosling, Benet-

Martinez, Potter, & Pennebaker, 2006).

Culture, and resulting patient and family perceptions within it, affects attitudes

about health care (Corin, 1995; DiGiacomo, 1999). These attitudes are the result of

received cultural streams that originate in both birth and host cultures (Schwartz &

Unger, 2010, p. 27). These streams can be understood as prevailing beliefs and

accompanying values, realities, and definitions from both cultures in which a patient and

family engage, the processing of which becomes more complicated as differences

between the two cultures are negotiated and dealt with, and decisions are made (see

Rhodes, Foley, Zometa, & Bloom, 2007).

This process of negotiation and internalization is referred to in the literature as acculturation, the navigation of differing realities that occurs when individuals and groups from different cultures have direct contact with one another. Biculturalism is a subset of acculturation and is thought to be the most adaptive form (Mistry & Wu, 2010; Szapocznik, Kurtines, & Fernandez, 1980). Exposure to two cultures, synthesis of multiple cultural norms, and an ability to switch between cultural frames in response to cultural cues are all marks of biculturalism (see Benet-Martinez, Leu, Lee, & Morris, 2002; Rotheram & Borus, 1993; Hong, Morris, Chiu, & Benet-Martinez, 2000).

Whether in direct contact or not, the cultures negotiated by bicultural individuals are often at odds with one another (Benet-Martinez et al., 2002). It has been suggested that "biculturals' meeting of such cultural contact zones where cultures may be at odds with one another leads to the development of more complex and integrative cultural representations" (Rhodes et al., 2007, p. 403).

Biculturals tend to be bilingual (LaFromboise, Coleman, & Gerton, 1993). Although the literature does not go so far as to specify exactly what percentage of individuals in the U.S. are considered or consider themselves bicultural, international estimates of bilingualism encompass approximately half the world's population (Grosjean, 1982). Ergo, it seems safe to assume that the bicultural experience is widespread.

Biculturalism has substantial implications for health and healing, particularly regarding the choices made about health care. This is because health and healing are intimately tied to fundamental cultural structures such as value systems, world views, and attitudes, beliefs, and identification of self (see the Health Belief Model of Hochbaum (1958) and Rosenstock (1972)). Biculturalism "implies not just behaving in ways

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consistent with the two cultural contexts, but also holding values from one's heritage . . . as well as identifying with both cultures" (Schwartz & Unger, 2010, p. 27).

Culture-specific ideas and values related to conceptions of health and healing inform reporting of symptoms, expectations of care delivery, and beliefs concerning treatments, and processes for decision-making. Biculturalism, then, further informs an individual's reality, and the ability and willingness to comprehend, manage, and cope with an illness, a diagnosis, and the consequences of treatment or lack thereof. However, much is still to be learned about the effect of culture on health and well-being: cultural influence on health has been called "distal and diffuse, pervasive but unspecified" (Eckersley, 2006, p. 252).

Health disparities. It has been demonstrated in the literature that processes of acculturation and biculturalism are linked to biculturals' integrated perception of the relevant cultures, which extends to biculturals' conceptions of health and healing (Rhodes et al., 2007). Nevertheless, these phenomena remain poorly understood (LaVeist & Isaac, 2013). This lack of understanding illuminates an inherent inadequacy in the healthcare system: current models do not reflect diverse populations' caregiving and care-seeking experiences, and are unable to satisfy the unique needs of these populations. Because of this inadequacy, these populations are at risk for health disparities.

Healthy People 2020 (U.S. Department of Health and Human Services, 2010) defines a *health disparity* this way:

> a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion (para. 5).

The National Institutes of Health, the Office of Minority Health, the Centers for Disease Control, the IOM, RWJF, and others are focused on reducing health disparities in growing, diverse populations.

The top 10 illnesses associated with health disparities, as delineated by the CDC and the National Center for Health Statistics, across all populations, genders, and ages are: heart disease, malignant neoplasms (cancer), cerebrovascular conditions, bronchitis/ emphysema/asthma, accidents, diabetes, Alzheimer's, influenza/pneumonia, nephritis/nephrosis, and septicemia. Asian and Pacific Islanders have a list similar to the all-populations disparities. Liver disease, homicide, and suicide are included in the top 10 for Black, Native American, and Hispanic populations across all ages and genders, and perinatal conditions are included in the Hispanic population's top 10 list.

Factors including lack of insurance coverage,[5] a regular primary care provider, access to appropriate preventative programs, and an adequate level of health literacy, in addition to food, reliable transportation and adequate housing, are all being examined by national agencies in an attempt to eradicate these disparities in diverse populations (Centers for Disease Control, 2011; Families USA, 2009; Robert Wood Johnson Foundation, 2011), but much is still to be done.

Medical pluralism. As demonstrated above, populations marked by increasing diversity are becoming more prevalent in the United States. Within these populations is occurring a process of acculturation and biculturalism as individuals negotiate the interplay between their birth culture and the host culture of the United States. Acculturation and biculturalism inform these diverse populations' perceptions of health

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[5] Interestingly, level of income does not dictate insurance coverage in all cases. Families earning more than $84,000 annually were more likely to be uninsured if they were ethnic minorities. In this income group, approximately one-third of Hispanics, one-fourth of African Americans, and one-fifth of other racial and ethnic minorities, 20.8 % lacked coverage, compared to 26% of Whites earning a similar income (Families USA Minority Health Initiative, 2009).

and healing, and in turn the choices they make and way in which they articulate their health and healing needs and expectations. The gaps in prevailing healthcare systems' ability to understand, anticipate, and answer these diverse populations' needs suffuse the continued existence of health disparities in these populations.

In addition to this current reality is what the literature has shown to be these populations' fluid and dynamic interaction with multiple health and healing systems. This interaction with diverse systems is referred to in the literature as medical pluralism. Medical pluralism is defined as use of or engagement in more than one medical system to address health and illness (Chun-Chuan, Yi-Chang, Chien-Chang, & Gaung-Geng, 2010; Wade, Chao, Kronenberg, Cushman, & Kalmuss, 2008). Healthcare research shows that diverse populations of caregivers within the U.S. often use biomedicine and what the literature defines as "alternative" or "complementary" or "traditional" or "folk" medicine unique to their culture when seeking and providing care to themselves and their families (Pescosolido, Wright, Alegria, & Vera, 1998; Waldram, 2000).

The debate in the literature that explores the purported decline in use of health and healing systems outside of biomedicine rages on: these declines may not be due to an actual decrease in use of multiple systems and ultimate reliance solely on biomedicine, but instead to increased rates of caregiver/care-seeker refusal to disclose to researchers continued use of both systems (Higginbotham, Trevino, & Ray, 1990; Martinez, 2009). Caregiver/care-seeker patterns of integration seem random, but are in fact very subtle, under examined, and often misunderstood (Brettel & de Berjeois, 1992; Yanagisako, 1977).

Further, adverse health outcomes related to drug/herb interactions and lack of adherence to prescribed biomedical treatment are often seen in conjunction with medical pluralism (Cobra-Bramble, Tielman, & Wright, 2004; Flores, Rabke-Verani, Pine, &

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Sabharwal, 2002; Gomez-Beloz & Chavez, 2001). Medical pluralism and its scope are explored further in Chapter 2's literature review.

Rationale and Significance

Healthcare in the United States finds itself in the midst of a transformational change—a change described above from two prevailing paradigms, one patient-centric and the other postmodern. This transformation seeks to re-envision care in a way that is focused on patient and family expectations and that resonates with increasingly diverse populations. Processes of acculturation, biculturalism, and medical pluralism are occurring. With these processes comes the current system's difficulty in responding to what are proving to be dynamic and fluid phenomena that are informed by interaction and environmental cues. Within this difficulty, health disparities persist. There remains much still to learn about patient-centered care vis-à-vis increasing diversity and health disparities within these diverse populations.

The literature demonstrates, however, that one specific population may serve as an exemplar: female Mexican American caregivers.[6] These women provide a critical lens through which to examine care within a growing demographic and context of acculturation, biculturalism, related health disparities, and medical pluralism. From a patient-centered care perspective (i.e. the increased engagement of consumers and the drive to reduce health disparities), the experiences of these women permit a clear examination of both the implications of increasing ethnic diversity in terms of health disparities and our current understanding of medical pluralism and how this bolsters or hinders health in this population. Within this population, it is the Mexican American

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[6] This project uses Keegan's (2000) definition of "Mexican-American": individuals of "Mexican descent residing on the U.S. side of the United States/Mexican border. They may be immigrants from Mexico or may have lived in the United States for generations" (p. 285). Similar to Martinez's (2009) definition, this project's population "includes those who speak only English, only Spanish, or both" (p. 129).

female caregiver who is arguably best able to provide this much-needed insight, as discussed in the following sections.

Mexican Americans: Ethnic and cultural diversity. Mexican Americans are the largest subgroup of the Hispanic population, comprising 66%, and are counted as the largest and most rapidly growing ethnic population in the United States (U.S. Census Bureau, 2000a, 2000b, 2002). The literature suggests that Mexican Americans who participate in both mainstream and Mexican American culture are bicultural and their participation in these two cultures deeply informs their perceptions about health and illness. The biculturalism of this population is explored further in Chapter 2. The literature also alerts us to increasing concern about health disparities and chronic illness in the Mexican American population, in addition to lack of insurance, regular health care providers, and other barriers experienced by this population (Fisher-Hoch et al., 2012).

Mexican Americans: Health disparities. Mexican Americans, men, women, and children are at greater risk for obesity and a number of chronic illnesses than other populations in the U.S. Approximately 81% of Mexican American men are obese, compared to 73.6% of White, non-Hispanic men; 78% percent of Mexican American women are overweight or obese, compared to 60% percent of White, non-Hispanic women; and in 2010, Mexican American children were 1.6 times more likely to be overweight than White, non-Hispanic children (Centers for Disease Control, 2012). The prevalence of diabetes among Mexican Americans is 10.4% compared to 6.5% among non-Hispanic Whites (Seshasai, Kaptoge, Thompson, Di Angelantonio, & Gao, 2011). This population is twice as likely to be diagnosed with diabetes by a physician and twice as likely to die from diabetes as non-Hispanic Whites (Centers for Disease Control, 2012).

Regarding what the literature identifies as negative health outcomes tied to Hispanic heritage, numerous factors have been implicated in these conditions and other health disparities, including genetics (QuHq et al., 2012) and socioeconomic status, limiting access to health insurance and preventive services (Morales, Lara, Kington, Valdez, & Escarce, 2002). The U.S. Centers for Disease Control and U.S. Office of Minority Health estimate that at least 39% of Mexican Americans are uninsured, compared to 13.6% of White non-Hispanics (Office of Minority Health, 2012).

However, the data manifest something interesting within the Mexican American population regarding the disparities most prevalent across groups: This population seems to have better outcomes than non-Hispanic Whites in certain health indicators. Importantly, acculturation seems to have an adverse effect on these positive outcomes in Hispanic populations and a range of others (see Eckersley, 2006). This is referred to in the literature as the Hispanic Paradox. It will be introduced here and discussed in more detail in Chapter 2.

In 2010, Hispanic populations, of which Mexican Americans are the largest subset, were 20% *less* likely to have heart disease than non-Hispanic White adults. In 2008, this population was 40% less likely to die from heart disease than non-Hispanic Whites. This population has lower overall blood pressure and smokes less than non-Hispanic Whites (CDC, 2011). Better health outcomes in this population versus non-Hispanic Whites is also present in regard to breast cancer, where acculturation adversely affects outcomes (Miranda et al., 2010).

Health disparities and what at first glance seem to be the odd outliers of positive outcomes like the Hispanic Paradox are a multidimensional set of phenomena. These phenomena are often in a dynamic interrelationship with the environment around them, and require diverse inputs as we seek to comprehend them fully. Exploring processes of

acculturation and biculturalism and how this population uses services across health and healing systems is important to understanding the factors contributing to health disparities and those related outliers of positive outcomes.

Mexican Americans: Medical pluralism. A review of the literature shows Mexican Americans' high rates of engagement in alternative health and healing systems. Estimates of the percentage of the population utilizing alternative health and healing systems range from 50% to 90% (Dole, Rhyne, & Zeilmann, 2000; Ortiz, Shields, Clauson, & Clay, 2007; Zenk, Shaver, Pergallo, Fox, & Chavez, 2001).

A growing body of research also attests to the pivotal role of culture in the use of health services across systems and adherence to recommendations (Gomez-Beloz & Chavez, 2001; Laganá, 2003; Ransford, Carrillo, & Rivera, 2010). In fact, researchers identified what Robleado, Wilson, and Gray (1999) referred to as the existence of "a Hispanic health subculture" (p. 240), within which caregivers select and integrate services from multiple systems (Boyle & Andrews, 1989; DeSantis & Thomas, 1990) that range from biomedical to traditional or folk.

Mexican Americans' interactions with multiple systems and one another result in "fluid, overlapping ideologies that allow for new ways of healing to be rapidly incorporated" (Belliard & Ramirez-Sanchez, 2005, p. 271). Use of multiple health systems as well as norms about sharing or hiding their use between providers is a significant part of this ethnic community's health subculture (Zenk et al., 2001).

In the Mexican American community, women caregivers provide entrée to the health subculture as it exists across family networks and the use of biomedical and indigenous providers (Belliard & Ramirez-Sanchez, 2005; Cobra-Bramble et al., 2004).

Mexican American women are the major caregivers for their families (Chavira-Prado, 1992; Hondagenu-Sotelo, 1995; Menjivar, 2002; Rubel, 1966). These women

are described by the literature as individuals who sit at the center of complex,

overlapping systems of familial, social, cultural, linguistic, and religious relationships that

inform selection of services across health and healing systems (diLeonardo, 1987;

Lamphere, Zavella, Gonzales, & Evans, 1993; Muir, 1988; O'Connor, 1990; Stack, 1974;

Wetherell, Plakans, & Wellman, 1994; Yanagisako, 1977). In addition, Menjivar (2002)

found that

> women are much more likely than men to be at the center of networks and
> procure remedies for both unusual and serious illnesses as well as the more
> mundane but also more frequent ailments that affect people in their daily lives.
> (p. 439)

Martinez (2009) echoed Menjívar's (2002) findings.

The female Mexican American caregiver. As the primary providers of care to

their families, female Mexican American caregivers are central to Mexican American

families' access to what Lopez (2005) called formal and informal healthcare systems in

the U.S. These women are also shown in the literature to determine whether these

services are used effectively and experienced by themselves and their families as

engaging and meaningful (Chavira-Prado, 1992; Hondagenu-Sotelo, 1995; Martinez,

2009; Menjivar, 2002; Rubel, 1966). However, the literature also notes that, in the

process of seeking care for their families and themselves, these women act and interact

with one another within their networks in subtle ways that require closer examination

(Brettel & de Berjeois, 1992; LaVeist & Isaac, 2013; Lovell, 2009; Xu & Farrell, 2007;

Yanagisako, 1977).

Purpose

The increased engagement of consumers and the drive to reduce health

disparities that are the hallmark of patient-centered care may be best understood from a

new perspective. This perspective takes into account increasing ethnic diversity in terms

of health disparities, along with the limits to our current understanding of medical pluralism, and how all these variables bolster or hinder health in this population.

With an eye to prevailing health disparities in the Mexican American population, this project sought to better understand the experience of the female Mexican American caregiver. The focus of this study was on these women in their pivotal role as individuals who navigate health and healing services as they negotiate received cultural streams. The purpose of this research was to describe the emergent[7] processes that occurred as these caregivers selected care for themselves and their families across multiple healing and healthcare systems.

Specific aims and research questions.

Specific aims.

1. Uncover the emergent patterns of female Mexican American caregivers as they interact with multiple healthcare systems.

2. Use these emergent patterns to inform the creation of a theory that seeks to describe the ways in which these patterns emerge.

Research question.

What are the patterns that emerge as female Mexican American caregivers seek out and integrate care for their families from multiple health care systems?

a) How do female Mexican American caregivers access these different systems?

b) What are the major obstacles to accessing Western and folk systems?

c) What processes do these women use to implement recommendations and treatments provided by Western and alternative providers?

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[7] For further clarification of the concept of emergence, see the exploration of this project's sensitizing concepts, i.e., concepts that serve to provide a general reference point when engaging with the data in qualitative research. These concepts are explored briefly in Chapter 2 and at length in Chapter 3.

d) Who else does the caregiver involve when making decisions about care?

Research Approach

The next section provides a brief treatment of this project's research approach. This material is explored more deeply in Chapter 3.

Constructivist grounded theory. The qualitative methodology for the project was grounded theory, specifically the constructivist, symbolic interactionist approach (see Blumer, 1969; Mead, 1934) of Charmaz (1995, 2000a, 2004, 2006). Constructivist grounded theory (Charmaz, 2006) asserts that neither data nor theories are *discovered*; rather, the researcher is part of the world being studied and the data collected. Grounded theories are *constructed* through interactions with participants and research practices and are not an exact picture of the world being studied but instead are interpretive.

A constructivist approach acknowledges the partnership of researcher and participant in co-construction of data resulting in an interpretation of reality and thus the research phenomenon. In the case of this project, the researcher adopted a nonjudgmental stance as a co-constructor of participants' exploration of their reasons for seeking out and integrating healthcare the way they do. Researcher positioning in the study lay in postmodernism.

Within the social constructivist worldview, the interpretative community providing the philosophical underpinning for this project was postmodernism.[8] The postmodernist approach denies a metanarrative (universals) and places importance instead on local narratives. It requires a deconstruction of "texts" (i.e. social systems and concealed power hierarchies) in order to bring to the fore oppressive structures, inconsistencies, previously ignored discourses, multiple paradigms, and unheard voices.

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[8] See Derrida (1982, 1997), Foucault (1976), Kristeva (1986), and Lyotard (1979).

Sensitizing concepts. Charmaz (2003) referred to sensitizing concepts as "those background ideas that inform the overall research problem" (p. 259), rather than addressing the data *tabula rasa* (Charmaz, 2000a; Schreiber, 2001). Used appropriately, "Identification of sensitizing concepts should not be an excuse for superimposing one's favorite theory onto the data . . . and the researcher must remain vigilant against this possibility" (Schreiber, 2001 p. 59).

Sensitizing concepts can act as a starting point for qualitative study, lay a foundation for analysis, and serve as devices for interpretation, or they can themselves become a framework (Bowen, 2006). In keeping with Glaser (1978), Padgett (2004), and Patton (2002), I used sensitizing concepts to act as catalysts to put the work in motion. I envisioned myself as tasked with an explication of my choice of the sensitizing concepts in terms of my own experience and background knowledge.

The sensitizing concepts I included in my project are found within the parent framework of complexity science. A cursory treatment of the specific concepts is offered in this chapter and is and discussed at length in chapters 2 and 3.

As stated immediately above, this project used sensitizing concepts with roots in complexity science. Complexity science maintains that the universe is full of systems, that these systems are complex and constantly adapting to their environment,[9] and that interactions among individuals are interconnected and result in emergent, non-linear behavior (Goldstein, 2008a; Page, 2009; Plsek & Greenhalgh, 2001).

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[9] Page (2009) uses the phrase *Complex Adaptive System* (CAS) to describe systems comprised of individual humans and their environments. There are other scholars, such as Goldstein (2008) who simply use *complex system* to denote all types of systems that are complex, including those comprised of individual humans. (Others use *fractal system* or emergent system, although these references are limited.) Goldstein's general categorization is useful for the broad overview of complexity science that I have provided immediately below and is congruent with my research perspective.

The sensitizing concepts drawn from the parent framework of complexity science fit this project for two reasons: first, because they allow for an examination of the tacit, internalized rules that caregivers use as they negotiate healthcare systems; and second, because they are uniquely useful in identifying and analyzing the patterns of the caregiver as she moves through the systems selecting and integrating treatment. Just as a complex system is tangled, imperfect, nonlinear, and dynamic, the caregiver patterns described by this project are similarly complex, nonlinear, seemingly random, and fluid.

Using concepts from complexity science to explore populations of caregivers and care-seekers allows this project to address the increasing diversity of those needing care and is instructive in effectively exploring the needs and care-seeking patterns of a culturally and ethnically diverse population that engages with multiple healthcare systems in a fluid, dynamic, and often nonlinear way.

The five sensitizing concepts drawn from the parent framework of complexity science guide the investigation of the phenomenon and are discussed in the paragraphs that follow. These five concepts are: chaos, co-evolution, darkness, emergence, and self-organization. A cursory treatment of each from Goldstein's (2008b) glossary of terms and the work of Skyttner (2001) and Cilliers (1998) is included below and then discussed at length in Chapter 3.

Chaos: "A type of system behavior which, although it displays random-like dynamics is actually deterministic, that is underneath the apparent randomness is a hidden order or pattern" (Goldstein, 2008b, p. 270). The behavior of chaotic systems is contained within a range, controlled by a particular space or state of being. In the case of the caregiver, chaos describes the caregiver's sensitivity to those conditions that are

occurring around her and posits that her responses may be anticipated within certain identifiable parameters.

Co-evolution: "The coordinated and interdependent evolution of two or more systems within a larger system" (Goldstein, 2008b, p. 271). Applied to the caregiver and her interactions with others, co-evolution refers to a change that occurs in the caregiver—whether manifested in her attitude, her interactions with others, and/or her caregiving patterns. This change may be triggered by or serve as a response to a change in another individual or overarching situation that may or may not be related to providing care but that informs caregiving nonetheless.

Darkness: "No system can be known completely" (Skyttner, 2001, p. 93). We can never ascertain the magnitude of an entire system and perceive all its complexities at once. Because it is impossible to comprehend the entirety of a system, those within and outside it are relegated to a grasp of only smaller, more localized pieces, whereupon "each element in the system is ignorant of the behavior of the system as a whole, it responds only to information that is available to it locally" (Cilliers, 1998, pp. 4-5). Darkness as a sensitizing concept is used to alert this project to the reality that the caregiver cannot and will not be aware of *everything*. In addition, even the most comprehensive and far-reaching health and healing system remains similarly unaware of itself in totality. The insight that darkness brings to this project has implications for both participants' ability to understand the larger implications of their actions and for systems to be regulated and examined effectively.

Emergence: "The arising of new unexpected structures, patterns, or processes in a system" that take on "a life of their own" (Goldstein, 2008b, p. 275). These new structures have their own rules and possibilities different from those at other levels of the system. In the case of the caregiver, emergence describes those unexpected complex

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patterns manifested by a caregiver that may be a response to interactions with other individuals and systems.

Self-Organization: "A process in a complex system whereby new emergent structures, patterns, and properties arise without being externally imposed on the system. Not controlled by a centralized, hierarchical, 'command and control' center" (Goldstein, 2008b, p. 286). Self-organization serves as an important sensitizing concept for this project because of its ability to identify potential mechanisms of caregiver collaboration that are not put in place by some overarching organizing force.

Research approach and parent framework. Constructivist grounded theory from a symbolic interactionist approach is congruent with the interest of complexity science in that both concentrate on individuals and complex interactions between them (Fonseca, 2002; Page, 2009). Both are also oriented toward the perspectives of individuals and the subjective meanings that are formed through interaction with others (Creswell, 2007). Further, like complexity researchers, constructivist researchers are interested in multiple and varied meanings provided by individuals, and they look for complexity of views. Both types of researchers also understand that they are never able to exist outside the system/phenomenon and look "objectively" at it, and they will never know everything about the system/ phenomenon.

Additionally, both types of researchers are mindful of the small, seemingly inconsequential occurrences at the outset of research that dictate the direction, perspective, and anticipated outcomes of a project. Such small occurrences may manifest themselves more deeply and broadly later in the project and may require something as drastic as re-direction or re-assessment of the entire underpinning of the project. Complexity science refers to this dynamic as the Butterfly Effect, named quite literally for the gentle flapping of a butterfly's wings on one side of the globe that

somehow results in a hurricane on the other side, in addition to the shape of the graphic representation of the phenomenon itself. The Butterfly Effect is a useful way for constructivist researchers to approach co-construction and for complexity researchers to address aggregation of complexity.

Secondary Data Analysis

A secondary analysis was performed on existing, de-identified data in the form of caregiver interviews, using the sensitizing concepts to guide the analysis. A general exploration of how secondary analysis of existing data is informed by specific methodological considerations is provided below. A more specific discussion of secondary analysis in terms of this project is addressed in Chapter 3.

History. Secondary data analysis has a long and knotted history. Its validity as a research method was initially recognized solely in quantitative research, and only begrudgingly by those who lamented that "chutzpah" or good connections alone got you the data for secondary analysis (Glass, 1976). Secondary analysis in quantitative circles was seen as "the re-analysis of data for the purpose of answering the original research question with better statistical methods, or answering new questions with old data" (Glass, 1976, p. 3), and all that was needed to accomplish this goal was simple: the preservation of old data and adequate funding. Secondary analysis was seen as a type of meta-analysis. And if begrudgingly accepted into quantitative circles, secondary analysis was even slower to be adopted in qualitative ones (Hinds, Vogel, & Clarke-Steffen, 1997).

Glaser (1963) saw the promise of secondary data analysis by independent researchers, however, asserting that secondary analysis could "lend new strength to the body of social knowledge" (p. 11). Heaton (2004) stressed that secondary analysis serves as a re-utilization or re-address of the existing data and not a re-analysis of the

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initial study, and thus secondary analysis in qualitative research differs from metaanalysis because it does not seek to compile and assess evidence (Popay, Rogers, & Williams, 1998).

When performing a secondary analysis on an existing data set, it is important to "make explicit the link between the primary study and all subsequent secondary analysis of the same qualitative data set" (Hinds et al., 1997, p. 411). This link serves to bolster and maintain the validity and confirmability of secondary data analysis results and is in keeping with good research conduct.

Methodological considerations. In a seminal literature review, Heaton (1998) distilled methodological considerations for secondary analysis as gleaned from Hinds et al. (1997), Szabo and Strang (1997), and Thorne (1994): compatibility of the data with secondary analysis, position of the secondary analyst, reporting of original and secondary data analysis, and ethical issues.

Heaton (2004) then examined at length the intricacies of qualitative research itself and the epistemological issues associated with secondary analysis of qualitative data in her book, *Reworking Qualitative Data*: the problem of data fit, the problem of not having been there, and the problem of verification. Long-Sutehall, Sque, and Addington-Hall added these additional considerations in a 2011 article:

> Is it ethical to ask the secondary research questions you are asking of the primary data? Is there enough being said in the primary transcripts about the topic of interest so that it would be reasonable to assume that the secondary research questions can be answered? How will the primary data set be assessed? Is there symmetry between the data collection and analysis techniques in the primary datasets? How will epistemological questions regarding the context of data collection be addressed? (pp. 342-343)

Overarching questions. A few overarching questions continue to shape the issues that may inform a secondary data analysis:

1. Is secondary analysis a worthwhile endeavor, given that qualitative research is co-constructed between researcher and participant (particularly in constructivist grounded theory) and secondary analysis has no such feedback loop (see Fielding, 2004)?

2. What is the requisite degree of uniqueness of a secondary analysis' inquiry that permits a secondary analysis to be separate from the primary?

3. How can a secondary analysis address the challenges posed by an extant text rather than elicited text or direct observation (see Charmaz, 2006)?

4. Is a secondary analysis able to grasp the context required to interpret the text when there was no personal involvement in data gathering (see Blommaert, 2001; Mauthner, Parry, & Backett-Milburn, 1998)?

5. Can we be sure of saturation when the primary data is finite, with no opportunity to collect further data (see Charmaz, 2006)?

6. Is the iterative and recursive nature of qualitative analysis (particularly in constructivist grounded theory) lost when the data set for secondary analysis is static rather than dynamic?

Effectively navigating these issues has the potential to produce a deeply grounded, transparent analysis that is authentic and realistic, although this is no easy task. This difficult endeavor is undertaken in Chapter 3.

Researcher Assumptions

I lay bare my assumptions here in Chapter 1 because in constructivist grounded theory there should be no secrets. What I brought to this project affected this research as much as what my participants brought. It is in the intersection of our experiences that

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re-presentation of the data is possible, but only if we are honest about we bring to the table, which clearly is not a *tabula rasa*. My journey is described below.

This secondary analysis of de-identified interviews with Mexican American female caregivers is the result of a long journey. The journey began with a focus on practitioners' perspectives of healthcare in terms of teamwork and then shifted to a focus on the patient's perspective in terms of her or his own ways of selecting and integrating care.

Initially I was curious about healthcare from the provider perspective and wanted to better understand how traditional and Western providers communicated and worked together. I was particularly interested in what made interdisciplinary teams tick, specifically those teams comprised of very diverse practitioners from altogether differing systems, such as biomedical and indigenous practitioners. My hunch was that there was some clue in their patterns of negotiation that would explain how satisfaction and a sense that one's voice is heard within the team might affect culturally responsive care and patient outcomes. My hypothesis was that the way to improve patient outcomes was to retain the individuality of the team member and the authenticity of that member's health worldview. This strategy, I thought, would allow for patterns of interaction that resulted in rich dialogue and collaboration between very diverse practitioners and that ultimately resulted in better outcomes and culturally responsive care.

However, as I dug deeper into the literature on what I perceived as diverse healthcare teams, I found that these diverse teams did not truly exist. (The unique instances in which there are small offices of providers incorporating two or more disciplines are not numerous enough to be considered representative in any way that would inform the literature about this rare set of processes.) In fact, the literature lamented the fact that these diverse practitioners did not communicate with one another,

let alone work together on teams. It was at this point that I began to shift my focus from examining the practitioner to examining the patient.

I began to think about what was realistically happening in healthcare, particularly for those populations who sought care from multiple systems. If the practitioners in these systems weren't collaborating (as was evidenced by my previous literature searches) but care-seeking populations were still using these practitioners, who was doing the selecting of care? It certainly wasn't the practitioner. It became increasingly clear to me that it was more likely the patient.

Simultaneously, I was becoming increasingly uncomfortable with some of the tenets of teamwork science (see Salas, Dickenson, Converse, & Tannenbaum, 1992; Salas, Goodwin, Burke, & Wildman, 2008). Teamwork science had become my theoretical home when I thought I would be moving in the direction of teamwork scholarship, the study of teams. Concepts such as group think and shared mental models made me question the utility of teamwork science because I worried about using a focus on constructs such as team socialization and consensus stifling member individuality when, in fact, I was most interested in looking at where teams may excel and retain their diversity.

This was an issue for me because I started to notice that the literature on teams told two different, conflicting stories: In the first, it trumpeted the importance of respect and diversity, and of honoring multiple opinions as a way to come up with innovative solutions. Conflict was good and moving through it even better. In the second, it extolled the virtues of team socialization and of group think and shared mental models— all of which, I felt, were meant to avoid conflict and find solutions at all costs, encouraging members to toe the party line, no matter whose voice remained unheard.

My foray further into the healthcare literature and my own philosophical grounding led me to focus on the individual caregiver/care-seeker. (My philosophical foundations are discussed at length in the Methodological Appendix to this project.)

Coincidentally, this shift in my thinking occurred during the rapid proliferation of discussions trumpeting the value of patient- centered care on the national stage. In thinking through my decision to focus on the patient and family, a sort of dialectical engagement of my prior knowledge/philosophical grounding and the prevailing dialogue around the importance of patient-centered care occurred. With all this in mind, I went in the direction of the patient, with all signs pointing to the individual caregiver/care-seeker as being most adept at providing the true insight and not the limiting and fragmented systems she must navigate, nor the disconnected practitioners.

Thus, for the purposes of this project, I sought understanding of how caregivers select care for themselves and their families from different, sometimes disparate healthcare systems. With this decision came a responsibility to set forth a few definitions regarding those disparate healthcare systems mentioned previously. I believe that clarification of my current understanding of health and healing systems and their associated modalities is important, as these definitions shaped my analysis and interpretation later in the project.

Definitions of terminology. Certainly, from a postmodernist perspective, undergirding these definitions are numerous sociopolitical assumptions and texts of power. However, as mentioned previously, a fundamental part of this project was to understand the scope and definition of the healthcare systems in which these caregivers find themselves. With these texts in mind, I decided upon the definitions offered.

Struthers and Nichols (2004) and Martinez (2009) express the same difficulty to which others examining the interaction between biomedical and other health and healing

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systems in the U.S. have admitted: the varying definitions, terminology, components included or excluded, research questions, and aims that describe these other health systems that make them difficult to study, let alone quantify. This difficulty is particularly prevalent in research within Mexican American populations.

For the purpose of providing definitions for the health and healing systems discussed throughout this project, biomedicine, complementary, and traditional medicine are explored briefly below. Further examination of these systems in terms of the corpora of literature that address them and the boundaries and juxtapositions that exist within this conversation is presented in Chapter 2's literature review.

Biomedicine. Biomedicine is often juxtaposed with other healing systems as the "normative" and unchanging system for health and healing, founded upon Western objectivity, analytic and continental philosophical traditions, and positivism (Clarke, Shim, Mamo, Fosket, & Fishman, 2003). For the purposes of this project, *biomedicine* was used to denote the formal or professional system (see Lopez, 2005; Kleinman, 1980) of healthcare in the U.S.

Complementary and alternative medicine (CAM). Martinez (2009) delineates two types of CAM therapies: mainstream and traditional. Mainstream therapies are associated with highly educated Anglo Americans with high incomes. Examples of these therapies include acupuncture, massage, and chiropractic. In contrast, traditional folk therapies are rooted in and vary by specific ethnicities or cultures and focus on both illness and the maintenance of well-being. Traditional folk CAM therapies are, according to Keegan (2000), "laypersons' use of household and traditional remedies" (p. 285). In a review of the literature, Martinez (2009) determined that Hispanic populations' use of folk therapies is well documented.

Like Lopez (2005), Martinez (2009) placed these folk CAM therapies under an umbrella of *curanderismo*. Others considered home remedies not administered by a specific practitioner to be part of this category of healing, although they did not call it *curanderismo* (Belliard & Ramirez-Sanchez, 2005; Campesino & Koithan, 2010; Feldmann, Wiemann, Sever, & Hergenroeder, 2008). Gomez-Beloz and Chavez (2001) included practitioners themselves, such as *curandero* (folk doctor, shaman), *santero* (saint-healer), and *espiritista* (spirit-healer), as falling under this umbrella, along with the herbs and other treatments they prescribe. Others added *partera* (midwife) and *huesoria* (bone setter) and *yerbalista* (herbalist) and the herbs and therapies they provide (Applewhite, 1995; Avila, 2000; Torres & Sawyer, 2005). However, the literature demonstrates a low percentage of Mexican Americans who report using a *curandero* and/or other similar practitioners like those listed previously or calling their traditional practices *curanderismo* (Higginbotham et al., 1990; Iniguez & Palinkas, 2003).

It is possible to denote the cultural systems of health and healing that Mexican American female caregivers access that exist outside the formal/professional biomedical and CAM systems as traditional/folk medicine (TFM), because of the dearth of reports that this population of caregivers considers their folk system that of *curanderismo*. However, for the purposes of this project, and in keeping with constructivist grounded theory, I feel a definition of any type of system is premature, particularly without consulting the data in terms of what the caregivers experience, their perceptions of what they're doing, and from where they select care.

Conclusion

Chapter 1 illuminated what has proved to be a moment of transformation in the realm of health and healing here in the United States. As scholars, policy makers,

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patients, and families strive to understand this transformation, make sense of its components, and ready themselves for its reverberations, two paradigms have surfaced.

The first is a patient-centric perspective, situated within a biomedical context that requires collaboration between provider and consumer. This perspective assumes the existence of cohesive health and healing systems from which consumers select for a myriad of reasons, and of which providers must be cognizant. The second is a postmodern perspective, a more philosophical approach that eschews the continuity of systems and concentrates more heavily on the experience of the consumer. Although the two are not entirely discontinuous, such differing perspectives lend themselves to very different interpretations of this transformation of health and healing in the United States.

Contained within this transformation are prevailing trends in the United States that speak to diversity and varied expectations of care. Coupled with these trends are issues of acculturation and biculturalism, health disparities, and a widespread pluralistic approach to health and healing in which caregivers and care-seekers move across systems.

In order to examine these trends and more deeply understand expectation and disparity, it is important to look at the experience of these diverse populations. Mexican Americans, the fastest growing ethnic population in the United States, possessed of diverse expectations, a high level of health disparity and degree of engagement in multiple systems, serve as an exemplar for this project. Of specific importance is the experience of the Mexican American female caregiver, who is shown in the literature to be the individual through whom health and healing information is filtered and processed.

This project took a constructivist grounded theory approach that uses sensitizing concepts drawn from a parent framework of complexity science. It sought to tease out

the nuances of the experience of the Mexican American female caregiver via analysis of secondary data collected during interviews with Mexican American female caregivers caring for their elderly parent with cognitive decline. Armed with insight gleaned from the caregiver experience, this project strove to contribute to a re-envisioning of health and healing systems according to both patient-centric and postmodern perspectives, mindful simultaneously of patient experience and the opportunities and limitations provided by extant health and healing systems.

   Summary/significance of this research. The effects of the rise of patient-centered care within this postmodern moment and the breaking down of the biomedical metanarrative are being felt clearly within U.S. Healthcare Reform (Conrad, 2008; Pescosolido, Tuch, & Martin, 2001). Emphasizing the centrality of the local narrative of consumer and family, these initiatives seek to identify what is valued regarding health outcomes and to reduce health disparities. This moment is marked by advocacy of patient- and family-centered care (Institute of Medicine, 2001; Joint Commission, 2010) that addresses diversity and interaction, rather than institutionalization of overarching policies that seek to encompass and homogenize all consumers and practitioners.

   The policies and guidelines emerging from the Agency for Healthcare Research and Quality (AHRQ) (2010; National Priorities Partnership, 2008), the Robert Wood Johnson Foundation (RWJ) (2009), the Patient-centered Outcomes Research Institute (PCORI), and the Institute of Medicine (IOM) (2001, 2003, 2009, 2011) demonstrated that there is tremendous interest in patient-centered care, this engagement of consumers and families in the design of new healthcare delivery systems in the United States that take into consideration the diversity of expectations of the caregiving and care-seeking populations and the variety of treatment modalities currently available in the country. These national initiatives seek to engage consumers and families in

understanding their needs and thus create healthcare systems that honor the diverse spectrum of localized narratives once overshadowed by an overarching biomedical metanarrative.

Above all, this patient-centric, postmodern moment is a liberating one, based not on a fixed and/or universal identity of patient, consumer, and practitioner, but instead on a fluid and dynamic interaction with health, healing, and one another. However, all is not well in the postmodern healthcare world. Mistrust, issues of access and integration, lack of practitioner collaboration, and a lack of clarity about why caregivers integrate care the way they do, prevails. There is much work still to be done.

Chapter 2

TRANSGRESSION?

Chapter 2 begins on the heels of a decision made and a path taken, situated within a contentious area of the grounded theory methodology literature: first, what is possible, permissible, or desirable to bring of oneself to a study; and second, whether to do a literature review, and if so, when and to what degree.

In the spirit of co-construction, I lay my decision and my path bare for the reader: Prior to performing a review of the literature, I chose to explore the data from the primary analysis that was to be used for this secondary analysis. Running alongside this decision made and path chosen, I also have a healthy amount of conceptual knowledge and a rich and varied background that I bring to this project. I explicate all this—what is to some a transgression of the tenets of grounded theory and to others, wise—and the implications in the sections that follow.

I begin this chapter by addressing the generalities of the grounded theory debate about researcher perspective and literature review. In addressing these generalities, I pit objectivist and constructivist approaches against one another according to what each side suggests it is possible, permissible, or desirable to bring of oneself to a study in addition to the timing, place, and content of a literature review. With this in mind, I situate myself within that debate regarding my particular perspective. Then, I introduce my review of the literature and my reasons for organizing it the way I did according to my prior knowledge and experience. Following all this, I present the literature review itself and my conclusions about what I read.

It is important to note that the concepts of juxtaposition and contraposition surface repeatedly throughout this chapter. Scholars' affinity for sharp-edged and clear-cut one-to-one comparison is found both in the debate about the literature review and in

the literature review itself. Where such opposing sides are useful, I try to retain them for purposes of discussion, and where they are not, I slough them off in favor of a more . . . syncretic typology. With the phrase *syncretic typology,* I refer to a way of intermixing what initially may look like incongruous views and re-envisioning them as a single, fluid recombination in dialectic with what is occurring around it.

I close the chapter by engaging my initial assumptions in rapprochement vis-à-vis what emerged in my review of the literature. I also explain how I anticipate the foundations of this project's shifting according to what emerged.

Literature review in grounded theory: The debate. To say that there is a debate in grounded theory about the place and purpose of self and literature review within a study is to drastically understate the depth and breadth of the conversation, which stretches back to the middle of the 20th century, across multiple disciplines and heterogeneous research projects. It could be said that central to the debate are diametrically opposed opinions about how much of oneself and the literature it is possible, permissible, or desirable to bring to a study. And when. Although their article explores Glaser's method versus Strauss's method and does not mention where Charmaz, who provides my constructivist methodology fits, Walker and Myrick (2006) would agree with me about the general debate. They described it as being "centered on the researcher's role and level of intervention in relation to the procedures used within the data analysis process" (p. 547).

I am aware that according to the postmodern perspective within constructivist grounded theory, labeling the opposing sides of any argument is in itself limiting and presupposes an objective reality that permits this juxtaposition. However, in order to fulfill what I set out to do in this chapter, I had to work from what the literature identifies as two sides of the debate: On one side are the objectivists (classicists), and on the

other side are the constructivists (postmodernists). Here, juxtaposition was useful for my purposes in this chapter. With these sides as identified by the literature, the debate for the purposes of this project is essentially a "collegial" discussion to agree to disagree between Barney Glaser and Kathy Charmaz.

When juxtaposing grounded theory methods with one another, it is important to note that the nuance and differing degrees of the method are often glossed over and ignored as the varieties are distilled down to the two categories to be compared. Also inherent in this juxtaposition is the appearance of the labels of *classical* (Glaser's term) and *objectivist* to describe Glaserian grounded theory, which seem to have arisen after the publication of Strauss and Corbin's work and Charmaz's inception of the constructivist method, respectively.

Objectivist

Glaser's method is one of discovering theory that is grounded in extant data (Glaser & Strauss, 1967) and is considered the classic form of grounded theory. There are three "hallmarks" (Christiansen, 2007, para. 2) of Glaser's grounded theory: First is the existence of many equally-justifiable interpretations of the same data, found by identifying the core variable, what Christiansen called "the main concern and its recurrent solution" (2007, para. 9). Second is the importance of suspending preconceptions, so that the researcher remains open and the data is permitted to emerge on its own. Third is an avoidance of descriptive interpretations, such as specifics about the data according to the researcher's interpretation) and the use instead of abstract conceptualizations, generalities about the data, via constant comparison.

Glaser considered grounded theory to be

the generation of emergent conceptualizations into integrated patterns, which are denoted by categories and their properties. This is accomplished by the many rigorous steps of grounded theory that are woven together by the constant

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comparison process, which is designed to generate concepts from all data. (Glaser, 2002a, p. 23)

For Glaser (2002b), data "is what the researcher is receiving, as a pattern, and as a human being (which is inescapable)" (para. 2). The resulting interpretation of that data is a grounded theory, an abstraction that should be able to be applied across disciplines.

Constructivist

Charmaz (2000) explicated her own methodology, constructivist grounded theory, this way: "Constructivism assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects' meanings" (p. 510). Although Glaser (2002b) allowed for the "humanness" involved when data is received by the researcher, he still maintained that classical grounded theory is not as interpretative as constructivist grounded theory and that researcher interpretations of the data have no place in the analysis. Charmaz (2006) disagreed vehemently: "Neither data nor theories are discovered. Rather we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements" (p. 10). The resulting interpretation of the data for Charmaz is an interpretation of a reality, not the only reality. And this reality unabashedly includes the researcher.

Objectivist grounded theory does identify the existence of different analyses of the data based on what is determined as central to the process and content of the inquiry. However, I offer that between objectivist and constructivist grounded theory the focus on "construction" differs by a matter of degree and disclosure, with constructivist grounded theory more intently focused on it and its centrality to findings.

Objectivist: Neither possible, permissible, nor desirable: Bring nothing.
Glaser (1978, 2001a, 2001b; Glaser & Strauss, 1967), the father of classical grounded

theory, admonished researchers to avoid preconceptions and stay open to what appears

in the data. Further, for Glaser, Strauss, and others who subscribe to the classical view

of grounded theory, the researcher must simultaneously set aside personal biases and

background and be competent and knowledgeable in conceptualizing the data (Hallberg,

2010). There are those within qualitative science who consider the setting aside of

oneself to let the data speak for itself to be bracketing,[10] but Schreiber (2001) pointed

out that grounded theorists understand that the researcher and her experience are

unable to be extracted from the research process and data analysis. Glaser disagreed:

> When I say that some data is interpreted, I mean that the participant not only tells what is going on but tells the researcher how to view it correctly…I do not mean that they are mutually built up interpretations. Adding his of [*sic*] her interpretations would be an unwarranted intrusion of the researcher. (B. Glaser, 2002b, para. 8)

Glaser (2002b), in his article questioning Charmaz's constructivist grounded

theory, asserted that the grounded theory itself, which is the product of grounded theory

methodology, "will be an abstraction from time, place, and people that frees the

researcher from the tyranny of normal distortion by humans trying to get an accurate

description" (para. 3). The researcher is released from "data worry and data doubts,"

and the focus of the project can be shifted from researcher uncertainty to "concepts that

fit and are relevant" (para. 3).

Glaser insisted that the literature review should be delayed until after completing

the data analysis (Glaser, 1963, 1978). Glaser maintained that exploration of the

literature prior to the study has its problems, because what is truly central to the data

should be trusted to emerge on its own with the objective researcher simply watching

and listening.

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[10] See Edmund Husserl and phenomenology in Behnke's (2011) helpful and thorough overview.

Constructivist: Possible, permissible, and desirable: Bring everything, and explain. For Charmaz and constructivist grounded theory, rather than bracketing, researchers should engage in thorough explication of what they bring to the research (Schreiber, 2001), in terms of both their experience prior to the literature review and their conceptualization of the data, which requires that a researcher read across disciplines and be knowledgeable.

Charmaz (2006) contended that Glaser and Strauss's position on the placement and timing of the literature review remains at best confusing: "In their battle to free new scholars from the shackles of old ideas, Glaser and Strauss either overstated their position or differed on it" (Charmaz, 2006, p. 165). As Charmaz understood their logic, a premature literature review may expose researchers to material that results in dangerous preconceptions and impositions on the data. In delaying the review, the researcher's own ideas are able to be articulated. However, Charmaz's interpretation of Glaser's reasons for delaying a literature review do lead us to look closer at Glaser's original assertions about objectivity. When a researcher articulates her own ideas instead of gleaning them from a literature review, is she actually bringing her own experience to the data? Charmaz questioned Glaser here: How does a researcher become aware of the theoretical codes that Glaser requires without first delving into the literature? I further note that a researcher's initial interest in this literature comes from her own experience in the world. She is fascinated for a reason that is woven tightly into her background: that which she cannot leave behind as she begins her study.

Charmaz (2006) insisted that while remaining mindful of the realities of research (i.e. funding, time constraints, proposal format, etc.), researchers should not let the "standard-rigid-format" of the literature review "stifle your creativity or strangle your theory" (p. 166). In fact, she supported using the structure and content, and the

assessment and critique of the literature, to a researcher's advantage: namely, to "set the stage" for later chapters' unfolding (p. 166). Charmaz laid out the literature review as a challenge to the researcher to do the following: Clarify your ideas, make intriguing comparisons, invite the reader to begin a theoretical discussion, show how and where your work fits or extends relevant literatures (p. 167). It was with this advice in mind that I engaged the literature in the way I did.

Situating Myself Within the Debate

As mentioned at the outset of Chapter 1, this project is a secondary analysis of de-identified interviews with female Mexican American caregivers. Prior to performing the requisite literature review for Chapter 2, I made the conscious decision to engage with the data and to read the grant proposal for the primary study within which these data were collected. Prior to that, I have lived 33 years on this planet, have traveled over a lot of it, and have experienced and studied things that directly informed my current project. In the following section I lay out the decisions I made regarding the literature review and the extant conceptual knowledge that accompanied me to this project.

Decisions made. My background notwithstanding (albeit important and explored throughout these chapters), my reasons for delving into the data and reading the primary study's grant report served two purposes: First, this project is a secondary analysis and second, doing so satisfied my curiosity.

First, this study was a secondary analysis. As such, it required an additional and entirely different conversation from primary analysis: namely, a tight conceptual tie of primary to secondary study. Along the way, links between the initial and secondary studies had to be put carefully into place; the relationship between the two had to be scaffolded in order to maintain the spirit of the first study as the second is embarked

upon. In order to accomplish what was required within secondary analysis, it was crucial

to understand the primary study and its data. For that reason, I looked at the data.

As explained in Chapter 1, secondary analysis had its beginnings in quantitative

methods and was at best reluctantly accepted there. Nor in qualitative circles is its

pedigree blemish-free. Indeed, secondary analysis in qualitative research has its own

epistemological problems, including the problem of data fit, the problem of not having

been there, and the problem of verification (Heaton, 2004). These epistemological

pitfalls of secondary analysis of qualitative data are further slogged through in relation to

this particular project in Chapter 3.

Second, I freely admit my curiosity. Charmaz (2008) echoed my sentiment: She

wrote, "The open-mindedness of grounded theory imbues the method with a certain kind

of curiosity and a sense of wonder about the world" (p. 132).

Although I consider my perspective to be Charmazian and my methodology to be

constructivist grounded theory, I was also very Glaserian in my decision to dip a toe into

the data prior to conducting the literature review. I was not, however, as objective as

Glaser recommended and brought myself and my perspective to that toe-dip. As the

stories started to swirl around me, I began to reach back into my experience, my

scholarship, and my travels to try to make sense of what was emerging, and at the same

time, to listen carefully for hints at the deep, underground flows of what was really going

on. As a Charmazian grounded theorist, my task then continued to be to explicate this

process authentically.

My extant conceptual knowledge. My conceptual knowledge tends to be very

abstract, both in general and in regard to this project. (In this sense perhaps I am more

Glaserian, in keeping with Glaser's assertion that the emergent grounded theory is an

abstraction.) Because I am comfortable dealing in abstractions, the sensitizing concepts

I identified in Chapter 1 as aiding me in addressing the data were, unsurprisingly, of a very high-level abstract nature. Couple this situation with complexity, the parent framework from which my sensitizing concepts came, and abstraction was inevitable. With this reality in mind, I looked at the literature, thought about what I've seen in my 33 years on this planet, and became more aware of the nature of what lay ahead in trying to understand and honor the complexity of caregiver processes of selection. Unfortunately, my discomfort with what I perceived as the extant literature's linearity and forced juxtaposition of health and healing systems became palpable. Here, I did not believe that juxtaposition would serve this project well. So, I decided to do what Charmaz (2006) suggested and go across disciplines and act as a true constructivist: to build the literature review according to what I felt was understood and what wasn't, with my population always in mind.

The sensitizing concepts I chose at the outset of this project held me to a particular vigilance—one that caused me to constantly question, re-visit, re-envision, and re-frame, all the while remaining mindful of interaction, interrelationship, and interconnectedness. Although these are good skills to have regarding theoretical sensitivity, the "standard-rigid-format" of the literature review (Charmaz, 2006, p. 166) does not lend itself kindly to such constant iteration. However, complexity science, the parent framework for these sensitizing concepts, does.

Complexity science, as discussed in Chapter 1 and excavated more thoroughly in Chapter 3, allows for the study of complex systems comprised of individuals who act and interact within and across these systems in nonlinear ways that are not always entirely predictable or readily visible (Richardson, Cilliers, & Lissack, 2001). According to complexity theory, actions among individuals are interconnected; one individual's actions affect those of other individuals and other systems, resulting in emergent,

nonlinear behavior and interaction that is fluid, dynamic, and fraught with tension and contradiction (Page, 2009). Complexity contends that there is always an inherent pattern to this behavior, however hidden it may be at the outset (Plsek & Greenhalgh, 2001). The sensitizing concepts used in this project that sit within the parent framework illuminate the choices of diverse caregivers moving within multiple healthcare systems. They are also well suited to examine the intricacy, dynamism, and fluidity that manifest within this population as explored in the literature reviewed that unfolds in the next section.

Literature Review

This literature review was built upon three premises. First, acculturation processes and biculturalism are prevalent in the Mexican American population, as members of this population receive and negotiate what was described in Chapter 1 as "cultural streams" from both their birth and host cultures. The reception of dual cultural streams informs this population's overarching perception of reality—the choices they make and how they live their lives. As demonstrated below, anticipating their decisions is difficult, with streams' strengths shifting in terms of influence and extant feedback loops within this reality. This bifurcated and fluid reality also informs this population's health and healing practices: One-half to 90% of the population engages in alternative health and healing systems comprised of Hispanic folk practices (Dole et al., 2000; Ortiz et al., 2007; Zenk et al., 2001). The literature also demonstrates the existence of "a Hispanic health subculture" (Robleado et al., 1999) of which Mexican Americans are a part. Second, little is understood about how patients and caregivers select from multiple, diverse, and sometimes contradictory healing and health care systems (Lovell, 2009; Xu & Farrell, 2007). This use of multiple health and healing systems is identified in the literature as a concept called medical pluralism. What is known about medical pluralism

in this population amounts only to identification of their interaction with multiple health and healing systems, which results in "fluid, overlapping ideologies that allow for new ways of healing to be rapidly incorporated" (Belliard & Ramirez-Sanchez, 2005, p. 271). Third, less still is known specifically about the interplay of acculturation, biculturalism, and medical pluralism and how this interplay informs Mexican Americans' selection and integration of care from multiple health and healing systems (LaVeist & Isaac, 2013).

At the center of these premises sits the female Mexican American caregiver (Martinez, 2009), who is often solely responsible for accessing care for herself and her family from both formal and informal health and healing systems (Lopez, 2005). Although central to further insight into Mexican Americans' selection of care, like the prevailing lack of clarity about Mexican Americans' engagement with health and healing systems, this woman's method of selecting care remains poorly understood and unexamined (Brettel & de Berjeois, 1992; Lovell, 2009; Xu & Farrell, 2007; Yanagisako, 1977). It is in this space that the literature review begins.

In keeping with the premises listed, I chose to examine the literature describing those concepts that sit closest to where the gap in the literature lies: acculturation/biculturalism and medical pluralism. Rather than keeping these concepts separate as has generally been the case in the literature, I chose to explore them in tandem in the belief that doing so had the most potential for taking us a few steps into that gap in order to begin to bridge it.

Acculturation/biculturalism serves to describe Mexican Americans' reality. As mentioned previously, bicultural individuals like this population negotiate dual cultural streams that may vary in degree from one day to the next or from one context to the next. In choosing to engage in or disengage from a cultural stream, these bicultural individuals make decisions about that reality that are of a dynamic nature, situated within

feedback loops that may also vary. Their decisions inform health and healing as well, and in turn this population's engagement or disengagement in particular health and healing systems or practices.

Medical pluralism organizes the perceptions of these individuals regarding health and healing according to systems and structures. Medical pluralism provides conceptual structures to organize those perceptions in ways that enable them to be examined and strives to understand how and why these individuals perceive and move through extant systems in the way in which they do.

In beginning to bridge the gap, my goal for this literature review was twofold. My first goal was to search for those variables within acculturation/biculturalism that may inform caregiver navigation of health and healing systems. My second goal was to explore the organizing frameworks and models provided by medical pluralism. In conducting this exploration, I hoped to determine what options were available in conceptualizing these variables from a healthcare system perspective and how the available options informed caregiver navigation. In the spirit of letting my journey through the literature emerge as the reader reads, I will not spoil my conclusions—but suffice it to say that I was surprised by what showed itself; even my prior knowledge was unable to adequately prepare me for my findings.

Acculturation/biculturalism. As mentioned in Chapter 1, acculturation describes what results when individuals and groups from different cultures have direct contact with one another.[11] Biculturalism is a subset of the processes of acculturation.

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[11] An exhaustive historical discussion of acculturation is outside the scope of this project; for such a discussion see Park's (1914) three-stage model: contact, accommodation, and assimilation out of the University of Chicago's School of Sociology (the "Chicago School"); anthropologists Redfield, Linton, and Herskovits's 1936 work on first-hand contact; Teske and Nelson's (1974) psychological perspective on acculturation; Berry's (1980) four varieties of adaptation: assimilation, integration, rejection, and deculturation; and Padilla (1980, 1987) and Keefe and Padilla's (1987) multidimensional model of acculturation with two "supraconstructs" that are

Biculturalism denotes an individual or collective reality that comes from negotiating two distinct cultural "streams" (see Schwartz & Unger, 2010): that of host culture and that of birth culture. In the case of the Mexican American population, the cultures to be negotiated are "Mexican" and "American" and whatever each of those may mean at any given moment. This similarly bifurcated reality informs the Mexican American population's perceptions about health and healing. The literature shows that this population is engaged in multiple systems and to a high degree (Dole et al., 2000; Ortiz et al., 2007; Zenk et al., 2001).

In their seminal literature review, Lara and colleagues (2005) demonstrated that acculturation and biculturalism are phenomena that are shown strongly in the literature as informing health outcomes in diverse populations, and in particular in Latino populations, of which Mexican Americans are a part. Latinas, which include Mexican American women and the population under scrutiny in this project, have been shown to be central figures in health and healing and are the subject of specific inquiry around acculturation and biculturalism (Amaro & de la Torre, 2002; Fuentes-Afflick & Hessol, 2008). Acculturation and biculturalism are also linked to prevalence of health disparities in Mexican Americans and inform this prevalence in unexpected ways (Pérez-Escamilla & Putnik, 2007; Ruiz, Steffen, & Smith, 2013; Zambrana & Carter-Pokras, 2010) that are explored in the following sections.

In examining what the literature presents as processes of acculturation and Mexican Americans' biculturalism that are fundamental to health and healing, I hoped to tease out a cluster of variables that may inform caregiver navigation of health and

outside the scope of this project but interesting nonetheless: cultural awareness and ethnic loyalty. Roger Bastide (1948/1998), a French sociologist, distinguished three types of acculturation: spontaneous acculturation, where contact between cultures is free; forced acculturation, as in slavery or colonization; and controlled acculturation, as in the case of the former Soviet Union. His book, *Initiation aux recherches sur les interpenetration des civilizations*, last published in 1998, remains out of print.

healing systems. I refer to these as indicators of engagement and disengagement in those health and healing systems.

The variables that the healthcare literature touts as dictating Mexican Americans' engagement or disengagement in health and healing systems, such as access[12] and insurance coverage, are, when understood through the lens of acculturation and biculturalism, the product of a constant re-definition and re-negotiation of individuals' identity. In keeping with the shifting, environment-informed feedback loops of cultural streams, this population's choices regarding health and healing are similarly fluid. However, current models of acculturation are not sufficient to understand this fluid process of choosing when to engage and when not to engage. Current models of acculturation

> rest too heavily on (a.) a static view of intergroup relations that does not address important concerns related to the motivation to acculturate; (b.) a belief that acculturation is more or less a uniform process across all newcomer groups regardless of race, culture, or social status; and (c.) a methodology that is limited to its reliance on self-reported language use preferences, entertainment practices, and friendship patterns. (Padilla & Perez, 2003, p. 50)

Padilla and Perez (2003) put forth a model instead that is better suited to facilitate understanding of the dynamic interrelationship between Mexican Americans and the systems in which they find themselves. Padilla and Perez asserted: "Acculturation is a social process that occurs in a context in which newcomers and members of the host culture are in dynamic contact with each other" (p. 51). In this context, "some identities relate to membership in the host culture, and others reflect attachment to values of their heritage culture (p. 50). There is recognition of a nonlinear quality of acculturation that characterizes the current theories seeking to explain it.

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[12] By using the word "access" here my intent is not to give merit to access in a biomedical context (i.e. having insurance or a regular physician). My intent instead is to use access in its broadest sense, meaning that this population's issues of access exist within all systems in which they participate—from decisions regarding from which culture to select treatment to the lack of collaboration on the part of practitioners within different systems.

Biculturalism, a subset of acculturation and understood as its most adaptive form (Mistry & Wu, 2010), provides further insight into acculturation's nonlinear qualities.

Biculturalism was initially defined in a straightforward and fairly reductionistic fashion: according to choice of language, choice of friends, and choice of media, particularly in the case of Hispanic Americans (Cabassa, 2003). Then, its definition began to grow in complexity as a personalized and unique amalgamation of heritage and receiving cultures (Benet-Martinez et al., 2002). Iterating this concept further, Schwartz and Unger (2010) wrote:

> A truly bicultural person would intermix their [*sic*] heritage and receiving cultural streams with regard to cultural practices, values, and identifications. This means that biculturalism implies not just behaving in ways consistent with the two cultural contexts, but also holding values from one's heritage and receiving cultural streams, as well as identifying with both cultures. (p. 27)

In its current iteration, biculturalism is more fluid and dynamic, and as articulated by Schwartz and Unger (2010), entails mixing practices and values and receiving diverse "streams" from each culture of which an individual is a part.

Their bifurcated and fluid attachments of acculturation and biculturalism extend to Mexican Americans' healthcare choices regarding engagement and disengagement. With this in mind, it becomes clear that these choices cannot be explained adequately by something as linear as whether an individual has insurance. Instead, the conversation is more about what occurs around these processes of engagement or disengagement that may inform them. I identified three variables in the literature as informing Mexican Americans' engagement or disengagement in health and healing systems. They were cultural frame switching, degree of acculturation, and degree of practitioner collaboration.

Cultural frame switching. Mexican Americans possess a unique health worldview that is built upon a foundation of culture (Spector, 2004), and within that

culture, according to Weidman (1982), a "health culture." This health culture is comprised of individuals' or groups' ways of maintaining health and addressing illness within the overarching culture's "social networks and institutional structure . . . an integral and essential part of the cultural tradition of an ethnic group" (p. 208).

Mexican Americans' unique health worldview (Dunn, 2002; Spector, 2004) is based on perceptions of health and illness. According to Lopez (2005), in her reading/translation of Videla, Leiderman, and Sas (1992), this worldview includes formal healthcare systems (the receiving country's practices—i.e. biomedicine) but also what Lopez (2005) translated as "complementary" or "parallel health care systems derived of traditional Mexican Indian folk practices and spiritual belief systems" (p. 23) (the heritage country's practices—i.e. Mexican folk practice).

One way of understanding this complex process of negotiation of multiple cultural streams in the context of health and healing is via what Ramirez-Esparza and colleagues (2006) identified as *cultural frame switching*. Cultural frame switching is "where bicultural individuals shift values and attributions in the presence of culture-relevant stimuli" (p. 100) (see Hong, Chiu, & Kung (1996) and Hong, Morris, Chiu, & Benet-Martinez (2000)). As mentioned previously, bicultural individuals are often bilingual, and it has been demonstrated that when people shift frames, the language they use changes as well.[13]

The mechanisms of cultural frame switching in biculturals provide further evidence of the relationship of bicultural individuals to their environment as one of dynamic interaction between environment and identity and prevailing cultural streams, particularly regarding health and healing. For example, in Mexican American adolescents, shifting cultural identities when responding to tobacco promotion and

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[13] In fact, previous research shows that language use affects bilinguals' responses to surveys (Bond & Yang, 1982; Ralston, Cunniff, & Gustafson, 1995; Yang & Bond, 1980).

prevention advertisements were demonstrated in one Robert Wood Johnson Foundation (RWJF) study (Comello & Kelly, 2012). The authors concluded: "Making it in America while remaining true to Mexican heritage is a much-admired outcome" (Comello & Kelly, 2012, para. 2). What "making it in America" and "remaining true to Mexican heritage" may mean from one moment to the next as these perceptions intermix with adolescents' received streams remains elusive.

Cultural frame switching permits bicultural individuals to make decisions about identification with cultural streams, but the literature demonstrates an inconsistent application of these streams regarding health and healing.

Regarding healthcare and health outcomes in bicultural Latinos (usually grouped with Hispanic populations, of which Mexican Americans are a subset), LaVeist and Isaac (2013) admitted that the data are "very complex and not well understood" (p. 225). For example, "selective biculturalism" was reported by Laganá (2003) in the context of pregnancy. Selective biculturalism is exactly what it sounds like—choosing when to engage in one cultural stream versus another and switching cultural frames when necessary. Obviously, there are no objective rules or guidelines for these choices; the choices are those of the individual. In the context of pregnancy, selective biculturalism was shown to be used specifically as a tool used by Mexican American childbearing women to reduce stress and promote health (Laganá, 2003).

Apparent in the literature review is that cultural frame switching clearly informs Mexican Americans' engagement or disengagement in systems. As evidenced by the examples of the selective biculturalism of pregnancy in Hispanic populations and the shifting Mexican/American identities demonstrated by the seminal Robert Wood Johnson study cited, this engagement or disengagement is fluid. The decisions that Mexican Americans make regarding which cultural stream to accept, when and to what degree,

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inform their choices about which culture to align with, when, and to what degree. The

reasons behind these choices are not well understood and seem to evince a host of

environmental cues and individual choices related to selection of one cultural stream

over another. The literature explores at length neither what happens when frames seem

to be congruent with one another nor how/if overlays of culture on top of culture may

occur. This may be a space for further research that could lend itself to finding

intersection points between these frames and identifying the resulting opportunities in

those intersections. For our purposes in this project, the cultural frame chosen informs

this population's subsequent involvement in the health and healing systems and health

subculture appropriate for that decision, leading to engagement or disengagement in this

or that health system.

     Degree of acculturation. The multidimensional quality of Mexican Americans'

negotiation of cultural streams regarding health and healing is demonstrated repeatedly

in the corpus of literature on acculturation. Clearly, "there is no doubt that acculturation

has to be understood as a very dynamic longitudinal process involving complex

interactions between individuals and the different environments in which they live at

different stages of their lives" (Pérez-Escamilla, 2009 p. 990). Degree of acculturation in

this population informs engagement in health and healing systems and related

outcomes, and there is a preponderance of evidence that associates degree of

acculturation with socioeconomic position and health disparities. For example, higher

degrees of acculturation have been demonstrated to positively affect socioeconomic

position and (biomedical) healthcare access and to reduce health disparities (Zambrana

& Carter-Pokras, 2010). Despite the theoretical relevance of acculturation, however,

research findings are mixed.

For example, some research claims that Mexican Americans' engagement in folk systems declines as certain variables, such as acculturation and resulting English language proficiency, increase (Arcia, Skinner, Bailey, & Correa, 2001; Lee, Goldstein, Brown, & Ballard-Barbash, 2008). Barron, Hunter, Mayo, and Willoughby (2004) echoed these claims, pointing to studies that show the more acculturated the individual, the more likely she or he is to engage in a biomedical paradigm for health and healing. Kiesser, McFadden, and Belliard (2006) offered a different perspective on these findings, writing: "This shift [to biomedicine] is not due to a change in preference, however, but because biomedicine becomes a more acceptable option as it becomes more familiar and accessible" (p. 227).

However, other studies show different results: that as acculturation occurs and generations maintain residence in the U.S., engagement in folk systems remains, specifically regarding health and healing (Lopez, 2005; Magana & Clark, 1995; Zenk et al., 2001). In this regard, acculturated individuals simply broaden their health and healing armamentarium to include options from both their host culture and their birth culture. They engage more readily in more diverse systems, drawing in the biomedical perspective and adding it to their extant systems. The literature does not demonstrate that they find this expansion conflictual but instead that these individuals move smoothly across broader health and healing paradigms, taking advantage of all options around them (Hunt, Arar, & Akana, 2000).

There also exists research demonstrating that variables such as language barriers and lack of insurance are reasons for an individual's continued engagement in folk medical systems. However, other studies show that these same groups are likely to disengage from folk systems, adhering instead to biomedical treatment for fear of harmful interactions with their traditional practices (Campesino & Koithan, 2010). Still

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other studies are unable to anticipate either engagement or disengagement: In Hispanic

adolescents, acculturation, insurance status, socioeconomic status, and having access

to a healthcare provider were found not to be indicative of engagement or

disengagement in folk medicine systems (Feldmann et al., 2008).

The literature has begun to reveal a relationship between individuals'

engagement in folk traditions and positive health markers in certain areas in ethnic

populations, and a relationship between increased acculturation and adverse health

outcomes (Coe et al., 2004). Put simply, the greater the degree of acculturation and

thus engagement in American culture and associated health and healing systems, the

higher certain adverse health indicators. Higher degrees of acculturation have been

shown to negatively affect factors such as diet and associated conditions, for example

diabetes and obesity (Pérez-Escamilla, 2009). Nowhere have these relationships been

more closely examined than within Hispanic populations, and specifically in the context

of Mexican Americans. This phenomenon is called the Hispanic paradox (Franzini,

Ribble, & Keddie, 2001).

The paradox has been hotly contested; Palloni and Morenoff (2001) and Smith

and Bradshaw (2006) argued that methodological flaws produced the data upon which

the Hispanic paradox is based. Morales et al. (2002) insisted that there are no

methodological flaws. A 2013 literature review by Ruiz et al. continued the discussion:

The group found that Hispanic populations have a mortality rate that is 17.5% lower than

that of other racial groups.[14]

Gonzales, Castro, and Coe (2007) illustrated the Hispanic paradox: Among

Mexican American women who are less acculturated than those who have been in the

United States for a longer time or who were born in the United States, continued

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[14] Hispanics had a lower mortality rate than non-Hispanic Whites and non-Hispanic Blacks.
However, Hispanics had a higher overall mortality than Asian Americans.

engagement in traditional ways may improve certain health outcomes; in contrast, a loss of cultural traditions during the process of acculturation may promote disease or disorder. This assertion stems from lower rates of adverse health outcomes in Mexican Americans with lower levels of acculturation.

Substitution of barriers such as lack of money or insurance to hide less quantifiable obstacles to access to care, such as lack of cultural compatibility (Belliard & Ramirez-Sanchez, 2005), religious differences (Ransford et al., 2010), and use of informal networks of "co-ethnics" (Menjivar, 2002), have also been cited in the literature. Folk systems have their own unique tensions, however, such as ostracization of the caregiver if care is perceived as not being in keeping with what the family or other networks recommend (see *familismo*, discussed in the next section), or if a particular favor is not paid back (Belliard & Ramirez-Sanchez, 2005).

Although a debate exists in the literature regarding the purported decline in engagement in folk practice, such a decline may not be due to an actual decrease in use of multiple systems and ultimate reliance solely on biomedicine. Instead, this decline may be due to increased rates of caregiver/care-seeker refusal to disclose to researchers and practitioners their continued engagement in both systems (Higginbotham et al., 1990).

Further obscuring the issue of acculturation and engagement/disengagement in health and healing systems is that research shows variability in findings according to the way in which acculturation is measured, as well as to the specific context. There are many ways to measure acculturation. A seminal literature review by Thomson and Hoffman-Goetz (2009) is exhaustive in terms of describing options for acculturation measurement but does highlight numerous conceptual issues that were touched on by others, including Hunt, Schneider, and Comer (2004), Lara et al. (2005), and Zsembik

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and Fennell (2005). There exists within measurement of acculturation, according to Alegria (2009), in her commentary on Thomson and Hoffman-Goetz (2009), "the tension between what we *need* to measure and what we *can* measure" (p. 996, emphasis in original). Alegria (2009) lamented:

> As a result, the field has been inundated with single item measures (such as language, place of birth, nativity, time in the US, and generational status) which serve as proxies for the acculturation process, rather than more lengthy acculturation scales that measure a whole range of behaviors and preferences. (p. 996)

Some scholars asserted that these single-item, or "proxy," scales are useful and effective in determining degree of acculturation (Cruz, Marshall, Bowling, & Villaveces, 2008).

Resurrecting a construct that has appeared numerous times throughout these first two chapters, Pérez-Escamilla and Putnik (2007) offered an additional way to limit what may be methodological weaknesses in acculturation measurement processes: by addressing levels of biculturalism. These scholars contended that bicultural individuals are better equipped to function in both their birth and host cultures, what Schwartz and Unger (2010) called negotiating "cultural streams," as discussed in Chapter 1, and thus may skew acculturation findings. To combat this possible skew, Pérez-Escamilla and Putnik suggested that individuals be placed into four distinct categories: *Assimilated*: gave up birth culture, participate fully in host culture; *Integrated/Bicultural*: integrate host and birth cultures; *Separated*: retain birth culture, do not attempt to participate in host culture; or *Marginalized*: did not retain birth culture and do not attempt to participate in host culture.

Also taking the limitations of measurement into consideration, Thomson and Hoffman-Goetz (2009) suggested using theoretical models rather than scales as a strategy for exploring degree of acculturation and its relationship to

engagement/disengagement, socioeconomic position, and health disparities. The utility

of theoretical models was echoed by Abraído-Lanza, Armbrister, Flórez, and Aquirre

(2006), Arcia et al. (2001), and Castro (2007). These scholars championed the use of

theoretical models, specifically in public health contexts, to bolster understanding of

acculturation processes.

I offer that perhaps theoretical models could be useful not only in public health

settings but also in projects such as mine that are dealing with multiple variables in

dialectic with one another and the environment around them. Also of use to my work is

the categorization laid out previously by Pérez-Escamilla and Putnik (2007) since

negotiation of cultural streams and levels of biculturalism also seem to inform

acculturation processes and their results. With this in mind, I continue on to the last

variable under consideration: degree of practitioner collaboration.

Degree of practitioner collaboration. The ability of members of the Mexican

American population to move between their birth and host cultures regarding

engagement in health and healing systems is influenced by the context of their

interaction with those systems. Research findings indicate that there is significant

fragmentation between traditional and Western systems, and patients have to contend

with health and healing practitioners and systems that collaborate with neither the

patient and family nor one another.

The difficulty in collaboration and lack of communication between providers,

patients, and systems are major contributors to underuse of services on the part of the

caregiver/consumer, lack of care coordination on the part of practitioners, and adverse

outcomes (Cobra-Bramble et al., 2004; Dunn, 2002; Hollenberg, 2006; Howell et al.,

2006; Iniguez & Palinkas, 2003). This lack of collaboration has also been shown to

exacerbate health disparities in many populations that use a combination of biomedical

and traditional medicine, including those populations living in Western countries possessed of a prevailing biomedical paradigm (Dunn, 2002; Gruen, Weeramanthri, & Bailie, 2002; McGrath, Ogilvie, Ravner, Holwea, & Patton, 2005; Mizrachi & Shuval, 2005; Murguia, Peterson, & Zea, 2003; Turton, 1997).

Regarding patient/practitioner relationships, Keisser and colleagues (2006) asserted that patients' choice to engage or not engage with a provider and the system is driven by what type of relationship they have or anticipate having with a given provider. These relationships are colored by four values, embedded and common in Mexican American culture and outlined by Barron and colleagues (2004): *simpatico*, which dictates that a patient be respectful and look as if he or she understands and intends to be compliant with the treatment recommendations; *familismo*, which dictates that family members be involved in healthcare decisions; *respeto*, which is the need to be respected by the practitioner; and *personalismo*, which is the need to be treated as a unique individual by the provider. *Simpatico* is a multifaceted phenomenon that may hinder a patient's ability or courage to clarify a misunderstanding with a practitioner. *Familismo* permits multiple opinions and family member perspectives to enter into the health and healing conversation with the practitioner, effectively complicating it. *Respeto* and *personalismo* may inform a patient's choices to continue working with a practitioner or adhering to treatment.

Regarding practitioner/practitioner relationships, the literature shows that collaborative efforts among practitioners are lacking (Belliard & Ramirez-Sanchez, 2005); biomedical and ethnobotanical/folk practitioners do not collaborate with one another at a level prescribed by current academic models and policy mandates (Gruen et al., 2002; Hollenberg, 2006; Hollenberg & Muzzin, 2010; McGrath et al., 2005). Several studies devoted specifically to studying this interaction found that biomedical

and traditional medicine practitioners have little or no communication (Hollenberg, 2006; Hollenberg, Zakus, Cook, & Xu, 2008; Willis, 2006). Illustrating the difficulties that may precipitate this lack of communication is a study by Clark, Bunik, and Johnson (2010). The authors described their collaborative efforts with folk practitioners (*curanderos*) in helping Latino families combat childhood obesity as "problematic" and "likely due to differing personal characteristics . . . and tension between our healing professions" (p. 4).[15]

Regarding system/system collaboration, a seminal study conducted by Kiesser et al. (2006) at Loma Linda University's School of Medicine with the participation of Southern Californian Mexican American families, determined that:

> Although these families sought to use an integrative, pluralistic approach to health care decisions, the antagonism of the biomedical system toward TCAM [traditional complementary and alternative medicine] and structural barriers in access, language, and provider-patient relationships often forced these families into either/or health care decisions. (p. 224)

Collaboration informs Mexican Americans' engagement or disengagement in health and healing systems. Reconciling differences between cultural values such as *simpatico* and practitioners' suggestions when they are incongruous or given without consideration of other treatments, in addition to hostility, disparagement, or simple lack of awareness on the part of one practitioner to another, affects the way in which patients and families use services and systems. According to Kiesser et al. (2006), "These barriers are erected from both sides—traditional and complementary and alternative

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[15] Luna (2003) suggested remedying these collaborative deficiencies with practitioners from an emerging group of providers called Nurse Curanderas. According to Luna, these individuals integrate curanderismo with allopathic healthcare, an approach that is believed to improve outcomes by improving compliance. Based on the experience of Clark et al. (2010), specifically regarding the "explosive" (p. 9) nature of their confrontations with curanderos, it seems likely that difficulties may continue. Although this topic is an interesting piece of the collaboration discussion, further exploration is outside the scope of this project.

medicine being stubbornly defensive while biomedicine often maintains a very

condescending attitude toward other healthcare systems" (p. 225).

The research exploring acculturation/biculturalism in the context of health and

healing identifies a dynamic interrelationship between cultural streams and negotiation of

these streams. An individual's or group's engagement in cultural frame switching, their

degree of acculturation, and the way that the individual or group perceives collaboration

between themselves, practitioners, and the diverse systems in which they find

themselves informs this interrelationship. At best, the corpus of literature on

acculturation and biculturalism hints at a complex and nonlinear pattern that may hide

underneath such straightforward variables that have been identified by the literature as

informing Mexican Americans' engagement or disengagement in health and healing

systems.

Medical pluralism. As demonstrated in my review of the literature thus far,

Mexican-Americans receive cultural streams from their host and birth cultures and

navigate these bifurcated realities. This navigation extends to health and healing as

well. The literature on acculturation and biculturalism demonstrates that this population

uses multiple health and healing systems, although a complete picture of the intricacies

of this usage remains to be seen. Highlighted by my review of the literature on

acculturation and biculturalism were the nonlinearity and dynamic interaction that

characterize this population's acculturation processes. Cultural frame switching, degree

of acculturation, and degree of practitioner collaboration were three variables teased out

that served to inform this population's engagement and disengagement in health and

healing systems. Although these three variables proved far from straightforward, they

did help me to continue moving through the literature, highlighted gaps, and provided

options for moving forward (like Thomson and Hoffman-Goetz's (2009) assertion of

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theoretical models' utility). With these variables and their lack of tidiness in mind, the sections that follow explore medical pluralism and the conceptual health and healing structures within which it may be possible to sort at least some of what was contained in these variables.

Medical pluralism is defined as use of or engagement in more than one medical system to address health and illness (Chun-Chuan et al., 2010; Wade et al., 2008). Medical pluralism as a construct is not new (Kaptchuk & Eisenberg, 2001; Starr, 1982). It has been widely demonstrated in ethnic populations within the United States (Crandon-Malamud, 1991; Janzen, 1982; Pescosolido et al., 2001; Reiff et al., 2003; Steuter, 2002; Waldram, 2000).

Gilbert (2004) provided an example of medical pluralism from South Africa: in pharmacies in Johannesburg, "Western" medicine (allopathic, pharmaceutical) and indigenous complementary/alternative medicine (spiritual, herbal) are both prescribed on the same premises. The two types of care are not necessarily prescribed on a one-to-one ratio, nor are they always prescribed simultaneously or separately. Gilbert concluded that the two separate systems demonstrate medical pluralism and exist in "relative harmony side-by-side" (p. 547).

Medical pluralism's focus is on illness/health classification, which can be understood simply as how the caregiver or care-seeker perceives the disease. For example, the disease could be spiritual or physical, or in some cases, like that of the Aboriginal Warlpiri people of the Northern Territory of Australia, as *yapa-kurlangu,* "belonging to the Aboriginal people" or *kardiyla-kurlangu*, "belonging to the white people" (Saethre, 2007, p. 97). In the case of the Warlpiri, both types of disease exist, and both can be contracted by Aboriginal people. This population says that they choose treatments according to the class of illness they believe they are suffering from—each

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type of practitioner, White (biomedical) and Aboriginal, is able to treat only her or his respective types of illness. Of course, the division in this example, as with many pluralistic systems, is neither clear-cut nor obvious, but is used here only as an example to illustrate the illness/health classification concept. Within the corpus of medical pluralism scholarship, scholars have attempted to define this classification, label the systems that are involved, discover how perception of the origin of illness or health dictates the health and healing systems used,[16] and determine what within the experience is measured empirically.[17]

As evidenced by Saethre's (2007) and Gilbert's (2004) examples cited previously, the most basic and prevailing distinction of the study of pluralistic medical systems is what Fabrega (1997) referred to as the "dichotomization" or "contraposition" of traditional and modern medicine. Although a contrapositioning of the two types of systems presents opportunities to study the systems' relationships with one another, there are those who believe this structure is limiting; this argument will be addressed.

Models of medical pluralism. Medical pluralism is included in this literature review because of its ability to provide models that aid in the conceptualization of extant health and healing systems and their interactions with one another. There are those, such as Kiesser and colleagues (2006), who profess that "medical pluralism is what we practice when given the freedom to do so" (p. 225). These scholars contended that "medical duality results from barriers erected that prevent access or seek to convince us that one method is better than another, or by a lack of research, validation and understanding of alternative approaches to health" (p. 225).

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[16] See Evans-Pritchard's (1937) super-natural forces of illness and Foster's (1976) naturalistic versus personalistic illnesses.
[17] See Browner, Ortiz de Mondellado, and Rubel's (1988) discussion of empirical components in traditional and folk systems.

Nevertheless, as with so many other concepts, phenomena, and paradigms within this project, texts of power, binary opposition, and the Other are present in the scholarly conversation concerning medical pluralism and deserve a brief examination. Although medical pluralism is seen as a "freedom" of sorts (Kiesser et al., 2006, p. 225), the medical pluralism scholarship and models explored in the following paragraphs clearly delimit certain "sectors" that are boundaried by specific types of care or paradigms containing associated health and healing modalities. Inherent in these sectors is a dualism that identifies a biomedical perspective and an "Other" perspective (traditional/folk). In the case of the models and scholarship I discuss, additional sectors are identified that attempt to reconcile this duality. Kiesser and colleagues (2006) also identified this dualism: "Efforts to understand people's health beliefs and choices are often framed against a dualistic backdrop. This seems particularly true when trying to understand the health practices of minority or immigrant populations" (p. 225). Aware of the texts of power and the Other, it still behooves us to examine medical pluralism and its associated scholarship and models for reasons discussed in the following paragraphs.

In the case of this project, focused on the Mexican American population and on female caregivers in particular, there are two medical pluralism models whose components are particularly useful. The two widely used medical pluralism models chosen for examination are those put forward by Kleinman (1980) and by Gray (1998). They are useful for our purposes here for three reasons. First, these two models serve to situate us in the medical pluralism scholarship, providing a snapshot of the field in its iterations. Second, the models share some common elements and provide some opportunities for comparison. Finally, a discussion of these two models opens the door to other possibilities that use these frameworks as a jumping-off point. Each of these

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models and its conceptual gaps is described in the following sections, followed by a discussion of an alternative perspective on medical pluralism.

Examining caregiver navigation of systems according to the various structural components of Kleinman's and Gray's models, described in the following paragraphs, lent insight to this project. However, as demonstrated previously, the complexities of the acculturation/biculturalism literature describing Mexican American caregiving and care-seeking populations, in addition to the texts inherent in the medical pluralism conversation itself, do not always tidily lend themselves to structure. With this in mind, the boundaries between the models' categories may not always be as distinct or exact as Kleinman and Gray suggested in terms of this project and its unique population.

Kleinman's model. Kleinman's (1980) model is a seminal medical pluralism model rooted in both medical anthropology and clinical psychiatry. While useful in understanding medical pluralism writ large, for the purposes of this project, Kleinman's model also provides us a straw man with which to explore differing opinions of what pluralism may mean.

Kleinman (1980) described his model as a "local cultural system composed of three overlapping parts" (p. 50). The core elements of his model are three sectors within healthcare systems: popular (laypeople), folk (indigenous), and professional (biomedical); the ways in which these sectors do or do not interact with one another; and the role of the patient in that interaction.

The professional sector is simply the organized healing professions. Generally this is modern medicine (biomedicine), although in countries such as India and China and in Muslim countries, traditional Ayurvedic and Chinese medicines are also part of this sphere, as is Galenic-Arabic medicine, respectively. Kleinman (1980) discussed "indigenization," changes to modern medicine that occur when this modality is

introduced into non-Western societies. Lock and Nguyen (2010) echoed this notion:

"Biomedicine is not (and never was) a monolithic institution largely confined to hospitals

and clinics" (p. 360). In fact, the authors emphasized so many "local sites" where

biomedicine was affected and transformed by local culture that they declared, "The

center could not hold without the periphery" (Lock & Nguyen, 2010, p. 360).

The folk sector is, according to Kleinman (1980), nonprofessional,

nonbureaucratic, and specialist. For Kleinman, the folk sector "shades into the two other

sectors of the system" (p. 54). The efficacy of folk healing is difficult to ascertain,

particularly from a biomedical, empirical perspective.

Kleinman's (1980) popular sector is the largest part of any system, the least

studied, and the least understood. It is concerned with health maintenance, not

sickness. Kleinman referred to the popular sphere as "a matrix containing several

levels: individual, family, social network, and community beliefs and activities" (p. 50).

The popular sector could contain the nudge to head outside for *la passegiata,* the

evening walk taken by Italians and transported to Italian American communities—good

for the health and good for socialization. It could also be dark chocolate and red wine

shared between female friends during "that time of the month." Another example might

be vitamin B for a hangover when someone has been "overserved." All these examples

are situated at the crossroads between scientific basis and cultural proclivity.

Kleinman's (1980) model leads us to two premises. First, Kleinman's model

implicitly recognizes what he categorizes as boundaried sectors that contain a

biomedical and a separate "Other" category, and an additional category that allows for

reconciliation of the two. In Kleinman's model, the two sectors manifest as

"professional" and "folk," and the third sector is "popular." Of the popular sector's

reconciliatory role, Kleinman wrote:

The structural components of healthcare systems . . . primarily interact because patients pass between them. The popular sector forms an undifferentiated matrix linking the more highly differentiated professional and folk sectors. The boundary lines between sectors function as points of entrance and exit for patients who follow the trajectories of their illnesses through the intricacies of the health care system. (p. 60)

For Kleinman, the popular sector is the nexus of the boundaries between the three different sectors, since the professional and folk sectors rarely come in contact with one another.

The second premise inherent in Kleinman's (1980) model stems from the first. Within these boundaried sectors, Kleinman observed that it is the layperson, and not the practitioner, who makes decisions about consulting with practitioners, complying with treatment, and choosing other alternatives. Kleinman wrote:

The customary view is that professionals organize healthcare for lay people. But typically lay people activate their health care by deciding when and whom to consult, whether or not to comply, when to switch between treatment alternatives, whether care is effective, and whether they are satisfied with its quality. (p. 51)

His observation is in keeping with the current literature on acculturation/biculturalism that laments the lack of collaboration of patient/practitioner, practitioner/practitioner, and system/system. According to Kleinman (1980), it seems that patients do the "collaborating" on their own—he calls it "activating (p. 51).

The first premise inherent in Kleinman's (1980) model is somewhat problematic for this project. First, although Kiesser and colleagues (2006) identified the "freedom" (p. 225) of medical pluralism, what we see reflected in Kleinman's model of pluralism is that the sectors across which patients and families move are boundaried and restricted indeed. In fact, there is even a boundaried sector in which reconciliation of these two other boundaried sectors can occur. Second, the model was not built to address the

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complexities of acculturation and biculturalism, which have been identified within this project as tightly tied to patient engagement/disengagement in systems.

The second premise is somewhat useful to this project, with its emphasis on the patient as the one who moves through the boundaried systems and decides what to do. This second premise leads us to ask whether the caregiver sees these systems as boundaried and how this informs her movement across them.

Gray's unconventional practices model. Gray's 1998 model is similar to Kleinman's (1980) model and reflects the prevailing thinking in medical pluralism scholarship. Gray's model explicates sectors in terms of one another, juxtaposing their differences with one another. Gray delineates four healthcare sectors. Gray's first three, biomedicine, alternative, progressive, are analogous to Kleinman's three. In Gray's model there is also a fourth sector—a postmodern category that blends all other sectors, or seeks to blend them all, as explained in the following paragraphs. The core elements of Gray's model are these four sectors cited and his exploration of what the addition of a postmodern category means for health and healing.

In Gray's (1998) model, the biomedical sector is a predominately Western, modernist one, focused on disease processes and the scientific eradication of disease and control of symptoms. The foundations of biomedicine as conceptualized by this model are shot through with modernism, the Western view that purports the existence of an objective and fixed reality (Clarke et al., 2003; Lock & Nguyen, 2010; Stevenson, 2002). In Kleinman's (1980) model, although biomedicine was certainly its own sector, it was not as much of an impermeable and objective structure as it is in Gray's model.

The alternative sector takes a systemic approach to illness and health rather than a symptomatic one and values a spectrum of healing approaches.

The progressive sector brings together both biomedical and alternative approaches with a "general even-handedness" and "application of research methods and even research funding, to the alternative domain" (Gray, 1998, p. 63).

The fourth sector, marked by a postmodern approach, eschews the key assumptions regarding dominant, modernist culture and an objective, fixed reality. This approach does not see the individual as an autonomous agent who remains untethered to social/economical/political cultural structures. Instead, context is important.

Gray's (1998) model leads to two premises. First, as with Kleinman's (1980) model, Gray's model contains the biomedical perspective and the "Other," in this case the alternative sector. Gray attempted to mimic the function served by Kleinman's third sector, the popular sector, by including a third sector, the progressive, where differences between the first two sectors can be worked out. Whereas Kleinman's model gave the patient the agency within this third sector to work out these differences by seeking out and selecting care, Gray gave import to research and funding to work those differences out. The first two sectors in both models are still seen as diametrically opposed, and Gray asserted that because they were inherently opposed to one another, the focus must be on even-handed exploration of each via research and funding. The two models were very similar up until this point, which brings us to our second premise. According to Gray, the postmodern perspective is concerned with "particular, as opposed to universal truths" and with "encouraging the articulation of perspectives on healthcare practices besides those of the dominant biomedical approach" (p. 70). Gray's addition of the postmodern sector provides a new perspective sector in which to situate emerging health and healing structures as it purports to move further away from the primacy of biomedicine.

However, these two premises are problematic because we see in neither model the "freedom" that Kiesser and colleagues (2006) mentioned. The prevailing juxtaposition and impermeable boundaries of biomedical and "Other" systems remains, with the third option created expressly to address reconciliation of the first two. Further, regarding Gray's postmodern sector and its promise, there is a debate as to whether postmodernism's efficacy in conceptualizing this fourth possible sector is measureable, and in particular about how effective this perspective is at fostering pluralism (Han, 2002).

As mentioned earlier, in exploring the medical pluralism scholarship I was cognizant that the boundaries set forth by both the scholarship and the models would likely not be clear-cut in the case of my population. In light of what was discovered in this section of the literature review, my hesitance to apply these models full-bore was warranted, but each provided useful insight.

My review of the two example models of pluralism revealed serious gaps for the purposes of my research. As was evidenced previously, neither Kleinman's nor Gray's model adequately described the type of caregiving and care-seeking I found in my review of the literature on acculturation and biculturalism in Mexican American caregiving and care-seeking populations. Teased out in the literature review of those concepts were the intricacies of care-seeker and caregiver engagement and disengagement that are both informed and unaffected by the systems around them. Instead of the medical pluralism's straightforward separation of sectors and caregivers and care-seekers who were cognizant of their juxtaposition with one another, more complex and nuanced indicators of Mexican Americans' engagement and disengagement in health and healing systems emerged.

The structures provided by medical pluralism scholarship were not entirely adequate for my purposes in this project vis-à-vis what I discovered in the literature review about Mexican American care-seekers' and caregivers' acculturation and biculturalism. I suggest that Gray's (1998) model comes closer than Kleinman's (1980), particularly because of Gray's focus on a postmodern perspective that examines care from the point of view of the individual and her or his unique circumstances, in keeping with healthcare's postmodern moment. But even Gray's model retains the juxtaposition of biomedicine and folk systems. We are sure of neither how effectively Gray's postmodern category explains individuals' use of different systems nor how it affects health outcomes. Put simply, research on the experience of the caregiver and care-seeker demonstrates a fluid quality of caregiver and care-seeker engagement and disengagement, what seems to be a moving in and out of systems that may or may not note where prevailing boundaries are and are not permeable. However, medical pluralism's prevailing contraposition of systems, as demonstrated by Kleinman and Gray, remains widespread in academic literature.

There are scholars who denied the existence of boundaried systems like those described in the medical pluralism literature above. These scholars suggested that it is an impossibility, that different sectors have no contact with one another, that they are easily classified and juxtaposed with one another, and that caregivers and care-seekers see them in this way (Cox, 1996; Fabrega, 1997; Han & Ballis, 2007).

Stoner (1986) suggested that such a classification creates artificial boundaries that do not reflect the *syncretism*—the combination of different forms of belief or practice that are not informed by systemic boundaries—documented in many health and healing contexts. Syncretism is often used in the anthropology of religion. It is a highly

contentious term, one that contains charged power and agency dialogues within it.[18]

Syncretism is also seen in linguistics. For our purposes here, syncretism is untethered

from the power and agency texts of other disciplines and is used in health and healing

scholarship as a way to describe caregivers' and care-seekers' selection of care and

their engagement and disengagement in systems described at length in the paragraphs

that follow.

For those within this vein of scholarship that looks to syncretism rather than to

the prevailing notions of contraposition of systems, medical pluralism in its current

iteration is something of an artifice. With its grounding in a contraposition of biomedical

versus traditional/folk and a third sector for their reconciliation and even a fourth for their

blending, medical pluralism is what these scholars identify as an oversimplification of a

more complex weaving-together of health and healing paradigms. I acknowledged these

different views and used them to inform my thinking. A syncretic alternative, to use

Stoner's (1986) term, may be more useful in ascertaining the ways in which caregivers

and care-seekers move through these systems and whether they perceive them as

such. In the next section, I provide research and literature supporting a syncretic view of

caregiver engagement and navigation.

Syncretic typology: A possible new option for understanding medical

pluralism. The literature demonstrates that the biomedical metanarrative urges the use

of categorization and boundary creation to separate systems, beliefs, and practices

(Baldus, 1990; Clarke et al., 2003; Lock & Nguyen, 2010) and that this ideology extends

as well into conceptualization of healthcare systems. Fabrega (1997) and Stoner (1986)

pushed us to see the more realistic messiness of these boundaries and the lack of

separateness.

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[18] See Shaw and Stewart (1994).

Pederson and Baruffati (1989) asserted that professional and folk systems simply give rise to what Kleinman (1980) considered popular systems. However, Belliard and Ramirez-Sanchez (2005), writing about the Hispanic population, of which Mexican Americans are a large percentage, countered this argument.

Belliard and Ramirez-Sanchez (2005) asserted that the caregiver, although aware of the types of care that exist within each system, moves away from these categories and rearranges them as she sees fit. This arrangement, according to Belliard and Ramirez-Sanchez, may change day-to-day or minute-to-minute and is dependent upon the carer's interaction with other caregivers and healthcare systems. An emergent, dynamic system results: her own "syncretic typology" (Belliard and Ramirez-Sanchez, 2005, p. 274). This typology ignores prevailing biomedical categorizations of health, disease, and treatment modalities It is this syncretic typology in which this project is interested.

A reading of Belliard and Ramirez-Sanchez (2005) provides an understanding of the syncretic typology as a deconstruction of categories of healthcare into something emergent—something completely new and dynamic that disregards all categorization.[19] This feat is something that even medical anthropology has not yet accomplished. This disregard for categories is in keeping with Stoner's 1986 argument and may be more able to provide insight:

> The definition and delineation of separate medical systems within societies is perhaps less valuable for the development of an understanding of health-seeking behavior and health care decision making than the clear and focused study of the actual health care alternatives that people utilize in times of illness. (p. 44)

This typology of care is marked by nonlinearity and described by the research as "fluid and dynamic" (Menjívar, 2002, p. 458) and rich with contradiction (Belliard &

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[19] This eschewing of categories raises the question about the role of categorization in our thinking and society—i.e. what fulfills this need if categories no longer exist.

Ramirez-Sanchez, 2005). Caregiver patterns that emerge as syncretic typologies are the result of interaction, informal networks and interconnectedness (Capra, 2002). Caregiver adaptation to tension in these informal systems is described in the literature as being simultaneously liberating and oppressive (Hondagenu-Sotelo, 1995; Menjivar, 2000).

Basing their decisions on internalized and what seem initially to be nonexistent rules, caregivers select myriad iterations of care from multiple healthcare systems that are not stark, separate, boundaried systems at all, but instead are nested within "multiple sets of social relations" (Walby, 2007, pp. 461).

This syncretic typology, characterized by emergent and dynamic properties that may shift from one moment to the next, may be suitable to describe Mexican American female caregivers' selection of care from multiple sources. This model of medical pluralism is consistent with the role of the caregiver at the center of the complex pattern of interrelationships demonstrated by the literature, in addition to the sensitizing concepts that this project has set forth to provide direction. This perspective permits a nonlinear examination of the caregiver's patterns of movement through multiple systems and adequately reflects her perspective that these systems are not in contraposition with one another but are instead overlapping and fluid. The syncretic typology is a sort of dialectic, the resolving of what seem to be two incongruous, opposing sides, in a fluid and dynamic way.

Notwithstanding its rare appearance in the literature, the syncretic typology is the model of medical pluralism that may most closely reflect the female Mexican American caregiver's fluidity in selection of care. Menjívar (2002) suggested that this lack of exploration lends itself to continued investigation and an opportunity for further research.

Conclusion

This chapter was one of transgression and juxtaposition. I made provocative decisions in my methodological approach to the literature review and sought to justify them. I explored the literature in keeping with a constructivist paradigm, moving across disciplines and weaving together content that made sense to me and to this project in its current iteration, with an eye for emergence.

Threaded through these discussions were juxtaposition and contraposition, sometimes providing opportunities for exploration and other times limitations to that exploration. In discussing the different approaches to this chapter, I pitted objectivist and constructivist grounded theory against one another. Although the theories are fundamentally different in many ways, I found that my own strategy at this point in the project was to take from both schools of thought and create a typology of my own.

My strategy was not unlike what my literature review revealed about of the caregiver, who, as demonstrated by the literature review, also eschews juxtaposition. Her way of seeing and understanding what is available is not in keeping with medical pluralism's boundaried sectors and is instead a way of accessing health and healing systems that, at this point in the project, literally defied all categorization. The variables that served as indicators of engagement and disengagement were able to be neither tidily summarized nor categorized.

Mindful of these early indications in the literature that suggested that the caregiver has a boundary-less, contextually ever-changing experience and approach, I remained, however, prepared to maintain balance. I acknowledged that my intent was to explore the data that examined the caregiver's approach from a wider perspective. Nevertheless, I was prepared for the emergence of other types of categorization and boundaries represented in the data as I examined it more deeply. In anticipation of such

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an emergence, I stayed close to the data and followed Charmaz's recommendations (which are described in Chapter 3 and operationalized in Chapter 4).

Rapprochement: An epilogue. Having flirted throughout this chapter with juxtaposition and contraposition, I believed that at this point it was not only permissible but desirable to hold different schema in mind as I entered the next phase of the project. I continued my attempt to peel back the biomedical metanarrative in this postmodern moment to see what local narratives lay underneath. My goal was to remain mindful of artifice in the categorization of healthcare systems and to see health and healing as Mexican American caregivers and care-seekers do. What was demonstrated by the literature review was the existence of hidden, emergent processes that are fluid, dynamic, and nonlinear, and always in relationship to the environment in which the caregiver finds herself. These processes remain elusive.

This project's sensitizing concepts—chaos, co-evolution, darkness, emergence, and self-organization, which were treated briefly in Chapter 1 and excavated more thoroughly in Chapter 3—made understanding these processes during data analysis a little less daunting. I chose these concepts purposefully because they reflect fluidity, hidden patterns, contradiction, emergence of new ways of healing, and rapid adaptation/adoption that results in dynamic new patterns yet to be discovered (Bragin, 2010; Manson, 2001).

With these sensitizing concepts in mind, alongside what was illuminated by the literature review, I made yet another provocative decision. I believed that this project's ability to most authentically reflect the ways in which this population engaged with health and healing systems was best served by a re-envisioning of the research questions that framed it up until this point. And with that, on to Chapter 3.

Chapter 3

EMERGING REALITIES

As established in Chapter 1, at this moment in healthcare's transformation we find a championing of patient-centered care and an increased concentration on the localized narratives of patient and family. Even using "patient-centric" to describe a system that should have been that way all along is a telling development in the history of healthcare. As one writer quipped: "Think on that for a moment—our system has gotten so far away from the patient that we give the malady a diagnostic classification like 'patient-centric' in order to treat it" (Blaustein, 2012, para. 1). These new perspectives, although full of potential, have yet to be fully operationalized.

The female Mexican American caregiver provides a lens through which to view this transformation. She exists within a population that experiences health disparities exacerbated by issues of acculturation, biculturalism, and lack of practitioner collaboration that are, as demonstrated in Chapter 2, exceptionally intricate. It is she who sits at the intersection of birth and host cultures and of health and healing sources; it is she who is tasked with managing care for herself and her family. The medical pluralism scholarship that attempts to describe the caregiver's experience in managing care across multiple sources has been, at best, a peripheral examination. And, as was demonstrated by a review of the literature in Chapter 2, other paradigmatic limitations further compound the problem.

The first paradigmatic limitation is whether prevailing medical pluralism models rely too much on the continuity of content within a "system" as dictated by Western/rationalistic logic traditions (i.e.—*all* treatments within the "biomedical system" are endemically and entirely biomedical and *all* treatments within alternative systems are nonbiomedical). The second is whether the stark contrapositioning of biomedicine and

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"alternative medicine" (i.e. traditional, folk, and other modalities) is a valid depiction of any relationship between the two types, or if the opposition is merely a vestige of the tendency to dichotomize systems within this area of inquiry. The third is whether it is appropriate and effective to view healthcare systems as cohesive "systems," when caregivers may or may not. And the final paradigmatic limitation is whether the deconstruction of the biomedical narrative and resulting permeable boundaries of the syncretic typology belie extensive restrictions elsewhere in the caregiver's experience.

This broad and deep shift of perspectives in health and healing, the multitude of variables involved, and the subsequent visibility of the patient-centered languaging that alerts us to this shift and where the new focus lies, provide both opportunities and challenges.

The literature's obvious dearth of insight into why caregivers do what they do seems to be nested within two limiting structures: first, the fact that patient-centered care continues to be bound by prevailing biomedical and oftentimes practitioner-centric notions, and second, that the variables that inform why caregivers do what they do are poorly understood and frequently subject to oversimplification. Put simply, the emerging research does not hear caregivers' voices above the din of prevailing perspectives, and current research methodologies are unable to honor the intricacies of the process of caregiver choice. In order to adequately and authentically articulate the caregiver experience, I deemed a methodology that assents to the unfolding realities of caregiver choice to be most helpful.

I begin Chapter 3 by bridging my chosen research methodology and the proposed project. This project is an exploratory secondary analysis situated within Charmazian grounded theory and the postmodern turn. In keeping with the emergent nature of this research, I have made substantive changes to my research question and

fully explicate my reasons for doing so in the paragraphs that follow. Next, I walk

through a discussion of purpose, population of interest, research design, methodology,

theoretical framework, inclusion and exclusion criteria, proposed methods of analysis

and synthesis of data, issues of trustworthiness, and limitations of the project. At the

close of the chapter I provide a brief conclusion.

I have been exceptionally fortunate to have the principal investigator for the

primary study as a resource for this secondary analysis. The literature shows that this

contact is a positive thing (Heaton, 2004) since connection with the primary study and its

investigators lends context to the data. Fielding (2004) noted that this connection is

simply an issue of practicality rather than something to be debated epistemologically.

And, frankly, I have found this connection to be fruitful and comforting. I lay out the

study as outlined earlier, paying particular attention to the components of secondary

analysis and to the design itself—both of which lend this project its unique perspective.

But first, I must tell the story of the reframing of my research question.

Substantive changes to the research question. It was because of the striking

paradigmatic limitations emerging out of my review of the literature in Chapter 2 that I

decided to make substantive changes to my research question and specific aims here,

at the outset of Chapter3. The result was minor changes in wording but major changes

in implication.

My logic in making the changes was this: In keeping with constructivist grounded

theory methodology, I was keenly aware of my own experience and background as they

shaped my perception of this project and its direction. Armed with this insight, I crafted

my initial specific aims and research question in Chapter 1, having looked at neither the

data this question sought to answer nor the literature that sought to explain it.

Notwithstanding the perpetual debate about whether to conduct a literature review prior

to beginning a grounded theory study—that is, arguments for not letting the great theories of the past sway current research versus the reality of time, money, and an inability to extract oneself from any project—I did not truly engage with the extant literature in an exhaustive literature review until after I had interacted with the data during the interim between completing Chapter 1 and writing Chapter 2. As mentioned in Chapter 2, I actually did what Glaser and Strauss (see Glaser, 1978; Glaser & Strauss, 1967) suggested (a suggestion that has been made and recanted, decried and celebrated, as evidenced by the consternation in the literature): I chose not to review the relevant literature prior to sticking my toe into the data.

That absence of a literature review, however, as explained in Chapter 2, did not ensure that I approached the project *tabula rasa*. In fact, like every other researcher attempting to do grounded theory (or any type of research for that matter), I came to the project full of paradigms and politics, biases and background. But, as suggested by Schreiber (2001), I was able to "make efforts to uncover and challenge [these biasing factors]" (p. 59).

Conveniently, much of my personal philosophical grounding lies in deconstruction and a large dose of multidisciplinary contrarianism, so dissecting, questioning, re-envisioning, and re-framing are processes familiar to me. In keeping with Schreiber's (2001) assertion, bracketing in grounded theory is not possible; it was for this reason that I chose to "explicate my background and not to isolate it from the study" (p. 61). This explication is peppered throughout this dissertation.

The journey to Chapter 3 has not been a linear process; nor did I, informed by constructivist grounded theory, expect it to be. According to Charmaz (2000b), "Writers use a linear logic to organize their analyses and make experience understandable, yet experience is not necessarily linear, nor is it always readily drawn with clear boundaries"

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(p. 527). I have had to reach back into the minutiae of Chapter 1, where seemingly inconsequential processes such as making a decision about word choice have re-shaped the current state of this project and altered its future. (See complexity's Butterfly Effect as described in Chapter 1.)

In writing Chapter 1, I struggled to conceptualize the difference and similarity between terms such as *navigating, integrating, selecting,* and *negotiating* to describe the caregiver's method of selecting care. I was struggling toward meaning. After writing Chapter 1, interacting with the data, and completing Chapter 2, I became increasingly aware that selection of the key words for my research question was not the confounding issue. The central issue instead was whether engagement with health and healing systems was seen by the caregiver as a process underpinned by cohesion and continuity, and whether the process was situated within a perception of systems as systems—for example biomedical, alternative, traditional, and so forth. I asked: (a) is perceiving cohesion within health and healing systems, (b) allowing for the juxtaposition of system against system, and (c) viewing healthcare through a lens of "systemness" a reflection of prevailing Western/rationalistic metanarratives needing to be deconstructed within this project's postmodern framework?

I decided the answer was yes.

It was for this reason that I made changes to my specific aims and research question here in Chapter 3. This process of reframing may seem very quantitative in nature. In fact, an online editorial by Hallberg (2010) contended, "In a conventional quantitative study, the aim of the literature review is mainly to refine the research question, determine gaps in earlier research, and identify a suitable design and data collection method for a planned study" (n.p.). I argue that Hallberg's comments do not apply to quantitative analysis alone. The same process occurs in qualitative analysis via

reflexivity, a conceptual tool that allows for the re-shaping of components of the study in response to what emerges in the research process (Creswell, 2007; Watt, 2007). I maintain that this process of reflexivity strengthened my qualitative inquiry, illuminating the iterative process in which I had been engaged and permitting me to better address my data with a question that reflected what was contained in them.

I have provided the original versions of my specific aims and research questions below with strikethroughs to visually depict substantive changes. Of particular importance are these four decisions I made:

1. to specify the population of care recipients as self/elders rather than self/family in order to stay close to the primary study,

2. to move from the use of "integration" to "management" of care,

3. to move from the use of "system" to "source," and

4. to remove labels for systems, such as Western or traditional.

These changes, I believe, better reflect a more constructivist perspective on all four counts: first, because one of the main criticisms of secondary analysis is a lack of tether to the primary study (Flores, Hinton, Barker, Franz, & Velasquez, 2009), which I believe has been now put in place even more tightly by a clearly stated focus on the same population (elders); second, because "management" is a neutral term and does not assume that there is cohesion or intent (i.e. "integration") involved in caregiver choices, when there may or may not be; third, because "sources" expresses the realistic nature of healthcare systems, which are not as cohesive as they look from the outside (Lock & Nguyen, 2010); and fourth, because to fully understand caregiver selection we must free the project from the contrapositioning of system against system when caregivers may not perceive these as systems at all (Stoner, 1986).

I contend that this reframe and the accompanying discussion of my reasons for doing it are the most organic and emergent way, in keeping with a postmodern, constructivist grounded theory paradigm, to demonstrate my thought process as I moved through this project. As Charmaz wrote in 2006: "The actual research you conduct through analyzing your data likely differs—at least somewhat—from what you may have planned earlier in a researcher or grant proposal" (p. 46). She wasn't kidding.

Specific aims and research questions.

Specific aims.

1. Uncover the emergent patterns of female Mexican American caregivers as they ~~interact with multiple healthcare systems.~~ manage care from multiple health and healing sources.

2. Use these emergent patterns to inform the creation of a theory that seeks to describe the ways in which these patterns emerge.

Research question.

What are the patterns that emerge as female Mexican American caregivers manage ~~integrate~~ care for themselves and ~~their families~~ their elders from multiple health ~~care systems~~ and healing sources?

a) How do female Mexican American caregivers access these different ~~systems~~ sources of health and healing?

b) What are ~~the~~ caregivers' major obstacles in accessing ~~western and indigenous systems~~ multiple health and healing sources?

c) ~~What processes do these women use to implement recommendations and treatments provided by western and alternative providers?~~

d) How does the caregiver's interaction with her environment affect her and those around her?

Purpose

  The purpose of this study was to describe the processes of access of care and the patterns that emerge as female Mexican American caregivers manage care, for themselves and older persons, across multiple health and healing sources.

Population of Interest

  The population of interest within this project was the female Mexican American caregiver. These women are uniquely able to provide important insight into the management of care from multiple health and healing sources for three reasons. First, these women are part of the fastest-growing ethnic population in the United States. Second, they are shown in the literature to have high rates of involvement in what the literature continues to call multiple healthcare systems[20] (Dole et al., 2000; Robleado et al., 1999; Zenk et al., 2001). Third, these women are often solely responsible for their families' access to healthcare services and for whether these services are used effectively and experienced as engaging/meaningful (Chavira-Prado, 1992; Hondagenu-Sotelo, 1995; Menjivar, 2002). Further, in keeping with the re-frame of this project to focus on caregivers' experience of caring for their elders, the literature shows that in Hispanic populations, of which Mexican Americans are a part, there exists a cultural expectation that adult children will provide care for their parents (Dilworth-Anderson, Williams, & Gibson, 2002).

  This population of caregivers is also at increased risk for adverse health outcomes, including poor health and emotional strain (Pinquart & Sorensen, 2003); 36% of caregivers are shown to experience fair to poor health or a serious health condition (Navaie-Waliser et al., 2002). Approximately one-third of caregivers of older persons with cognitive decline suffer from depression and emotional stress (Covinsky,

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[20] I use "systems" in deference to the literature while recognizing that this label is under scrutiny in this project.

Newcomer, Dane, Sands, & Yaffe, 2003). Female caregivers providing care for their

elders who suffer from cognitive decline or other impairments are at an even greater risk

since the research shows higher levels of depression and anxiety in this population than

in noncaregivers (Spector & Tampi, 2005). Demonstrating increased awareness of the

difficulties of caregiving, the literature has begun to assert the importance of

psychosocial interventions that, in effect, care for caregivers. One seminal example is

the REACH (Resources for Enhancing Alzheimer's Caregiver Health) project, "a

cooperative agreement funded by the National Institutes of Health to examine

interventions for alleviating the burdens associated with caregiving" (Coon, Gallagher-

Thompson, & Thompson, 2003, p. 125), which looked at home-and community-based

caregiving interventions in minority populations (see Coon et al., 2003; Coon, Schulz, &

Ory, 1999).

Research Design

The research design for this project was exploratory and employed Charmazian

constructivist grounded theory methodology. The study is a secondary analysis of de-

identified interviews with female Mexican American caregivers caring for older adults

originally collected as part of a funded grant under the direction of Dr. Bronwynne Evans

and including the work of M. J. Belyea, F. G. Castro, and D. W. Coon, titled "The

Caregiving Trajectory for Community-Dwelling Mexican-American Elders." The

approach of both the primary and secondary studies is case oriented. Each case is

comprised of a care recipient and a caregiver, with the caregiver serving as primary data

source. The data contain no protected health information. Again, the theoretical

framework of the original project was life course perspective, detailed later in this

chapter, and sensitizing concepts drawn from the parent framework of complexity

science—emergence, chaos, co-adaptation, self-organization, and darkness—undergird this secondary analysis.

Methodology. This project employed the grounded theory methodology of Charmaz (1995, 2000, 2003, 2004, 2006), rooted in the tenets of co-construction via postmodernism and symbolic interactionism (Blumer, 1969).

Constructivist approach. Charmaz's approach is a constructivist one, oriented toward the perspectives of individuals and the subjective meanings that are formed through interaction with others (Creswell, 2007). Charmaz (2000) explained, "A constructivist approach to grounded theory reaffirms studying people in their natural settings and redirects qualitative research away from positivism" (p. 510). This approach is contrasted with what Charmaz reported are the more positivist, objectivist approaches of earlier grounded theorists Bernard Glaser and Anselm Strauss, in addition to Strauss' current co-author, Juliet Corbin.

Constructivists are "antifoundational"; their beliefs are marked by "a refusal to adopt any permanent unvarying or 'foundational' standards by which truth can be universally known" (Charmaz, 2011, p. 119). For constructivists, universal truths are understood in philosophical terms as metanarratives: overarching truths that are universally applied and must be viewed with suspicion (see Derrida, 1967; Derrida, 1982; Derrida & Defourmantelle, 1997; Foucault, 1975, 1976; Kristeva, 1986; Lyotard, 1979, 1984). Constructivists' awareness of these truths and their accompanying texts about power and control, along with prevailing cultural structures, lead constructivists to continue to seek what lies under these truths. During this process, they search for other realities that reflect other structures, what Lyotard (1984) described as "an incredulity toward metanarratives" (p. xxiv).

Postmodernism. This constructivist grounded theory project is positioned within postmodernism. Postmodernism is a philosophical framework that strives to hear local narratives and deconstructs both cultural and physical structures that foster what Derrida (1982) called binary oppositions—the selection/valuing of one thing over another—for example, man/woman, white/black, soul/body. As demonstrated by the unfolding of this project, omnipresent healthcare metanarratives and a reluctance to deconstruct assumed categories and systems find their way into healthcare research as well, and a constructivist researcher must question these "truths," as I do.

Symbolic interactionism. Charmaz's approach is rooted in symbolic interactionism. Blumer[21] laid out three premises of symbolic interactionism (1969, p. 2):

1. The first premise is that human beings act toward thigs on the basis of the meanings that the things have for them.
2. The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows.
3. The third premise is that these meanings are handled in, and modified through, an interpretativeprocess used by the person in dealing with the things he encounters.

Symbolic interactionism provides fertile ground for a constructivist inquiry in that individual meaning (both for the researcher and for the participant in the case of constructivist grounded theory) arises out of relating to one another and the environment. A reality—one of many, rather than "the" reality—is co-constructed in the interaction.

Charmaz (2000) contended that grounded theory need not be tethered to positivist or objectivist philosophies in order to be used to study worlds empirically

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[21] Herbert Blumer, who wrote extensively on symbolic interactionism, was a student of George Herbert Mead. Mead spent the early years of his career at the University of Michigan and then the next 40 years at the University of Chicago. Although his interests were in philosophy and psychology, it is widely accepted that he trained some of the best sociologists to come out of "The Chicago School." Although Mead is credited with the creation of the field of symbolic interactionism, he never published a book on it. His students got together after he died and put their notes and conversations with Mead together into a book that they published on his behalf, called *Mind, Self and Society.*

without assuming the existence of a universal truth. This conclusion, for Charmaz, allowed for a link back to Blumer's (1969) assertion that subjective meaning should be studied empirically.

Secondary Analysis: A Prelude

Mindful of the messy realities of co-construction, I attempted to engage in some of the more hotly debated pieces of grounded theory. Bringing my own experience and background to the project and delaying the literature review have brought this work to its current iteration here in Chapter 3. As Glaser (2001) observed, "All is data" (p. 145), and although he is more positivist and objectivist in his expounding of grounded theory than I am, this idea applies to my constructivist approach as well: I am part of the data, too.

When defining grounded theory, Patton (1980) placed inductive analysis at the center of the method, explaining: "Inductive analysis means that the patterns, themes and categories of analysis come from the data; they emerge out of the data rather than being imposed on them prior to data collection and analysis" (p. 306). One might assume that this attitude is anathema to the co-construction of data, due to the assumption that patterns, themes, and categories simply emerge out of the data and the researcher has little or no effect on the data whatsoever. Charmaz (2000b) dismantled this assumption: "Like wondrous gifts waiting to be opened, early grounded theory texts imply that categories and concepts inhere within the data, awaiting the researcher's discovery. Not so" (p. 522). Sandelowski agreed with Charmaz and wrote of research's purpose: "Data analysis always entails a process by which data are teamed or made docile to those purposes regardless of whether analysis is conceived as primary or secondary, or qualitative or quantitative" (p. 374). Mindful of both of these sides of the story, that the data speak *and* that their voices are filtered through the researcher's ears, Schreiber (2001) instructed the researcher to remain vigilant about not mapping

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paradigms to the data if they do not fit and instead cultivating theoretical sensitivity, that is being open to other options.

In the case of this secondary analysis, another two sides to the story appear. On one hand lies the importance of a strong link to the primary study via insight into its context and to its spirit (see Flores et al., 2009; Heaton, 1998, 2004; Hinds et al., 1997). On the other hand is the opportunity provided by secondary analysis to "transform" the existing data through "the process of recontextualising and reconstructing data," what Watt (2007) called "a primary analysis of a different order of data" (para. 2.3) and Sandelowski asserted is a "change with person and time" (p. 347). These two pieces of advice require a holding in tension of the primary data and its context and the primary data, re-envisioned, to be stepped through carefully in chapters 4 and 5.

With all this under consideration, I offer simply the notion that the data speak *and* the primary study speaks, and rightfully so—the secondary researcher, then, must scaffold sturdily with support from the primary study as far as she can and then take a few steps unsupported on her own, in earnest, the wind whipping around her. This, I believe, is the courage of secondary analysis.

Although Flores and colleagues (2009) warned of the pervasive nay-saying regarding secondary analysis within grounded theory, they neatly dismantled the current arguments that decry this type of secondary analysis, particularly those that tout the importance of "an intense personal involvement in the fieldwork," explaining:

> [This] constitutes a necessary prerequisite in order to grasp the relevant context and to interpret interview transcripts. From this viewpoint, secondary analysis of qualitative interviews amounts to doing the impossible. The researcher defines him or her self as the privileged insider and as a consequence any outsider is declared as unable to reanalyze the textual data. A further implication of this approach is that it is impossible to check the interpretation and analysis of these data. In other words, this argument on context may function as immunization against possible criticism. In this respect, the argumentation resembles the way context is used in everyday discourse as a rhetorical device to undermine

undesired interpretations and to impose desired interpretations of someone's utterances. (para. 23)

Heaton's (1998, 2004) methodological considerations, in addition to those of Blommaert (2001), Fielding (2004), Hinds et al. (1997), Szabo and Strang (1997), Thorne (1990), and Sandelowski (2011), Charmaz's thoughts (1995, 2000a, 2003, 2004, 2006), and my humble additions were briefly discussed in Chapter 1. Here in Chapter 3, they supply the fruitful prompts to dissect secondary analysis and disinter its less obvious implications, re-visited here and operationalized in Chapter 4.

Organizing frameworks. Of fundamental import to this secondary analysis is a sturdy tether to the primary study. One such tether is the relationship between the organizing structures of the two studies, which was discussed briefly in Chapter 1. Here in Chapter 3, I examine more deeply the primary study's theoretical framework, life course perspective (LCP) vis-à-vis this secondary analysis's sensitizing concepts, which are drawn from the parent framework of complexity science.

To begin, LCP aligns closely with this project for four basic reasons. First, elements of LCP are found within the social constructivist perspective, from which this project gets its research design. Second, LCP contains the concept of acculturation, which has appeared and re-appeared numerous times throughout these first three chapters. Third, LCP is found to be amenable to a systems perspective, of which complexity science is close kin (Coon et al., 1999, p. 35). Finally, LCP is well suited to research involving Mexican American caregivers of older adults (Evans, Crogan, & Coon, 2009), the population under scrutiny in this secondary analysis. For our purposes at this point in the project, of greatest interest is the existence of a conceptual tether between the organizing frameworks for the two studies. Each framework is discussed in terms of the other in the following paragraphs.

Life course perspective and complexity science. Life course perspective (LCP) served as the primary study's organizing framework (Evans, Belyea, Castro, & Coon, 2008). Evans (2008) and her team determined that LCP would serve as a "powerful organizing framework for intensively studying caregiving in Mexican-American families across time" (p. 5). A "particular strength" of this organizing framework is that it contains "a powerful set of cross-disciplinary organizing concepts that can be used for intensive study of family caregiving across time" (Evans et al., 2009, p. 3). The framework also, according to the primary study's investigators, "allows integration of disparate explanations for differences in caregiver burden/strain and gain, including cultural and contextual influences" (p. 5). The six salient concepts drawn from LCP are cultural and contextual differences, timing of life events, adaptive strategies, trajectories, transitions, and turning points (Wethington, 2005).

This secondary analysis draws its sensitizing concepts from a parent framework of complexity science (see Bragin, 2010; Cilliers, 1998; Ferraro, 2009), which, like LCP, permits an appreciation and exploration of numerous, sometimes conflicting, variables, experiences, and outcomes. I offer here a brief revisit of Chapter 2's discussion: Complexity science focuses on patterns of human interaction, including those that emerge spontaneously from exchanges between people and their environments (Goldstein, 2008a; Page, 2009; Plsek & Greenhalgh, 2001). These interactions are similar to LCP's themes: Timing of lives, Linked or Interdependent Lives, and concepts: Biological Age, Psychological Age, Social Age, and Spiritual Age. I connect the two frameworks further in terms of my sensitizing concepts.

The *sine qua non* of complexity is best put forth by Miller and Page (2007):

It is the interest in between stasis and utter chaos. The world tends not to be frozen or random; rather it exists between these two states. We want to know when and why productive systems emerge and how they can persist. (p. 7)

Complexity science is often described as a group of sciences that borrows its areas of inquiry not only from biology, mathematics, and physics, but also from psychology, anthropology, management, and sociology, to name a few disciplines. LCP similarly moves across disciplines, including public health, management, finance, sociology, psychology, education, and religion.

In keeping with the primary study, this project was conducted in an effort to better understand the caregiver's experience. In this secondary analysis, the understanding sought was filtered through her management of care (or lack thereof) and her interaction with those around her, and how her choices (and what may or may not dictate them) result in changes—to herself, to those around her, and to the environment in which she finds herself. The health and healing sources she manages are both static and dynamic, and the literature shows that her management of care may seem random.

Armed with the findings from the primary study and insight gleaned from conversations with its principal investigator, I believe I can confidently conclude that the caregiver experience is a complex one indeed and is reflected in the sensitizing concepts selected for this secondary analysis. This complexity is present particularly in regard to the effects of numerous contextual factors and the interactions that take place between caregivers and systems/sources, in addition to a caregiver's adaptive strategies and those moments of transition and identifiable turning points in the caregiver's experience.

From this framework have come five sensitizing concepts that light the first steps of the path upon which this secondary analysis embarks. They permit the emergence of that which is unable to be anticipated, or that which can be anticipated only within certain parameters but never predicted exactly, and they alert me to those pieces of the system that may simply remain unknowable. These concepts are described at length.

Sensitizing concepts. Patton (2002) provided a useful summary of the role of

sensitizing concepts in qualitative research:

> The notion of "sensitizing concepts" reminds us that observers do not enter the field with a completely blank slate. While the inductive nature of qualitative inquiry emphasizes the importance of being open to whatever one can learn, some way of organizing the complexity of experience is virtually a prerequisite for perception itself. (p. 279)

Patton offered that sensitizing concepts aid both "experienced observers" (p. 276) and

"less experienced researchers and dissertation students" (p. 278). He did warn that care

must be taken with sensitizing concepts and their explication—and a researcher always

runs the risk of a sensitizing concept's becoming desensitizing—particularly if that

concept is widely used in popular culture (Patton, 2002). In the case of this project, I

took great pains to heed this warning in explicating clearly my own paradigms and

perspectives and in being very frank about my own biases. I engaged in a type of

constant comparison, knowing that "the researcher must recognize and constantly

challenge her or his personal theories and biases against the data" (Schreiber, 2001,

p. 61). This constant comparison and review are critical activities in mediating the

desensitization of sensitizing concepts. In the course of conducting this project, I found

that my sensitizing concepts emerged from a broader organizing framework and were

repeatedly hauled out, re-examined, and challenged throughout the project. This

dynamic, I believe, lent further (although never complete) objectivity to the concepts

themselves by providing me with a body of extant literature that helped me to bound

possible misinterpretation and to avoid the unwelcome creep of popular culture's grasp

of complexity into my research. As mentioned in Chapter 1, the definition of complexity

for this project came from Goldstein's (2008) glossary: "a description of the phenomena

demonstrated in systems characterized by nonlinear interactive components, emergent

phenomena, continuous and discontinuous change and unpredictable outcomes"
(p. 271).

This project used five sensitizing concepts found within the theoretical framework of complexity science to guide the investigation. These five concepts were chaos, co-evolution, darkness, emergence, and self-organization. Exploration of the sensitizing concepts began in Chapter 1 with the definitions from Goldstein's (2008) glossary of terms and the work of Skyttner (2001) and Cilliers (1998) and was built upon here with others' insights into the depth and breadth of these terms.

Chaos. Li and Yorke (1975) were the first researchers to depart from the general definition of chaos as "a state of utter confusion" (Sharp & Priesmeyer, 1995, p. 74), ushering in the current perception of chaos as systems that act in seemingly random ways. From this perspective, one small change on one end can result in large changes at the other, as described by Lorenz's Attractor, known widely as the Butterfly Effect (Wallace & Facio, 1972) and mentioned in Chapter 1.

Although Lorenz's model is often understood in terms of weather patterns, his 1972 paper highlighted questions that can be applied to many phenomena, including those of this project. Lorenz noted, "The influence of a single butterfly is not only a fine detail—it is confined to a small volume" (p. 3). Here, Lorenz questioned the ability of the influence of a butterfly's delicate wing flap to travel farther in certain environments. Lorenz hypothesized that the butterfly's influence would travel further in turbulent air than in calm air.

Although he did suggest that his hypothesis would likely remain untested for the near future, Lorenz's (1972) initial musings are important to this project. The actions of a butterfly are more likely to affect a greater space when those actions take place in a physically turbulent environment.

Lorenz's 1972 hypothesis was effectively mapped onto the female Mexican American caregiver population and onto what the literature demonstrates is an environment fraught with fragmented care and health disparities. In this context, it seems to be a prevailing adversity and turbulence that marks the caregivers experience and the systems that lend caregiving its context and the caregiver her reality. With this in mind, and returning to Lorenz's initial thoughts, I conclude that chaos sensitizes this project to the possibility that the caregiver's interactions with individuals and health and healing sources immediately around her, like the influence of a butterfly's wing flap, may be more impactful in ever-larger circles than initially envisioned, placing even greater urgency on an examination of her choices.

Coupled with Lorenz's (1972) thoughts is that quality of chaos that speaks to systems' tendencies toward apparent randomness. As Gleick put it, "Chaos is a kind of science that deals with the parts of the world that are unpredictable, apparently random . . . disorderly, erratic, irregular, unruly—misbehaved" (as cited in OpenRoadMediaVideos, 2011, 2:48). The behavior of chaotic systems, although seemingly random and "misbehaved," is thought to be in reality contained within a range and controlled by a particular space or state of being.

In regard to the caregiver's interactions with systems around her that include other caregivers and health and healing sources, lying under this apparent randomness is the structure lent to her experiences by that which is happening around her. What underlies her interactions is what Devaney (2003) determined to be the third component of chaos:[22] sensitivity to initial conditions. In this sense, chaos sensitizes the project to a caregivers' experience in terms of that which is occurring around her. Not only are these

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[22] Devaney's (2003) theorem of chaos is situated within the discipline of mathematics. For our purposes in this project and this project's view of complexity science, Devaney's discussion of the third component is most applicable to the caregiver.

conditions influential at the moment of her experience, but also the context of how she

perceived her caregiving responsibilities initially emerged. Chaos highlights the

nonlinearity of the caregiving experience as that experience responds to what takes

place in the environment around it. Gleick (as cited in OpenRoadMediaVideos, 2011)

offered a poetic simile: "It's about branching—twisting—things that curled on themselves

like a snake eating its tail" (1:23).

　　　　Co-evolution. Co-evolution is defined as "the coordinated and interdependent

evolution of two or more systems within a larger system" (Goldstein, 2008b, p. 271). Co-

evolution is best understood in the context of a complex responsive process (CRP). The

CRP is undergirded by a robust literature of its own that overlaps with complexity

science at many points. Stacey, Griffin, and Shaw (2001), in their editorial preface to

Stacey's (2001) seminal work on the complex responsive process, divided complexity

theorists into those who honor the CRP and those who do not. Those who do not speak

from what the three authors call "the dominant voice" see complex systems as

> networks of autonomous agents that behave on the basis of regularity extracted
> from their environments. They talk about complex systems as objective realities
> that scientists can stand outside of and model. They . . . see their modeling
> work as a route to increasing the ability of humans to control complex worlds.
> (Stacey, Griffin, & Shaw, 2001, p. xi)

Those who honor the CRP, according to Stacey, Griffin, and Shaw (2001), are those

who speak from the fringes of sociology, psychology, and other disciplines (probably

even health-related fields) and see complexity as emergent, participative, unpredictable,

and unable to be objectified because all those who are involved are inherently part of the

system: "They argue that humans are themselves members of the complex networks

that they form and are drawing attention to the impossibility of standing outside of them

to objectify and model them" (p. xi). Relating to one another and the systems around us

is, for Stacey (2001), one of the "transient processes in which human futures are

perpetually constructed" (p. 3). These futures are constructed solely of relations between individuals and systems. This relating shapes individuals and shapes the environments in which they find themselves.

The CRP sheds light on the concept of co-evolution because it is in the relationship that individuals and systems co-evolve in a sort of symbiosis with one another. In the case of this project, the female Mexican American caregiver may be no exception. This particular sensitizing concept reflects the possibility that the caregiver shapes and is shaped by her environment and by those around her, resulting in constant evolution and iteration.

Darkness. The sensitizing concept of darkness draws attention to the inability to understand everything there is to know about a given system or systems. Skyttner (2001) asserted, "No system can be known completely" (p. 93). Building on Stacey's (2001) stance that we all exist within systems and therefore cannot objectively examine them, it becomes clear that neither can we know them in their entirety, since "each element in the system is ignorant of the behavior of the system as a whole; it responds only to information that is available to it locally" (Cilliers, 1998, pp. 4-5). Darkness sensitizes this project to the reality that some of what it seeks to examine will simply remain unknown. These unknowns will likely exist both in the context of the caregiver and in her inability to ascertain why systems and individuals act or react in the way they do, in addition to what I'm examining in the context of the project itself. Within a framework of constructivist grounded theory, the concept of darkness is very helpful in examining the "texts" of the caregiver and her experience because "the processes that shape them may be ambiguous, invisible, and perhaps, unknowable" (Charmaz, 2006, p. 39). Darkness also lends language to the nonpositivist position of the constructivist: It is impossible to simultaneously and completely know and fully illuminate *every* reality

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that exists. Therefore, "the constructivist view assumes an obdurate yet ever-changing world but recognizes diverse local worlds and multiple realities . . . the complexities of particular worlds" (Charmaz, 2006, p. 132).

Emergence/emergents. Solé and Goodwin (2000) asserted that emergence is best understood by asking this question: "How can systems made up of components whose properties we understand well give rise to phenomena that are quite unexpected?" Emergence is most often understood within the complexity science literature as being opposed to reductionism, the understanding of a system as simply a sum of its parts (Kim, 1999). In the case of the caregiver, emergent patterns of care selection cannot therefore be understood solely in terms of their components. For example, we cannot anticipate a caregiver's decision solely by listing the elements that went into it. We must be aware of other unanticipated possibilities, looking for what arises out of her interactions.

Christen and Franklin (2004) showed that emergents may be understood by their component parts, contrary to the claims of Solé and Goodwin (2000). These differing opinions were helpful to this project because there was room for emergence and reductionism to be held in tension in the context of understanding emergence within the caregiver experience. In other words, the project was able to be mindful of the unexpected (emergence), but stayed cognizant of those extant sources that supplied the unexpected outcomes (reductionistic).

Christen and Franklin (2004) also demonstrated that the concept of emergence is in opposition to *epiphenomenalism*. Epiphenomenalism claims that there exist phenomena that lack any causal or explanatory power. The opposition of emergence to epiphenomenalism is helpful to this project because it allows for the possibility that

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inherent in emergence are causal aspects of caregiver behavior able to be explained and explored.

Also important within the concept of emergence is the element of time. Systems are not static. The interplay between individual-as-system and environment-as-system across time results in emergent phenomena. Regarding this project, emergent phenomena were captured as snapshots across time, situated within the six consecutive interviews performed within each case.

Self-organization. Self-organization is a "process in a complex system whereby new emergent structures, patterns, and properties arise without being externally imposed on the system. [It is] not controlled by a centralized, hierarchical, 'command and control' center" (Goldstein, 2008b, p. 286). Ibarra (2003) described self-organization as consisting of social interactions that are comprised of patterns of relating. For these patterns to persist, "they must be continuously re-enacted or recreated in each moment, rather like a piece of music that exists only so long as musicians play new notes in each new moment" (Suchman, 2006, p. S41). These patterns may be stable or novel, and the emergence of these patterns, Suchman (2006) contended, "is a self-organization process; these patterns form spontaneously without anyone's intention or direction. While we may seek to influence these patterns intentionally and we may even succeed for a time, they are ultimately unpredictable and beyond our control" (p. S41). Suchman offered an example from healthcare:

> You are joining a preexisting group—say, your first day in a new practice . . . Before long, you know how to act within the group's norms. Meanwhile, another new person joins the practice and watches you to learn what the rules are. Over the course of time, the practice's staff might turn over completely, yet the patterns of behavior may continue unchanged (e.g., a practice culture of competition and individualism, or of friendliness and mutual support). Again, no one directs this process. It just happens, a self-organizing stable pattern of relating. (p. S41)

In the context of the female Mexican American caregiver, self-organization reflects her potential to function without some sort of "prime mover," and instead order or coordination arises out of localized interactions. This concept also alerted this project to the idea that attempting to dictate objectively or linearly the direction of a system, and a healthcare system in particular, may be ineffective.

Demographic Data: Inclusion and Exclusion Criteria

In the primary analysis, male and female Mexican American caregivers over the age of 18 were selected. Each case consisted of at least one caregiver and one care recipient, with the caregiver as the primary data source. The individuals who were included in the study had telephone service, scored average or above on a mental status evaluation inventory, and, as determined by screening, had no self-reported psychiatric history other than depression. (Evans and her team anticipated a degree of depression in caregivers, as previously noted in the literature.) Care recipients were required to be 60 years of age or older, informally cared for by their family, and willing to participate (or their legal representation stated caregiver willingness on their behalf). Severe cognitive impairment in the care recipient population did not confound the data collection because care recipients were not interviewed. However, if screening demonstrated a possible indication of depression, the team alerted the caregiver to the need for further assessment of the care recipient.

In the secondary analysis, female caregivers from the ages of approximately 18 to 80 were included. Mexican American female caregivers were the focus of this secondary analysis because the aims could be answered only through the selection of female caregiver data. Therefore, male caregivers were excluded. The relatively broad age range that dictated which interviews were selected allowed for the inclusion of women who had diverse and relevant experiences caregiving for elders: (a) women who

were caring for elders at the time the study was conducted, and (b) women who had completed a time of caregiving for older persons and could reflect back upon it.

Approach to Data Analysis

To begin, it is important to mention that unlike quantitative analysis, qualitative analysis is neither about using data to represent an entire population nor about achieving statistical generalizability (Charmaz, 2006). As a constructivist researcher, I looked instead for what Miles and Huberman (1994), Patton (2002), and Sandelowski (1995) called "information-rich cases" that, according to Charmaz (2006), "show how a basic process [in the case of this project, management of care] develops and changes" (p. 103). Heeding Charmaz's advice, I sought to begin to construct a grounded theory that emerged directly from my data and reflected that data. With this goal in mind, my approach to data analysis concentrated primarily on the challenges of secondary analysis—the problem of data fit, the problem of not having been there, and the problem of verification (Heaton, 1998; Hinds et al., 1997; Thorne, 1990)—and their unique manifestation within constructivist grounded theory. In responding to the challenges of secondary analysis, I followed a suggestion Charmaz (2000b) put forth for all constructivist grounded theory researchers, "compar[e] data with data" (p. 519), first regarding the organizing frameworks that lent conceptual structure to the primary and secondary analyses, and second, regarding the caregivers' experiences themselves.

Because this project sits at the crossroads between constructivist grounded theory and secondary analysis, I have addressed these two perspectives simultaneously in laying out my sampling strategies that informed my analysis of the data in Chapter 4. The challenges of secondary analysis mentioned—data fit, not having been there, and verification—were used to organize the discussion and explication of the sampling strategies used to address each challenge. The qualitative data sampling strategies, as

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aligned with each of the three challenges of secondary analysis, were consistent with a constructivist approach to grounded theory. This section concludes with plans for supporting trustworthiness of the results of the secondary analysis and possible limitations.

Data collection: The problem of data fit. In secondary analysis, data are already collected. It may not be assumed *a priori* that the primary data fit with the goals of the secondary analysis. The first challenge in the analysis process, then, is to determine whether the primary data address the phenomenon of interest, that is, the degree of data "fit."

Heaton (2004), in her distillation of the work of Hinds et al. (1997) and Thorne (1990), stated that there are three considerations regarding fit: the extent of missing data (i.e. some content within the study is explored more deeply than other content), the degree of convergence between questions posed by the primary and secondary studies, and lastly, the extent to which the methodology of the primary study produced data that can be examined by the methodology of the secondary study (p. 58).

Heaton's (2004) first consideration, the extent of missing data within the primary study and the implications this has for secondary analysis, is best addressed by Sandelowski (2011), who troubled the prevailing notion that "data in question already exist out there independent of users" (p. 347). By prompting secondary analysts to consider what data may be missing from the primary study, Heaton (2004) presupposed that these "same data" (Sandeloswki, p. 347), missing data included, will be analyzed in the secondary study. On the contrary, according to Bishop (2007), Moore (2007), and Silva (2007), with a new project comes an entirely new perspective that co-constructs the data anew. So, in this sense, "what is commonly referred to as the 'same' [i.e. primary study] data is different, at the very least, because they are now viewed within the

context of a different project [i.e. secondary analysis]" (Sandelowski, p. 347). In the case of this project, speculation about missing data from the primary study becomes moot as entirely new questions within the context of this secondary analysis arise about what is and is not in the data, in keeping with this fresh co-construction of the data.

Heaton's (2004) second and third considerations are the degree of convergence between the two studies' foci and the congruence of their methodologies. Addressing these required that I look at what the primary study sought to understand and what my project sought to understand, and then examine the concepts that served as catalysts to put each methodology in motion and the methodologies themselves.

The preliminary study sought to address what, according to Phillips, Torres de Ardon, Komnenich, Killeen, and Rusinak (2000) and Escandon (2006, 2011), was missing in the caregiving literature: the perspective of Mexican Americans in general and, of interest to this secondary analysis, the perspective of the Mexican American caregiver specifically. The primary study was built around three aims that examined caregiver burden and caregiver strain, the impact of cultural and contextual variables on caregiving in Mexican American caregivers, and what leads to nursing home admission for Mexican American elders while they are under the care of these caregivers.

This secondary analysis sought to uncover the emergent patterns of Mexican American caregivers as they manage care across sources in caring for elders to facilitate understanding of how and why they access these sources and what their major obstacles are. Also under examination were the ways in which the caregiver's interaction with her health and healing sources and other individuals affect her and those around her.

The primary study's first and second aims addressed caregiver burden/strain and the impact of cultural and contextual variables on caregiving. Reflecting these aims, the

secondary analysis sought to tease out caregivers' patterns of management of care across sources, access, and obstacles, which are informed by what the primary study identified as components of caregiver burden and strain (the emotional, physical and financial toll of caregiving) in addition to cultural and contextual variables. The primary study's third aim, determining what leads to nursing home admission, was reflected in the third aim of the secondary analysis, discerning the ways in which the caregiver's interaction with environment and systems around her affect those around her, including the elder for whom she is providing care.

Similar to this secondary analysis' focus on patient-centered care, the primary study sought to craft patient-centric interventions to help Mexican American families continue to provide care to the elder in the home rather than admit them to a nursing home. Both studies also focused on looking for patterns across caregiver experiences.

The primary study began by examining the six concepts within the life course perspective (LCP) framework listed previously: cultural and contextual differences, timing of life events, adaptive strategies, trajectories, transitions, and turning points. These concepts served as the basis for start codes for the primary study and were drawn from the theoretical framework and the LCP literature. These concepts provided the skeleton of the coding manual, and the remainder of the codes used were derived from the data and organized into domains. If there was truly a fit between the primary and this proposed secondary analysis, shadows of the sensitizing concepts of the secondary analysis would be apparent somewhere in the interstices of the LCP constructs used in the primary study. To determine whether there was a fit between concepts and thus whether I could proceed with the project, I began with operational construct sampling. It is important to clarify that although in this context operational construct sampling resembled theoretical sampling, my objective at this point was

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different. I needed to first determine a fit between studies conceptually and was not in a position to sample actual data yet.

 Operational construct sampling. Operational construct sampling entails "finding manifestations of a theoretical construct of interest so as to elaborate and examine the construct" (Patton, 1990, p. 183). The primary study's coding manual was a product of domain analysis (see Spradley (1979)). Domain analysis is based on "key topics" of interest found in the context of the data and the relationships that exist among those topics (Atkinson & Abu El Haj, 1996, p. 438). In examining the primary code book and its use of LCP concepts, I looked for those concepts that resonated with my sensitizing concepts drawn from the parent framework of complexity science. I also, in keeping with Sandelowski's (2007) suggestion, used the two frameworks and the relationship between them to pare back the data under scrutiny.

 I determined that three domains from the coding manual seemed to encompass something similar to those of my sensitizing concepts and were derived from LCP concepts: Transitions, Turning Points, and Adaptive Strategies. These three LCP concepts were defined by Evans and colleagues (2009) building upon the earlier work of Wethington (2005).

 Transitions are "significant changes in social roles or in responsibilities of an existing role, often accommodated into a trajectory as a gradual change." Turning points are those occurrences that "may be of sufficient magnitude to result in a break in the life course trajectory;" a "fateful turn." Transitions and Turning Points overlap somewhat in their definitions. Both are situated within an individual's life trajectory, comprised of health, social, and other factors, that develops over time and tends toward stability. Adaptive strategies are "templates that guide the interaction between the context and

culture of a group and the conscious decisions that one makes to adjust to external events" (Evans et al., 2009, p. 12).

Transitions, Turning Points, and Adaptive Strategies occur in the context of cultural and contextual influences. I have provided a page from the primary study's codebook that illustrates the three domains chosen and their themes immediately in Table 1.

These domains and their component themes provided evidence that the interview data contained information that could answer the research aims of this secondary analysis. These three domains fit well with my sensitizing concepts.

LCP's *Adaptive Strategies* are similar to *Emergence* in that *Adaptive Strategies* are those strategies that result as an individual adjusts to external events. Like *emergents*, these changes occur in response to interactions with existing structures such as culture, health and healing sources, and family. For example, the code "using information from the Internet as a resource" could be an emergent strategy. This strategy emerges when the caregiver responds to the external circumstances of caregiving and not having the information she needs and she goes looking for it on the Internet.

LCP's *Transitions* look like a manifestation of *Co-evolution*, particularly salient in regard to this project because the primary analysis was case oriented and this secondary analysis is as well. Each case contains a caregiver and a care recipient, with the caregiver as the primary data source. By virtue of always containing two individuals, interaction was an inherent feature of each case. When interaction occurs and decisions are made, *co-evolution* occurs in all parties involved since a change in one is in symbiotic relationship to change(s) in the other(s).

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Table 1

Three Domains With Associated Themes From the Primary Study's Coding Manual

Transitions	Turning Points	Adaptive Strategies
Facing gradual decline in CR cognitive status	Detecting the reckoning point	Assessing social services
Facing gradual decline in CG cognitive status	Facing gradual decline in CR cognitive status	Taking CR to MD< NP, ER, etc. for care
Facing gradual decline in CR functional status	Facing gradual decline in CG cognitive status	(Primary CG) supporting another primary caregiver(s)
Facing gradual decline in CG functional status	Facing gradual decline in CR functional status	Actively promoting/ encouraging improvement in health/wellness
Adding a spouse or partner to household	Facing gradual decline in CG functional status	Using traditional herbs and teas/medications
Having a child	Making a decision about CR institutionalization	Seeing a folk healer
Facing a separation from child leaving home	Trying to meet job, family, CR demands simultaneously	Making room for the elder
Adjusting to separation/divorce from spouse or partner	Dreaming about the future	Using a pet for assistance
Facing widowhood	Facing CR's death	Fostering independence/ feeling useful
Facing job loss	Facing auxiliary/other primary CG's death or incapacity	Changing family food or habits
Facing loss of home		Manipulating CR
Facing loss of paid CG		Planning ahead for CG coverage
Facing CR fear, worry, disappointment, sadness		Participating in outside activities (CG)
		Paying an informal CG
		Seeking care in Mexico
		Putting life in order
		Acting as a paid CG
		Seeing things in a positive way
		Setting limits
		Withholding information to prevent distress
		Staying consistent
		Identifying CR (bracelet) to avoid becoming lost
		Using information from internet as resource

Note: CR denotes Care Recipient; CG denotes Caregiver

For example, the code "facing gradual decline in CR cognitive status" could

demonstrate co-evolution. As the caregiver recognizes the increasing cognitive

limitations of the CR, she may take on more caregiving responsibilities. The co-evolution occurs here in the declining cognitive status of the CR and the increased caregiving responsibilities required of the CG, which result in a symbiotic change that occurs in both individuals.

Within *Adaptive Strategies* could sit *Self-organization*, as individuals engaged in *self-organization* respond to outcomes of interactions within contexts of culture and groups rather than some objective or controlling "prime mover." For example, the code "primary CG supporting another primary CG" could be an instance of self-organization in that there was no directive from "on high" that one CG should support another. The caregivers support each other for localized reasons that are not dictated by a removed system. Support may be required according to cultural parameters, and self-organization can also occur in this context. Individuals act according to rules of all kinds, no matter how subtle. But for our purposes here, it is important to remember that the self-organization taking place in this instance is not objectively ordered.

Turning Points, those "occurrences of sufficient magnitude" that occur along the life trajectory, are similar to *Chaos.* It is possible to anticipate a caregiver's response to those occurrences, within certain parameters, regarding the resulting break with the trajectory.

For example, "detecting the reckoning point" would be an example of chaos in that based on the conditions occurring, it may be possible to anticipate this break with the life trajectory within broad parameters like a given amount of time or based on levels of stress. By being cognizant of the "sufficient magnitude" referred to earlier, reaching the reckoning point may be "predicted," just as occurrences within chaotic systems can be "predicted" within a range.

Darkness does not relate specifically to any one construct from LCP but is useful, as mentioned, within constructivist grounded theory. *Darkness* reminds the researcher that she or he cannot know everything about the relevant phenomena and the context in which it occurs; nor does the study population have such omniscience.

The primary study's methodology was narrative analysis and used a longitudinal case- and variable-oriented approach. The primary study employed stratified purposeful sampling and participants' scores on seven standardized measures to determine caregiver burden, level of caregiver oversight, acculturation and cognitive status of both caregiver and care recipient, and depression and function of care recipients. The primary study conceptualized participant interviews and trajectories as narratives and sought to highlight within these narratives and trajectories the relationships among social and cultural phenomena that influence caregivers. The primary study was also interested in whether these phenomena were understood in similar ways across caregivers.

This secondary analysis used constructivist grounded theory methodology and a longitudinal case-oriented approach. Each case contained a care recipient and a caregiver, with the caregiver as primary data source. (Participant scores from the primary analysis' seven scales were not included in the data to be examined in the secondary analysis.) Analysis strategies included operational construct sampling and, as in the primary study, mixed purposeful sampling. Similar to the primary study, the secondary analysis was interested in perceptions across caregivers and in what phenomena inform their choices and their interactions with one another, their health and healing sources, and the elder to whom they provide care.

Theoretical sampling: The problem of not having been there. A secondary analysis is by its very nature begun at a distance from the primary study. The population

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of interest is accessible only through the primary study's data and the researcher's access to the primary study's investigators. The second major challenge of secondary analysis, then, is the problem of not having been there. There are those who contend that not having been there is perilous and there are those who contend it is not. As Irwin and Winteron (2011) noted:

> Primary analysts have a privileged relationship to the data that they have generated, but do not necessarily have a privileged claim on the arguments which can be made from that data . . . data will support different theoretical understandings, and "being there" is not the final arbiter of the adequacy of such understandings (p. 8).

Not having been there, I needed to create a point of entry into the data.[23] In order to address the problem of not having been there, I had to "sort" the data (Heaton, 2004, p. 59), which involves re-shaping it to answer the purpose of the secondary analysis and, often, reusing only part of the data as opposed to all of it. From a constructivist grounded theory perspective, sorting the data was an activity very similar to theoretical sampling. Theoretical sampling is a "defining property" of grounded theory that is used to "develop our emerging categories and to make them more definitive and useful" (Charmaz, 2000b, p. 519). I had to do some extensive preliminary sorting of the data (Heaton, 2004) in order to carefully bring to the fore the categories that were relevant to my secondary analysis. To accomplish this task in keeping with the methodological rules of qualitative analysis, I engaged in what Patton (1990) called "mixed purposeful sampling" (p. 183).

  I began with a purposeful sampling technique in which the qualitative analysis software, *ATLAS.ti*, was employed to search for these three themes in the data. I looked

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[23] The primary investigator of the primary study mentioned to me that neither was she there when her data were being collected—after all, she quipped: "One cannot do 660 interviews by oneself."

for cases that permitted me to explore my sensitizing concepts in the context of the caregiving experience data.

This approach "selects information-rich cases for in-depth study" (Patton, 1990, p. 182). At this stage, the number of cases selected was based upon the aims of my study and the interview data available to me. Creswell (2007) suggested that a grounded theory study contain either 20-30 interviews for analysis or 50-60 interviews (p. 67). In the 1998 edition of his book, *Qualitative Inquiry and Research Design: Choosing Among Five Traditions* (titled slightly differently than the 2007 version), Creswell suggested 20-30 interviews as the guideline for sample size in grounded theory. Mason (2010) pointed out: "While these numbers are offered as guidance the authors do not tend to present empirical arguments as to why these numbers and not others for example" (para. 11).

In purposeful sampling, this project arrived at six cases comprised of pairs of caregivers and care recipients, each containing six interviews over time, in keeping with Sandelowski's assertion that qualitative research is case-based rather than variable-based. This way, I retained Sandelowski's "empirical intimacy" and thus stayed close to my population, which provided me simultaneously with a focus on the separate interviews and their continuity across caregivers and across time and with a focus on each case in its entirety.

As I began to look at the six cases chosen in the purposeful sample, I used criterion sampling to concentrate on "preconceived criteria" (Sandelowski, 2000, p. 248) as reflected in the interstices of the theoretical frameworks of LCP and my sensitizing concepts. According to Patton (1990), criterion sampling looks for "information-rich cases that may reveal major system weaknesses that become the targets of opportunity" (pp. 176-177). Criterion sampling at this moment before data analysis provided me with

a frame for thinking about and operationalizing the decisions I had made conceptually. These decisions informed my data collection and later informed my analysis in Chapter 4 and the implications and recommendations discussed in Chapter 5. I anticipated having to sample further if, when I began analysis, I was unable to make the necessary comparisons across all six cases. The reader is treated to my adventures in analysis in Chapter 4.

With the first two challenges of secondary analysis explored, the discussion turns now to ways in which I ensured the quality of conclusions that were drawn from the data. This discussion fleshes out strategies for delimiting the problem of verification.

Standards for the quality of conclusions and limitations: The "problem of verification." In her review of the literature, Heaton (2004) admitted that generally accepted strategies for verification are, in actuality, not generally accepted. She found that secondary analysts

> have not shown a great deal of enthusiasm . . . for fully utilizing techniques such as the audit trail and referential adequacy for establishing the trustworthiness of qualitative work, both of which involve the external scrutiny of the work. (p. 71)

In order to address secondary analysis's "problem of verification" in the context of trustworthiness (Szabo & Strang, 1997), much of the onus lies on the secondary analyst and the questions she poses within the analysis of the data.

Trustworthiness. A secondary analysis goes a long way toward "enhancing quality control by verifying original research, thus adding to the transparency, trustworthiness and credibility of the original findings" (Nguyen & Benet-Martinez, 2007, para. 5).

Important to trustworthiness is reportage, describing the research methodology in enough detail to make it accessible and able to be evaluated by others. Heaton (2004) found that many of those researchers who defined their work as secondary analysis "did

not usually claim to be using a particular type of qualitative secondary analysis" (p. 103).

It is a foregone conclusion that reportage in qualitative research is often limited by

available space in journals or even dissertation chapters, and Heaton worried that this

inability to explicate a research project fully "limit[s] the extent to which the quality of

work could be appraised" (p. 103). She did make it clear, however, that "a lack of

information is not necessarily indicative of a lack of quality" (p. 103). The balance is a

precarious one, with cries for more journal space and advice to researchers to more

effectively explain themselves in the space provided ringing out on each side.

Heaton (2004) did offer some prompts that can direct the reportage toward

answering questions that may be important for appraisal. Here are only a few she listed

(p. 104): "What was the aim of the primary research?.... Were the data re-coded for the

secondary analysis? .... What was the function of the secondary analysis?…. What was

the analytical framework used and why?....How was the primary researcher involved in

the secondary study?"

Miles and Huberman (1994) wrote extensively about the quality of conclusions in

qualitative data analysis and how to judge them. They referred to the quality of these

conclusions in terms of "goodness of conclusions" and provided what they call a

question "we think can be fruitfully posed when you are reflecting on the question: how

good is this piece of work?" (p. 277). This query is intended to assess trustworthiness

and authenticity. The authors categorize such queries under different headings and

describe their approach as "pairing traditional terms with those proposed as more viable

alternatives (Miles & Huberman, 1994, p. 277)." The headings are:

Objectivity/Confirmability, Reliability/Dependability/Auditability, Internal

Validity/Credibility/Authenticity, and Utilization/Application/Action Orientation. In the next

paragraphs I walk through a cursory overview of each and provide selected examples of the relevant queries.

Objectivity/Confirmability is "framed as one [insert noun] of relative neutrality and reasonable freedom from unacknowledged researcher biases—at the minimum, explicitness about the inevitable biases that exist" (Miles & Huberman, 1994, p. 278). Two example queries from the authors' list are: (a) Are the study's general methods and procedures described explicitly and in detail; do we feel that we have a complete picture, including "backstage information?" and (b) Has the researcher been explicit and as self-aware as possible about personal assumptions, values and biases, affective states—and how they may have come into play during the study?

To address Objectivity and Confirmability, this project engaged in extensive discussion of researcher positioning in the study throughout the chapters and includes a methodological appendix that further explores researcher positioning.

Reliability/Dependability/Auditability seek to determine "whether the process of the study is consistent, reasonably stable over time, and across researchers and methods. Have things been done with reasonable care?" (Miles & Huberman, 1994, p. 278). Two example queries from the authors' list are: (a) "Are basic paradigms and analytic constructs clearly specified? (Reliability depends, in part, on its connectedness to theory.)" and (b) "Were any forms of peer or colleague review in place?" (Miles & Huberman, 1994, p. 278).

To address Reliability/Dependability/Auditability, this project outlined not basic paradigms and analytic constructs, but advanced conceptual frameworks and overarching paradigms that were connected clearly to theory. This project also enlisted the help of three faculty debriefers. The responsibility of these faculty debriefers was to provide feedback to me by reading drafts of my analysis in addition to my preceding

dissertation chapters for continuity and meeting periodically with me during data analysis. I provided regular reports to the faculty debriefers and field questions from the faculty debriefers regarding pieces of the dissertation already written, in addition to data analysis and synthesis. At that point, these sections of the project were still taking shape, and conversations with the debriefing team proved helpful in keeping me moving forward.

Internal Validity/Credibility/Authenticity measures the "Truth Value", which is to say: "Do the findings of the study make sense? Are they credible to the people we study and to our readers? Do we have an authentic portrait of what we're looking at?" (Miles & Huberman, 1994, p. 278). Two example queries from the authors' list are: (a) "Are the presented data well linked to the categories of prior or emerging theory? Do the measures reflect the constructs in play?" and (b) "Are areas of uncertainty identified (there should be some)?" (Miles & Huberman, 1994, p. 279).

To address Internal Validity/Credibility/Authenticity, this project bound the primary analysis to the secondary analysis via an in-depth exploration of categories from each study's organizing framework that resonated with the other and discussed these connections at length. The two studies were also explored in terms of one another vis-à-vis Heaton's (2004) three problems of secondary analysis. This project also built in a theoretical construct, *darkness*, to remind the researcher and the reader of areas of uncertainty and to enable these areas to be recognized and described.

External Validity/Transferability/Fittingness speak to the "larger import" of a study (Miles & Huberman, 1994, p. 279), as well as to their ability to be transferred to other contexts and the degree to which they can be generalized. Two queries from the authors' list are: (a) "Have limiting effects of sample selection, the setting, history and

constructs used been discussed?" and (b) "Is the transferable theory from the study made explicit?" (Miles & Huberman, 1994, p. 279).

To address External Validity/Transferability/Fittingness, I present theoretical claims, not incidence, in the chapters that follow. Although generalization is not possible regarding explications of causality, this project does stay within the parameters of generalizability and explores causal mechanisms. Researcher positioning within this project is that of "passionate participant as facilitator of multivoice reconstruction" (Lincoln, Lynham, & Guba, 2011, p. 99). Therefore, I am not seeking a positivist, objective "truth" but instead am interested in the nature of interactions occurring in the data—and the theory that may be implemented in this emergent environment. Of utmost importance is to provide readers ample material to make their own decisions about whether this project's conclusions are transferable to their setting. To accomplish this goal, the project deeply excavated numerous paradigms and disciplinary conversations in addition to the opportunities and limitations of secondary analysis in the context of this study, its population, the qualitative methodology chosen, and the frameworks employed.

Utilization/Application/Action Orientation asks: How does the study serve its participants—both researcher and researched? This way of verifying conclusions is a sticking point for me because of my theoretical orientation as a scientist and scholar. Although I discuss my personal philosophy and that which influenced me at length in the methodological appendix, I touch on my reality briefly here. Since I am a student of political science, much of my grounding lies first in political philosophy. I am an anarcho-libertarian. I believe in the arbitrariness and thus the abolition of the state in all its forms. (If a state is to be permitted at all, it must be severely restricted to protection of persons and property within its borders.) I support individuals' right to private property in the

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broadest sense, recognize the existence of multiple realities, and do not support organizations such as the United Nations and other international bodies, military or otherwise, seeking to foster "peace" cross-culturally. I subscribe to Austrian Economics, an extreme laissez-faire perspective, and to the anti-statist philosophy of von Mises, Rothbard, and Nobel laureate von Hayek. Philosophically, I am a postmodernist and a cultural relativist. I believe in multiple realities, and I do not believe that there is continuity across cultures. For me, "good" and "bad," "ethical" and "unethical" are words not possessed of universal, standardized meanings. Because of this belief, it becomes impossible for me to generalize across cultures and, speaking from my perspective as a healthcare scholar in the context of this project, to "prescribe treatment" for what ails them.

Not surprisingly, some of Miles and Huberman's (1994) prompts here are deeply troubling to me, for example: (a) "Are the findings intellectually and physically accessible to potential users?" (b) "Do the findings have a catalyzing effect leading to specific actions?" (c) "Have users of the findings experienced any sense of empowerment or increased control over their lives?" (d) Are value-based or ethical concerns raised explicitly in the report?" (Miles & Huberman, 1994, p. 280)

Yes, the findings are accessible—I concentrated heavily on making my writing accessible and engaging for the reader in a fine balance of aesthetic and rigor that was hard-won. I was cognizant as I laid out my chapters of my desire to attain this balance in a way that was emergent, to draw the reader in with me on the journey. However, with the rest of Miles and Huberman's 1994 standards, I find myself at issue.

As an individual who believes first and foremost in individual rights, which include the right to multiple realities and the inherent, thoughtful freedom that "ends where the other's nose begins," action orientation, particularly on my part as researcher, becomes

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the greatest disservice to my study's participants. Put simply, who am I to know what my participants want? It is a scary, violent proposition marked by hubris to assume that one person knows what another needs. And acting on it is an even greater violence.

In this same vein of the incongruence of my beliefs with Miles and Huberman's (1994) way of verifying conclusions is a larger conceptual issue that is even more antithetical to my perspective: the social justice of constructivist grounded theory. This ethic runs through Charmaz's writings and is widely present within qualitative research itself. Charmaz (2008) wrote:

> An interest in social justice means attentiveness to ideas and actions concerning fairness, equity, equality, democratic process, status, hierarchy and individual and collective rights and obligations. It signifies thinking about being human and about creating good societies and a better world. It prompts reassessment of our roles as national and world citizens. Social justice studies require looking at both realities and ideals. Thus, contested meanings of "shoulds" and "oughts" come into play. (p. 207)

I find troubling Charmaz's nebulous terminology such as "fairness," "good societies," and "a better world." As a postmodernist, I am wary of metanarratives that require a person to subscribe to an overarching sense of "the fair" or "the good." And what are the "obligations" to which Charmaz refers in her statement? Who determines these "shoulds" and "oughts"? And contests them? As an anarcho-libertarian, I worry about decrees of obligation that come from "on high"—whether from a statist or religious organization, or as a meta-ethic. And as a cultural relativist, I seek not to be a "citizen of the world," since I believe my presence and my actions in places other than the seat of my culture and reality does violence via texts of power, colonialism, fear, prevailing "Western" notions, and so many others that are never fully eradicated. I am reminded of the perils of hospitality, as described by Derrida (1997) in a later section of this chapter.

Strategies to draw, verify, and ensure conclusion legitimacy and formulate theory. This project used tools described by Miles and Huberman (1994) and Creswell

(2007) for drawing meaning and testing and confirming findings. Theory formulation was

be guided by Charmaz's (2006) "fundamental concerns and contested values" (p. 138).

Key strategies from Miles and Huberman (1994) for drawing meaning included:

noting patterns and themes, in keeping with the focus of this study, which is caregiver

processes of selection; noting relations between variables to determine what may or

may not affect her choices of care; finding intervening variables that may or may not

facilitate more effective selection of care; and determining whether caregiver patterns

are best described using the sensitizing concepts I chose to lend conceptual/theoretical

coherence.

Key strategies for testing and confirming findings included: checking for

representativeness regarding whether the data illustrate the caregiver processes in a

trustworthy way; checking for researcher effects as data is co-constructed with

participants even in this secondary analysis; and checking the meaning of outliers and

following up surprises in keeping with this project's sensitizing concepts that seek out all

experiences, even those that are not immediately apparent, and recognize that not

everything is knowable.

Creswell's (2007) suggestions included studying a process, action, or interaction

as the key element in the theory, which this project addresses explicitly as caregiver

selection of care from multiple health and healing sources; using a coding process that

works from the data to a larger theoretical model; and employing reflexivity or self-

disclosure on the part of the researcher about his or her stance in the study—this latter

suggestion was discussed in Chapter 1 and also is touched on in Chapter 4 and briefly

in the Methodological Appendix. I think it is also important to mention here that Charmaz

(2006) listed four strategies for confirmability: credibility, originality, resonance, and

usefulness. Denzin and Lincoln (2011) wrote, "She moves these strategies into the

space of social justice inquiry" (p. 248). Denzin and Lincoln referred to Charmaz's strategies as "basic questions that can be asked of any grounded theory of social justice" (p. 248). In light of my discussion regarding the incongruities of Charmaz's social justice and my theoretical orientation, these four strategies were not used in my work.

The advice of Charmaz (2006) aided in grounded theory formulation. Of particular utility as suggestions for theory construction were Charmaz's "fundamental concerns and contested values" (p. 138), including individual and collective action, cooperation and conflict, and choice and constraint. These juxtaposed terms address the interactions between caregivers and systems and the tensions, conflict, and patterns inherent in them. The study's conclusions were verified via a return to the data, making sure claims were justified and findings are useful.

Limitations. In previous chapters I was clear about my peculiar *idées fixes*: a near-obsession with texts, labels, preconceptions, binary oppositions, and presuppositions that inform realities and thus my work on this project. Here, at the end of Chapter 3, these *idées fixes* surfaced again in the context of limitations. I refer to them here because every endeavor, including scholarly research, has its limitations. However, labeling a section of this dissertation as "limitations," with its corresponding texts of shortfall, worry, loose ends, and faults, presupposes that issues here are solely that—limitations. They are not. In the spirit of constructivist grounded theory, I present these issues below so that their limitations and opportunities are in dialogue *with* one another rather than in binary opposition *to* one another. I invite the reader to join me in re-envisioning this discussion of limitations as hindrances and helps—simultaneously restricting the project and keeping it moving forward.

Secondary analysis. The elephant in the room regarding limitations to this project is named Secondary Analysis. As mentioned earlier, situating the elephant within this section on limitations, a section usually reserved for that which worries the study, presupposes that secondary analysis does not provide an equally strong set of opportunities for this project. It does.

The arguments for and against secondary analysis are nuanced and subtle. They deal with a variety of debates. For our purposes here in the context of this project, limitations to secondary analysis are examined via a discussion of use and re-use of data, the secondary study's degree of distance from the initial study, and the intuitive element of qualitative research that is thought to be present in the initial study and not accessible after, deemed the "privilege" of the primary researcher. Opportunities afforded by secondary analysis are explored through a discussion of the ways in which a researcher defines data and how those data are necessarily shaped during both the primary *and* the secondary analyses.

The privilege of primary analysis. Mauthner et al. (1998) asserted that secondary analysis is subject to limitations because of the distance of the researcher and her secondary study from the primary study and its initial context. Whatever occurred during the primary study is not accessible to secondary analysis, they contended, and therefore valid findings are unable to emerge. In order to cement the validity of this assertion, the three authors gave thought to their attempts at one time or another to return to a previous research project of which they had been a part, with the intent of precipitating new theories. Mauthner and colleagues reported that they found their data "to be constrained both by the concepts and ideas which were current at the time of our research, not only in the academic world but also in our own worlds and the worlds of the respondents" (p. 741). Unable to re-create the initial context in this return to the

data, the authors lamented what they called a "loss of privilege" (p. 742). If, in returning to their data, they found themselves in such a state, then the situation, according to the authors, is worse still for those unfortunate secondary analysts who had no such relationship with the data to begin with.

According to Irwin and Winterton (2011), Backett-Milburn's recounting of her own experience of returning to the data in her 1998 article with Mauthner and Parry included an "intuitive appreciation of her participants' lives evident within her data collection and analysis which she was unaware of at the time" (Irwin & Winterton, 2011, p. 6). The authors reported that what is implied here is that "primary researchers have a specific and privileged relationship to the data they generate, through their relationships with research participants and the immediate context of the research" (p. 6). Even in a primary researcher's return to the data, this type of relationship, by its very nature of being unique and specific to the primary study and researchers who collected the data,[24] is not accessible to secondary researchers. Thus, "it is implied such knowledge is key to the adequacy of subsequent analyses and claims being mounted on the data" (p. 7).

Irwin and Winterton's (2011) "adequacy of subsequent analysis" (p. 6) and the favored position of the primary researcher were explored by Hinds et al. (1997) in their discussion of closeness versus distance from the primary study. Hinds et al. (1997) stated:

> Closeness carries the benefit of knowing the context of the study; however, it could also allow the researchers to develop a premature certainty about a phenomenon that may be present in the data set but that was not a focus of the primary study. (p. 420)

For Hinds and her team, the secondary analysis carries implications as well:

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[24] I use the word "collection" here as it is used in the scholarship on primary data and analysis. As the reader will remember from earlier in this chapter, "collection" also occurs in secondary analysis via sorting and sampling data.

Distance may benefit the research purpose by introducing a researcher who does not have firm or fixed ideas about the phenomena in the data set. However, too great a distance, including sensitivity to the study context of both the primary and secondary studies, may allow for misinterpretation. (p. 420)

Hinds and her colleagues (1997) also worried about "the sensitivity of researchers to the context of the primary study" (p. 414). To address this issue, Hinds et al. asserted that primary study researchers must "sensitize the researchers conducting this secondary analysis" (p. 414). Although the authors did find secondary analysis practically and epistemologically feasible, their assertions here did presuppose the privilege and insight of the primary researcher and primary study. Hinds et al. suggested that primary researchers undertake "actions that help the [secondary] researchers to feel close to a condition of 'having been there' and to imagine the emotions and cognitions experienced by the participants and the researcher during data collection could be particularly valuable" (p. 414).

It is apparent that there exists a conversation in the literature on secondary analysis that, while differing in degree and sometimes semantics, does rely on the primary study to guide the secondary. Within that reliance are assumptions about primacy of interpretation and the dangers of a secondary analysis that may ignore these assumptions.

What constitutes data. On the other hand, backing far out from questions of primary study privilege to more conceptual questions of what constitutes data, Sandelowski (2011) encouraged us to re-think data's objectified existence, whether they exist "out there independent of users" (p. 374). The way in which this question was answered informed the paradigm under which analysis took place and called into question the primacy of the primary study. This project contended that data do not exist objectively outside of interpretation and are instead shaped according to who is

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engaging with them. Questions of use (primary study) and re-use (secondary study) and of researcher privilege regarding primary data fall away, and the data are "transformed" (Watt, 2007, para. 2.3).

Mauthner et al. (1998), in the same article referenced earlier that addressed secondary analysis' limitations, agreed: "The meanings of data are not to be found in the data" (p. 735). Their assertion opened a space for Sandelowski (2011) to add that these meanings are instead found "by persons looking for meaning in the material construed to be data" (p. 374). The data are, as Moore (2007) wrote, "here and now being constructed in the process of a new [my] research project" (para.3.5). Thus, if meaning is created only when data are analyzed and within the context of whatever project is seeking that meaning, then the texts of primary and secondary analysis become moot. Data are born anew each time a researcher reaches for them. Prior births are rendered inconsequential, as are prior meanings of the data.

Nevertheless, it is important to remember, for our purposes here, that within the confines of research we can reshape "the logico-deductive model" (Charmaz, 2006, p. 17) only so much. And so, a delicate balance must be struck. Although taking place within the semipermeable boundaries within which the literature labels "secondary analysis," this project concurred with Bishop (2007): No matter how you slice it, re-using data is using data. My distinct *idées fixes* always recognized the texts inherent in the positioning of primary and secondary study and the binary oppositions that accompany it. Although I had to remain mindful of the positioning of primary and secondary analysis and address what this positioning means within the larger, linear context of secondary analysis scholarship, I was also sure the data would (and must) "change with person and time" (Sandelowski, 2011, p. 374), and that is exactly what I wanted them to do.

Sample size. The second limitation to the project was sample size. Again, the fact that this discussion occurs here in the limitations section is not intended to assert that decisions made around sample size did not help the project. They did. And, like any decision made within any type of research, they also restricted the project in other directions.

The debate in the qualitative literature explored here about how many of this or that type of data should be used in a research project is almost as broad and deep as the debate about the literature review's place in grounded theory explored in Chapter 2. The debate also has an almost Taoist, meditative character to it: Sandelowski (1995), recounting a personal communication with Stern, suggested that "we often have all the data we will need in the very first pieces of data we collect, but that we do not (or cannot) know that until we collect more" (p. 180).

Part of the sample size conundrum is what seems to be an inherent relativity of sample size to project:

> Adequacy of sample size in qualitative research is relative, a matter of judging a sample neither small or large per se, but rather too small or too large for the intended purposes of sampling and for the intended qualitative product. (Sandelowski, 1995, p. 179)

Baxter and Edwards (2012) posed the "perennial question" of how many interviews to carry out in qualitative research, and Wolcott answered:

> It depends on your resources, how important the question is to the research and even to how many respondents are enough to satisfy committee members for a dissertation. For many qualitative studies one respondent is all you need–your person of interest. But in general the old rule seems to hold that you keep asking as long as you are getting different answers, and that is a reminder that with our little samples we can't establish frequencies but we should be able to find the RANGE of responses. Whatever the way the question is handled, the best answer is to report fully how it was resolved. (pp. 3-4, emphasis original)

Also presenting challenges to specifying sample size in qualitative research is the fact that sample may "refer to numbers of persons, but also to numbers of interviews

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and observations conducted or numbers of events sampled" (Sandelowski, 1995,

p. 180).

Ultimately, the hindrance and help posed by decisions about sample size is that those decisions are not prescriptive. As Sandelowski (1995) noted,

> An adequate sample size in qualitative research is one that permits—by virtue of not being too large—the deep, case oriented analysis that is a hallmark of all qualitative inquiry, and that results in—by virtue of not being too small—a newly and richly textured understanding of experience. (p. 183)

In other words, the researcher has the ability and responsibility to make, articulate, and justify those decisions for better or worse, and to step back and let others see her or his choices. As the *Tao Te Ching* advises, "Do your work, and then step back. The only path to serenity" (400 B.C.E./1999, section 9).

The strange and the familiar. The primary study engaged Spanish-speaking Mexican-American research assistants and cultural consultants who were well versed in Hispanic caregiving. The team of research assistants acted as cultural brokers, and the cultural consultants guided the research assistants in procedures of data collection and coding. Study participants, all Mexican American, were able to choose to complete the interviews in Spanish or in English. The team of Spanish-speaking research assistants transcribed those interviews completed in Spanish verbatim and then translated them into English. A second Spanish-speaking research assistant then performed a blind back-translation of the interview into Spanish. Translators corroborated their work across transcripts, using their knowledge of both cultures, to ensure culture and language uniformity and to identify errors in meaning. In short, an extensive network of cultural insiders and culturally-sensitive and knowledgeable individuals collaborated on the primary study.

This secondary analysis had no such team. The interview data I used was in its English translation state, having gone through back-translation when applicable. Although I have some knowledge of the Spanish language and customs, they are not, as described by the principal investigator of the primary study, "bred to the bone" as with the team who addressed the data in the primary study. This admission brings me to the final limitation of the study, and one, like the others already cited, that was both a hindrance and a help to the project.

In order to address my status as neither Latina nor an expert in Hispanic caregiving, and how this status limited/did not limit this project, I haul out the age-old discussion of *the strange and the familiar* as it sits within the discipline of anthropology (see Geertz (1973)).[25] And, returning to the postmodernist roots of constructivist grounded theory, I also entertain the thoughts of Derrida (1997) from his book *de l'Hospitalité* (*on Hospitality*).

It would seem that my neither/nor status would have limited this project severely, particularly according to prevailing anthropological perspectives. It could be said that my neither/nor status led me to *make the strange familiar,* that is, to bring the phenomenon under examination into a reality and language outside that of Mexican American culture that others who are also neither/nor like me can understand. Drawing it all in closer than arm's length, I sought to make it *familiar* though it currently existed as *strange* to non-Mexican Americans*.* This process could, however, be particularly important should this project's findings be shared with those who are tasked with designing better ways of ensuring access to care and honoring localized narratives. If 21st-century literature and

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[25] I came across this almost-dreamy commentary on an internet message board about Clifford Geertz, posted under the pseudonym *Lytle*: "Meta-anthropologists are, at the end of their fieldwork, allowed to take on the name Clifford--signifying a special combination of observing from the cliff and participating as one fords the river of fieldwork." I thought it was particularly poetic, and fitting.

policy statements are to be believed, the majority of these designers are also neither/nor.

Nevertheless, in *making the strange familiar*, was I the proverbial anthropological "ogre" Lévi-Strauss wrote about in *Tristes Tropiques* in 1955 (Lévi-Strauss, 1992, p. 389), a slobbering, angry laggard arrogantly misinterpreting what I have been tasked with analyzing? With a dearth of cultural knowledge about the population I study, I ran the risk instead of violently pulling participants' realities (the *strange*) into my own and those of my culture (the *familiar*), replete with Western metanarratives.

By virtue of my reality as a neither/nor, being engaged in secondary analysis of this data without the skilled cultural experts of the primary study, and translating this research for the larger American culture, I am *making the strange familiar*. And I am both helping and hindering this project.

Alternatively, I could seek to *make the familiar strange*. Fully acknowledging my biases as a neither/nor who lacks intimate knowledge of the culture she is studying, perhaps I must leave the data where it is at arm's length and let its familiarity rest with those who experienced it directly and can therefore understand it directly. Rather than addressing the data and the findings on terms that are *familiar* to me and those like me, where it makes sense to the larger, neither/nor audience, it instead stays *strange.* To address this idea of retaining *the strange,* I return to Chapter 1 and the postmodern perspective on my research methodology as illustrated by Derrida (1997).

Derrida (1997), in his book *de l'Hospitalité*, wrote of *pas d'hospitalité.* This phrase translates from the French as both "no hospitality" and "the first step of hospitality." (It is widely known that Derrida used the beautiful vagaries of the French language to illustrate inherent ambiguities in reality and perception.)

Derrida (1997) demonstrated that for every action of hospitality, there is an element of transgression. I welcome an individual into my home, and as soon as the individual steps over my home's threshold, that individual is re-envisioned by me according to my perception. He becomes *familiar* to me. As a guest in my home and in my *état* (the word in French for both nation-state and state of being), he is also subject to the legal and cultural laws to which I subscribe as well as to my particular reality. He is no longer outside my reality and is thus not free of my perception of him. Derrida saw this act of welcoming as an act of violence committed by the person offering the hospitality.

Derrida's thoughts are important to this discussion of *the familiar and the strange.* In refusing to address the data via channels or perspectives that were familiar to me, the status of the data for the project was retained as *strange* and not re-envisioned according to a non/neither, Western perspective. Thus, it remained free of outside perception and the dangerous prevailing metanarratives that seek to do it violence from a Derridean (1997) perspective. Spiro (1990), writing from an anthropological perspective, echoed Derrida: "The strange can only become the equal of the familiar, not, paradoxically enough, by being made familiar, but by remaining strange" (p. 54). Nevertheless, again, by retaining *the strange*, I simultaneously hindered and helped this study. Unwilling to bring the data to a place where they might be used, for better or worse, by those neither/nor designers of new health and healing systems who seek a patient-centered perspective, have I done a disservice to the study participants? Or, have I done them the greatest respect, permitting them no hospitality that would have them cross my threshold and saving them from violence?

The dialectic between *the familiar and the strange*, and the journey toward one or the other, is just that—a journey that is taken toward understanding the Other. In taking

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this journey, I was at once familiar and strange, self and Other. A daunting and precarious position, but a liminality that is required of a neither/nor scholar engaged in co-construction with participants from whom she feels distanced both physically and culturally. And one that has borne and will continue to bear extensive examination.

Conclusion

The peregrination through this project's methodology was no easy task. As Heaton (2004, p. 106) observed, "Clearly there is more to secondary analysis than analysis alone." Heaton is correct, but "more" is somewhat misleading. I offer that there is, rather, a near-boundlessness to the undertaking of secondary analysis. Its bounding requires great mental dexterity and a holding in tension of both a tether to the primary study and the opportunity, as Sandelowski (2011) called it, to "transform the data to fit the purposes of the projects in which they are put to use" (p. 347.)

Secondary analysis adds a thick, foggy layer of requisite internal reflection and outward articulation to what would otherwise be a (relatively) clear discussion of methodology and plans for analysis. Directions as to how to engage mind and heart in this process are sparse. However, it seems to be within that fog that data are best able to tell their story. Like the proverbial butterfly flapping its wings in turbulent weather, the un/structured environment of secondary analysis allows for the movement of the story over ever-greater distances, permitting an examination here and there and defying all logic elsewhere. This, I believe, is the terrifying and the sublime of secondary analysis, and particularly constructivist grounded theory secondary analysis: We will never be able to illuminate everything. And that's okay.

It is in this chapter that I have attempted to cantilever my work from the sturdy foundation of the primary study, scaffolding out as far as I can using support from the primary investigator of the primary study, my faculty debriefers, the extant secondary

analysis texts, completed studies. The end of Chapter 3 marks my first steps on my

own, in earnest: the courage of secondary analysis.

Chapter 4

CHARTING CAREGIVER PROCESSES

Chapter 4 simultaneously maps two journeys: The first is that of researcher through data, and the second that of caregiver through process of management. These journeys are situated within and bound to Charmaz's (2006) analytic turn to "make an interpretative rendering that begins with coding and illuminates studied life" (p. 43). To reflect the anxiety that is rumored to occur at the outset of analysis, I include Munhall's percipient admission regarding analysis here: "Each of us is trying to measure up to an elusive 'right way' and thus feels like an impostor" (Munhall, 2007, p. 239). Thankfully, Charmaz tempered Munhall's admission a bit, reminding us that there is a whimsical quality to grounded theory (albeit rigorous): "Theoretical playfulness enters in. Whimsy and wonder can lead you to see the novel in the mundane" (pp. 135-136). To retain this balance of the rigorous and the whimsical throughout the analysis, I tightly tethered the analysis, even when at its most provocative, to the data.

I lay out the steps I took in analysis in the following sections. I did this with a certain mindfulness, not unlike that of this project's parent framework, complexity science, that the whole is often more than the sum of its parts. Reductionistic division and dissection does not always make things clearer. As Charmaz (2006) warned: "Writing our analysis entails more than mere reporting" (p. 154). It is a delicate balance of unfolding the data's story and a linear listing of task that followed task coupled with the iterative feedback-looped quality of qualitative analysis that I strived for in my work in this chapter. For, as Charmaz noted: "The path is not single . . . and today [I] can write about the bumps in the road as well" (p. 155).

I begin by laying out my methodological considerations and follow that with an unfolding of the data's story. The reader is treated at the outset to my overview of the

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data-driven, emergent model that reflects caregivers' management of health and healing

sources. Then I dive more deeply into that model via a description of the component

processes I identified. Within this discussion of story, model, and process, I touch on

Charmaz's (2000) six data analysis strategies of constructivist grounded theory: "(a)

simultaneous collection and analysis of data, (b) a two-step data coding process [—initial

and focused coding,[26]] (c) comparative methods, (d) memo writing aimed at the

construction of conceptual analysis, (e) sampling to refine the researcher's emerging

theoretical ideas, and (f) integration of the theoretical framework" (pp. 510-511).

Methodological Considerations

      I identified three methodological considerations throughout the process of

analysis: the importance of a linear organization to the chapter, an explication of my

sampling strategies, and my reasons for not using qualitative analysis software. These

considerations arose in an iterative fashion as I moved through Charmaz's suggested

steps of coding and interpretation, but I present them in a more linear manner for

purposes of discussion.

      Linear organization of this chapter. Although the process of analysis is quite

iterative, grounded theorists lament the fact that researchers can present it only in a

somewhat linear fashion (Charmaz, 2006; Elder et al., 2009). I concentrated heavily in

the first three chapters on effectively presenting the emergent quality of this project.

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[26] Charmaz (2006) added axial coding as an additional possibility for researchers who are constructing grounded theory using a constructivist frame. Axial coding is one of the mainstays of Strauss and Corbin's grounded theory methodology, but for Charmaz it was optional. Charmaz explained axial coding as that step in coding that "specifies the properties and dimensions of a category" (p. 60). She suggested it "provides a frame that researchers can apply to the data; this frame may extend or limit your vision, depending on your subject matter and your ability to tolerate ambiguity" (p. 61). I was confident that the framing work I had done up until this point was sufficient and at the same time left enough room for insights to continue emerging, and I was very used to tolerating ambiguity. I did not perform axial coding *per se* according to Strauss and Corbin's prescription. However, in my process of coding and analysis I did examine the links between codes and thus categories of codes, and this process informed my analysis and thus my findings.

However, in light of the corpus of literature that warns of sloppy grounded theory and the prevailing lack of explication of a methodology or steps taken through analysis, I chose to present the analysis in a somewhat linear fashion. With the iterative quality of grounded theory set aside at this juncture to a degree, I laid out the analysis according to the steps outlined.

"Problems" of secondary analysis. As discussed in Chapter 3, the intricacies of secondary analysis posed unique challenges to this project. According to Heaton (2004), these challenges can be summed up as the three "problems of secondary analysis." I used specific methodological strategies to address these challenges. I began with two sampling strategies to sort and sample the data. Operational construct sampling helped to determine conceptual linkages between the primary and secondary studies. This strategy addressed the first problem, data "fit." Theoretical sampling (purposeful and criterion sampling) helped to find rich cases in the data that were able to answer my research question. This strategy addressed the second problem, "not having been there." Finally, I tackled the third problem, the "problem of verification" of findings in secondary analysis. To do so, I explored numerous strategies within qualitative research used to verify conclusions and formulate theory and suggested how each might be used in my work.

Use of qualitative analysis software. I made a conscious decision not to use qualitative software. As mentioned in Chapter 3, the research assistant for the primary study employed *ATLAS.ti* to aid in my initial sorting of the data, but I chose not to continue to depend upon computer-assisted analysis to explore and analyze the data.

I concluded that the amount of data, six cases comprised of six interviews each, was reasonably addressed without the help of an analysis program and that I could handle it myself. The amount of data notwithstanding, the discussion around using

software (or not) is, for me, more about the ability to treat the data, like the participants it reflects, as being alive and breathing, needing room to shift, change, and interact. Not using software, I believe, allowed the data to settle into codes and meaning without being boxed in too soon. The lines instead remained blurred as new codes emerged. My sense is that language is delicate and at my hands could be done violence enough, and perhaps more so with a computer program. Aware of this possibility, I also wanted to stay as closely connected to the data as possible. After all, this was a secondary analysis and I was already somewhat distanced from my participants, Albatora, Iliana, Jovana, Madalena, Nalda, and Sancia (my pseudonyms for each). I had spent an inordinate amount of time carefully scaffolding from the primary to the secondary study conceptually and methodologically. I didn't want any further mediation. Although varying opinions about the utility of qualitative software programs abound, I was confident that the decision I made was appropriate for my particular project.

In this regard, Charmaz (2000b) recounted a personal communication she received from Yvonna Lincoln that speaks to my choice: "Why would you want to engage in work that connects you to the deepest part of human existence and then turn it over to a machine to 'mediate'?" (p. 520). I also agree with Charmaz's (2000) "reservations about these programs," including the fact that software programs seem to be of a more objectivist than constructivist bent and that they "may unintentionally foster an illusion that interpretive work can be reduced to a set of procedures" (p. 520).

Unfolding the Story

This project was conducted in an effort to better understand the processes that emerge as female Mexican American caregivers move across health and healing sources, managing care for an elder. *Charting caregiver movement across health and healing sources: An emergent process* was the nascent conceptual model that

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germinated and grew out of the data examined within this project. The model was

fleshed out in a way that was consistent with the available data and the decisions made

regarding sampling that data as discussed in Chapter 3. The model was brought to life

via rich vignettes and their thick description as gleaned from secondary analysis of

interviews across time, sorted and sampled from the primary study.

The model took the first step toward depicting an emergent process of managing

care that began with *identifying the need* and then moved through *accepting the*

caregiver role and into *searching for help* and *managing care*. The model described

management of care as an emergent process because the phenomena that were

identified as antecedents of and drivers/tensions within that management arose from

dynamic and fluid interactions and feedback loops that were in constant dialogue with

the environment and individuals around the caregiver.

Because the model depicted an emergent process, some aspects of the model

may never be illuminated or anticipated completely. Hardly a limitation, these "dark"

aspects provide fertile ground ideal for the model's growth and development in future

exploration at the edges of that darkness. Further, extant and identified constructs and

components of the model may take shape anew as fresh insight and new data are

integrated into it via future research. For example, what were referred to in the previous

paragraph as drivers and tensions in the model may be later developed as mediators

and moderators to the care management process. At this moment in the course of the

model's development, however, it seems that the drivers and tensions played out at

different places in the data, and it is unclear whether they informed the entire care

management process or acted within processes. Determining their role may shift the

way they are described in later iterations of the model, but in this first iteration of the

model the data did not support the use of mediator and moderator to describe the presence of these phenomena, and neither did the methodology used in the project.

With its iterative and emergent quality grounding our discussion and our understanding of what the model seeks to depict, the model is best understood as an evolving picture of need as defined by caregiver in dialectic with others around her. I describe the model and then explore more deeply its stages. In exploring the stages I move between the caregiver's process of management via the codes that delineate its stages and my own process of analysis via memoing and Charmaz's strategies as listed earlier.

As depicted in Figure 1, the first part of the process is what I identified as the emergent role of the caregiver—comprised of Stage 1, *identifying the need* and Stage 2, *accepting the caregiver role*. The second half of the model is what I identified as the emergent behavior of the caregiver—comprised of Stage 3, *searching for help* and Stage 4, *managing care.* It is important to mention here at the outset that stages 3 and 4 are inextricably bound together in feedback loops and are discussed throughout the analysis with that understanding. The four stages and their components are explored in the paragraphs that follow.

The process begins with *identifying the need*. At this first stage, it is determined that the elder needs care. If this need is not identified and the interaction between caregiver[27] and others does not begin, the rest of the process does not occur. This is because, as mentioned previously, this conceptual model is built upon a dialectic between caregiver and others. The process moves forward when the need is identified

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[27] I use "caregiver" here out of linguistic necessity. At this juncture in the model the need has not been identified and thus the individual who would provide care is not either, so how could I call her a caregiver? Language limits me to articulate the role so we can look back at its acceptance. The step between stages 1 and 2 is full of ambiguity, positioning, texts of power, compassion evoked, feelings of entrapment…

and a determination is made about necessity of care. This determination occurs in

different ways and is put into motion by different individuals and systems around the

care recipient. It may ultimately be the individual who identifies the need who then

provides the bulk of care, but this is not always the case.

drivers/tensions

emergent behavior

sources

managing care

searching for help

accepting caregiver role

emergent role

antecedents

identifying the need

evolving picture of need

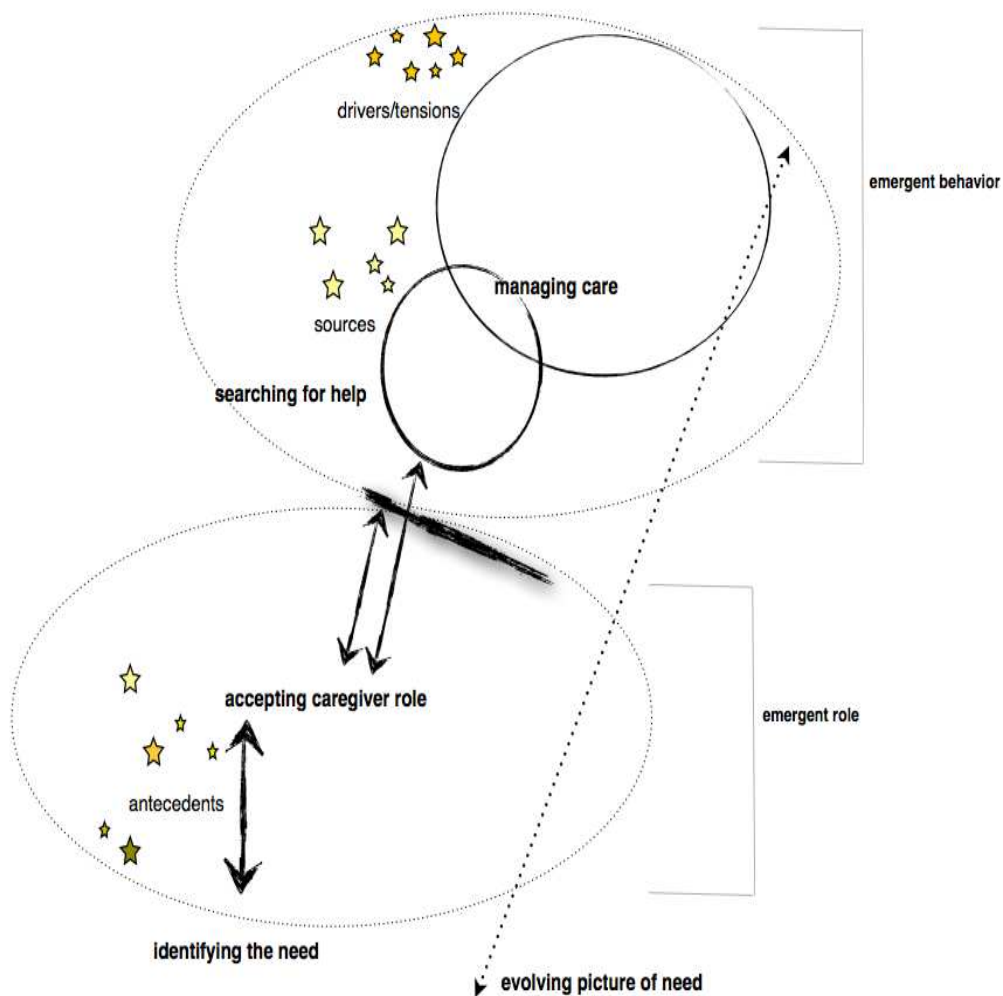*Figure 1.* Charting caregiver movement across health and healing sources. This is the
nascent conceptual model that emerged from the data.

The second stage is *accepting the caregiver role*. At this stage, an individual or

group of similarly-minded individuals takes on the responsibility of caregiving for the

elder. It is this individual or group that the rest of the process follows. In the move from

the first to the second stage, a constellation of antecedents inform the caregiver's decision and are discussed later in the chapter. In moving from the second to the third stage, *searching for help*, the caregiver passes through a space that the data were not able to illuminate fully. Although not completely clear, the data did show that in this space, the caregiver makes decisions and reflects internally on such decisions as whether to take on caregiving, provide care herself, search for help, and continue or cease caregiving. Regarding the data sampled for this project, this space was where the caregiver returned when she was ambivalent about continuing to provide care and/or perceived that searching for help was not entirely successful. This space and the next two stages of the model were traversed frequently.

The third and fourth stages, *searching for help* and *managing care*, respectively, were bound tightly together in feedback loops. In the third stage, *searching for help,* the caregiver searched for help from four types of sources: family, friends, traditional, and biomedical, detailed further in paragraphs that follow. My use of "help" in the third stage is purposefully vague in reflection of the data—this stage is both about needing others to actually take a turn at caregiving and about searching for the sources to complement the care role that has just been taken on. The fourth stage, *managing care*, described caregiver management of sources and management of self in a sort of dialectic. There were processes embedded within this dialectic that, as mentioned earlier, were described in the model as caregivers' emergent behavior. Although this behavior was present and apparent in the data, this behavior was illuminated only in terms of the data itself—speculation about its spectrum of manifestations outside of what was present in the data was not possible. What was apparent, however, was that the caregiver's emergent behavior included responding to the absence or inadequacy of sources by returning to and relying upon herself. Within the data were repeated examples of self-

organization on the part of the caregiver. In some instances, she was not alone in this self-organization, and in other instances she was. Regardless, there was no systemic "prime mover" who dictated her movements either in her management of sources or in her reliance on herself. In all cases, when sources around her were absent or inadequate, she returned to herself, and this action often preceded exceptional levels of stress for the caregiver versus when other sources were involved. In some cases, reliance on self precluded a caregiver's refusal to continue providing care.

Because the caregiver's process of management was in constant dialogue with that which was occurring around it, it could be said that she was always acting in response to her environment. However, the data demonstrated that this determination, although somewhat accurate, did not tell the story in its entirety. Caregivers were not simply reactive. They too were in dialogue with the environment—and sometimes not a polite one. Caregivers pushed the process in this or that direction; some anticipated and others simply ignored the environment in managing care. Contributing to this dialogue was a constellation of drivers that informed the caregiver's continued movement through the model and interactions with sources.

The fourth stage, although the last stage described here, should not be considered the final stage, given that the data demonstrate that the emergent model was somewhat cyclical. In some cases, caregivers cycled back to the second stage and determine anew whether to accept the caregiver role. With this brief overview provided, the stage-by-stage description vis-à-vis my own analysis process is laid out in the following section.

Charting my journey through analysis. As I mentioned, I used Charmaz's (2006) suggestions as markers to guide me through analysis: "(a) simultaneous collection and analysis of data, (b) a two-step data coding process, (c) comparative

methods, (d) memo writing aimed at the construction of conceptual analysis, (e) sampling to refine the researcher's emerging theoretical ideas, and (f) integration of the theoretical framework" (Charmaz 2000, pp. 510-511). Although the steps look like a straightforward, ordered list here, they were employed at different times and in different combinations, as described within the analysis that follows. Consistent with a constructivist approach, the view I have of the data is part of their "rendering" (Charmaz, 2006, p. 149).

Within the parameters of Charmaz's (2006) strategies, I am able to identify three clear moments in the analysis process that will serve as landmarks to safely and sanely move us through it. These three moments correspond somewhat to the identification of the different stages of the emerging conceptual model that describes the caregiver's process of management. First, initial and focused coding per Charmaz teased out the feedback loops that were evidence of caregiver interaction with individuals and systems around her. Second, engaging in constant comparison of data to data and data to research question, I went back to the data at a very literal level to determine the sources used by the caregiver as discussed in the interviews. Third, aware of feedback loops and with sources identified, I began to look at what was antecedent to her process and at what drove and restrained it.

In the sections that follow I explore these three moments that marked my own experience with the data and that lent direction to the emergence of the conceptual model born from that data. As Charmaz (2006) permits, I "pursue[d] my hunches and [offered] potential analytic ideas about them" (p. 3). My corresponding memos are transcribed here from the voice recorder on my iPhone, as another perspective from which to triangulate the discussion.

First moment: Coding and feedback loops. As I began the coding process, I was cognizant of Charmaz's (2006) forewarning about the ease (and the trap) of mistaking "routine rationales for analytic insight," and that "picking up general terms from an interview like 'experience' or 'event' and calling them codes tells you little about the participant's meaning or action" (p. 49). I was also wary of Charmaz's warning to "be careful about applying a language of intention, motivation, or strategies *unless the data support your assertions* (p. 68, emphasis original) and avoided assuming I knew what my participants were thinking.

To do so, I used Charmaz's (2006) questions to "check" how I coded:

How does my coding reflect the incident or described experience? Do my analytic constructions begin from this point? Have I created clear evident connections between the data and my codes? Have I guarded against rewriting—and therefore recasting—studied experience into a lifeless language that better fits *our* academic and bureaucratic worlds than those of our participants? (p. 69, emphasis original)

And, for every theme I identified in the data, I had the centrality of Charmaz's "enacted processes" and sense of in the back of my mind.

Memo 1. What do I really want to know about these caregivers? How are they managing care? What are they doing? Yep—that's it. I want to know what the heck she's doing.

With this question of "doing" in mind, I concentrated on looking closely at the data and used gerunds to reflect what I was finding [see Glaser (1978)]. "Adopting gerunds fosters theoretical sensitivity because these words nudge us out of static topics and into enacted processes," noted Charmaz (2006, p. 136), and it was indeed enacted processes I was looking for in the data. Charmaz offered examples:

Think of the difference in imagery between the following gerunds and their noun forms: describing versus description, stating versus statement, and leading versus leader. We gain a strong sense of action with gerunds. The nouns turn these actions into topics. (p. 49)

Additionally, using gerunds made organizing themes/codes into clusters/categories easier because all were framed similarly.

The codes that emerged in my initial coding of the data described what the caregiver was doing and the actions and reactions of those around her. For example, she did things such as *doing [her] own research, requesting help*, *creating networks*, *staying organized* (in-vivo), *doing whatever was necessary* (in-vivo), and *taking it one day at a time* (in-vivo). Others around her did such things as initially *refusing to participate* in caregiving and then *suddenly shifting* to agree with the caregiver that the elder needed help. *Conversing without the caregiver* occurred when individuals made decisions about the care recipient without the caregiver's input or when discussions were had that the caregiver could not understand. In some instances, the care recipient expressed *wanting the family to care for him/her.*

Looking back to this moment in my process, I found that the initial themes captured more than I'd intended them to. I broadened my scope too far at the outset and pulled in not only caregiver process, but also the actions and reactions of those around her to this process. What I found in this first coding of the data, however, was that the caregiver's process of management or nonmanagement seemed to be partnered in a feedback loop with those around her.

Caregivers reported *feeling guilty*, *feeling ashamed*, *feeling frustrated*, *feeling depressed*, *[feeling] angry*, *misunderstood*, and *trapped* (all in-vivo), particularly when the caregiver had to deal with this interplay between what she was doing, what she was not doing, and others' reactions to that. It was a fortunate error that I made; these feedback loops would not have become apparent without it.

It was in identifying this interplay between caregiver and what/who was around her that I began to feel that, although my coding process was initially too broad and I had to rectify that, I had simultaneously limited myself in a different direction.

> **Memo 2.** The data are showing the caregiver's process of managing care is not a static event that happens and then stops. On the contrary, based on what I'm seeing in the data, a host of interactions continue. Feedback loops continue, even in cases where the caregiver says "no" to caregiving.

I remained cognizant of the feedback loops that I'd identified when my initial coding process was too broad, and of the fact that there was more to the story than simply a process as a static event that stopped. Looking at the data again, I used a focused coding process. I concentrated on the caregiver's perspective and her perceptions of her interactions and the feedback loops in which she was involved. I took the advice of Miles and Huberman (1994): "The analyst should be ready to refine or discard codes when they look inapplicable, overbuilt, empirically ill-fitting, or overly abstract" (p. 65). Thankfully, alleviating my anxiety, Charmaz (2006) was one step ahead of me: "The first reading and coding of the data need not be the final one" (p. 70). In keeping with my research question and the focus of this project, I removed those codes that applied to people other than the caregiver—remaining mindful, of course, of the feedback loops that I'd discovered due to my initial "error."

Second moment: Constant comparison and sources. I began to re-examine what I'd found in the data through focused coding that reflected the caregiver's experience in terms of her interactions with others. I wanted to identify processes of management and follow those processes further, if possible. At that point, I was not sure whether this course of action was possible—I just kept looking and reading and using constant comparison.

> **Memo 4.** I'm not entirely sure that I can follow the processes any further. I've identified feedback loops—the caregiving experience doesn't occur in a vacuum.

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Although I'm looking for the caregiver's experience, because of the existence of these feedback loops, I am examining her interactions with others. Not others' interactions per se, but instead the caregiver's perception of them and her involvement. Jovana's story really struck me. I think she's the one who can provide clues as to how this might continue unfolding. I'm going to check my hunch out more closely.

The data that first alerted me to what these next steps might look like and how to describe them were those of Jovana's experience. Jovana repeatedly asked her siblings for help in caring for her father. She said in her initial interview: "I just kept asking and asking and they really didn't feel it was a need." Although she sought care for her father by asking her siblings to help, she did not receive the help she requested. In Jovana's case, and as was later evidenced in other caregivers' experiences similar to hers (and even in those that weren't similar), the process did not end at *searching for help*. Instead, the process continued—she'd get a "no" from her siblings and look elsewhere, return to her siblings, and then move away again in search of other options. As mentioned, however, she was always acting in response to her environment, but her actions were not simply reactive. She was either receiving the help she needed, balancing her responsibilities, and successfully managing care, or not. And likely, other things happened around this dynamic.

> **Memo 5.** Grounded theory is about a process—in this case, the process of managing care. I have to understand what drives the process and the tensions that activate and deactivate this process. In Jovana's story, what are the components I see? Are those components present in other stories? Yes. At this point, my hunch is that there are phenomena that set the process in motion and phenomena that keep/don't keep it moving. These phenomena are tied to a "what" and/or a "who" with which/whom the caregiver is interacting. The question here becomes—What/who does she use within her process? What/who does the caregiver involve?

Engaging in constant comparison, I moved across cases and interviews, looking at the data vis-à-vis my research question and what emerged in the initial and focused coding processes. At this moment in the analysis process, everything seemed to be in

communication—the data, my question, the codes. My goal regarding constant

comparison, in keeping with Miles and Huberman (1994), was to fashion an "emerging

map of what is happening and why" (p. 65). In order to achieve this goal, I engaged in

cycles of induction and deduction and remained, as the authors suggested, "flexible"

(p. 65). Part of that flexibility was my ability to re-frame and re-envision, moving down

alternative paths as determined by the data and how they were reflected in my research

question, and vice-versa. Evidence of this flexibility was in my response to what I

discovered in the literature review of Chapter 2 and the resulting re-frame of my

research question regarding health and healing sources in Chapter 3, and shaped the

resulting scope of analysis here in Chapter 4.

Third moment: Refining theoretical ideas and Charmaz's data "movement."

After caregivers' sources were identified via constant comparison across and within

cases, I began to look more conceptually at what was happening in the data.

> **Memo 6.** I see now that the caregiver is engaged in feedback loops that occur in her interactions with sources. As I memoed previously, these interactions are not static and they do not occur in a vacuum. Instead, a process occurs. If a process is occurring, that means that there are antecedents to this process and, hypothetically, drivers *that keep the process in motion or tensions that limit it.*

Here, I used Charmaz's (2006) strategy of refining theoretical ideas. I was interested

specifically in "fostering movement" (p. 136). By "movement," I mean keeping these

three plates spinning: (a) identification of across- and within-case caregiver interactions

with sources, and (b) what preceded or informed her interactions, and then (c) what

perpetuated those interactions—successfully or otherwise. Employing the creativity and

wonderment that constructivist grounded theory permits, even after re-coding and re-

interpreting the data earlier in the process of analysis, I sought again to see the data

differently. I worked backward through each case and across each interview, watching

the process move in reverse from the conclusion of each interview back toward the

beginning. This bizarre constant comparison-ish exercise proved fruitful: I began to

discern what I understood as her process and watched the components of the process

settle in relation to one another. I had sources. I noticed two other categories of data

that emerged in the caregiver's process: These I understood as antecedents and drivers.

This third moment proved to be the final step prior to beginning to build a

conceptual model. I identified the three components: sources, antecedents, and

drivers/tensions. Continuing to refine my theoretical ideas, I began to explore how these

three components fit together and how the process occurred. My steps toward

cementing this conceptual model follow.

Charting Caregiver Process

The model, as described much earlier in this chapter, illustrates a process—an

evolving picture of need as defined by the caregiver in her interactions with others.

Regarding this process and its reflection in the conceptual model, it is important here to

remain cognizant of the constructivist perspective that grounds this project. My

interpretative renderings of what the interviews contained are the result of co-

construction, the voices of the caregivers as well as my own. The interview process

supplied me only implicitly with caregivers' movements through this process. In other

words, caregivers did not come out and explicitly say, "This is where I was managing

care, and this is where I was not."

The stages of the model correspond directly with overarching categories that

emerged in the data and contain within them numerous codes. The codes from the

focused coding process seemed to "pool" in certain areas, describing experiences that

played out within and across cases. The first place that codes seemed to cluster was

when caregivers were managing care. Working backward from this point in the process,

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I noticed that there were four definitive clusters of codes that described the caregivers' experiences.

I've sliced up the model up in the following discussion to reflect these four definitive clusters of codes, translating them to stages that correspond to the way in which the process was illuminated by the data. I use the model in slices at this juncture because it illustrates this process and the myriad feedback loops associated with it. It is also is a powerful visual accompaniment to the words I use to describe what I saw conceptually in the six cases. Although I worked backward initially, the explanation of the model is from "start" to "finish," in quotes because this process is neither linear nor temporal. It backtracks on itself often. Nevertheless, as discussed previously, some linearity in analysis is necessary. I will begin, then, where the process started: with what I had identified during the coding process as *identifying the need.*
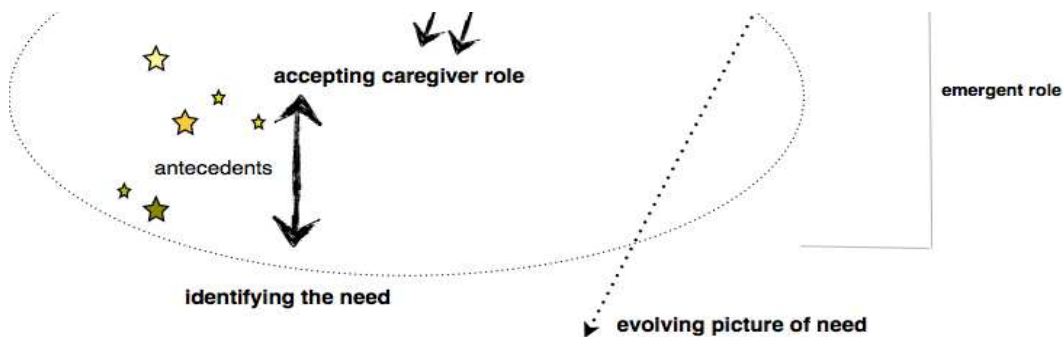
Figure 2. Stage 1: Identifying the Need. *Identifying the need* was the first stage in the process. The model moves upward since subsequent stages seemed to grow out of this initial stage.

Stage 1: Identifying the need. *Identifying the need* was the point at which the model was put in motion. The code I chose to describe this stage is particularly important. My intention was to illustrate that an individual or individuals must have noticed that something was wrong with the elder for the process to be put in motion. Otherwise, the problem remained unidentified and therefore unaddressed, because, as

explained previously in the overview of the model, the process is built on a foundation of

the dialectic between the caregiver and the sources around her. As the model born from

this project was still a nascent one continuing to take shape, the specific conceptual

components of *identifying the need* had yet to be discerned at this time. The most

robust evidence the data could provide at this early juncture was actual examples of how

the need was identified. According to the data sampled for analysis, *identifying the need*

played out in different ways. In some cases, the person or persons who determined

there was a problem with the elder were those who eventually cared for the elder. Or

this decision was made according to the influence of a constellation of antecedents

described in Stage Two of the model. In both instances, *identifying the need* was

understood in terms of what the outcome of that identification was. Put simply, I could

describe how the need was identified only by noting that care was somehow evoked for

the elder. In this respect, Stage One was understood in retrospective relationship to

Stage Two. Although making conceptual assumptions was impossible at this point, the

data-driven examples did demonstrate that the way in which *identifying the need*

manifested itself informed how the subsequent process unfolded.

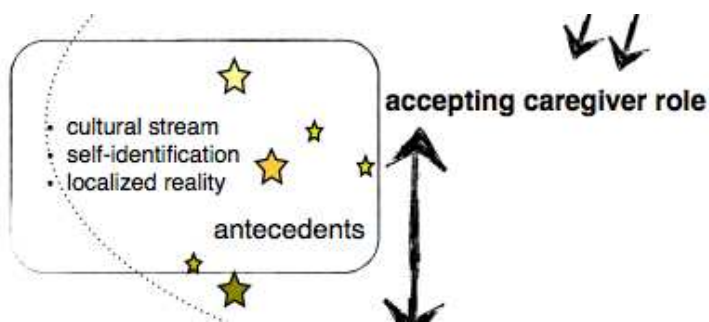*Figure 3.* Stage 2: Accepting the Caregiver Role. *Accepting the Caregiver Role* was the second stage in the process. The journey toward accepting the caregiver role was informed by a constellation of antecedents, explored further in the next section.

Stage 2: Accepting the caregiver role. After *identifying the need,* the journey

toward the next stage, *accepting the caregiver role,* took place. In looking at the data

sampled for analysis, I found a constellation of antecedents that informed the journey toward *accepting the caregiver role.* Although in Stage One I was hesitant to speculate conceptually about how the need for caregiving was identified, I did begin to think about how the antecedents in Stage Two were organized conceptually. The data brought forth three different examples. Accepting could occur through cultural streams, self-identification, and localized realities. These antecedents that informed the caregiver's journey toward accepting the caregiver role overlapped and informed one another.

The birth culture stream was demonstrated in the data as dictating that the unmarried daughter provided care. Within the birth culture stream were texts about cultural and gender expectations and their inevitable interpenetration. These texts and their admixture lend themselves to future research that was outside the scope of this project but that could provide insight into what comprises a birth culture stream and how that affects caregiving decisions.

The host culture stream in the case of this project was the mainstream culture of the United States. The literature is replete with debate about what exactly the "culture" of the U.S. is. This debate and its implications for minority caregivers navigating birth and host culture streams also begs for further examination that was outside the scope of this project. The host culture stream in this project dictated that United States citizenship, a professional job, and English language ability were the qualities of the person who provided care. At this early point in the research, I was unable to determine whether there was an interpenetration of gender and host culture expectations regarding caregiving similar to that which occurs in the birth culture stream. Illustrating the interrelationship of birth and host culture streams was this vignette from Albatora: Albatora told the interviewer that the reason she was "chosen" to care for her mother was that she "has papers," "speaks English," and is a "professional." Although it is likely

that informal caregivers who accepted the caregiving role were not "competing" to get

the job of caregivers, there were cases in which families identified cultural characteristics

in line with "success" in the host culture that the caregiver possessed as being the

reason for their selection. Juxtaposed with these examples were other cases of families

determining the role according to birth culture—that is, the unmarried female daughter.

Accepting could also occur through self-identification, when one individual

identified a need and others in the family did not. In the data sampled for analysis, the

process of self-identification intersected with the birth culture stream. This could have

been the case because all caregivers included in the project were female, and as

mentioned above, there exists an interpenetration of culture and gender expectations in

the birth culture stream. This also could have been the case because there are some

important subtexts that emerged. Either way, the phenomenon deserves further

examination.

And the subtlest possibility, the darkest star in the constellation of antecedents,

accepting could occur through a localized reality that was individual or family-dependent

and could not necessarily be employed as a generalization outside the participant's

experience.

Having taken the first steps in teasing out antecedents and how they inform

caregivers' acceptance of the caregiving role, we turn to the next slice of the model.

Although not a stage *per se,* the next slice of the model moves upward from accepting

the caregiver role to the first stirrings of the cycles of management and nonmanagement.

The model moves in an upward direction overall because the entire process is grounded

in the initial step, identifying the need. All other parts of the process that occur rise from

that initial interaction. I include an image of the model at this juncture because it is

important to identify where darkness remained in the model, providing an opportunity for

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further examination and further research. I call this point in the model Inadequate
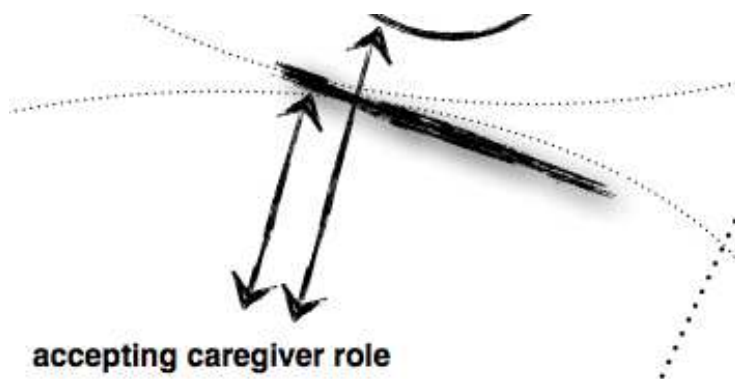
Illumination.

Figure 4. Inadequate Illumination. This figure illustrates a point in the model that the data sampled for analysis were unable to clarify.

       Inadequate illumination. After *identifying the need* and *accepting the caregiver*

role, the caregiver passed through a stage that the data were not able to fully

illuminate.[28] I have illustrated this moment with a jagged black line, signifying my own

lack of insight into this period. Within this space, the caregiver internally reflected on

whether she could provide care on her own and whether she should continue. *Feeling*

conflicted, trapped, angry, guilty, and depressed all emerged, in-vivo, as codes here.

The caregiver returned to this space when her efforts at managing care were perceived

by the caregiver as not successful or when she doubted her own decision to be involved

in caregiving.

       Stages 3 and 4: Searching for sources and managing care. The third and

fourth stages of the model, as mentioned previously, are bound tightly together in

feedback loops. Because of their relationship to one another, they are discussed in

tandem.

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[28] It is important to keep in mind that there are several possible reasons for this inadequate illumination. Perhaps the primary study's interview questions were unable to address what emerged in the secondary study as part of my project's conceptual model. Or, caregivers felt the influence of texts of Mexican culture such as *familismo* or *marianismo*, which would require that caregivers not talk about certain difficulties.

In Stage Three of the model, the caregiver is *searching for help,* and in Stage

Four, she is *managing sources.* From the data sampled for analysis, I determined that

neither of these stages could occur without the other. In the confines of Stage Three is

explored what the data showed were the caregiver's sources for this help in providing

care to an elder. In the confines of Stage Four is explored how she managed this care,

comprised of managing the sources and managing herself.

Figure 5. Stages 3 and 4: Searching for help and managing care. This stage of the
model illustrates caregivers' movement across sources and management of care.

Stage three: Searching for help. The constellation of sources identified in the

data is comprised of four categories. These are: Family (other parent, siblings, children,

kin relations); Network (friends, friends-of-friends, neighbors); Biomedical sources

(primary care practitioner, long term care system/caseworkers/caregivers); and

Traditional sources (herbs/folk medicine, advice from Mexico, cultural expectations,

caregivers with cultural knowledge). As with the constellation of phenomena that inform

the journey from *identifying the need* to *accepting the caregiver role*, the sources that the

caregiver searches for and manages are also a constellation of sorts. Sources are not

equally clear-cut or apparent in the data. Sources overlap one another, interact with one

another, and have subcategories of sources within themselves.

In a postmodernist, constructivist paradigm, sole reliance on such categories as

static and objectively predetermined should be avoided at all costs. However, the

categories that best illustrated what was evidenced in the data are useful in that they

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give a general idea of basic constellations of sources and their overlaps, differences in their composition, and their shifting configuration over time. In addition, the categories, although I admit they are by nature limiting, enable an examination of how these constellations and the caregiver's perception of them may affect what she does in relation to them.

My approach to analyzing the sources (Family, Network, Biomedical, and Traditional) is to provide an overview of each type of source and present the findings in table form. Then, I describe sources in addition to their important features as illustrated in the nascent model. Stage Four takes this discussion one step further and explores the components of caregivers' management of these sources.

Family sources. A number of different family members were identified in the interviews as sources by the caregiver: other parent, siblings, children, and what I have identified as fictive kinship structures (see Hall, 2008; Johnson, 1999; Jordan-Marsh & Harden, 2005; Voorpostel, 2013). These structures are referred to in the data as "family," like god-children not related to the caregiver by blood or marriage and culture-bound kin relations like *comadres*. In order to keep a deep grounding in the data, I introduce each source as it manifested within the caregivers' interviews. The ordering of sources as presented is solely theirs.

Figure 6. Family sources. This slice of the model specifies the family sources that the caregiver uses in her process of managing care.

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The first source that caregivers depended upon was their other, healthy parent. Not all caregivers had another parent, however, and this deficit shaped the way they managed other sources, including themselves, as demonstrated in Stage Four. In this same vein, it is important to mention here that there were caregivers who did not have a traditional "family" comprised of parents and siblings. These caregivers created their own structures of support that they turned to first. These are discussed in a later paragraph about fictive kin relationships.

After the healthy parent, the next source that the caregiver would turn to as demonstrated by the data was her siblings. Again, the order in which caregivers turned to their sources is their own—demonstrated by the data. Caregivers had varying relationships with their siblings that manifested in different ways both across cases and across time within cases. Caregivers talked about these relationships only in the context of caregiving. In the data sampled for this project, no caregiver mentioned a relationship with a sibling outside of a caregiving context. Even Iliana, whose family seemed to work so well together, did not mention friendships with her siblings outside their caregiving duties. While this omission may have been somewhat informed by the tenor of the interview questions, caregivers did mention "going out" with their friends (complex relationships in themselves), but they did not mention similar time spent with their siblings. So, in keeping with what the data showed, the sibling category was examined in a caregiving context.

Caregivers also provided evidence of fictive kinship: relationships that seemed to be culture-bound, or more broadly, outside of prevailing American cultural conceptions of blood- and marriage-ties that characterize "family." Regardless of kin realities across the world, in American culture—the host culture, reaching back to Chapter 2's discussion of cultural streams—the prevailing cultural norms for kinship are blood and marriage ties.

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The fictive kin relationships present in the data are evidence that Mexican American caregivers identified with their birth culture in this instance. Non-blood-and-marriage kin was valued equally with blood-and-marriage kin.

I purposefully included kinship structures in the source categories because I didn't want the project to be limited by prevailing ideas of what family consists of, particularly when fictive kin structures seem to be so strong in the interviews. What the data show here has implications for the ways in which prevailing systems can more effectively respond to and use those sources that may not be easily identified due to the prevailing cultural norms of the host culture.

Regarding "true kin" ties of marriage, interestingly, no caregiver mentioned her husband as a resource for helping her to provide care.[29] The only mention of a husband was Iliana's comment to the interviewer that she and her husband would be going on vacation to Washington, D.C., and that Iliana was looking forward to not thinking about her caregiving responsibilities. Other caregivers mentioned being divorced or, like Madalena, "recently ending a relationship." We cannot be sure whether the stress placed on intimate relationships is somehow tied to caregiving. And we cannot infer from this small sample that Mexican American men do not provide the bulk of care in cases other than those sampled for analysis. However, is important to hold relationship strain as a possibility, particularly if it will inform better ways to help caregivers deal with their caregiving responsibilities and retain the relationships they find valuable in the face of those responsibilities.

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[29] Little is known about Mexican American sons as primary, informal caregivers for their elderly mothers. Evans, Coon, and Crogan (2007) signaled this configuration, however, as an emerging caregiving trend, what the authors deemed "transcending taboos" in caregiving. More recently, Evans, Belyea, and Ume (2011) followed up with a descriptive case study and suggestions for further research.

Table 2 illustrates each of the specific types of family sources as found in the data and corresponding examples. Also offered is a discussion of attributes of sources in terms of what they provide the caregiver and instances of their presence or absence. The discussion continues in the context of Stage Four, *managing sources.*

Table 2

Family Sources

SOURCE	PROVIDES	EXEMPLAR
OTHER PARENT	Caring in the context of *la familia*	Jovana, who cared for her father with her mother's help, described her mother's care of her father as helping to avoid anything worse when he fell: "He slipped coming
	Living an everyday spirituality	out of the shower and he had a very bad fall. Thank God he didn't break any bones. He drinks lots of calcium; thanks to my mom" (*laughing*).
	Caring for the CG	Jovana's mother told her to "lie down, you look worn out" after Jovana's father fell while in Jovana's care.
	Role modeling caring for self to care for another	Jovana's mother took time away from caregiving responsibilities: "She wants to have her free time to be gone because it's hard for her to be there all the time and she needs her time away."
SIBLINGS	Providing inconsistent auxiliary caregiving support,	Nalda referred to her sister's lack of sustained caregiving for their mother: "She never really cares for any length of time; she gets freaked out too."
	Having to deal with auxiliary caregiver's emotional reaction	
	Restricting CG ability to decompress	Albatora needed privacy when she got home from her mother's, but her sister was there: "Like sometimes in the night I come home and I want to be alone, you know, I just
	Desiring but lacking privacy	want to lay down . . . but she likes to spend time with me, you know . . . it's a whole privacy thing."
	Taking responsibility for caregiving	Iliana explained how her siblings stay organized in caring for their mother: "Well there's eight of us that come see her every day, well not every
	Organizing family resources for CR care	day. We have a calendar and somebody's here twice a day to see her."
	Experiencing increased caregiving responsibilities due to sibling's relationship with CR	Albatora's mother stayed with her: "Now she doesn't want to go with my sister, because they fight too much." My sister doesn't have the patience, you know. I just let her be, you know. But sometimes I do get mad but I don't show it, you know."

SOURCE	PROVIDES	EXEMPLAR
CHILDREN	Supporting primary CG, as auxiliary caregivers	Iliana depended on her children to help in caring for her mother if she was not available: "There's been a time where I had to leave early for one thing or another; I have to leave and my son will come and he'll you know, stay with her and have dinner with her . . . or my daughter will stay with her, you know for an hour or two because I'm busy."
	Lacking sibling involvement in caregiving	Jovana reasoned that it was because of their children that her siblings didn't help her: "They have kids, so I don't know if that maybe had something to do with it."
KINSHIP STRUCTURES	Helping with housework Acting as auxiliary family to CG	Sancia relied on relationships that could be classified as fictive kin structures situated within Mexican culture: "And I have another *comadre* who works right next door to me, and she will come over. She cleans my house and she will watch her (Sancia's mother) while I go to the grocery store." Sancia referred to this woman as "family.
	Providing a caring presence	Later in the interview, Sancia talked about her godchildren as family as well, saying, "Yes and all my godchildren, they're all my families," but she did not mention relying on them in the context of caring for her mother. This could be an instance in which the source is used by the caregiver and not necessarily for caregiving.

Note. CG denotes care giver; CR denotes care recipient

Family sources were identified by caregivers in all cases as the first set of sources to which they turned. For caregivers who had the other parent to help them, that parent was the initial resource. This method had its challenges, however, because in some cases the other parent was unable to provide sustained help to the caregiver. Inconsistent support was an attribute of this source. Sometimes it was the result of a conscious choice on the part of the parent, who did not want to be constantly caring for the care recipient, and therefore the caregiver had to increase her caregiving duties. In other instances, the other parent's health was reported by the caregiver to be deteriorating, creating more responsibility for the caregiver. Simultaneously, another attribute of this source was that the parent was often seen by the caregiver as a source of care and concern for the caregiver, particularly regarding the caregiver's caregiving duties and how they affected her health and well-being.

When a caregiver felt unable to depend on the other parent, she moved to her siblings for help. The spectrum of sibling attributes was broad—ranging from qualities that led them to give no support to complete support to the caregiver. In some cases, the caregiver experienced siblings' outright angry refusal to help or a repeated attempt to find a formal caregiver without consulting her. Lack of privacy, restriction of caregivers' ability to decompress after a hard day, and even increased caregiving burden when it seemed that siblings were trying to help were all attributes of sibling-as-source. Also in the data was one instance of a caregiver's asserting that her siblings worked successfully as a team and organized accordingly.

Corollary to siblings-as-source were siblings' children—the nieces and nephews and sons and daughters of caregivers. The data provided examples of children stepping in when their mother was out of town or working, children being concerned about the care recipient, and children having no role at all in caregiving. Children's involvement was informed by what their parents did. In the case of the siblings who all worked together in caring for the elder, the children participated. In the case of caregivers' siblings who refused to participate, siblings' children did not participate, although the data do not demonstrate whether the children were even aware that caregiving would be an option. In one instance, a caregiver who was providing care by herself, with no sibling help, reported that her children helped her care for the care recipient. When siblings were not able to help a caregiver, she often relied on herself. In no cases did a caregiver hire a formal caregiver after her siblings refused to help. In fact, even when her siblings suggested hiring a formal caregiver, she refused. However, in the case in which siblings were working together as a team, the collective decision was to hire a formal caregiver as well. In this case, the realization that the elder needed care and the way in which the siblings self-organized around her seemed to form, unspoken and

assumed, via some invisible cultural formula—or just a close relationship between siblings with a common drive to care for their mother.

Caregivers who reported fictive kinship structures as sources did not report having another parent or siblings. This omission does not mean that those individuals did not exist, but simply that the caregiver did not perceive those individuals as playing a role as sources for her. Fictive kinship was not as linear as caregivers' move from the other parent to siblings and children of siblings. Caregivers who had culture-bound relations such as *comadres* to help them relied on these individuals only for short periods. Otherwise, caregivers reporting fictive kin relationships depended upon themselves. Caregivers were mindful of these individuals' schedules and expected their help during morning errands, for example. Fictive kinship was the only family source that had a positive relational attribute—it was discussed in terms of a positive relationship for the caregiver, and not necessarily in the context of caring. Although the tenor of the interview questions may have steered caregivers' comments about their relationship with their other parent and siblings into a solely caregiving context, the fictive kin relationships were discussed in the context of caregiving and positive personal relationships.

Network sources. Also identified as sources by the caregiver were friends, friends-of-friends, and neighbors, and networks stemming from these individuals. Caregivers used friends, friends-of-friends, and neighbors as sources of less immediacy in providing care compared to the sources that comprised the family category above. It also became apparent in examining the sources in this category that friends have a sort of duality as they are represented in the caregiver interviews.

It is useful to explore here briefly how friends as sources were discussed in the caregivers' interviews. As mentioned earlier, siblings were always referred to in the

context of caregiving responsibilities. In the data sampled for analysis, there were no instances of caregivers mentioning friendships with their siblings or doing things with their siblings other than in the context of caregiving. Albatora's sister was at her house and wanted to spend time with her, but this desire restricted Albatora's ability to decompress, and, for example, to drink when she wanted to without "her being in front of me."
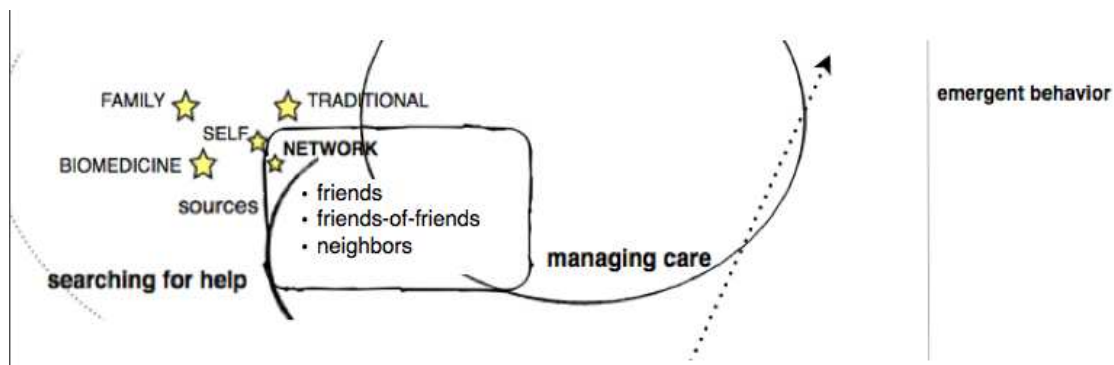

Figure 7. Network sources. This slice of the model specifies the network sources that the caregiver uses in her process of managing care.

Friends-of-friends were mentioned in one caregiver interview in this source category, and a similar case was mentioned in the biomedical category. Both demonstrate the existence of networks, particularly around caregiving and seeking-out caregivers.

Neighbors were a good example of that differing degree of immediacy referred to. They were depended upon "in an emergency" or were identified by the caregiver as "watching out" for the care recipient to the degree that a neighbor would according to given cultural expectations—less than a family member, less than a friend, but more than a stranger.

Table 3 illustrates each of the specific types of network sources as found in the data and corresponding examples. A discussion of attributes of sources in terms of what they provided the caregiver and instances of their presence or absence follows.

Table 3

Network Sources

SOURCE	PROVIDES	EXEMPLAR
FRIENDS	Helping with transportation of CR	Madalena's friend helped her with her mother: "I have this one friend. If she (my mother) needs a ride to the doctor and I'm working and my sister is working, she'll take her and then my sister will pick her up."
	Source of guilt for CG	Jovana recounted her relationships with friends prior to her decision to stop providing care for her father: "I have a lot of friends and they invite me out. I tell them no; they used to make me feel guilty you know, that I didn't want to go but, I pick and choose when I want to go."
	Source of power for CG to choose	
	Social support	However, after Jovana was no longer caring for her father, she returned to her friendships: "I've gone out with some of my friends out to dinner, to their house."
FRIENDS-OF-FRIENDS	Ear-to-the-ground Network	The interviewer asked how Iliana heard about the caregiver she and her siblings used in addition to themselves: "Through a friend of a friend. You know we asked around, does anybody know of anyone and a friend of a friend, a sister's friend, says there's a lady who's wanting to do this, and so that's how we got her."
NEIGHBORS	Watch out for care recipient	Illiana said: "The neighbors here, they always keep an eye on my mom. Like when we started getting this lady (a caregiver), the neighbor says, 'You know she has company. Do you guys –it's ok for her to have company?' And we told them 'yeah.' So they kind of watch out for my mom, the neighbors do."
	Perceived dependability in an emergency	Although never in a situation where she had to directly depend on her neighbors, Iliana reported she could in an emergency: "They're really good neighbors. I mean we've never asked them to take care of my mom, but in an emergency if something were to happen, yeah we could say can you watch her for like a minute, or while I run down to the store for her, you know. If I needed I could tell the neighbor could you come over I've got to go to the store and get medicine for her."

Note. CG denotes caregiver; CR denotes care recipient

The network category of source, comprised of friends, friends-of-friends, and

neighbors, was the first instance in which the emergence of roles based on what

caregivers needed could be discerned. Put simply, an attribute of the network category

was that its characteristics shifted in relation to the caregiver's perception and what she

felt she needed. Unlike caregivers' discussion of family sources (save the fictive kin

relationships), network sources were not discussed solely in the context of caregiving. Although their management and how these roles manifested are discussed later in this chapter, I think it is useful to explore it all briefly here.

Regarding friends, in one case a caregiver's friend played two roles: She served as a friend to the caregiver and also as another type of source—in this case a biomedical one. She was a nurse and in this capacity helped the caregiver's family monitor the care recipient's blood sugar. She was available both to the caregiver as a friend and to her family as a nurse. In other cases, friends were relied upon when family was either not present or not reliable. In all cases in which friends were discussed by the caregiver, an attribute of this source was that friends helped caregivers with the caregiving burden. In one case, the caregiver described her friends in a way that belied her sense that friends increased her caregiving burden. They placed more stress upon her when they wanted to spend time with her relative to her caregiving duties. But this same caregiver referred at other points in the interview to another friend with whom she was excited to spend time, although this particular vignette blurred boundaries and is discussed at length later in that respect.

Friends-of-friends provided what I described as an "ear to the ground" network.   I was not sure that this attribute of extensive networks was limited to Mexican Americans, but their reach was extraordinary. Friends-of-friends were obviously not as close relationship-wise to caregivers as their more immediate friends were. However, caregivers often reported asking friends-of-friends about who they might know who could help with caregiving, both formally ("from an agency") and informally. Caregivers' discussions of friends-of-friends always took place in the context of caregiving. Although outside the scope of this project, closer examination of these networks would likely yield much insight into diverse groups who rely on each other to successfully manage care.

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Neighbors were still further removed from the caregiver and were always discussed in the context of caregiving. Caregivers reported that their neighbors often watched out for the care recipient and that they could be trusted to do so. Caregivers often referred to being able to depend upon neighbors "in an emergency" or if they had to run a quick errand. In each case in which neighbors were trusted by caregivers, the interviews also showed that care recipients had lived in their neighborhoods a long time and were well known. The interview schedule for the primary study included questions about the neighborhood where the care recipient lived, and caregivers were prompted to discuss this topic with interviewers. Although these questions may have informed caregivers' comments, caregivers' thoughts are important because there seems to be a time-dependent quality to caregivers' trust in neighbors.

Biomedical sources. The biomedicine category encompassed primary care, long-term care in the dual contexts of long-term care systems (including physical facilities and insurance companies), and long-term care caseworkers/caregivers.

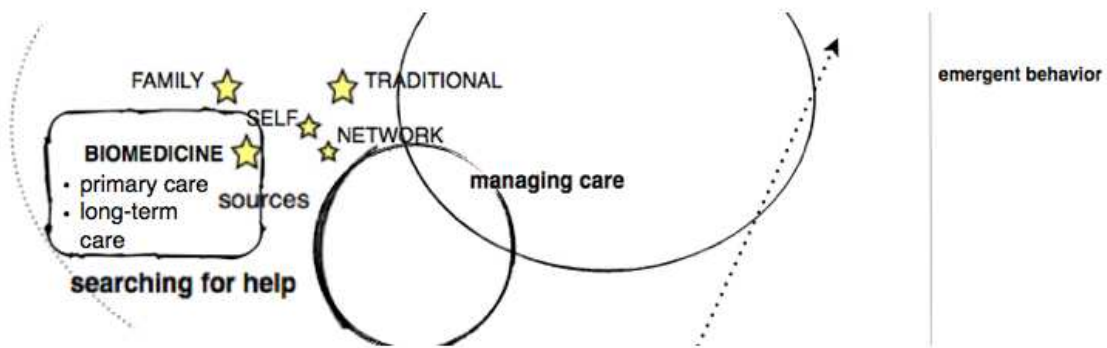
Figure 8. Biomedical sources. This slice of the model specifies the biomedical sources that the caregiver uses in her process of managing care.

For the caregivers interviewed, it seems that reliance on a hired additional caregiver or caregivers was most common. However, there were instances in which caregivers discussed other sources and their experiences with them. Table 4 illustrates

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each of the specific types of biomedical sources as found in the data and corresponding

examples.[30] A discussion of attributes of sources in terms of what they provide the

caregiver and instances of their presence or absence follows.

Table 4

Biomedical Sources

SOURCE	PROVIDES	EXEMPLAR
PRIMARY CARE PRACTITIONER	Care for caregiver and in the course of conversation, checks on care recipient "Doctoring" CG with accessory care of CR	Sancia said: "She (Sancia's mother) really only needs to see him once a year because I take care of all the medicines. She doesn't have diabetes. She doesn't have anything except that broken hip. Since we've gotten her on a regular regiment of medicine she's fabulous. I go see him. I go cuz he gives me a prescription and he'll say, 'How is she. What is she doing?' We'll change medicines that way. She usually only sees him once a year."
TREATMENT REGIMEN	CR feeling overmedicated CR knowing what he/she needs	Madalena's mother wanted to cut back on her prescription medication: "She says she just—if she doesn't want to take all the medicines she can take whatever she feels is necessary."
	Exemplifying *familismo*	Iliana explained her siblings' schedule in terms of caring for their mother, which included ordering medication: "My sister M sets up the monthly calendar for us to be here. My sister L orders all the medications. My sister C takes care of all the bills. I take her to her medical appointments."
	CG caring for self	Sancia mentioned medication she was taking: "I started on an antidepressant. Is that what they're called? It's Zoloft." Madalena talked about her counselor: "And then I see my counselor on Monday. And people laugh at me because they're going, well, especially family, they say, you know, 'Mexicans don't go to counselors, why are you doing it?'"
LONG TERM CARE/INSURANCE (SYSTEM)	Experiencing uncertainty regarding available formal support	Sancia said: "I get four hours of respite care . . . But of course we got a new insurance company. We have a new case worker. We don't know if that's gonna continue. It may change and it may not. I may not get that."

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[30] I repeat what I mentioned earlier about the opportunities and pitfalls of categorizing sources: The system is not perfect. Categories limit and distort, but also provide a structure within which to explore what was taking place in the data. Certainly, some of the sources in the source categories may not be what one immediately thinks of as being situated within this or that type of source. However, I ask that the reader simply be mindful of the imperfections of categorization.

SOURCE	PROVIDES	EXEMPLAR
LONG TERM CARE (CASEWORKER)	CG lacking information	Sancia recounted her discussion with the caseworker: "And she (the different caseworker) said, 'Don't forget, you have 720 hours' worth of respite care.' I didn't know what respite care was. I'd never heard that word."
	Receiving information from a culturally congruent caseworker	Sancia recounted her interaction with an Hispanic caseworker: "I don't mean this to be anything but informative, but the lady was Hispanic, who is now a caseworker, and she said, 'It's ok, you need time away and this is what you can use," because I would have never thought to ask, I would have just continued to do it the way—"
LONG TERM CARE (CAREGIVER)	Being dissatisfied with formal CG resources Recognizing the need for good food in caregiving	Nalda recounted her previous experiences with caregivers for her mother that were supplied by caregiving services: "Caregivers that we've had in the past, some of them just sat here and talked on their cell phone all day long and haven't done anything. The caregiver we had before, she was ok, I mean she was there for moral support. But she didn't cook. She couldn't cook."

Note. CG denotes care giver; CR denotes care recipient

Biomedical sources were not discussed as explicitly as other sources. This lack of explicit experience could be considered an attribute of the biomedical source that could be generalized to most cases. In fact, in only one case did the caregiver refer to an actual interaction with a biomedical practitioner. In that interaction with the primary care practitioner, the caregiver was able to discuss her mother's health status and change her medications in collaboration with the practitioner if necessary. Her interactions with the provider accomplished both her own care for herself and her care for her mother, and the caregiver noted that this interaction reduced her anxiety. Regarding the primary care system, caregivers often spoke of increased burden. Confusion, frustration, and a general lack of knowledge about how the system worked were attributes of the primary care system and permeated caregivers' comments. Also in the context of the primary care system were caregivers' discussions of caring for themselves—in two cases, caregivers were prescribed antidepressants. This topic is discussed further later in the chapter. The long-term care system, comprised of

insurance, caseworkers, and caregivers, was also described in disparaging terms by caregivers. Here too were attributes of caregiver confusion and increased burden. In only one instance did a caregiver comment on being helped by a long-term care caseworker. In that instance, the caregiver reported that she had been confused as to what was available to her as a caregiver regarding time and financial resources, and the only individual who was able to explain to her what she could access was a Hispanic caseworker. Her interactions with the Hispanic caseworker and how these informed her management of sources and directions for future research are discussed further later. Caregivers spoke frequently about long-term care resources as things they could not control and did not understand, referring frequently to caregivers who were simply "assigned" to them and the increased stress that resulted when these individuals were not appropriately or culturally qualified.

Traditional sources. This project's initial research question focused on caregivers' use of biomedical and traditional sources. Upon analyzing the data, I determined that sources used by caregivers are of a much broader nature than simply a juxtaposition of biomedical and traditional sources and must be examined from that broader perspective. However, I still included biomedical and traditional sources within my source categories. Traditional sources encompass herbs and folk medicine, advice from those with ties to Mexico, cultural expectations, and caregivers with cultural knowledge.

In the context of traditional sources, herbs and folk medicine provide care for "minor things" and the ability for the care recipient to manage care. In the data sampled, herbs and folk medicine were discussed only in the context of female care recipients' using it for themselves, and corollary to their use, sometimes a hired caregiver (always a female in the data sampled) offered this type of care to the primary caregiver, as well.

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The interviewers asked direct questions about herbal medicine, and it is important to be

mindful that those questions might have prompted the discussion we see in the data.

Nevertheless, it is evident, both in the larger corpus of scholarly literature and as

demonstrated here in the interviews, that such sources exist for caregivers. Advice from

Mexico was included in the traditional source category because the data showed that for

some primary caregivers, ties to Mexico and to those from Mexico remained strong.

Figure 9. Traditional sources. This slice of the model specifies the traditional sources
that the caregiver uses in her process of managing care.

Cultural expectation and caregivers with cultural knowledge were touched on

previously in terms of the caregiving component of *choosing* that characterized the

caregiver's management of network sources and of *navigating* that characterized her

management of biomedical sources. Cultural knowledge is also seen here in traditional

sources in this context as a rivulet of cultural expectation that is within the larger birth

culture stream that these caregivers negotiate. Repeatedly, caregivers say that there

are certain rules that a hired caregiver must abide by in interacting with the care

recipient and, in the case of this source, even in interacting with a primary caregiver. As mentioned earlier, caregivers often stress the importance of a hired caregiver's knowing how to cook. The data demonstrate the possibility that cooking and all its accoutrement may also signify another rivulet within the cultural stream that is manifested in caregivers' thoughts in a less abstract way. Cooking may serve for this population as a type of synecdoche, the naming of a particular quality or element to represent a larger whole that goes unnamed, which in this case could be caregivers' larger desire for particular cultural sensitivity or awareness that is evidenced specifically by the ability to cook.

Table 5 illustrates each of the specific types of traditional sources as found in the data and corresponding examples. Also included here are what I determined, based on the data sampled for analysis, each type of traditional source provided to the caregiver.

An overarching attribute of traditional sources was that they were used and discussed only secondarily to biomedical sources. Although biomedical pharmaceuticals were rarely discussed by caregivers (elders in the data sampled for analysis were suffering from cognitive decline but were often otherwise healthy), caregivers' perceptions tended to the primacy of the biomedical system, regardless of its difficulty. Herbs and folk medicine were used for "minor things" but were also discussed by caregivers as implements that care recipients used to manage their own care. In this respect, an underlying attribute of traditional sources is that they could be understood as empowering to the care recipient. Advice from Mexico contained a spectrum of attributes—ranging from providing other options for the caregiver and care recipient to increasing caregiver burden because she had to decide what was acceptable and useful for the care recipient. Further was the interfacing of biomedicine and traditional sources—caregivers never mentioned use of traditional sources in a biomedical context.

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Cultural expectations provided structures and rules to the caregiver around expectations for caregiving that were defining attributes within this source. The interview schedule for the primary study included these questions specifically, so caregivers' comments might have been prompted by those questions, but caregivers reported far-reaching requirements in relation to cultural expectations for caregiving. Finally, the importance having loved ones tended by formal caregivers with cultural knowledge was frequently discussed by caregivers. Attributes of this source included being able to cook, which is discussed frequently in the course of this analysis in terms of its synecdoche and its likely representation of a much larger set of attributes.

A corpus of literature explores what I have identified here in the analysis that can be traced back to Lévi-Strauss's seminal work, *L'origine des manières de table,* published in 1968 and then translated into English (see Lévi-Strauss, 1978) and forward to Bordieu (1979) and Rozin (see Rozin and Vollmecke, 1986; Rozin, Hormes, Faith, & Wansink, 2012). A superb reader, edited by Counihan and Van Esterik (1997), explores food, identity, and culture, it comprises seminal works by Barthes, Douglas, Harris, Lévi-Strauss, Mead, and Soler—among others. Mexican identity has also been treated specifically vis-à-vis food—including Pilcher's (1988) *Que vivan los Tamales!: Food and the Making of Mexican Identity,* and Devos's (2006) examination of food and bicultural identity in Mexican American college students. There is an importance of food in relation to cultural meanings/identity that appeared in the data sampled for analysis and is worth examining in future projects.

Table 5

Traditional Sources

SOURCES	PROVIDES	EXEMPLAR
HERBS AND FOLK MEDICINE	Using traditional remedies to care for for minor things	The interviewer asked Madalena: "As far as medications and things, is there anything that she takes that's not prescribed by a doctor?" Madalena pointed to a spot on her leg and said: "For her legs like that one part right there she gets really red in there and the way she manages it is herbs."
		Iliana said: 'The lady (a caregiver) that's here with us, she kind of does some little home remedies when my mom has difficulty with her bowel movements, or upset stomach. But those are the things we use for minor things, you know, like upset stomach, you know, indigestion, things like that."
ADVICE FROM MEXICO	Trying traditional remedies	The caregiver wanted me to drink tomatillo for my neuropathy Interviewer: Tomatillo?
	Being wary of some traditional remedies	Aha. You know, she grinds it up and you mix it with water and drink it. Interviewer: Aha. And it was like drinking glass. Interviewer: Oh! But she said that would help the neuropathy and bring my blood sugar down. Interviewer: Mhm. She's from Mexico, so (*laughing*). Interviewer: Mhm so have you done that? No I've tried it; I've tried it for about a week. That stuff was nasty.
		And then she bought some [A] tea.
		Usually it's in a sack; it's a little thing that you can get in Mexico and [A] is very good for healing, but she brought some tea to make to use it on my mother's legs; she was going to use it on my mother's legs; she hasn't done it yet. I haven't quite let her yet.
		Aha, she boils it and then she wanted to put it on her leg—but I don't think she has enough—I don't know how you say it in English. Trust with me.
		Like she doesn't have enough confidence in me to say, "Let me just try it" (*laughing*).
		Why she hasn't done it
		I think she's not comfortable quite yet.

SOURCES	PROVIDES	EXEMPLAR
CAREGIVERS WITH CULTURAL KNOWLEGE	Providing culturally-appropriate care	Sancia described the caregiver, M., with whom Sancia replaced her friend L.: "She feeds my mother a certain way. She cooks a certain way. She takes care of my mother first. She knows what my mother means to me . . . And there are definite rules that you do and there are definite respectful things that happen that do not happen outside the culture."

Note. CG denotes care giver; CR denotes care recipient

Stage 4: Managing care. Stage 4 is *managing care,* the point in the process at which caregivers managed the sources described in previous sections. In this stage, the data provided insight into what was involved in caregivers' management of sources—and what behaviors, activities, ways of perceiving the situation, and making decisions or not making decisions—informed this management. In the model, behaviors, activities, ways of perceiving, and making/not making decisions were represented as the components of caregiver management of sources. The components are explored in the following paragraphs within the context of their respective sources.

The core components of caregivers' management of family sources at this stage of the model were: *teaching, not forcing, not dwelling, not controlling, staying organized, making self available, and saying no.* It could be said that there was more than one grouping of components in the family sources: managing through interaction (i.e. *teaching, staying organized, making self available*) and managing through non-interaction (i.e. *not forcing, not dwelling, not controlling, saying no).* Although outside the scope of this project, specifically exploring caregivers' managing through noninteraction might provide useful insight into an aspect of the caregiving experience that has not yet been fully illuminated.

Caregivers often took on the role of teacher in their interactions with family sources. *Teaching* was a component of interacting with family sources and within this component were less visible actions, such as *doing own research* and *learning,* which

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led to the caregivers' ability to teach family members to care for the care recipient.

Caregivers used their own experiences, searches on the internet, primary care

resources such as information sessions, and conversations with friends and others, and

brought them back to bolster both their own and their families' ability to provide care.

Jovana taught her family how to check her father's insulin levels after having learned to

do it herself. Caregivers also taught family members to care for themselves, as was the

case with Iliana, who reported, "Last week I went to an Alzheimer's work shop, and it

was really good." Iliana's mother had Alzheimer's disease, and Iliana and her sisters

watched each other for signs and symptoms. They were vigilant about learning more

and sharing information with one another.
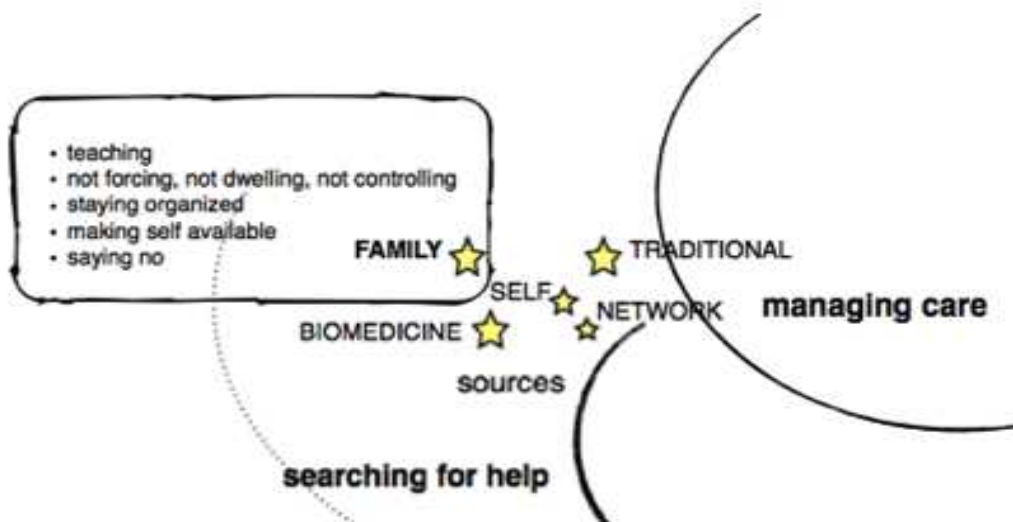

Figure 10. Components of managing family sources. This slice of the model specifies
the components of caregivers' strategy in her process of managing family sources.

Also in the data were those instances in which a caregiver had learned

something that informed her ability to provide care but did not teach it to her family.

Jovana said of learning to bathe her father:

How I learned, it was just natural. Bathe him, no one can bathe him except me. They just can't lure him into the shower the way I do. It's very rare that they can get him in the shower, but I learned how to do it. Sometimes on his mood, he'll do it and sometimes he won't. Yeah.

Although the data do not tell us why Jovana didn't teach her family to "lure" her father into the shower, other clues in the data may provide hints. She mentioned that she was able to "nurture" her father, although this behavior didn't sit well with her mother.

I have more time to nurture him. And I don't do it a lot in front of my mom because then she gets a little uncomfortable but . . .

Within the component of *teaching,* the data provided fodder for speculation as to a caregiver's need to feel needed, or subtexts of the existence of power dynamics with other members of her family that were held in place by her unique knowledge that she chose or did not choose to share. And in managing care, these subtexts may come into play and inform how a caregiver interacts with members of her family.

Many of the other core components of caregiver interaction with sources that are explored later dealt with ways in which caregivers interacted with sources and how they managed care. Not so with this particular set of components. *Not forcing, not dwelling, not controlling* are a trio of sorts—seen throughout the data and all reflecting the same thing: managing through noninteraction. This trio illustrated something in the family dynamic that did not show up in interactions with other sources: There were instances in the data when caregivers' way of dealing with their families was to *not* deal with their families. Caregivers reported in vivo their decisions not to force their family members to do or think certain things related to caregiving—usually regarding what the caregiver thought was best. Caregivers' refusal to dwell on the negative aspects of caregiving in terms of their interactions with their families appeared across caregivers. Caregivers reported realizing the importance of not controlling family members in instances in which

those family members could not be depended upon to help to the degree that the caregiver needed them to.

As mentioned earlier, often caregivers returned to their healthy parent when family members refused to become involved in managing care. However, the data also demonstrated that the healthy parent was not always able to be depended upon by the caregiver. Enter this trio of components, illustrated clearly by Jovana. According to Jovana, her mother "wants to have her free time to be gone because it's hard for her to be there all the time and she needs her time away." Her mother had difficulty accepting the new circumstances surrounding her husband's illness, and those difficulties resulted in greater responsibility for Jovana. This situation informed Jovana's decision to stop trying to control everything. Crying, she explained, "I can't control everything. I realized I can't control everything and everybody."

Also within this component of letting go of control was caregivers' use of antidepressants. Sancia and Madalena illustrated this phenomenon in the data. Both began taking antidepressants. The data did not demonstrate that taking antidepressants was directly related to these caregivers' conscious decisions to seek help regarding their experience in caring for their mothers. However, after taking the antidepressant, both women reported relinquished some control over caregiving.

Sancia's responsibilities and her worries regarding caring for her mother weighed heavily on her and affected her well-being. In an early interview, Sancia said, "I have to find a happy medium," as she was discussing her need for balance in her own life and what that meant in terms of the level of care she could provide for her mother within reason. She told the interviewer of how vigilant she was with her mother: "You think of whatever. You're always watching." After beginning to take the antidepressant, she explained, she was so relaxed and un-fazed that her friends thought she had been

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drinking. She recommended in a later interview, "As soon as you know [you are] going to be a caregiver, start taking it." Talking about her experience taking the antidepressant, she remembered:

> Dogs were here and kids were here and my mother was here and everything was falling apart and I was not having any trouble coping. I was going from one thing to the other without . . . "Okay. That's fine. We'll take care of this. Okay."

She reminisced with the interviewer about how she was before taking the antidepressant, saying, "Remember when we would just sit here and I would be constantly moving if she moved. I was constantly watching her like something was going to happen." Her vigilance and her need to control the situation seemed to lessen drastically. She said of her experience before and after taking the antidepressant:

> You try to become a super person. Super human and it doesn't work that way. This medication calms you down and that it's ok. If they [the dishes] don't get done right away if the dogs don't eat 'til ten after six instead of 6 p.m. it's ok. That's a big difference. Totally big difference.

Madalena had an experience similar to Sancia's that also included depression medication. For Madalena, there was a sort of inverse relationship between Madalena's seeking control over her own life and at the same time lessening her control over care provided to her mother. After going on the antidepressant, Madalena's attention seemed to shift from a focus solely on her mother's needs and what her family felt she should be doing in that context, and she began to talk more to the interviewer about what she, Madalena, wanted to do and what her plans were. She said, "Well, I got, I went to the counselor, I got my depression pills, I joined a gym, and I am doing a financial plan." She also mentioned preparing to begin graduate education.

In both cases, there existed a point at which a caregiver would begin to manage care by not managing care. *Not controlling, not dwelling, and not forcing* are a unique

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trio of components that allow the other side of caregiving to be seen: those instances in which caregivers do not manage care and how that choice plays out in the data.

A large part of managing care seemed to be *staying organized*—keeping everyone on track and working together and knowing what caregivers could expect from family members. The data did hint at the possibility that the component of *staying organized* could be conceived of as a separate process unto itself or one that overlapped with other ways of managing sources. In some instances, *staying organized* included family members and the caregiver. For example, in Iliana's family, all eight siblings worked together and adhered to a schedule.

> You know, everybody kind of has their duties that they do. My sister M sets up the monthly calendar for us to be here. My sister L orders all the medications. My sister C takes care of all the bills. I take her to her medical appointments. I go through all her paperwork, any letters that come in, any things that need to be filled out, I take care of that. But between all of us we take a little piece of everything. My brothers take care of the yard, take care of the repairs. So we all take a piece of things. We all kind of try to share it because most everybody works.

Iliana and Albatora reported organizing schedules for their children to act as substitutes for them in providing care to the caregivers' mothers.

> There's been a time where I had to leave early for one thing or another; I have to leave and my son will come and he'll you know, stay with her and have dinner with her . . . or my daughter will stay with her, you know for an hour or two because I'm busy you know . . .

Albatora's son was similarly aware of the schedule and of his mother's way of organizing care for his grandmother. He cooked for his grandmother, took her on outings, and worried about her when she stayed by herself. He was also aware of whether she was being provided adequate care. Albatora reported,

> He's going like, "Grandma is going to stay by herself all weekend, what is she going to do? Maybe she should go with (my sister)." And I say, "No she's going to be ok." He says, "That's a long day to be by herself." I said, "Don't worry about it."

Conversely, family members would refuse this organization, as in the case of Jovana's siblings. They refused to abide by the schedule that she had created and placed the responsibility back on their mother:

> I even wrote it down, you know, on a schedule. "Please don't call, just come over after work: . . . They felt it was my mom's obligation—her husband. She should take the load and I would always tell them, "No it's a lot of work. Come and help." They were just too involved with their own lives and they didn't understand.

Staying organized might also have fit within the initial stage of the model, *Identifying the need*, as evidenced by Jovana's comments about her siblings' refusal to help her and adhere to her proposed schedule.

In other instances, *staying organized* manifested more as self-organization, where the caregiver relied on herself to stay organized. For example, Madalena, Sancia, and Nalda reported that they organized, but managed the caregiving responsibilities themselves. All caregivers reported that it was necessary to drive the care recipient to appointments and to run errands for the care recipient, such as picking up prescriptions. Even Jovana, whose mother helped her take care of her father, did not know how to drive. According to Nalda, Nalda's sister "never really cares for any length of time; she gets freaked out too." And so Nalda organized doctors' appointments, caregiving services, and other necessities around her own schedule. Due to the nature of self-organization as reliance on self versus others, these examples could also fall into self-as-source, the components of which are discussed in a later section.

Additionally, *staying organized* could have been understood in the context of management through noninteraction, as mentioned. Caregivers sometimes chose not to rely on a family source and to rely on another instead. For example, Madalena and Sancia's responsibilities included taking the care recipient to doctor's appointments, scheduling caregiving services, and managing other sources that were identified in the

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data when family members couldn't be depended upon or when the caregiver perceived those other sources as more useful. Madalena told the interviewer, "None of my brothers help," but she had a close friend who helped her take her mother to her doctors' appointments. Sancia told the interviewer that she wrote everything down and made lists and depended upon her *comadre,* whose schedule she was aware of and whom she considered family, when she needed her. Sancia added, "And I have another *comadre* who works right next door to me, and she will come over. She cleans my house and she will watch her while I go to the grocery store."

In managing with family sources, caregivers frequently mentioned the importance of their constant availability—*making themselves available* to help with the care recipient and managing what occurred within the context of other sources such as doctors' appointments, sibling vacations, and emergencies. Jovana stated clearly what she felt was required of her in helping her mother manage care for her father: "I'm just on call whenever my mom needs."

In addition, caregivers talked about being available to other family members. A caregiver's availability to other family members and her sense of her relationships with them inside or outside a caregiving context affected the caregiver's ability to provide care to the care recipient. For example, Albatora reported needing privacy when she got home from work or her mother's house, but that her sister was staying at Albatora's house and the expectation seemed to be that Albatora was available to her sister, which left Albatora unable to tend to what she described as her own needs. And this dynamic may have affected her ability to cope with her caregiving duties.

> I don't drink very much but I feel weird drinking in front of her . . . and I just wish, I could just drink you know, without worrying about her being in front of me . . . but she likes to spend time with me, you know . . . it's a whole privacy thing.

In this same vein, Madalena's sister went to the grocery store at the request of their mother. She bought everything their mother asked for and seemed to be an available source of help to Madalena as Madalena managed care for their mother. At first glance, this behavior seemed supportive, part of a strong relationship between sisters, similar to the initial impression given by Albatora's sister staying with her. But, as Madalena explained further, with those groceries, Madalena's mother cooked and would forget she was cooking and leave the kitchen, putting herself and Madalena in danger. This situation seemed to cause added stress to Madalena's caregiving responsibilities and likely affected her relationship with her sister, because not only did Madalena have to watch her mother and be responsible for all that entailed, but she also had to monitor their mother's use of the stove when her sister provided the groceries. Madalena expressed her frustration with her mother: "And it's like stop cooking, you know?" The data do not demonstrate that Madalena was frustrated with her sister, however.

Jovana was the only caregiver who reported *saying no* to her caregiving responsibilities. All the other caregivers used the components of managing care previously cited and carried on. Jovana's experience was included here as reflecting one of the components of caregiving because *saying no* is unlike anything the other caregivers did, but it is something, as evidenced in the data, that many caregivers circled around repeatedly. Jovana's decision to say no to her caregiving responsibilities set a few things in motion within the caregiving process that are worth exploring. First, her mother stepped in and told her siblings that they would have to help her, their mother, in caring for their father now. Jovana said of her siblings: "It's all on them and I'm totally out of the picture." What the data do not tell us is whether, if the siblings determined that they could not do what they needed to, Jovana would step back in to resume her

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responsibilities. Jovana explained: "My mom told me that they [Jovana's siblings] will continue to do it [care for their father] until they say no and right now they haven't said no." Second, Jovana had a poignant moment with her father wherein she seemed to be asking his permission to stop managing his care. And in recounting the story to the interviewer, she made it clear that she felt she did receive his permission.

> Just when I went back he just held my hand for a long time. Then I explained to him that he was not a burden to me but that I was tired and I needed to rest and he closed his eyes and shook his head ok . . . I was happy that he shook his head ok that it was ok.

This vignette prompts questions about interactions between caregiver and care recipient, and about whether even those care recipients serve as sources for the caregiver. In Jovana's case, it seems that her father was a source for her in her decision to discontinue her caregiving duties—she looked to him to be sure he was ok with this choice. And his assent seemed to inform Jovana's ability to walk away from her responsibilities.

> ***Components of caregiver management of network sources.*** The core components of caregivers' management of network sources at this stage of the model were *choosing* and *disconnecting/reconnecting*.
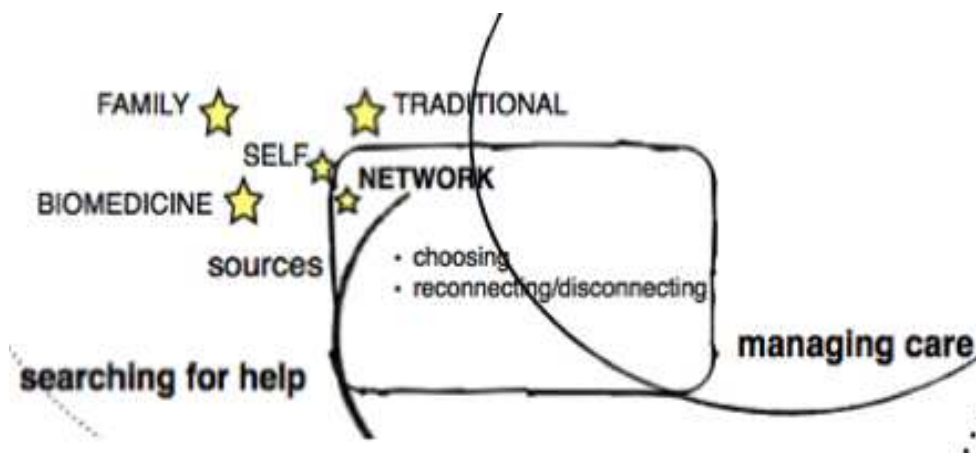

Figure 11. Components of managing network sources. This slice of the model specifies the components of the caregiver's strategy in her process of managing network sources.

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These two components, *choosing* and *disconnecting/reconnecting,* were in a feedback loop of sorts and seemed to be in dialogue with one another. Caregivers talked about choosing to spend time with friends or choosing not to spend time with friends—their decisions were based on their own caregiving duties and the degree to which they felt they, the caregivers, could accommodate friendships. Within this conversation about choosing were subtexts of power; caregivers often referred to their ability to decide when to spend time with friends and when not to. Caregivers spoke often of what could be described as their lives being dictated by others. One area of control they suggested that they had was in their relationships with their friends. Bound to this area of choosing and caregivers' control over friendships was a caregiver's decision to disconnect from or reconnect to friends. For the majority of the caregivers, their friendships had been pushed to the side when they began caregiving. And their friends were not always able to understand the caregivers' experience. But, when friends did understand the caregiving experience and caregivers felt could they rely on them, those relationships seemed to bolster and re-energize caregivers, and these friendships contributed to caregivers' management of care.

Caregivers talked about *choosing* when to spend time with their friends and when not to. Caregivers also seem to choose their friends based on caregivers' current experience with caregiving. Although not the case in the context of her caregiving duties, Jovana referred to her decision to spend time with her friends in a way that spoke to her sense that she controlled what happened in this context and she could make decisions that worked for her:

> I have a lot of friends and they invite me out. I tell them no; they used to make me feel guilty you know, that I didn't want to go but, I pick and choose when I want to go.

Caregivers' decisions about *disconnecting* from current friends or *reconnecting* to old friends appears frequently in the data. Disconnecting and reconnecting was informed by social norms within these Mexican American caregiving networks. Here are two brief examples: (a) avoid actions that may cause a woman to be ostracized from the network and (b) obey cultural norms. In mentioning these examples, my intent is not to imply that value judgments or labeling of these realities as "good" or "bad" is warranted. Norms simply are, and they deserve examination in that regard. Important to note is that the interview questions posed to the caregivers in the primary study elicited answers that illuminated what was discussed in the literature. This discussion does to some extent overlap with the traditional category that follows, in that it is about friends and cultural expectations, and I explore it briefly here with that in mind.

Regarding actions that are in keeping with the expectations of the network and obeying cultural norms, Sancia provided the example in one rich vignette:

> L and I had been very good friends, but I had an awful lot of trouble at the beginning with her family because people would walk in and not say hello. Or they'd leave and not say goodbye, and I thought they were angry at me. You know the rules. You walk in, you address everybody in the room. You do not leave unless you say goodbye. I do not sit my mother in the backseat of the car. She sits in the front seat. I kiss her hello and I kiss her goodbye. There are rules and L and I had a lot of trouble because I didn't understand why they would do the things they did.

> It influenced getting M coming in. It's much better because you know the rules. She hugs me hello she hugs me goodbye she's the caregiver.

> She feeds my mother a certain way. She cooks a certain way. She takes care of my mother first. She knows what my mother means to me.

> And there are definite rules that you do and there are definite respectful things that happen that do not happen outside the culture.

What the data demonstrate here is that L. was a good friend of Sancia's but she, and by extension her family, did not abide by the prevailing cultural expectations to which Sancia subscribed regarding treatment of her mother. The data do not show what

happened to Sancia's friendship with L., but from her words it seems that their friendship ended, since Sancia talked about her friendship with L in the past tense.

Sancia said that her experience with L. "influenced M. coming in." Even though she and Sancia were good friends, when L. didn't act in accordance with what Sancia perceived to be important, Sancia found another caregiver, M. This woman acted in keeping with the cultural norms that seemed to inform Sancia's decision to disconnect from L. Sancia referred to M.'s knowing how to "cook a certain way" and the fact that she "knows what my [Sancia's] mother means to me." In her statements here, Sancia referred directly to those "respectful things" that "do not happen outside the culture."

Jovana's friendship with an elderly woman was replete with nuance around disconnecting and reconnecting that begs for further examination: Jovana mentioned to the interviewer a friendship that she was recently able to rekindle with a woman she'd met 30 years before. Within the context of her story, this relationship could be understood as one that served to re-energize her, amid all the difficulty she was having in her own caregiving experiences.

> And I'm so excited because I want to go visit one of my friends. I'm not sure what age she is but she's probably in her late seventies or eighties . . . I'm just really emotional because I met her in—let's see . . . . In the '80s I met her (*crying*) and she was so good to me.

We see the woman here as an individual whom Jovana perceived as being "good" to her, possibly supportive in some way that likely did not have to do with Jovana's caregiving duties. Jovana continued, recounting her visit with this woman at the nursing home where she was living: "I was able to give her some breakfast and that made me feel really good." Jovana's words here could be interpreted as the woman's being yet another care recipient to whom Jovana was providing care, or an example of

the tendency of a caregiver to seek out others who need care, as demonstrated in the data.

But, we then get the sense that this woman had also been a resource for Jovana, in this case a spiritual one: "She was always a very glamorous lady; poor but glamorous. And she was actually the first lady that taught me about the Bible (*crying*) so, she was special."

Some of Jovana's comments in this particular vignette painted this woman as a friend, other comments painted the woman as a care recipient, and still others painted this woman as a source that satisfied some sort of spiritual need in Jovana. As with other vignettes from the interviews, the categories blur and we see sources are perceived by caregivers from many different angles.

Jovana also told the interviewer about her other friends, and her comments demonstrate that she disengaged from them to a degree while caring for her mother but then when she stopped caring for her mother, she reconnected with her friends. This progression of events is discussed further in the section on sources' waxing and waning, but it does deserve mention here to illustrate the myriad iterations of friendship and how it unfolds within the caregiving experience and elsewhere.

The core components of caregivers' management of biomedical sources at this stage of the model were *navigating* and *regurgitating.*
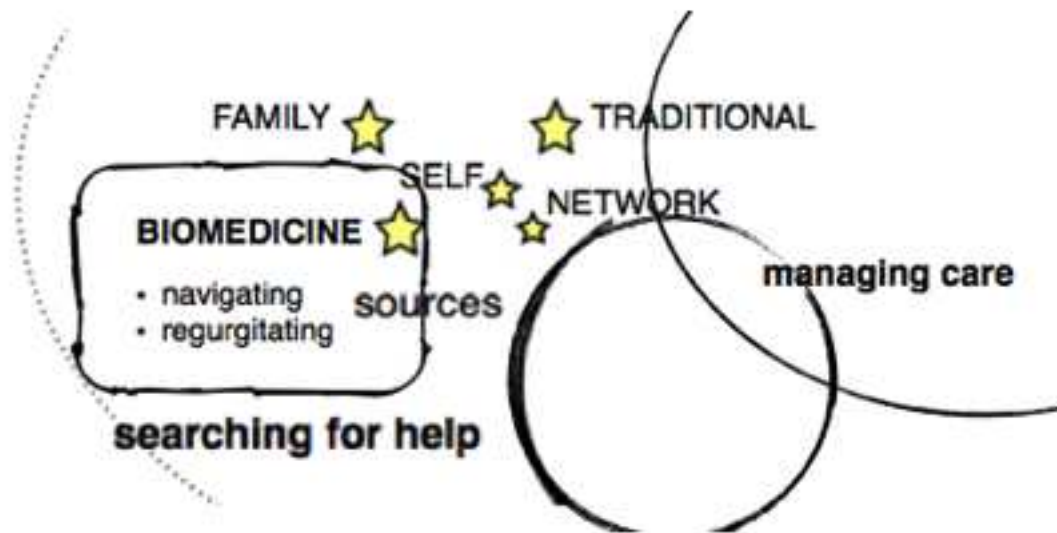
Figure 12. Components of managing biomedical sources. This slice of the model specifies the components of the caregiver's strategy in her process of managing biomedical sources.

Caregivers spoke frequently of making choices about recipient care as they interfaced with biomedical sources, *navigating* the intersections of care recipient expectations, their own expectations, and system realities. In the data sampled for analysis, Sancia provided the lone example of a caregiver mentioning the specifics of an experience with a primary care practitioner (other caregivers spoke in generalizations about medication or taking the elder to appointments) as a source. And Sancia's interaction with the primary care provider was for her own care. In the confines of her own appointment with the physician, he asked about her mother. Sancia provided him with an overview of how her mother was doing and she said, "We'll change medicines that way." In the context of this discussion with the physician, it was Sancia who was navigating her mother's care on her behalf: serving as an intermediary, monitoring her mother, relaying this information to the physician, and navigating her mother's care by

conversing with the physician about what she saw and working with him to decide what her mother needed.

What is interesting about the exchange between Sancia and her physician is the fact that most care recipients described here do not require much medication or medical care within a primary care setting. Moving to a broader perspective, this finding may inform where central sources are located. For example, a medical home run by a primary care practitioner may not be the best system in which to situate care recipients like those cared for by the caregivers in this study. This brief tangent will be explored in Chapter 5.

Madalena provided another example of the component of navigating. She told the interviewer that her mother wanted to cut back on her prescription medication: "She says she just—if she doesn't want to take all the medicines she can take whatever she feels is necessary." We get the sense that Madalena's mother wanted to take back control over her health—and make decisions about "what is necessary" in terms of "whatever she feels is necessary." It was Madalena who had to intervene on her mother's behalf with those primary care practitioners who were prescribing the medications.

Nalda discussed how she navigated her mother's care as she interfaced with biomedical sources regarding her mother's wanting to get the flu shot, a treatment mass-marketed directly to patients:

> Had a flu shot so hopefully we can get over that hurdle, because every time she sees it on the TV you know promoting paying for the flu shot at [pharmacy] but because she is on Medicare or whatever, wouldn't do it or they wouldn't cover it. I guess you would have to pay them the fee, which it's 30 bucks or something like that. And we would end up going to the doctor eventually.

Nalda's comments here, when viewed in a larger context, speak to texts about power, biomedical primacy, patient empowerment, popular medical culture, and what the

reality is for the caregiver as she has to see her way through these texts on behalf of the care recipient. As mentioned above, that which is said, and perhaps more importantly, that which remains unsaid, requires further study.

Corollary to this discussion of texts within Nalda's interview are comments made by Sancia and Madalena that belie similar texts. For example, as discussed previously, Sancia had difficulty with her caregiving responsibilities and began taking an antidepressant. What was important in this vignette was that caregiving is often a cultural expectation, and in navigating how to manage care Sancia engaged a source that sat outside that cultural boundary, biomedicine, and suggested that other caregivers do so as well. In this sense, Sancia navigated care for herself, interfacing with biomedicine, so that she could then provide effective care, both biomedical and cultural, to her mother. This measure was shown in the literature to be especially difficult because to admit one is depressed is to acknowledge the burden of caregiving, a culturally unacceptable action according to structures situated within Mexican culture such as *marianismo.* Gil and Vasquez (1996) listed "Ten Commandments" of *marianismo*—cultural rules about how to be *una mujer*: Among these rules were "do not forget a woman's place," "do not ask for help," and "do not put your needs first" (p. 6).

Madalena talked about her decision to see a counselor, who was helping her through some difficulty, which included the recent end of a relationship whose breakdown was confusing to Madalena. As mentioned previously, the data do not demonstrate whether the dissolution of this relationship was tied in some way to her caregiving responsibilities, but Madalena did mention that she "goes to work mad" due to the stressors of caregiving. She was navigating care within a biomedical context for herself, like Sancia, interfacing with biomedicine to find a way to better balance her life

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and her caregiving duties. Madalena's family did not agree that this was a useful

exercise. But Madalena said to the interviewer:

> I hope it works because I hate that awful feeling inside your heart that it's almost
> like you want to have a big old scream inside your heart and you can't get it out,
> it's an awful feeling. I can't even explain it.

Both women highlighted similar texts about cultural and gender expectations, conformity,

and the ramifications of decisions, both within the context of caregiving and without it.

Definitely a striking code, *regurgitating* reflects a stark component of caregivers'

management; what was identified as *regurgitating* in the data was, in actuality, present

frequently. When using biomedical sources, caregivers seemed to be on the receiving

end of information, and they would recount it and their experiences with it to the

interviewer in a way that seemed to indicate a lack of processing or understanding on

the part of the caregiver. Within the component of *regurgitating* were data that reflected

providers *conversing without the caregiver* and that often, in her interactions with

biomedical sources, things seemed to be *happening to the caregiver.* And she would

have to manage these realities. *Regurgitating* illuminated texts of power and prevailing

ideas about health and healing and systems' frequent inabilities to answer questions

about what caregivers and care recipients needed.

For example, Sancia admitted that what she had been doing in her capacity as a

caregiver for her mother was less difficult, confusing, and foreign to her than what the

home care and insurance services were asking her to do, although she was using them

as sources for her mother's care.

> We've had to do—which has been more stressful than what I'm doing because
> they've got these—I had to find death certificates, and I had to find—she had to
> open a checking account of her own which I'm not sure why. She doesn't get—
> she doesn't go to the bank. She doesn't do any of those things but she had to
> have her own checking account so the money could go in there. Separately . . .
> So I think the biggest stress has been trying to jump through all the hoops that
> they're making me jump through.

Sancia's description of her experience of this source was rife with her confusion about why things had to be done the way they did and the style's poor fit into her mother's life and Sancia's understanding.

Sancia also discussed her experience with caseworkers within the long-term care system. Regarding the respite care to which Sancia was entitled, we see Sancia's initial confusion at the information given to her by a caseworker:

> And she said (the caseworker), "Don't forget, you have 720 hours' worth of respite care." I didn't know what respite care was. I'd never heard that word.

As a caregiver, Sancia was unaware of the options she had, and the source with which she was interfacing had not made that information available to her before.

As mentioned at the outset of this section, primary caregivers seem to depend most heavily on hired caregivers rather than on providers or systems. Often in the data, these hired caregivers were assigned to the care recipient. All caregivers talked about hired caregivers' being assigned to them and the care recipient, and only in Sancia's case was there talk of communicating with the service that supplied hired caregivers. Hiring and assignment seem to go on without the input of the caregiver, and caregivers are unaware of their role and whether they have options to contribute to the hiring and assignment process. And then, caregivers must deal with the shortfalls of the hired caregiver. Often, these shortfalls result from a lack of cultural knowledge, such as cooking, as evidenced in Nalda's comments. Nalda recounted her previous experiences with caregivers for her mother that were supplied by caregiving services:

> Caregivers that we've had in the past, some of them just sat here and talked on their cell phone all day long and haven't done anything. The caregiver we had before, she was ok, I mean she was there for moral support. But she didn't cook. She couldn't cook.

As evidenced by Nalda's experience, caregivers' experiences here fall under the category of *regurgitating* because the data show that they are simply told what to do,

receive the information as it is given to them, and are given no opportunity to engage in dialogue or to suggest that the system respond more fully to their needs.

The core components of caregivers' management of traditional sources at this stage of the model were *navigating* and *deciding.*

As in the biomedical source category, navigating was also a component of caregivers' management of traditional sources. My hunch is that this was so because *navigating* characterized ways in which caregivers interfaced with *actual* established and pervasive health and healing systems—in this case biomedical and traditional—and the subsystems and individuals of which they are comprised.

In the biomedical source category, navigating was rarely discussed in terms of actual experiences with practitioners. Instead, caregivers referred to medications, appointments scheduled, and their experiences with hired caregiver services. The same held true for navigating in the traditional source category. Caregivers did not refer to visits to or encounters with traditional practitioners *per se*, only to the armamentarium of traditional medicine. Furthermore, their discussion of the armamentarium was limited solely to herbal pastes and herbal teas in terms of what caregivers and care recipients used. And when these medications were discussed in the interviews, caregivers presented them using languaging that illustrated that these remedies did not occupy a place of primacy in the larger job of caregiving and interfacing with sources.

Figure 13. Components of managing traditional sources. This slice of the model specifies the components of the caregiver's strategy in her process of managing traditional sources.

For example, Iliana referred to the remedies used by the caregiver that she and her siblings used for their mother as being "little home remedies . . . for minor things" and listed upset stomach and difficult bowel movements as examples of these minor things:

> The lady (a caregiver) that's here with us, she kind of does some little home remedies when my mom has difficulty with her bowel movements, or upset stomach. But those are the things we use for minor things, you know, like upset stomach, you know, indigestion, things like that.

Although the literature does show that often patients and caregivers feel uncomfortable telling biomedical practitioners about their traditional practices, the interviewers in the primary study were Mexican American and were trained by cultural experts and cultural brokers to interact with caregivers. The primary investigators were aware of the prevailing mistrust and cultural differences that characterized this population's interactions with biomedicine. They built into the interview process

requirements and training that sought to alleviate discomfort or embarrassment as they discussed their traditional practices. Although it is still possible that caregivers were uncomfortable, it is also possible that the caregivers sampled for this study, when navigating the traditional sources at their disposal, chose to relegate those sources to a less important periphery. The data do not provide clues as to why the caregivers may have chosen to do so.[31]

In a different vein, caregivers did report that care recipients used traditional medicine. Caregivers' explanations brought to light another element within the component of navigating: a text of care recipient empowerment.

The interviewer asked Madalena about what her mother might use that was not prescribed by a doctor. Madalena pointed to a spot on her own leg to demonstrate what her mother did and said: "For her legs like that one part right there she gets really red in there and the way she manages it is herbs." Madalena's use of the word "manages" hinted at the possibility that herbs provided care recipients an ability to manage their own care. Reaching back to the data that addressed biomedical sources, care recipients admitted feeling that their control over their lives and their decisions was being taken away—whether by the primary caregiver, hired caregivers, or larger health and healing systems that dictated what would and would not happen. Use of herbs and the larger metaphorical ties back to birth culture, ancestral knowledge, a time when care recipients were healthy and in an environment that was possibly less stressful than their current one, may have served to return some of that sense of control to the care recipient. The larger implications of this possibility are discussed in Chapter 5.

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[31] The literature often speculates about generational differences in perception of traditional medicine. However, the findings remain inconclusive—as explored in Chapter 3. Some studies show that younger generations use traditional medicine more than their parents do, and other studies show the opposite. Still others suggest that the widespread use of traditional medicine in first- and third-generation Mexican Americans skipped the second generation for many reasons that are informed by processes of immigration and acculturation.

When interfacing with traditional sources, caregivers also reported *deciding* when or when not to use a traditional remedy. No caregiver sampled for analysis mentioned speaking to her biomedical practitioner about traditional remedies. It was the caregiver who made the decisions.

For example, Sancia talked about the hired caregiver she employed for her mother. The hired caregiver, Sancia told the interviewer, is from Mexico. Sancia explained what types of care the caregiver wanted to provide to Sancia and her mother and how their interaction unfolded:

Sancia began by explaining that the caregiver wanted to treat her (Sancia). And Sancia obliged her, although the tomatillo "was nasty."

> The caregiver wanted me to drink tomatillo for my neuropathy.
> Interviewer: Tomatillo?
> Aha. You know, she grinds it up and you mix it with water and drink it.
> Interviewer: Aha.
> And it was like drinking glass.
> Interviewer: Oh!
> But she said that would help the neuropathy and bring my blood sugar down.
> Interviewer: Mhm.
> She's from Mexico, so (*laughing*).
> Interviewer: Mhm, so have you done that?
> No I've tried it; I've tried it for about a week. That stuff was nasty.

Then Sancia told the interviewer that for her mother, the caregiver brought a type of herbal tea, although in the interview transcripts the specific name was omitted.

> And then she bought some [A] tea.

> Usually it's in a sack; it's a little thing that you can get in Mexico and [A] is very good for healing, but she brought some tea to make to use it on my mother's legs; she was going to use it on my mother's legs; she hasn't done it yet. I haven't quite let her yet.

> Aha, she boils it and then she wanted to put it on her leg—but I don't think she has enough—I don't know how you say it in English. Trust with me.

> Like she doesn't have enough confidence in me to say, "Let me just try it" (*laughing*). Why she hasn't done it, I think she I think she's not comfortable quite yet.

In describing what the caregiver wanted to do for Sancia's mother, Sancia explained that the caregiver seemed uncomfortable or unsure as to whether Sancia would accept the use of the herbal remedies. At the time of the interview, Sancia hadn't said yes to the caregiver's treatment suggestions for her mother. This lack of acquiescence is interesting because it may reflect the fact that, as in the literature, caregivers demonstrate mixed responses to herbal remedies and traditional medicine. Some scholars feel that it's because they don't use them, others feel that it's because they don't feel comfortable telling interviewers who may exist outside their immediate cultural circles about them, and still others contend that it is simply the decision of each unique caregiver.

Caregivers also decided whether to subscribe to certain cultural expectations in the context of caregiving, in particular those nuanced traditional practices reflected in rules for caregiving of which caregivers were aware. These expectations could be understood metaphorically as rivulets within the birth culture stream discussed throughout the previous chapters. Although the interview questions prompted caregivers to articulate what these cultural rules might be, the data demonstrate that there are clear cultural expectations in caring for a care recipient and that caregivers decide whether to follow them. Jovana mentioned to the interviewer that when she fed her father, she did certain things that had been "shown" to her. Although it is possible that these cultural expectations do not exist in Mexican culture alone, *marianismo* could be seen reflected in the example given. (A cross-cultural examination of constructs similar to *marianismo* could be useful in this context in later projects.) Jovana recounted that she provided his food on a ceramic plate, something her mother taught her to do for all men.

> I like to give him his food on a [ceramic] plate usually. Why not? We were just
> shown to give them food on a—I don't even think we were told, we just did it;
> cause my mom it was always something they always—she did. So uhm that's

just a rule, now they have lots of paper plates but I still like to stick to the old rule (*laughter*).

In a later vignette, Jovana told the interviewer that she had to replace her father's ceramic bowl with a plastic bowl because he would beat his spoon on it and make a lot of noise. Here, Jovana decided that she would stop acting in accordance with that cultural expectation when faced with the noisy disturbance her father caused.

As with the discussion of cultural streams in the previous chapters, it has become clear here, deep into the data, that these streams are not simply conceptual structures that exist somewhere outside the caregiver's reality. On the contrary, they are very real to the caregiver. In managing traditional sources, the caregiver decided what parts of this stream she would accept and that which she would not, and these decisions were the result of her reactions to what she was experiencing and what she perceived was best for the caregiver.

Self as source. Caregivers also used themselves as their own sources. Often, self-as-source would occur in cases when the caregiver felt she was on her own, without resources such as family, friends, or others to help her. There was only one case in which a caregiver did not return to herself as a source. All other caregivers did. The core components of self-as-source were *taking it one day at a time, praying,* and *becoming comfortable.* All these components appeared in-vivo in the data. Not all caregivers chose to articulate their strategies. Sancia was the clearest about what she did to cope with her caregiving responsibilities. Caregivers' strategies are included here in vivo as components because they were described by the caregivers themselves in their own words, limiting co-construction in this instance. I thought it a fitting tribute to caregivers' unique experiences in managing sources, both positive and negative, and illustrated caregivers' strategies as they themselves saw them.
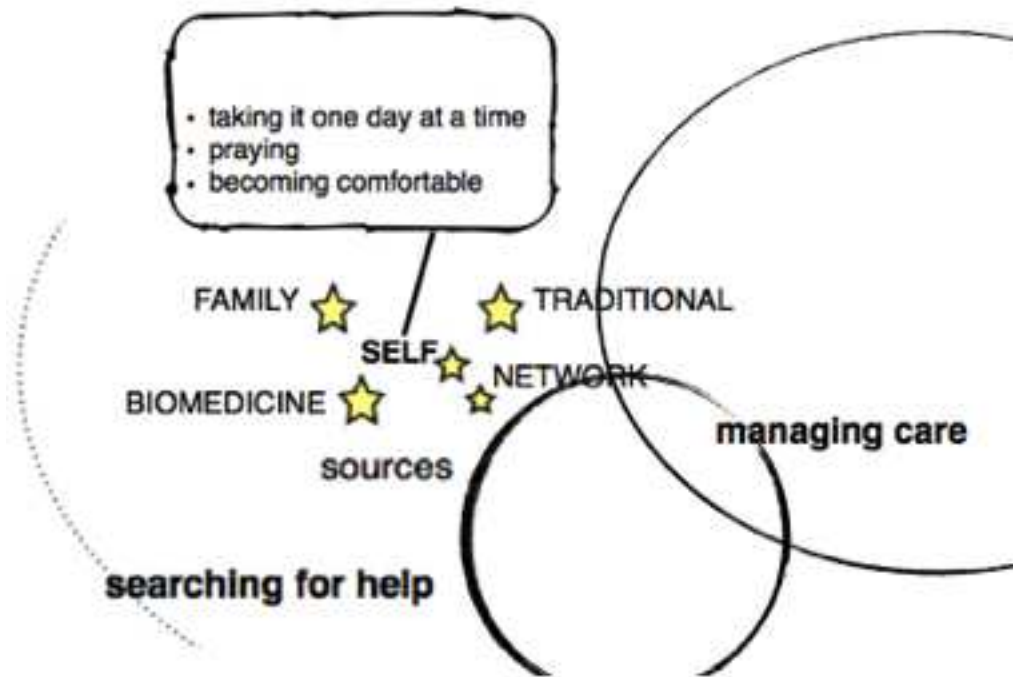
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Figure 14. Components of self-as-source. This slice of the model specifies the components of the caregiver's management of herself as a source.

Taking it one day at a time was a strategy that emerged from Sancia's interviews.

Since Sancia was unable to rely on her sister, the majority of the caregiving was

Sancia's responsibility. Not only did she take care of her mother, but she also took care

of her father before that. She cared for her mother for 8 years and her father for 10

years before that. She told the interviewer that she didn't remember life before

caregiving.

> I've been at it for eight years. I don't know—I don't remember what it's like.
> Before then it was my dad. I took care of my dad before he died for about 10
> years. It's been going on for quite some time. I was a young person, and still—
> now I'm an old person and I'm still doing it. It gets overwhelming sometimes. I
> don't begrudge it. I don't ever regret that I'm doing it. I just get overwhelmed.
> But I got to do it (*laughing*); there's not much you can do. You just take it one
> day at a time.

Caregivers mentioned the importance of *praying* in the context of spirituality and reliance on God to take care of things in the way that was best. For example, Jovana shouldered the caregiving responsibilities for her father on her own and had moments when she simply did not want to continue. Prayer was what helped her to go on.

> I felt so trapped. I had to really pray to go over there. I just didn't want to go anymore . . . I felt a little bit hopeless not too much cuz I knew I would find a way out, that God would help me.

The data did not tell us much about caregivers and their spirituality, or whether all caregivers were religious, or whether religious belief began during caregiving and continued after caregiving stopped. However, even after Jovana ceased caring for her father, she continued to pray and reported that she meditated and attended religious services.

The literature examining faith in this population, and the larger Hispanic culture of which it is a subculture, would tell us that what is manifested in the data is evidence of a larger way of being for our purposes here, in the population sampled for analysis. Arredondo (2002) discussed the Latina experience as situated *entre fronteras* (between borders) and characterized this liminal space using the metaphor "wild-zone." Her research took a psychohistorical perspective. She identified several themes that permeate Latinas' realities: "struggles for emancipation and empowerment under a mantle of colonization; marginalization imposed by societal, political, and religious norms; and an aura of sacredness, self-containment, duty, compassion, and beauty" (p. 313).

Sancia stressed the importance of *becoming comfortable* with her situation. Nalda and Madalena made similar comments that were coded as having patience, not becoming frustrated, being realistic about caregiving responsibilities, and finding balance. In the context of the vignette offered, Sancia discussed her caregiving

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experiences, her mother's worsening cognitive decline, Sancia's lack of direction in terms of what to do for her mother and what to expect or not expect of her, and her own frustration with herself and with her mother.

> It was all hit and miss. It's taken me a year to learn and to be more comfortable with it. And to be more comfortable with her and for her to be more comfortable.

Like Nalda and Madalena, Sancia's strategy here was to become comfortable with the situation and not to let it overwhelm her.

The data also showed that caregivers sought out sources devoted to caregiving, but the data also included examples of caregivers' using other types of sources to support themselves. Madalena's comments illustrated this clearly. Madalena told the interviewer that she was going to see a counselor for a "broken relationship." She admitted that she didn't know what happened and that it "bothers me a lot." The trouble in the relationship may have been tied to her caregiving duties, but the data do not indicate as much. What the data do show is that, in this example, the source Madalena was using was for herself and for her relationship, not for the care recipient, and possibly not even in the context of caregiving for the care recipient. Madalena's family told her, "Mexicans don't go to counselors," and Madalena's sister made fun of their family and said: "You just instead of paying the counselor you just pay a witch doctor." This passage from Madalena illustrates the depth and breadth of sources and the importance of recognizing that caregivers are not always singly focused on sources of care for the care recipient, and that these other sources may inform their caregiving experience as well.

Interactions of sources. As demonstrated in the previous sections, each source has its own role, its own attributes, and its own managing strategies. Boundaries between sources, as mentioned above, also blur. Next I explore a few examples of this

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phenomenon. In examining the blurring of boundaries, I noticed that the components of caregiver management did not change. I identified the same components in the overlaps of sources that were discussed at length in Stage Four concerning each type of source—they just occur simultaneously.

In order to illuminate the spaces occupied by overlaps of categories in the examples offered, I used a memoing strategy similar to what proved successful during constant comparison. I posed a question of the data related to what I determined, in the spirit of co-construction, to be of importance to the caregiver and least illuminated in the current research. This section on interaction of sources is driven by my memoing.

Memo 14. What is required of individuals who provide care from the perspective of the primary caregiver?

In this example, traditional sources, encompassing cultural expectations and cultural knowledge, informed the extensive networks of caregivers and others that caregivers tapped into for help. Each of the caregivers expressed the importance of possessing what proved to be a rather nebulous cultural knowledge, an element identified within the traditional source category that was difficult to quantify. Bearing in mind that this is a qualitative grounded theory study, its nebulous quality isn't so much of a problem. To address what seemed to be so difficult to define, I looked to the data for direction.

The data provided two examples as to what was required. First, knowing how to cook was identified as important when determining who may serve as an acceptable caregiver. As I mentioned earlier, my hunch is that "knowing how to cook" is simply synecdoche for a larger understanding of Mexican culture in general. In this context, my reasoning behind this hunch is that cooking and knowing how to cook seemed to be a line in the sand for both identifying when a care recipient was declining and determining

who got to care for the care recipient. For example, the time that Iliana identified as being the moment when her siblings determined that their mother's cognitive ability was declining was related to food:

> We'd come over to eat and her food was different she was forgetting to season it . . . And just in the cooking and her cleaning. . . . But I think more in her conversation, she was asking more questions and the fact that she wasn't cooking the same way.

Iliana mentioned that her mother's course of conversation was peppered with more questions, but again and again, the way she was cooking came up as an indication that something was wrong. In another example, when Nalda was prompted by the interviewer to explain how a caregiver who was less than acceptable came to care for her mother, Nalda was clear about feeling that she had no choice in the matter and was disappointed in the caregiver's cooking:

> Interviewer: Did you choose her or was she just assigned to you?
>
> Nalda: She was assigned to us. So far as the agency that sent her. She just wasn't a real good cook, she didn't cook.

Second, I identified discussions of what rules a caregiver needed to be aware of. The interview schedule asked questions about these rules specifically. Fortunately, the schedule reflected what the literature asserted—that these rules are of great importance in understanding the caregiver experience. Here, caregivers' responses proved fruitful. The interview questions enabled the caregivers to articulate clearly what these rules entailed.

> Sancia explicitly listed the rules as she understood them:
>
> You know the rules. You walk in, you address everybody in the room. You do not leave unless you say goodbye. I do not sit my mother in the backseat of the car. She sits in the front seat. I kiss her hello and I kiss her goodbye.

Alongside the rules of interaction, we see cooking identified by Sancia again as an important attribute of the caregiver, M.:

It's much better because you know the rules. She hugs me hello she hugs me goodbye . . . she's the caregiver. She feeds my mother a certain way. She cooks a certain way.

What goes on within this overlap of sources is worth noting because it does indicate a certain cultural synecdoche, as I mentioned earlier. Yes, caregivers provided extensive information regarding "rules" as prompted by the interview questions, which was certainly useful. And these rules informed their interactions with others in their network. However, we see repeatedly a return to the caregivers' sense of what was meaningful as being somehow woven into their perceptions of food, cooking, and all that those things entail. A rivulet within the cultural stream. Cooking, as demonstrated by the data, is replete with cultural awareness of shared traditions, memories, and of course certain flavors and how to correctly execute a dish. When these delicate balances are off, something is wrong—whether it is with a hired caregiver who is part of the broader network or the with the care recipient. The data discussed here are also reflective of the scholarly community that explores food and culture populated by Lévi-Strauss (1978, 1992) and colleagues, in addition to Arredondo's (2002) work in the space of women, borders, and *marianismo*.

Network and biomedical sources. The bleeding edge of interaction referred to earlier was prevalent in this overlap of sources. What made this overlap particularly interesting was that it actually resembled a responsive informal structure within a larger, formal structure.

Memo 15. How do informal networks of individuals inform the care an elder receives in a larger biomedical context?

Iliana mentioned that her siblings stayed organized and that she had a friend who was a nurse who provided support and answered questions:

Whoever is here in the morning will give (insulin) to her, and then whoever is here in the afternoon will give it to her. If we're running late then J will give it to

her . . . Plus my best friend is a nurse, and we have her number up there. She says if there's ever a question or concern, we just call her.

Iliana's best friend was part of a larger, formal structure—a hospital or other biomedical establishment. This structure sat within the parameters created by the host culture. Iliana's friend existed there but also existed simultaneously in a world where she was open and able to provide help for Iliana and her siblings, who were receiving a very different cultural stream. Her telephone number was posted for the siblings to use if they needed to, and Iliana's friend responded. Iliana's friend bridged a gap, providing her medical knowledge from the biomedical paradigm to individuals who were working within cultural expectations of their own. This bridging of the gap informed the care that Iliana's mother received, influenced both by the biomedical paradigm that Iliana's best friend brought and by the family caregiving being situated within Mexican American culture.

Memo 16. When these sources interact, where is the caregiver?

In this next example, the overlap occurs between biomedical and family sources, the data demonstrated that the caregiver was situated in a somewhat precarious position that I was prompted to explore further. When biomedicine and family overlap, it seems as if two worlds are colliding. A delicate balance of sorts has been thrown off, and the caregiver's experience was often discounted.

Jovana's sister wanted to hire an Alzheimer's caregiver. Jovana had been providing care to her father (able to depend only sometimes on her mother) for 4 years. Her sister did not recognize this accomplishment; nor did she recognize the tremendously difficult learning process that Jovana underwent and the insight she gained in caring for her father. Jovana was not pleased with her sister's idea and reported to the interviewer that she told her so. The data do not demonstrate how much

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of Jovana's response is driven by a code I identified in the data, *receiving credit,* but we can ascertain some degree of disappointment from Jovana's words:

> And what I tried to explain to my sister cuz my dad's already like into his fourth year of Alzheimer's and she says well we want to hire people that are qualified to take care of people with Alzheimer's . . . I told my sister, we don't need anyone that knows anything about Alzheimer's anymore because my dad already went through all that, the sun downing, the not knowing what he wants and guiding him. And I was there when my dad knew what was happening and that he was losing it I said. And me and my mom were there trying to figure it out. I said that's when we needed somebody with expertise. Right now we need somebody that knows how to sit there and watch someone be safe that doesn't know how to do anything.

In the case of Jovana, her experience was discounted in the face of someone with "training," likely training in a biomedical paradigm for the management of Alzheimer's. In another vignette, we see a different type of discounting during the overlap of biomedicine and family.

In a second vignette, Sancia talked to the interviewer about deciding to take the antidepressant Zoloft: "Yes I started taking Zoloft. I would recommend it. The minute you know you're gonna be a caretaker, start it." However, earlier in this interview she could not remember what this type of medicine was called in English: "I started on an antidepressant. Is that what they're called? It's Zoloft." And at a point in a prior interview, Sancia told the interviewer that there was no one to say "it's ok." But the biomedical system's answer was not to have a dialogue; the answer was to have Sancia take Zoloft. The overlap here has larger implications for caregiver choice and cultural competency in addressing caregiver needs. As for elder care, the data demonstrate that Zoloft caused Sancia to become more relaxed with her mother and to spend more time sitting with her rather than worrying about things like the dishes. Although the data do not demonstrate this finding directly, it is possible that Sancia's relationship with her mother became less stressful for both of them. However, we will never be certain

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whether satisfying Sancia's initial desire, to be told that "it's ok," would have had an

effect similar to that of Zoloft's on her relationship with her mother.

Memo 18. What about this overlap may inform the creation of more effective systems?

In this third example, I looked at the intersection of biomedical and traditional

sources in a sort of "shout-out" to my initial research question. When discussing

biomedicine and traditional expectations about health and healing coming in contact with

one another, the caregivers were very frank in their responses. In seeing their clear

suggestions emerge, I memoed a question of the data that I thought would help extract

those suggestions, which seemed replete with ideas for better communication between

the two systems.

Sancia's suggestions to the interviewer were prescient:

> I think the main part that's harder for us, as Hispanic caregivers, is that we don't seek help. It's our responsibility, we don't seek help and there's no one to say, "Hey, you know what, this is what you can do; this is how you can do it." I don't mean this to be anything but informative, but the lady was Hispanic, who is now a caseworker, and she said "It's ok, you need time away and this is what you can use," because I would have never thought to ask, I would have just continued to do it the way—

In these overlaps that involve biomedicine, family, and traditional sources,

cultural knowledge is not sufficient. Instead, what seems to be demonstrated by the

data, and here in Sancia's examples, is that insiders who intimately understand the

caregiver's situation are very important. In addition, caregivers, when prompted (and

sometimes when not, as in the case with Sancia), seem to provide piercing insight into

their own experiences, insight that could be helpful in designing systems that answer

their needs. This reality has further implications that are discussed in Chapter 5.

Drivers and tensions. Not a stage *per se,* this area of the model reflects the

drivers and tensions associated with managing care. At this point in the model's

development, it seems that derivers and tensions are best situated in the stage of

managing care. This state of affairs, of course, could change. Regarding drivers and

tensions, put simply, in the data were tracks left by phenomena that directly informed the

caregiver process. For our current purposes as reflected in the current state of the

model and its growth, these tracks were deemed drivers and tensions. At a later stage

in the model's growth, they may become mediators and moderators, but at this juncture

the data do not support this shift, nor does this study's methodology. They are for our

purposes at this point, according to the data sampled for analysis, what serve to drive

the process and delimit it. These drivers and tensions may also shift within the model,

moving to places inside it where they are more closely identified with the process as it

takes shape. But again, the data do not support this shift at this time.
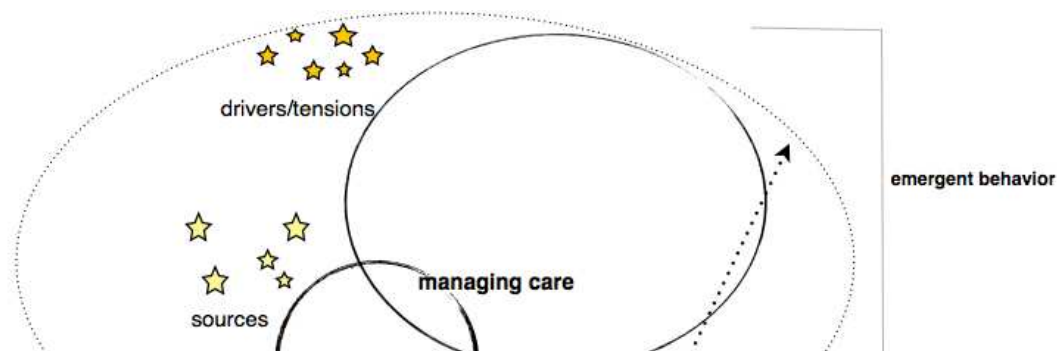
Figure 15. Drivers and tensions. This slice of the model locates the drivers and tensions
of the caregivers' process as identified by this project and determined by the data
sampled for analysis.

These five drivers emerged as codes in the focused coding process, and I now

introduce the code and then describe each driver at length using examples found in the

data.

Driver #1: *Relying on a parent.* Having or not having a parent whom the

caregiver considers a resource likely affects *accepting the caregiver role* and the

caregiver's subsequent cycles of management/non-management. Jovana was the first

to notice her father's deterioration and her mother's increasing inability to care for him by herself. Iliana's siblings, however, became aware of their mother's deterioration at about the same time: "You know what, it started off we were seeing that of course she needed help and we were seeing that she was getting forgetful and couldn't do things." Jovana didn't mention what she saw that alerted her to the importance of helping her mother with her father, except to say that she saw it was "crucial." Iliana did provide examples:

> Little things. She'd call us at our house and say, what day is it today. I can't remember what day it is. We'd come over to eat and her food was different she was forgetting to season it . . . And just in the cooking and her cleaning. . . . . But I think more in her conversation, she was asking more questions and the fact that she wasn't cooking the same way.

Nalda noted her parents' aging and their increasing feebleness and inability to do things for themselves.

Jovana sensed a problem, helped her mother herself initially, and then went to her siblings for help, but they refused. Iliana's and Nalda's realization that their respective parents needed help was a little more gradual. Iliana estimated that her mother might have had the symptoms of Alzheimer's for the previous 12-15 years. But, after dealing with this situation gradually and then noticing that their mother was having increasing trouble remembering things and that her cooking and cleaning habits had changed, Iliana and her siblings determined that something had to be done, and they began by having a family meeting. They got organized. Iliana's brothers were not expected to perform the same tasks as her sisters. Iliana explained that she and her sisters took on the bulk of the intimate care and hygiene, and her brothers did the lawn care and repairs. Of the intimate care/hygiene for her mother, Iliana said: "Now the guys, we don't expect that because they don't feel comfortable doing that."

Driver #2: *Relying on a family schedule.* Being able to depend upon siblings and other family members to adhere to an agreed-upon schedule may affect the cycle of

management/nonmanagement, regardless of additional caregiving services. Jovana

attempted to get her siblings organized and posted a schedule, but it wasn't followed:

> They just kept saying, "No, you know, she (Jovana's mother) can do it." I
> couldn't believe what I was hearing. I even wrote it down, you know, on a
> schedule, "Please don't call, just come over after work." So that didn't work.

When Jovana's schedule fell flat, Jovana returned to herself as a resource and again

became the primary caregiver for her father. Iliana's siblings, on the other hand, were

very organized and shared the load. They were resources for each other: "We have a

calendar and somebody's here twice a day to see her." They had a book they shared in

which they wrote notes to each other and monitored medicines and things such as their

mother's blood sugar, for example. Whereas Jovana perceived her siblings as being too

busy with their families to help, Iliana saw the value of a schedule in avoiding just that

excuse: "It (the schedule) forces people to come over because if we didn't have this

schedule, I think people get busy in their lives, then you—you—are committed. You

have to do it."

Like Jovana, Nalda did not have help from her siblings (she mentioned her sister

"not doing her part in caring for her parents"). She depended upon herself as the

primary resource in caring for her parents, and the schedule she was most cognizant of

was dictated by the availability of each of the assigned caregivers. Nalda ran errands in

the morning: "While she (Nalda's mother) sleeps I can take advantage of her being

down." The caregiver who tended to Nalda's mother during the week was from a

caregiving service and the one on the weekend was a friend of this caregiver.

Driver #3: *Culture-specific caring.* Being able to depend upon caregiving

services to supply individuals who are well-suited to care for the population to which they

have been assigned—whether requiring patience, a set schedule, or knowing how to

cook—may affect the cycle of management/nonmanagement. In the course of

mentioning a caregiver she was sorry to see go, Nalda alerted us to the ever-shifting

schedules of caregivers:

> We actually had another lady that had been with us for a couple of months but she was another caregiver for another agency and her Monday through Friday job changed and she was working Saturdays and stuff, so we were sorry to lose her.

Nalda also recounted her experience with a caregiver assigned to her mother who

wasn't very good. The interviewer asked: "Did you choose her or were they, was she

just assigned to you?" Nalda responded: "She was assigned to us. So far as the

agency that sent her." But there was a problem, according to Nalda: "She just wasn't a

real good cook, she didn't cook."

> Nalda worried about the longevity of caregivers:

> My mom is very aggressive and stuff and actually very abusive; that has always been the problem with the caregivers. In the past, she has alienated them and insulted them one too many times and they say, "I can't take this anymore."

One of the caregivers took a leave of absence from her caregiving duties with Nalda's

mother, and Nalda admitted that she was very depressed at the prospect that this

caregiver would not return.

> She took a week off and see if it would pass and she would get over her anger and stuff. She came back, I don't know; I was a little bit concerned that she wasn't going to come back; I was very depressed. That depressed me.

> Driver #4: *Reflecting.* Having freedom and time to reflect on caregiving

experiences and duties, even if in the middle of the course of caregiving responsibilities,

may affect the management/non-management cycle. Jovana and Nalda both talked

about a lack of freedom. For Nalda, "My time was not my own in that it was curtailed

and my freedom to come and go was curtailed." Jovana told the interviewer, "I felt so

trapped. I had to really pray to go over there. I just didn't want to go anymore. I just felt

I wasn't doing anything for myself."

Driver #5: *Receiving credit.* Receiving credit from loved ones for caregiving duties and decisions may affect the management/nonmanagement cycle. Jovana talked frequently about "credit" in the course of her interviews—receiving credit, not needing credit, and giving herself credit. Of the situation with her sister, Jovana said:

> They ignored it and then one day my sister sat there in the living room and she goes "Oh my god my mom needs help in the evenings" after a whole year she had heard about it for me. So then it was her idea that she set everybody up coming to help and I said fine. You know I don't need credit but that's just the way she is.

After her breakdown, Jovana said: "And now I can give myself the credit that I don't need it from anybody but God knows what I did. My mom knows what I did and I know my dad is thankful."

In ending the discussion of the model at this juncture, I do not intend that the conclusion of the discussion be seen as demonstrating the final stage of the process. In the data, even if the caregiver says no and ceases her caregiving duties, questions still remain as to whether she will be asked to do it again by others around her or determine that she must return to her caregiving duties. Further, as demonstrated by the data, the feedback loops between caregiver and sources will continue as long as the caregiver's decision to provide care stands. The looped quality of the model is directly informed by the antecedents of the process and by its drivers and tensions.

Conclusion

In Chapter 4 I sought to map two journeys simultaneously: my own through the data and the caregiver's through her process. I began by laying out my methodological considerations, three issues to be dealt with prior to analysis. These issues were the linear organization of the chapter, the problems of secondary analysis, and the use (nonuse, really) of qualitative analysis software. Following that consideration of method, I began to unfold the data's story. In unfolding the story, I tracked my own movement

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through Charmaz's (2000) suggestions for data analysis to the stages of the nascent

conceptual model of caregiving as they emerged. I used three moments in my analysis

process as landmarks to navigate through it. The first moment occurred when I was

coding according to Charmaz and noticed the feedback loops that the caregiver

experienced. The second moment was when I was performing constant comparison as

recommended by Charmaz and found the sources that the caregiver used. The third

moment was when I was refining my theoretical ideas, looking at the data more

conceptually, and noted the data's "movement" à la Charmaz.

The model moved through four stages, all marked by clusters of codes directly

from my initial and focused coding processes: *identifying the need, accepting the*

caregiver role, searching for help and managing care, and *experiencing drivers and*

tensions. Twinkling throughout the process were constellations of antecedents, sources,

and drivers/tensions. The antecedents informed the caregiver's journey from the stages

of *identifying the need* to *accepting the caregiver role* and touched subsequent stages as

well. The sources were present in the stages of *seeking help* and *managing sources.*

The drivers and tensions sustained caregivers' movement within the feedback loops of

sources and self. Or didn't.

The nascent conceptual model that emerged from the data began to illuminate

the caregiver's process of managing care. Although the data were not able to shed light

on all aspects of the caregiver's experience, much of what was available in the data

provided useful insight into the first steps of the journey toward better understanding the

caregiver's process.

Chapter 5

RECOUNTING THE STORY

Moving Forward

This project was situated in a current moment of deep and broad transformation within healthcare—a shift, as stated in Chapter 1, that is of a complex and intricate nature. With this shift comes a re-focusing. In a move away from a solely practitioner-based perspective, patient and family expectations and their accompanying localized narratives are taking center stage, replete with nuance and emergent unknowns.

The interpretation of these narratives is moved forward via two prevailing schools of thought: a patient-centric paradigm, born from a more traditional biomedical view of healthcare, and postmodern paradigm, a more revolutionary, de-constructed view of healthcare.

This shift is brought to life by those who sit within it—populations characterized by increasing ethnic/cultural diversity, acculturation, and biculturalism, and who continue to experience widespread health disparities. Health and healing for these populations is shaped by medical pluralism. Medical pluralism is the use of multiple health and healing systems that encompasses what the literature examining acculturation and biculturalism calls the host and birth cultures of these populations.

Researchers continue to strive for a better understanding of how these populations move across health and healing sources within their birth and host cultures. However, difficulty persists in pinpointing the intersections of what are thought to be myriad variables informing this movement. Little remains known about the complexities that inform diverse populations' interfacing with health and healing systems. The resulting conversation has been one that is static and linear, seeking to list and

categorize variables, predict phenomena, anticipate outcomes, and generalize across populations.

This project was fortunate to engage women who were experiencing this shift and its repercussions: female Mexican American caregivers. Insight was gleaned within the parameters of longitudinal intensive interviewing focused on each woman's experience caring for an elder in her family who was suffering from cognitive decline. Each caregiver's experience was brought to life via co-construction of data within the parameters of constructivist grounded theory, wherein we were privy to her experience of managing care for the elder and, in some instances, herself. From this co-construction of data came careful yet innovative methodological work, provocative findings, and the first stirrings of a conceptual model.

To explore this current moment, its dual realities, and their implications, this constructivist grounded theory project, with its parent framework of complexity science and sensitizing concepts born from that framework, purposefully eschewed the current scholarship's linearity and the anticipatory and predictive quality of accompanying models. This decision, of course, informed the analysis and thus the findings, which were able to describe caregivers' localized experiences rather than providing overarching generalizations. The findings' localized quality presented both opportunities and challenges regarding how they may be best used, excavated thoroughly below.

This chapter begins with a brief review of key findings and then situates them within the parameters of this project's specific aims, research questions, and literature reviewed in previous chapters. Following this, the findings' implications are explored, and I offer my resulting recommendations.

Key Findings

As I observed deep in the wilds of Chapter 2, "Caregiver choices cannot be explained adequately by something as linear as whether an individual has health insurance." The findings of this project affirm clearly this observation, although with additional requisite nuance. Through the lens of acculturation and biculturalism, these choices were the product of a constant redefinition and renegotiation of individuals' identity. At issue, then, throughout this project was the utility of predictive, static variables identified in the current literature on acculturation and biculturalism and caregiver experience. Of particular discomfort to this project was their linear manifestation—that the literature sought to ascertain and from which it attempted to generalize. The data sampled for this project demonstrated instead that the phenomena informing caregivers' processes of management of care for the elder were intricate, tangled, nonlinear, and only marginally predictable. In keeping with the constructivist methodology of this project, these phenomena were not conceived of as variables, a decision aligned with Charmaz's (2006) signaling of the perils of "reducing qualities of human experience to quantifiable variables" (p. 5). The phenomena were generalizable only within the data sampled for analysis, and further scholarship is tasked with determining whether they provide illumination, even peripherally, in other contexts.

These phenomena that informed caregiver processes were identified in the data in two ways: first, as antecedents, informed by cultural streams and described within the scholarship on acculturation and biculturalism; and second, as drivers and tensions of caregivers' processes of management that emerged directly from the data.

Additionally, the data showed that caregivers used multiple health and healing sources in caring for the elder, and that they managed these sources via specific strategies evidenced in the data that were unique to each type of source. These

strategies took their places as components of the management process of the caregiver vis-à-vis the health and healing sources. Caregivers moved from source to source, and these components were visible in caregiver interaction with those sources. A caregiver's pattern of management and the components of that management were informed by important factors in her immediate vicinity. These highly localized responses were the result of caregiver interaction with sources and sources' subsequent actions coupled with the antecedents and the drivers and tensions that lent context to those interactions within the environment where this all took place. The antecedents, drivers/tensions, sources, and components of the caregivers' process of management are explored in the following paragraphs in the context of this project's specific aims and research questions.

Present in the data as well were the first stirrings of a conceptual model that began to illuminate caregivers' experience of moving through the process of managing care for an elder. Caregivers passed through a four-stage process that was in constant dialogue with the environment around it. I have referred here and elsewhere to the model as representing an evolving picture of need—marked by an emergent role for the caregiver that took shape during the first stages of the process and the emergent behavior of the caregiver that characterized the second stages. The process played out as a reflection of the caregiver's dialogue with the environment around her and was comprised of four stages: *identifying the need, accepting the caregiver role, searching for help,* and *managing care.*

The first stage, *identifying the need,* was built upon a dialectic between caregiver and others. In this stage, it was determined that care was needed for the elder. If the need remained unidentified and no interaction or discussion took place, the rest of the process did not occur, reflecting the dialectical foundation of this first stage.
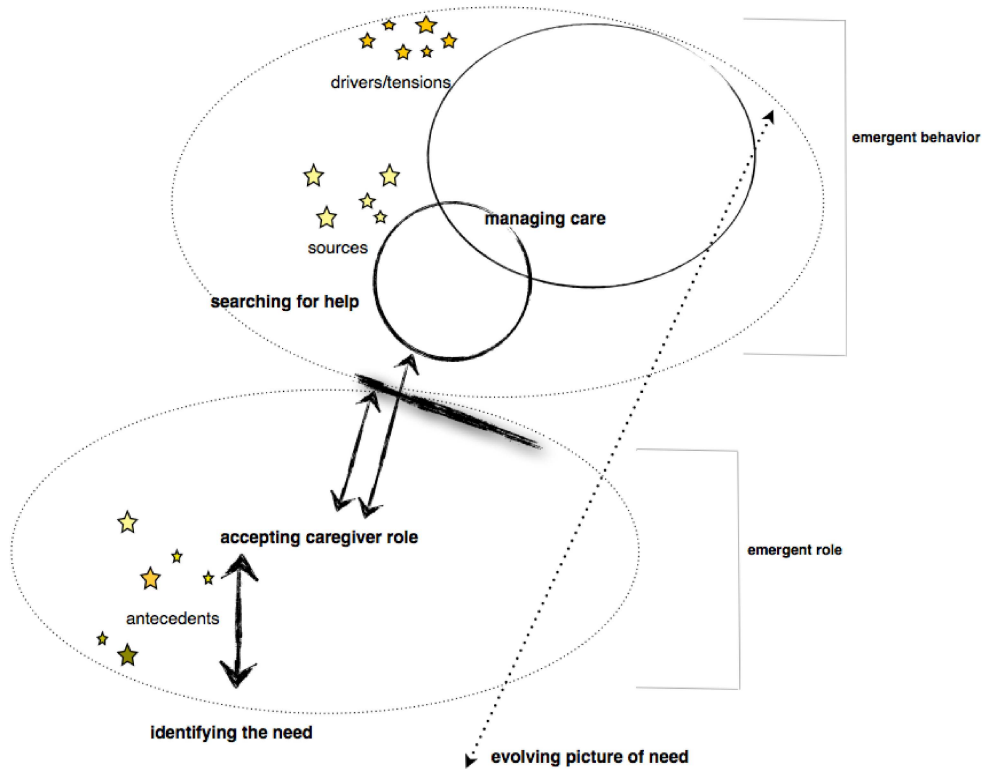
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Figure 16. Charting caregiver movement across health and healing sources.

The second stage was *accepting the caregiver role.* Here, an individual or a group of individuals accepted responsibility to care for the elder. In moving from the First Stage to the Second Stage, a constellation of antecedents was identified. In all cases in the data, antecedents were discussed explicitly by caregivers as informing caregivers' decisions to take on the caregiving role. I categorized them conceptually into: (a) cultural stream (grounded in the literature on acculturation/biculturalism), (b) self-identification, and (c) localized reality (caregiver-specific, unable to be used for generalization within-case or across cases). The three types overlapped and informed one another. For example, self-identification could have been the result of an expectation situated within a cultural stream. However, because the antecedents were discussed by caregivers explicitly within the data, I did not speculate about implicit

meanings. There might be a place for this speculation in future research, but it was outside the scope of this project. The antecedents informed why and whether the responsibility for caregiving was accepted. *Accepting the caregiver role* was most clearly understood in retrospect. The antecedents that informed caregiver choices at this second stage were visible only after the choice to accept the caregiving role was made.

The third stage was *searching for help*, which was bound in a feedback loop with Stage Four, *managing care*. Within these two stages I identified the types of sources that the caregiver used in her process of managing care, including family, network, biomedical, and traditional sources and the components of her actions within that process, discussed later.

The model also helped illuminate broader conceptual findings—those theoretical and methodological structures that informed the co-construction of data and its subsequent interpretation. These structures, constructivist grounded theory, secondary analysis, complexity science, and social justice, are explored within the sections on implications and recommendations.

Situating the findings: Specific aims and research questions. Two specific aims were identified by this project at its inception: first, to uncover the emergent patterns of caregivers as they managed care from multiple health and healing sources, and second, to use these patterns to inform the creation of systems that address caregivers' experiences and their difficulties. The aims of this project were in keeping with the current patient-centered care initiative regarding designing patient-centric systems that respond to consumer needs (Agency for Healthcare Research and Quality, 2010; Centers for Disease Control, 2011; Families USA, 2009; Institute of Medicine, 2001; National Priorities Partnership, 2010; National Quality Forum, 2008; Robert Wood

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Johnson Foundation, 2011) and aware of prevailing texts of power, culture, and forced categorization of modalities that remain embedded in these prevailing biomedical perspectives.

The research questions that guided this study sought insight into caregiver management of health and healing sources in caring for an elder with cognitive decline. The initial focus of this project was on caregiver management of health and healing *systems* in this capacity. Only after I had conducted Chapter 2's literature review did it become apparent that caregivers did not perceive health and healing as confined within internally cohesive, boundaried systems. Instead, caregivers and care-seekers alike participated in what Robelado and colleagues (1999) identified as a "Hispanic health subculture" wherein they selected from diverse and sometimes contradictory systems about which little was known (Lovell, 2009; Xu & Farrell, 2007).

As a result of this realization, the project's languaging shifted from *systems* to *sources* to approach caregivers' processes in a way that resonated with their actual experience as demonstrated by the literature. The focus then was on caregivers' patterns of management of different sources of health and healing, caregivers' major obstacles in managing these sources, and how a caregiver's interaction with the environment affected her and those around her.

These patterns of management were described in the literature as possibly changing from day to day, marked by iteration and reassembly that was in constant dialogue with the environment around the caregiver and/or care-seeker. The strength of this corpus of literature was that it stepped outside the prevailing notions of health and healing as situated within boundaried and internally consistent systems. It posited instead that there was value in seeing health and healing as those moving through the varied modalities do: as possessing a fluid character engaged in dialectic with the

environment around it, not bounded by an inherent system-ness. Acknowledging that the development of knowledge is often incremental, this conversation took courageous steps toward the birth of a new paradigm. This paradigm was one that placed centrality on seeing through the eyes of those navigating health and healing, whether they perceived them as situated within systems or otherwise. The fault with these discussions, however, was identified by a few lone voices in the scholarship whose thoughts were aligned with the constructivist nature of this project. Their contention was that these prevailing discussions remained situated within a biomedical paradigm and thus were colored by that paradigm's drive toward categorization and separation of beliefs and practices (Baldus, 1990; Clarke et al., 2003; Fabrega, 1977; Lock & Nguyen, 2010). Also colored by a need for categorization, although positioned within the discipline of anthropology, was the scholarship on medical pluralism and its similar quality of boundary creation to understand the use of multiple types of health and healing (Fabrega, 1977; Stoner, 1986). Scholars in this realm were not convinced that caregivers' realities were truly reflected in the scholarship (Fabrega, 1977; Stoner, 1986).

In an alternative area of the literature, populated by the lone voices mentioned, the reassembly of categories of health and healing described earlier were understood quite differently. This area of the literature described the iterative quality of this reassembly as *syncretic* (my emphasis) and existing outside the biomedical paradigms of the host culture. This typology was situated instead primarily in the birth culture and moved outward from the paradigm of the birth culture, carrying with it perceptions of health and healing. Belliard and Ramirez-Sanchez (2005) wrote of the reassembly as a *syncretic typology*. It was explored sparsely in the context of health and healing—delved into by Belliard and Ramirez-Sanchez (2005), mentioned briefly by Stoner (1986) and

Capra (2002), and thought by Menjívar (2002) to provide opportunities for future research.

The syncretic typology was not widely examined in the literature. However, syncretic typology proved helpful in answering this project's research questions. It provided the project with a conceptual position situated at the intersection of both paradigms discussed at the outset as informing the transformation of health and healing in the United States: patient-centrism and postmodernism. The syncretic typology reflected the unique needs of the caregiver and care recipient as they existed within the host culture's biomedical paradigm. Simultaneously, it asserted caregivers' and care-seekers' perceptions of these systems as nonsystems and their continued engagement in health and healing informed by both their birth culture and the host culture.

However, the data sampled for use in this project demonstrated that there was a caveat regarding the syncretic typology. The data show that caregivers' movement across health and healing sources was indeed as Robelado and colleagues (1999) had described it—combinations that were sometimes harmonious and other times discordant—and in dialogue with the environment. The syncretic typology seemed to lend language and support to caregivers' perceptions of sources as boundaryless and fluid, characterized by freedom to move across sources and the importance of seeing the systems (or lack thereof) as caregivers did. Nevertheless, what appeared in the data for this project that the scholarship exploring the syncretic typology had not identified previously was twofold. First, the literature on the syncretic typology had not explored caregivers' actual processes of managing sources. Other than its characterization by Belliard and Ramirez-Sanchez (2005) as encompassing contradiction, Capra (2002) as interconnected and informal, and Menjivar (2002) as "fluid and dynamic" (p. 458) the actual components of the caregivers' processes remained unidentified. Second, the

antecedents of caregivers' movement across sources, and the accompanying

drivers/tensions caregivers experienced that drove the process, remained unidentified.

These two gaps were addressed by this project's first two research questions, which

explored the caregiver's process and her obstacles.

It is important to remember here that in answering this project's research

questions via the findings of the study, the data are not intended to represent an entire

population or to achieve statistical generalizability. I am putting forth theoretical claims,

and seeking to answer the project's research question in a way that illuminates caregiver

processes. My priority is to provide enough information for readers to draw their own

conclusions.

First question: Patterns of managing sources. This project's first research

question sought insight into the caregiver's patterns of managing sources. As the

overarching processes of the caregiver were teased out of the data, the conceptual

model emerged from the data. As explained above, the model was comprised of four

stages replete with feedback loops that moved from *identifying the need* to the

caregiver's *accepting the caregiver* role, *searching for help,* and *managing the sources.*

These sources were family (other parent, siblings, children of siblings, fictive kin),

networks (friends, neighbors, and networks stemming from these individuals),

biomedical sources, and traditional sources. Sources emerged from the data in the

order in which caregivers turned to them, and this similar order was noted across cases

even within specific source categories. This order is in keeping with the older, seminal

accounts of Anotucci and Akiyama (1991), Brody (1981), Cantor (1979), Marks (1996),

and Shanas (1979). Although children were evidenced in this particular project, Himes

and Reidy (2000) did not note them as sources for caregiving.

The components of caregiver management according to source were also identified. In caregiver management of family sources, the components identified were *teaching, not forcing/not dwelling/not controlling, staying organized, making self available,* and *saying no*. These components charted the caregiver's patterns as she moved across sources. Caregivers' actions here were divided into the categories of managing through interaction and managing through noninteraction. *Teaching, staying organized*, and *making self available* were all components of managing through interaction, although each had its contrary cases. One caregiver referred to herself as "always on call," a sentiment echoed verbatim in the work of Levine (2004). Regarding *saying no*, many types of informal caregiving materials—including textbooks, handbooks, and websites—offered caregivers advice on how to say no or when to say no. But the research did not explore this advice formally. *Not forcing/not dwelling/not controlling* and *saying no* were manifested in the data as management through noninteraction. Similar to the findings of Munck, Fridlund, and Mårtensson (2008), a lesson that caregivers frequently reported learning was that they were unable to control everyone around them and had to let go of control in order to be effective caregivers and to retain their own health and well-being.

The components of caregivers' interactions with network sources were *choosing* and *reconnecting/disconnecting.* As mentioned in Chapter 4, there was a text of power in caregiver choices regarding friendships. Caregivers reported deciding when to spend time with friends and when not to. In the confines of the interviews, friends were discussed in terms of being both allies in the caregiving process and depended upon for support, in keeping with the findings of Armstrong and Goldsteen (1990), Roberto (1996), and Roberto and Scott (1984). Friends were also discussed in the interviews as

individuals who drained the caregiver and resulted in added burden to the caregivers' already burdensome caregiving experience.

The components of caregivers' interactions with biomedical sources were *navigating* and *regurgitating*. The data sampled for analysis demonstrated that caregivers spent much of their time interfacing with biomedical sources but not with specific individuals. Only one interaction with a biomedical practitioner was reported. Caregivers expressed a lack of knowledge about what was available and frustration at the tangled nature of policy and services that they were required to quickly grasp upon *accepting the caregiver role* (as reflected in Stage Two of the model). These findings are in keeping with the findings of Heinrich, Newfeld, and Harrison (2003) and of Toseland, McCallion, Smith, and Banks (2007), who reported that informal caregivers experience increased burden in navigating primary care and caregiving services. Informal caregivers who were provided with counseling on how to work within these systems reported less stress. Foster, Brown, Phillips, and Carlson (2005) showed that when care recipients were given the ability to take some control over the in-home services they were provided, the burden of informal caregivers was also reduced. This finding is reflected in care recipients' comments as recounted by the caregivers—that care recipients also wanted to make decisions about their care—for example deciding on appropriate medications and when to take a bath.

The components of caregivers' interactions with traditional sources were *navigating* and *deciding*. Like the biomedical source category, traditional sources were marked by a component of *navigating*. Whereas the caregiver had to address prevailing host culture systems and policy in biomedicine, within the traditional category, she had to address that which informed health and healing within her birth culture. Coupled with her navigation of her birth culture's expectations regarding health and healing is the

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component of *deciding*. The caregiver had to decide, according to what proved to be shifting perceptions—both on her part and on that of the care recipient—what was valued and useful, a reality for the caregiver that was mentioned at the outset of this project, far back in Chapter 1.

The components of caregivers' use of self-as-source were *taking it one day at a time, praying,* and *becoming comfortable*. Caregivers often returned to themselves when they felt that they were unable to depend on those around them, a finding echoed by Munck et al. (2008). In this respect, caregivers spoke often of not looking too far into the future and of relying on their spirituality. Regarding caregivers' reliance on spirituality, 84% of African American caregivers and 79% of Hispanic caregivers identified prayer as a way to cope with caregiving duties, as opposed to 71% of White caregivers and 50% of Asian American caregivers (National Alliance for Caregiving & American Association of Retired Persons, 2004). Also important to caregivers was accepting the reality both of their parents' cognitive decline and of their reaction to that deterioration—*becoming comfortable* on both levels. This component, *becoming comfortable,* is in keeping with the findings of Sawatzky and Fowler-Kerry (2003), who identified adapting and coping with the reality of caregiving and the deterioration of the elder's condition as one of three dominant themes in the caregiving experience.

Although throughout the project I consecutively numbered the stages of this model, it should not be assumed that it contains an end point. Even in the case of a caregiver's refusing to continue providing care, feedback loops continued. Nor was there an specific outcome expressed by caregivers in the data.

The key findings of this project orbit around one fundamental insight: Caregiver processes of managing care are complicated and nuanced; replete with texts of power, culture, gender, the Other; and informed by prevailing assumptions in both the birth and

host cultures. Widespread support of variable-based inquiry and perception of the caregiver's experiences as linear and wholly predictable missed much of what this project found to be the nuance and intricacy of her experience. It was, according to the findings of this project, within the nuance and intricacy that the process was actually situated.

The first steps taken in the literature to see care as the caregiver did, via the syncretic typology, marked a paradigm shift. Building on this foundational insight, this project scaffolded further out from those first steps toward a subsequent shift—one that sought to move away from the biomedical paradigm that infused that scholarship and toward something, in keeping with the philosophical underpinnings of this project, more emergent and deconstructed. Grounded within this conversation and the data sampled for analysis, this project identified constellations of phenomena that informed the caregiver's process. These phenomena were clustered into antecedents that informed the first stages of the caregiver's process and into drivers and tensions that perpetuated and/or hindered its later stages. The health and healing sources with which the caregiver interacted were also identified, accompanied by components that comprised her strategies in interacting with them.

These findings begin to illuminate the path forward for future researchers who seek to better understand the caregiver's process in *her* terms. Coupled with the requisite exploration of researcher positioning that is a fundamental part of constructivist methodology, analysis based on what *she* experiences and *her* sense of how to move through the process of managing care may be put forth. *Her* process in *her* terms takes us the first steps toward truly patient-centric care, or in this case patient- and caregiver-centric care that sees systems (or lack thereof) the caregiver does and can respond to her articulated needs.

Second question: Obstacles to caregiver management. The project's second

research question focused on obstacles to caregivers' management. Similar to what

occurred in Chapter 3 following the insight gleaned from Chapter 2's literature review, at

this juncture in Chapter 5 this second research question required some additional

broadening to reflect what was found in the data. With an eye to identifying obstacles

regarding the research question, what I drew from the data was more than simply

obstacles. Instead, what I found were phenomena that informed, helped, *and* hindered

the caregivers' movement across and interaction with sources. These obstacles, in

addition to that which informed and perpetuated the process, were identified as a

constellation of antecedents and a constellation of drivers/tensions.

The antecedents informed whether and how a caregiver chose to take on the

caregiving role. These antecedents were cultural streams (birth and host), self-

identification, and localized reality. The birth culture stream contained within it numerous

cultural expectations about who would provide caregiving to the elder and why. In a

metasynthesis of cultural perceptions of the onset and diagnosis of cognitive decline,

Latino caregivers reported worrying about increased acculturation (Mahoney,

Cloutterbuck, Neary, & Zhan, 2005). In particular, caregivers were concerned that

increased acculturation into the host culture would somehow result in less family home

care (Mahoney et al., 2005). The host culture stream relied on prevailing mainstream

cultural expectations and norms. Host and birth culture streams informed one another, in

keeping with the findings of Padilla and Villalobos (2007) and Mahoney et al. (2005).

Padilla and Villalobos (2007) identified patterns within the Mexican American female

caregiving population regarding cultural expectations: They can function

complementarily, add more tension/stress, and become less important when interfacing

with the mainstream (in the context of this project, identified as the host culture)

healthcare system. Caregivers could self-identify and noted a need when others in the family did not. O'Connor (2007) found that caregivers' self-identification occurred in interaction with others and without external influence, referred to previously by this project as self-organization, since no prime mover was present. O'Connor understood self-identification as being situated within a process of "positioning" (2007, p. 168) and described self-identification as empowering but also as running the risk of marginalizing the care recipient. Although O'Connor's insight has proved valuable to a discussion of this project's findings, in keeping with the philosophical underpinnings set forth in this project thus far, it is important to mention that empowerment is in itself a text of power. I also suggest that there are other patterns found in the caregiver data beyond those that O'Connor identified, such as texts of power, texts of culture and gender expectations, and the interfacing of these texts. Arredondo (2002) and Gil and Vasquez (1996) provided frameworks for thinking about these texts in Chapter 4, including the cultural construct of *marianismo.* A few examples follow that illustrate my assertion regarding texts. One caregiver described her caregiving duties and in particular the experience of bathing her father. She reported that no one in her family except she was able to do it successfully. She did not mention teaching them her way of doing it—why did she not teach them? Was it a sense of "owning" the information? Of having a relationship with her father that others were unable to? She referred later in her interview to being able to "nurture" her father, which she was unable to do with her mother present because it made her mother "uncomfortable." Are there gendered disputes here? Mother versus daughter? Sexuality- or sensuality-related texts? The vestiges of incest? In another example, one caregiver was selected by her family because she spoke English and had U.S. citizenship. What texts are at play here? Caregiver as mainstreamed Other performing the job of caregiving as built of texts of playing by host culture rules? Texts

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of race? Another caregiver was chosen for reasons situated within her birth culture—

she was unmarried and female. Gender texts and cultural expectations might have been

at work in that instance. It is important to point these texts out. Current research is not

consistently effective in alerting us to the binary oppositions, presuppositions, and

metanarratives that serve to underpin our reality. In order to understand the caregiver's

experience, we must ask these questions of the data: What mechanisms are at work

here? What oppressions, freedoms, expectations, and structures inform caregivers'

realities?

Piercy and Chapman (2001) found that expectations and family rules informed

these patterns in keeping with my assertion, and their work added religious training, role

modeling, and role making to this list. Decisions about caregiving could also be made

through a localized reality that was individual or family-dependent, generalizable in no

other context than the participant's/participants' experience. These antecedents were

also in dialogue with one another, responded to environmental cues, and were in

feedback-looped relationships of their own.

As for the drivers and tensions, these freedoms and their accompanying

restrictions were central to what kept the process in motion. As explained in Chapter 4,

within the data were these phenomena that left "tracks": echoes within the data about

interactions and environmental cues that directly drove and limited caregivers'

processes. These took their places in the conceptual model as drivers and tensions,

those phenomena that had occurred in the course of caregiver interactions and that kept

the caregiving process moving or hindered it. I identified five drivers/tensions that

emerged as codes from initial and focused coding during analysis. These drivers were:

relying on a parent, relying on a family schedule, culture-specific caring, reflecting, and

receiving credit.

Whether a caregiver had a healthy parent and could rely on him or her to help with the caregiving responsibilities served as a driver/tension in the data. *Relying on a parent* was not explored in the literature in terms of how it informed the caregiver's experience. However, in this project, the data demonstrate that inconsistence in the healthy parent's availability to help with caregiving also affected the choices a caregiver made about care.

Within the driver/tension *relying on a family schedule* were numerous interactions, such as the cooperation or noncooperation of siblings, their children, and in some cases sources such as friends who also shared in the responsibility. Siblings were the least dependent source, as demonstrated by the data. Willyard, Miller, Shoemaker, and Addison (2008) outlined three ways in which caregivers made sense of siblings' participation or lack thereof that reflected the findings of this project. First, a caregiver thought herself especially suited to the caregiving responsibility and if a caregiver perceived siblings as nonparticipative, she often used herself as a source. Second, caregivers understood caregiving as part of *familismo* and justified siblings' nonparticipation by seeing them as outside the family. Third, caregivers who remained unable to make sense of siblings' behavior made excuses or changed their stories to justify siblings' nonparticipation.

The driver/tension of *culture-specific caring* spoke to caregivers' comments about being provided with hired caregivers from this or that agency and about these hired caregivers' lack of knowledge regarding what caring for a Mexican elder entailed. In the context of nursing home care, Abrahamson, Pillemer, Sechrist, and Suitor (2011) examined how race influenced conflict between staff and family caregivers and stressed the importance of the family's communication of expectation. In the context of the data within this project, informal caregivers repeatedly identified hired caregivers' inability "to

cook." The data demonstrated that this statement may have suggested a synecdoche of sorts--referring to the larger import of cultural knowledge and communication as an expectation of hired caregivers and to what informs informal caregivers' use of these formal services. In conducting focus groups comprised of diverse caregivers caring for an elder with cognitive decline, Sharlach et al. (2006) identified as among the major themes caregivers' mistrust of formal service providers and the unavailability of culturally appropriate services.

The driver/tension of *reflecting* repeatedly appeared in the interviews as caregivers referred to the importance of being able or not able to take a moment away from caregiving. This "taking a moment away" is often understood in the caregiving literature as *respite,* and caregivers in this project used this term also, sometimes knowing what it meant and in other instances not. Caregivers spoke of thinking about their needs, their realities, and the caregiving experience and of how the ability or inability to take a break and re-energize affected their process and the choices they made regarding care. This finding echoes the work of Borrayo, Goldwaser, Vacha-Haase, and Hepburn (2007) in the context of use of respite care. Borrayo and colleagues asserted that culturally tailored interventions for female Mexican American caregivers should take into account *marianismo* and its cultural texts of self-sacrifice and nurturing and should encourage caregivers to take time away from providing care to avoid experiencing adverse outcomes (2007). According to Strang and Haughey (1998) in their exploration of respite, caregivers referred to respite as "getting out of the caregiving world and 'into their own world'" (p. 236). Strang and Haughey also identified five factors that influence caregivers' use of respite: the nature of their relationship to the care recipient prior to the onset of illness, the relationship between the caregiver and her dependents, expectations of roles, respite services available, and time.

Although the literature does not widely explore it, *receiving credit* appeared in the data frequently as a driver/tension. Caregivers with healthy parents reported seeking credit, recognition, appreciation, and thanks from those parents, in addition to seeking credit from the ill parent. In one instance the caregiver reported that her father, suffering from cognitive decline, had held her hand and nodded to her in a moment of clarity, which she took as his assent to her assertion that she needed time away from caregiving. In another instance, a caregiver commented that she would not receive credit from her mother who was suffering from cognitive decline: "and no 'thank-you' [for the care I provide], you can't argue with a crazy person." Other caregivers were unable to receive the credit they sought since the cognitive decline affected parents' ability to recognize their efforts. Spirituality also played a role in seeking credit, and caregivers referred to a higher power as knowing what they had done and recognizing their efforts.

Although it is possible that there are drivers and tensions to be found elsewhere throughout the process, drivers and tensions identified from the data sampled for this project appeared most often within the caregiver's interaction with her family. Only one driver/tension, *culture-specific caring,* appeared outside the context of family—in this case, it was situated simultaneously within the rest of the types of sources the caregiver usd—network, traditional, and biomedical sources.

Third question: Caregiver interaction with the environment and vice-versa. This project's third research question explored interaction. In particular, it sought to tease out the intricacies of caregiver-source-environment interaction. I began to answer this question at the end of the analysis in Chapter 4 after identifying sources and components of behavior, antecedents, and drivers/tensions. Only after identifying those phenomena could I begin to look at their intersection with one another. These intersections manifested in the data as dyadic source overlaps that played out in the

environment, situated within feedback loops that also included the caregiver. Via the constructivist strategy of memoing, I was able to ask questions of the data in these overlaps about the caregiver and the environment. Memoing proved useful for charting my conversation with the data inside the confines of the third research question. Next I offer the implications of this exercise.

Implications

As demonstrated in the review of findings above, caregivers' processes of managing care for an elder and the obstacles shaping that process are far more diverse and complicated than was previously uncovered in the literature.

This project was, in keeping with Charmaz's (2006) description, "a small study with modest claims" (p. 114). Thirty-six interviews with six caregivers over time provided me with a specific slice of reality and experience within the female Mexican American caregiving population managing care for an elder. Although certainly appropriate for the exacting scope of my research question, my project and these six caregivers provided a perspective on processes of care selection that do, however, have larger implications.

First, this project found that the variable-focused approach, which underpins the ways in which current literature seeks to better understand why caregivers make the choice they do, may be inadequate. Variables such as time spent in the host country, income, education, language ability, and insurance, although seemingly very transparent factors, have been shown in the literature to both demonstrate and nullify the prevailing hypotheses that describe caregiver choices. Put simply, they illustrate a spectrum of findings that, as demonstrated by the literature, continue to contradict one another.

The anticipatory and predictive models that rely on these variables provide sparse insight for those who come face-to-face with the actual realities of caregivers. Interestingly, the same corpus of literature dealing with acculturation, biculturalism, and

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medical pluralism that seeks to list variables is also, as identified by this project, the corpus that provides the most opportunity for further development of new approaches to understanding caregiver realities. Reviewed in Chapter 2, this scholarship revealed a fluid quality of caregiver management of sources that incorporated the conjunctions and disjunctions of cultural streams, personal preference, and localized responses to situations that were in dialectic with the caregiver's immediate surroundings.

In examining this permeable, feedback-looped process, this project conceived of what was found in the data as being phenomena, not variables. Because this was a constructivist grounded theory study, generalization was not possible across populations, and therefore the specific phenomena identified in this project were not to be seen as occurring universally (although they may have done so in some cases). However, conceiving of data as phenomena alerts researchers to that which was contained within each singular phenomenon: clusters of occurrences and experiences that were not distilled into a singularity. Phenomena are messy, intricate, and tangled, both within themselves and in relationship to one another. Phenomena, via the structures built into Chapter 4's analysis—antecedents, drivers/tensions—were able to be understood in terms of one another, as constellations comprised of myriad phenomena that took their places at the outset of processes or served as those mechanisms that perpetuated and/or hindered the process.

In keeping with constructivist grounded theory methodology, data-as-phenomena also broadened the insights available into this population. Phenomena were not assumed to manifest in a way that was universal to all caregivers. For example, in a variable-based approach, speaking English (or not) means the same thing across all caregivers—one either speaks all or part of the language or does not. Education, time in the country, and other variables may dictate the caregivers' command of English. In this

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project's phenomena-based approach, take the example of the birth culture antecedent that informed caregivers' *accepting the caregiver role:* Although identified as a type of antecedent, it played out differently across caregivers. The antecedent contained a cluster of phenomena within it and was writ larger as one of a constellation of antecedents that were identified. Speaking English was only one component of this cluster of phenomena that comprised that antecedent and that manifested in other antecedents. Phenomena identified in one antecedent were marked by intersection with other antecedents. These phenomena that made up the antecedents were drawn directly from the data and reflected the characteristics of the experience of caregivers sampled for analysis—fluid, permeable, and complicated.

Although these phenomena may not be generalizable across large swaths of caregiving populations, this project's findings demonstrate the project's attempt to shift the paradigm of research focused on these populations toward phenomena-based findings rather than variables. Although phenomena may be localized to a population, the constellation of antecedents and drivers/tensions that these phenomena comprise may be more universal. The manner in which these phenomena were uncovered in the data may inform efforts that seek to replicate identification of unique and applicable phenomena informing other populations' processes of management. This project pushed the boundaries of prevalent perceptions of data as transparent variables and questioned the utility of that prevalent thinking. It provided fodder for postulation about what can be expected of new perceptions, such as phenomena-based approaches. In moving away from a variable-based approach, it planted the seed for theory generation and methodology creation that is phenomena focused and conceived of as populating constellations of antecedents, drivers, and tensions.

Focusing on phenomena presents new opportunities for constructivist grounded theory generation in this area of inquiry. Conceptually, a focus on phenomena rather than on categorizing data according extant variables is an impetus to continue peeling back the layers of what lies over the data and would otherwise impede its closest, or most "grounded," examination. Methodologically speaking, a phenomena-based approach lends credibility and validity to research that does not seek to generalize across populations, an important asset both in stand-alone constructivist grounded theory research and in the context of mixed-methods work. This focus on phenomena may serve to further the science that seeks to study these populations and the intricacies of their interactions in a nongeneralizable, data-grounded way. This hope is discussed in the "Recommendations" section of this chapter.

Second, this project and its findings affirmed the utility of constructivist grounded theory and secondary analysis in expanding the science. These methodologies not only proved complementary to one another, but, I believe, also served to bolster and validate each other, strengthening the design of the study and the analysis—and thus the findings.

I will admit: I was initially unsure of how to go about studying emergent phenomena such as those of this project. Certainly, the project required a methodology that would allow for dynamic interaction, fluidity, permeable boundaries, and nonlinearity, all of which by nature accompany emergent phenomena. Nevertheless, at the outset of the project, I struggled with how to reconcile what I perceived as the prevailing static rigor of other methodologies and the fluid analysis process of constructivist grounded theory. I was troubled particularly by what Charmaz (2000) asserted: "Grounded theory methods specify analytic strategies, not data collection methods" (p. 514). As I moved into co-construction, I began to realize that tools such as constant comparison and

cultivating theoretical sensitivity brought not only rigor to the constructivist methodology but also an ability to successfully transpose this rigor to whatever the shifting state of inquiry was at that moment as the data emerged. This capability proved central to the success of this project. Charmaz, echoing my experience, stated: "We shape the data collection and redirect our analyses as new issues emerge" (pp. 522-523).

Impossible to overlook is the fact that the scope of the research question was changed halfway through this project in response to a literature review and my toe-dip into the data. During the analysis, I allowed the languaging of the overarching (re-written) question and subquestions to remain the same but asked new, more specific questions via the constructivist tool of memoing to excavate the data more effectively and authentically in response to what I saw in the data.

As Schreiber (2001) wrote of grounded theory: "What is key in this process is learning the ways that people understand and deal with what has happened to them through time and in changing circumstances" (p. 57). Just as participants' circumstances change over time, so must the methodology and the questions we ask of the data be flexible. Methodology and questions should honor and explore the changing circumstances of analysis in ways that are most effective depending on what emerges from the data. This is "the interactive nature of both data collection and analysis" (Charmaz, 2000, p. 522). Grounded theory possesses a flexible quality that permits researchers to "modify their emerging or established analyses as conditions change or further data are gathered" (Charmaz, 2000, p. 511). This flexibility proved to be a very useful conceptual tool as I sought to identify caregivers' emergent processes and then responded to that which arose in the context of those processes. As healthcare researchers seek to better understand the localized narratives of patients and families, with all their unknowns and their nuance, a research methodology is required that allows

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those stories to be heard in all their iterations; constructivist grounded theory proved a staunch ally in my own foray into this area of inquiry.

Chapter 3 provided me with the opportunity to explore the situation in which I found myself regarding secondary analysis. I initially assumed the existence of a blueprint of sorts that sat out in the ether of scholarship that would guide me through how to "do" secondary analysis within a qualitative context. Unfortunately, or rather fortunately, it did not exist. In fact, what I found instead was scholars' lament: Rare is the qualitative secondary analysis that "names" itself regarding its research methodology, and rarer still the study that deeply excavates that methodology. Most often in qualitative secondary analyses, the explanation of methodology goes only so far as to call itself simply "a qualitative secondary analysis." In the case of this project, I took great pains to both specify and explore my chosen methodology, constructivist grounded theory, vis-à-vis secondary analysis. In a description that is a mouthful each time it's mentioned throughout this dissertation, this project was a constructivist grounded theory secondary analysis of de-identified data.

I noted earlier that fortunately this elusive blueprint did not exist, because I was given the opportunity, in the context of this project, to do something that not many others have done: thoroughly excavate a specific methodology, constructivist grounded theory, in the context of a secondary analysis. Constructivist grounded theory requires that its methodologists walk through their own perspectives and preconceptions and lay them bare for the reader. This task is not an easy one. Secondary analysis requires a tight tether from the primary study to the second. This task too is not easy. Both tasks require a frank transparency, reflexivity, and theoretical sensitivity, and a certain sense of what is realistically able to be accomplished within the confines of a study. This work, from my experience, makes the study stronger.

Constructivist grounded theory permitted me to recognize and explore how I co-created the data analysis with my participants. In any other type of qualitative secondary analysis, this co-creation would not have been explored. I suggest that in a secondary analysis, the importance of recognizing and dissecting this co-creation is very important—particularly if the participants are not present, as they are obviously not in secondary analysis. Recognizing and dissecting co-creation is important because, lacking the feedback and interaction with participants upon which it is more comfortable and secure to lean, a secondary analysis relies more heavily on the researcher's ability to hear what amounts to the echoes of participants' voices—and to make analytic decisions that reflect what is heard not as "an objectified product," but as "a construction" (Charmaz, 2000, p. 528). Constructivist grounded theory permitted me the space and the framework to engage in what I believe is a richer secondary analysis than one that is simply "qualitative."

Third, this project identified a space in the caregiver process that was, as I wrote of it in Chapter 4, inadequately illuminated. It was to this space that the caregiver returned when she perceived herself as not managing care effectively. It existed at the place in the conceptual model after *accepting the caregiver role* where the caregiver's emergent role began to shift toward the emergent behavior required in the subsequent stages *seeking help* and *managing sources.* Clustered in this space were codes that appeared in-vivo across caregivers: *feeling conflicted, trapped, angry, guilty, and depressed.* The identification of this space in the process prompts further examination into what occurs in that space. Insight into what occurs here may inform the creation of data-driven caregiver support models that address the difficulty caregivers experienced at this point in their process, possibly alleviating some of the stress and burden they reported in their caregiving responsibilities at this point in the model.

Finally, in keeping with the project's research questions, the first steps toward examining the interactions and intersections between sources and caregiver and environment were taken. From this exercise, I began to understand sources' overlaps as dyads that manifested in the data in the context of caregiver action and environmental cues. I undertook this task to the best of my ability with the tools I had available to me. I employed the constructivist strategy of memoing to monitor and report my conversation with the data. I am confident that I took the data sampled for analysis as far as they could go in this respect, but I am hopeful that these first steps will prompt the development of other ways of looking at interactions that could bolster future findings and provide further insight into this area of research. Methodological tools that answer the complexities of caregiver-source-environment interaction and their reverberations via crisp and clear explanation, while retaining the fluidity of the process, would serve future projects well. Also helpful would be a memoing strategy to accompany these tools, particularly in a constructivist paradigm, to illustrate co-construction of data and questions asked in analysis.

Implications and Recommendations for Nursing and Healthcare Innovation

This project's findings, characterized by emergent, localized experiences and a balance between prevailing perspectives and an eschewing of those perspectives, have specific implications for scientists, scholars, and policy makers situated within the disciplines of nursing and health innovation. In its 2011 landmark report, *The Future of Nursing*, the Institute of Medicine (IOM) identified the centrality of nurses and the discipline of nursing in both its research and practice contexts to healthcare improvement. Healthcare innovation has been identified as an area of inquiry that looks at "the introduction of a new concept, idea, service, process, or product aimed at improving treatment, diagnosis, education, outreach, prevention, and research and with

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the long term goals of improving quality safety outcomes efficiency and costs"
(Omachonu & Einspruch, 2010, p. 5). These two disciplines are ideally positioned to
lead change in collaborative care models and system design for diverse populations of
caregivers and care-seekers like those studied in this project, for two reasons: first,
because of the priority they place on the Triple Aim of the Institute for Healthcare
Improvement (Bisognano & Kenny, 2012) of reduced cost and increased quality and
safety, and second, because of what the literature demonstrates to be their commitment
to evidence-based practice and patient-centered care (Burman, Robinson, & Heart,
2013; Omachonu & Einspruch, 2010; Quill & Holloway, 2012).

To this end, nursing and healthcare innovation are focused in tandem on
preparing practitioners and creating systems that reflect the fluid quality of patients'
unique needs and that are able to respond to what is occurring within this moment of
healthcare's deep and broad shift. This project illuminated the centrality of this tandem
focus to effectively addressing health disparities, honoring patient needs and values, and
examining the co-construction that occurs between provider and consumer in all
interactions within the health and healing space.

Implications for nursing and health innovation are most acutely felt within the
actual content of caregiver conversations in the data. I present these implications in the
context of how they may inform creation of more effective systems containing skilled
practitioners who are able to accommodate the admixture of the two paradigms that
have followed us through this project and to listen to the voice of the caregiver as she
reflects upon her needs.

The first implication is what appeared in the data as caregivers' articulation of
what they needed regarding caring for elders and caring for themselves. This
information was coded in the data as *needing to talk, needing to know,* and *needing to*

rest. The importance of acknowledging and understanding these needs is directly reflected in nursing's unique focus on the intersection between evidence-based practice and patient-centered care, and the discipline's leadership in moving forward in accomplishing the Triple Aim. Healthcare innovation, then, may be instrumental in implementing the research- and practice-based findings of nursing in the education of practitioners and the design of new systems that reflect this insight.

Two conversations. The process of analysis illuminated two important conversations taking place in the data, a phenomenon I think might be more widespread in research similar to that undertaken for this project than one would imagine, and requires what I have deemed a "localized response."

The first conversation is that which was examined using the constructivist grounded theory methodology I chose. This conversation was one with a high degree of co-construction. I read the interviews in a variety of ways, slicing, dicing, and re-envisioning them over and over again; I coded them, collapsed the codes, analyzed them in terms of the data, and then re-constituted the data in a way that I felt honored the participants and remained true to the methodological considerations I had previously delineated.

The second conversation, however, while still co-constructed to some extent (even my reading the transcribed interview and thinking about it constituted co-construction, in my mind), was built from sections of the interviews lifted from the data "whole cloth." This second conversation, although in a more raw form, spoke as clearly about this population of caregivers and their experience as the extensive coding and analysis process I engaged in as part of my methodology. I believe that this second conversation is one that may be missed in some qualitative research due to the methodology's focus on coding and pulling the data up to increasingly conceptual levels

to tease out a grounded theory or model. Regardless, this second conversation is very important for re-envisioning healthcare via nursing and health innovation. What I discuss in the following paragraphs and what we choose to do with it amounts to what I've decided to call a "localized response." What the caregivers told us requires an intervention that reflects what they want: not system-wide reconstruction, but specific changes that can be injected into existing pieces of multiple systems in a localized way. I explore these changes in the following paragraphs.

This second conversation is still connected to this project in that it does address one of the subquestions of my overarching research question. That subquestion asked about caregivers' obstacles in seeking out and selecting care from these multiple sources and resources the project identified. But the second conversation also provides straightforward suggestions to scholars and scientists within nursing and healthcare innovation concerning how caregivers would re-envision the system if given the chance. It was their insight into this topic that I was searching for all along—but initially I thought that insight could be gleaned only from a constructivist process of coding and re-assembling. Instead, the caregivers told me exactly what I wanted to know loud and clear—coding notwithstanding. The clarity of caregivers' thoughts as presented in interviews like those analyzed in this project could be invaluable to nursing and health innovation as members of the two disciplines work to educate practitioners and design systems that respond directly to patient needs.

Caregivers mentioned three things during the interviews, in some cases outside the confines of the interview questions. As I mentioned previously, the process of coding may sometimes contribute to researchers missing material that is more explicit in the data. With this possibility in mind, I still used a coding process, but I used these codes to alert me to caregivers' actual suggestions—straddling both an implicit view of

the data (codes) and an explicit view of the data. I coded caregivers' suggestions as "*needing to_____",* needs that could be translated into the nascent pieces of a new patient- and caregiver-centric system. In presenting these codes I am mindful of the meaning that co-construction maps onto data, and although I avoided this to the greatest degree possible in exploring caregiver needs, for purposes of clarity I labeled these needs as *needing to talk*, *needing to know*, and *needing to rest*. The three needs identified by this project are somewhat similar to caregiver needs identified by Rosenberg, Jullamate, and Azaredo (2009) in their examination of informal caregiving in a cross-cultural context: information, assistance, and support. Interestingly, it is possible then that what I identified in the data is not culture-bound within Mexican- American populations. I explain each need in the following sections and, corollary to these, offer my suggestions for nursing and health innovation in re-envisioning the healthcare system according to caregivers' comments.

    Needing to talk. There were instances in the data in which a caregiver expressed her gratitude to the interviewer for simply listening to her telling her story. Even though the caregiver and interviewer interaction was part of a research study and the interviewer was not a licensed therapist, the positive response to the interviewer's ability to listen manifested in the data repeatedly. "This study was a lifesaver for me. It was. . . . I know it's your job but still." The time spent with the interviewer was even referred to as "therapeutic": "Thank you very much because in the times that you've come it has been very therapeutic for me." One caregiver noticed that she was better able to move through the caregiving process after speaking with the interviewer:

> The lady that recommended this study—I told her—I said, 'You know what I can't
> tell you how much better in control I feel after she's [the interviewer] gone. She
> just listens. There was no one to just listen. There isn't anybody, so.

"There isn't anybody": this is an important comment and one that could inform the creation of a new, more patient- and caregiver-centric system.

Regarding *Needing to talk,* perhaps the first localized intervention could include access to individuals with whom the caregiver could simply talk—a space where the caregiver could get some of what she is experiencing out of her own sphere and into dialogue with another individual. From the caregivers' comments, it did not seem that what they were looking for was someone to solve their problems. On the contrary, it seemed more that they were looking for someone to be there to listen.

Attree (2001) and Thorsteinsson (2002) identified patient-centered communication as central to nursing in that it fosters positive relationships between patient and nurse, opens the dialogue for discussing patient needs, and results in quality care. In the context of this project, that communication, articulated by caregivers as *needing to talk,* would occur in the interaction between nurse and caregiver and would be able to address both care recipient needs and caregiver needs. There could exist as well an opportunity to introduce an individual trained to help these caregivers solve their problems, but at this point that strategy isn't supported by the data. In fact, one caregiver mentioned that she felt better after having talked to the interviewer and felt more control over her situation—so perhaps merely listening does help the caregiver to regain and maintain control. Shipley (2010) identified listening as central to nursing, and Davidhizar (2004) demonstrated that listening is a tool nurses can employ to transcend cultural differences. Davidhizar's assertion is particularly appropriate for the findings from this project, which illuminate the diverse needs of diverse populations. Healthcare innovation may be able to further inquire into extant systems and models[32] to determine

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[32] One extant model that could be mirrored would be the *promotora* model (see Elder, Ayala, Parra-Medina, and Talavera (2009) and Rhodes et al. (2007)). However, in keeping with the findings of this particular project as well as my stance as a researcher, an interventionist

where nursing's skillset and insight could be best applied in this context of *needing to talk.*

Needing to know. Outside the confines of the specific interview questions, one caregiver explained to the interviewer what she thought was "missing for caregivers." Her comments are redolent with ideas and suggestions for re-envisioning healthcare systems according to caregiver needs:

> I think what we're missing as caregivers is that when they discharge the person that you're gonna give the care to, you're on your own. They put 'em in the car and "See you." They don't do any kind of counseling before you take home your loved one to care for them. How much better it would have been if somebody would have sat with me and said, "This is what you need to expect. This is what you look for. This is how you're gonna feel. This is how they must feel." It was all hit and miss. It's taken me a year to learn and to be more comfortable with it. And to be more comfortable with her and for her to be more comfortable. They don't know how to express themselves, especially when they have dementia. They have no idea. Every once in a while she has a lucid moment. When she does she's been educating me. How wonderful if I had had the education to start with.

Regarding *needing to know*, the caregiver identified a few things in the context of discharging an elder with cognitive decline into her or his child's care: Discharge planning is not clear. Caregivers do not know what to expect when their parents are put solely into their care. The caregiver quoted felt ill-prepared to take her parent home. She envisioned a better way as one that provides some sort of discharge counseling, tells a caregiver what to expect, and provides education regarding how to deal with caring for a parent with cognitive decline. A systematic review by Shepperd et al. (2013) determined that discharge planning tailored to each patient may reduce the length of hospital stay and readmission rates in elderly populations. Regarding mortality, health

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perspective to the degree of that espoused by the *promotora* model is not supported. Further research would have to explore from where this person would be sourced, and which gender would work best according to each situation and in addition, what cultural background would be most appropriate for these individuals to have. Further, conceptual work would have to be done around addressing interventionist thinking versus what the data said—which is not that caregivers wanted their problems solved, but rather just someone to talk to.

outcomes and cost, however, the review was unable to come to specific conclusions and

asserted that further research must examine outcomes and cost. Cox (1996) found that

the caregiver's level of satisfaction with this process is dependent upon the degree of

her involvement in it. Her findings were echoed in a 2010 study by Kaplan et al.

Here, perhaps current models of transitional care in which nursing takes a

leadership role could be useful. These models would depend more heavily on the skill of

an interdisciplinary team of health professionals, led by nurses who are members of

most (if not all) transitional care teams. One possible model has been designed by

Griffiths, Bridges, Sheldon, Bartlett, and Hunt (2013): a dementia nurse specialist role for

implementation in the United Kingdom. Griffith et al.'s vision was that this individual

would undergo training in this highly specialized role and would be devoted specifically

to providing care for elders with cognitive decline and information for families. The

individual would be a central figure in transitional care for these patients, ensuring open

communication and coordination of care and information for patient, family, and others.

The cost-savings estimate for hospitals across the United Kingdom, according to the

authors, although conservative, equaled £11 million, which is, at the writing of this

dissertation, approximately $16.5 million. Of equal importance would be patient and

family satisfaction, free flow of information, and effective coordination. This is one such

model that could be employed with the population sampled for analysis in this study, and

it could be examined and tailored for U.S. healthcare by researchers and scholars within

the discipline of healthcare innovation in collaboration with nursing.

Needing to rest. In another vignette, a caregiver said:

I think the main part that's harder for us, as Hispanic caregivers, is that we don't
seek help. It's our responsibility, we don't seek help and there's no one to say,
"Hey, you know what, this is what you can do; this is how you can do it." I don't
mean this to be anything but informative, but the lady was Hispanic, who is now a
caseworker, and she said, "It's ok, you need time away and this is what you can

use," because I would have never thought to ask, I would have just continued to do it the way—

Regarding *needing to rest*, central concepts in the literature on female caregiving experiences in Hispanic populations are *familismo* (see Marin & Van Oss Marin, 1991; Wallace & Facio, 1987), *marianismo* (see Gil & Vasquez, 1996), and feminist inquiry into women's roles in caregiving (see Ibarra, 2003). Flores et al. (2009) examined what they called the "cultural scripts" that accompany the Latina caregivers' caregiving experience and their expectations, as well as the expectations placed upon them by institutions, including family and culture. What we see in these comments here is what Flores and colleagues would deem a "cultural script" regarding seeking help in the context of caregiving.

Caregivers recognize the shortcomings of their culture when it comes to requesting help, and the hired caregiver, who was Hispanic, according to the caregiver's explanation, understands and is aware of this deficit. This caseworker's comments to the caregiver seem to have walked the fine line between cultural expectation and taboo and the reality of needing time away. There is value to this sort of navigation: The caseworker was able to give her advice from a perspective and in a way that was in keeping with both the cultural script about caregiving that Ibarra (2003) wrote about and the realities of caregiving and its draining quality. Nursing identified the importance of situating caring within culture via transcultural nursing, wherein practitioners and researchers alike are attuned to the cultural nuances of diverse populations (see Leininger, 1988; Leininger & McFarland, 2006; and Ray, 2010). Culturally competent nursing contributes strongly to patient satisfaction and positive outcomes (Maier-Lorentz, 2008) and is based on a patient-centric perspective that could effectively reflect what caregivers said they needed. Also important to this role for nursing would be the

discipline's ability to direct and transition patients to culture-specific resources who can help.

Perhaps what is needed is an individual like the caseworker described by the caregiver, one who intimately understands the nuanced, fine line between the cultural script and caregiver reality, and the larger assortment of options that may also exist outside these two realities. This discussion, and its success at walking that fine line, should be replicated with caregivers, according to the caregiver. It could be situated within a context of transcultural nursing and healthcare innovation, with nurses well versed in transcultural care and their positioning in spaces within the healthcare system where they would be most effective. The caregiver was forthright: She admitted that in her culture people do not seek help, and helping her gain insight in dialogue with someone who is part of her culture or understands her culture may increase her perception of options available to her, and those options could be made more accessible.

Theoretical Recommendations

I conclude with conceptual recommendations intended for scholars of research design, methodology, philosophy of science, ethics, and freedom. I make two recommendations regarding the importance of re-envisioning perceptions of research and intervention: first, the utility of complexity science as a framework for qualitative inquiry and second, the place of social justice in constructivist grounded theory.

Complexity science. This project also identified theoretical and methodological structures that may serve to further the science that seeks to better understand the movement of caregivers across health and healing sources. As discussed previously, required first would be a shift in our understanding of data as variable based to instead perceiving it as phenomena. Required second would be theoretical and methodological

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structures that enable examination of these phenomena. Complexity science proves particularly useful in informing future research in diverse populations' experience, as does a critical look at the place of social justice research in constructivist grounded theory.

Complexity science proved very useful to this work. Davies (2013) asserted, echoing my distaste both personally and methodologically for overarching meta-narratives, "It is not a grand narrative in terms of overarching explanatory theory of behavior, but more a way of seeing connections and possibilities" (p. 19).

Complexity served as the parent framework from which were pulled the sensitizing concepts that informed this project: *chaos, co-evolution, darkness, emergence,* and *self-organization*. Each of these concepts enabled the data to speak of its own accord, holding prevailing boundaries at bay for a moment and peeling back the biomedical metanarrative to let the localized experiences of caregivers show through. Above all, complexity science facilitated a certain humility in both researcher and findings—with *darkness* always a reminder that we cannot know everything. *Chaos* enabled the analysis to allow for movement in the data, even when it seemed messy and wouldn't fit into certain thematic categories, providing me the opportunity to see what lay outside the structures that I had built into this constructivist grounded theory secondary analysis. *Co-evolution* helped to alert me to the feedback loops inherent in caregiver relationships with family, friends, the surrounding environment, and the care recipient. Of poignant importance was the shift in parent/child relationships that ran like swift currents below the data. *Emergence* encouraged me to question the prevailing notion of variables and prediction in current scholarship and shifted my thinking toward phenomena and those constellations of antecedents, drivers, and tensions that contained myriad phenomena that played out in unique ways across caregivers. *Self-*

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organization kept me primed to see the caregiver's power and, as I wrote earlier, her ways of "pushing" the process in one direction or another. It was the appearance of this construct many times in the data that led me to begin thinking about the place of theories of freedom in this research and about the implications of social justice and its opportunities and limitations, discussed at length in the following section. Most of all, complexity permitted me to engage in what Richardson et al. (2001) called "boundary critique" (p. 537)—boundaries between health and healing systems, between caregiver /source/antecedent and driver/tension/environment, and between overarching paradigms that would color this entire project.

It is in the identification and sorting of phenomena that a parent framework such as complexity science and sensitizing concepts drawn from it would be particularly useful. In avoiding static categorization according to variables, a phenomena-based approach allows for the unique experience of each caregiver to show through, in addition to the fluidity and intersection of that experience as reflected within other phenomena that emerge along with it from the data. Concepts such as *darkness* remind the researcher that all cannot be known and that generating insight from the data is an infinite process. *Co-evolution* helps to tease out the interrelationship between caregiver experiences and the resulting ways in which caregivers and their environments change symbiotically in relation to one another. *Self-organization* encourages the researcher to think critically about structures of power and mechanisms that control, oppress, and/or liberate this population. In particular, it sensitizes the researcher to the possibilities that lie within theories that seek to free caregivers to decide what is best for them and how to operationalize this knowledge.

Conceptually, a focus on phenomena rather than on categorizing data according to extant variables is an impetus to continue peeling back the layers of what lies over the

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data and would otherwise impede its closest, or most "grounded," examination. These layers may include researcher bias, study design flaws, overarching metanarratives, and presuppositions. Because generalization across populations is not possible with constructivist grounded theory, most important is staying closest to the data to discover what lies at the heart of each unique caregiver's experience and grounding the theory at that heart. Peeling back the layers, then, is a necessary exercise in what becomes a constant search for what the caregiver is *actually* experiencing. Rather than attempting to put data into static categories as being caused by or resulting from this or that overarching variable, phenomena are able to be looked at as grounded in their own context and then sorted only according to whether they are antecedent to the caregiver's process and/or drive/restrict it.

In a beautiful metaphor for this work, the scholarship I feel most reflects this project and provides promise for furthering this rivulet of research has not been published yet. It arrives in print in few months and in that sense is an emergent phenomenon itself. Its authors explore the tensions of complexity as a methodology— on one hand agent modeling and on the other what the book's description calls argument against "restricted complexity." Not unlike this project's holding-in-tension of the paradigms that explore this moment of healthcare's transformation, the book holds in tension these two very different paradigms of complexity—written from my own perspective in the preceding sections. As stated at the outset of this section by Davies (2013), complexity is not a "grand narrative" (p. 19). It is, as the title of the article by Richardson, Cillier, and Lissack (2001) refers to it, a "Grey" science for the "Stuff in Between" that "offers an alternative way of legitimizing the current interest in boundary critique, creativity, and pluralism" (p. 537). Richardson and colleagues (2001) wrote:

> By illustrating the inherently problematic nature of boundary selection, complexity science warns of the risks of employing off-the-shelf perspectives, and the need

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to partake in an intra-and inter-paradigmatic negotiation to facilitate the development of context-specific representations of perceived reality. In a way, dare we suggest it, complexity science provides a modernist argument for affirmative postmodernism. (p. 537)

I echo their sentiment: "Boundaries are constructed for convenience" (p. 536).

There is nothing convenient about the work that this project has put in motion, nor should there be. "Furthermore in acknowledging the partiality and provisionality of any attempt to describe a particular 'problematic situation,' complexity science also raises concerns for how we recognize ethical behavior" (Richardson et al., 2001, p. 537). These comments provide a perfect segue into the final conceptual discussion, which is the place of social justice in constructivist grounded theory research.

Social justice. Methodologically speaking, a phenomena-based approach lends credibility and validity to research that does not seek to generalize across populations, an important asset both in stand-alone constructivist grounded theory research and in the context of mixed-methods work. The strength of this focus on phenomena is that it is able to generalize only to the sample it studies, thereby balancing the requisite cross-population generalization that takes place in quantitative work. The data sampled for analysis in this project showed time and time again that caregivers have ideas about how to best provide care, how to create better systems, and how to organize sources in ways that make sense to those providing care and those receiving it. In short, the data spoke to the reality that caregivers know better what would work for them than do many of those who designed the interventions intended to help caregivers.

Conceiving of this methodology, one that is willing and able to solicit caregivers' ideas about what *they* want, should cause us to more closely examine the place of social justice since it is so deeply ingrained in constructivist grounded theory. Social justice in constructivist grounded theory as articulated by Charmaz (2006) was explored in

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Chapter 3 in terms of its emphasis on the importance of "attentiveness to ideas and actions concerning fairness, equity, equality, democratic process, status, hierarchy and individual and collective rights and obligations" (p. 207). Charmaz mentioned the creation of "good societies" and "a better world" and "shoulds" and "oughts" (p. 207). We must take pause simply because, as we strive to get ever closer to the data, the stakes get higher—whether we would admit this or not: Participants' voices get louder (as they must) and we, as researchers, lose some of our power—the power to interpret, the power to suggest, the power to prescribe, and the power to intervene. These texts of power are particularly prevalent when we as researchers undertake the betterment of our participants' worlds. A phenomena-based approach requires that we see as caregivers do and listen closely to what the data tell us. I am not confident that the paradigms prevalent in 2013, whether deconstructed, critically examined, or otherwise, permit researchers such requisite humility. Thus, we are perhaps not the ones to create, or even co-create, these "good societies" or "better worlds" and instead must hold in tension our own drive to help and the restraint of that drive, silencing ourselves to hear the Other.

Christians (2002) posited the utility of feminist communitarianism, as explicated by Denzin (1997, 2003, 2009), as what may be helpful in creating and facilitating socially just research. According to Denzin (2009), feminist communitarianism is "a sacred, existential epistemology that locates persons in a noncompetitive, nonhierarchical relationship to the larger moral universe" (p. 158). I suggest that the epistemology of feminist communitarianism is nearly impossible to accomplish. No matter how insightful we are about self-as-researcher or what structures we put in place to study a population and co-construct data, even Buber's (1958) "I-Thou" (p. 3) interactions are besotted with texts of power. In research of any kind, it is the examiner vis-à-vis the examined—the

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"doer" and the "done-to." Illustrating this reality in a healthcare context, Dubbin, Chang and Shim (2013) examined power dynamics in the space of the primary care examination room—illustrating those dynamics' continued existence between examiner (provider) and examined (patient) in the context of how this construction still is an impediment to patient-centered care. Benjamin (2004) suggested that a concept of intersubjective "third-ness," characterized by surrender and accommodation, can alleviate this binary opposition (to use Derrida's term) of doer and done-to. However, even if this were possible, who would surrender? Who would accommodate? Does accommodation and surrender not bring about a power dynamic once again?

Grounded theory, by nature, grounds itself in the data. Constructivists, in turn, are tasked with asking questions about participants' construction of their experience. We are neither dispassionate nor objective. With this reality in mind, of concern is, again, the nebulous quality of what Christians (2002), Denzin (2009) and Charmaz (2006) proposed—a common good, a moral universe, a noncompetitive framework as informing a socially just approach. We are not to describe, we are to interpret (Charmaz, 2006)—and it is in that interpretation that we place ourselves in dangerous territory, particularly in the face of these ill-defined concepts we are to facilitate. Perhaps the answer is, as I asserted above, staying close to the data. Doing so may also involve asking the participants—what do you want? We may be surprised by what they say. One caregiver in this project stated that she simply wanted someone to "talk to." She did not bemoan the inequity of women in her culture, decry *marianismo,* or trounce any of the other academic jargon we scholars so enjoy tossing around as we identify power relationships and try to eradicate them on our participants' behalf. An ambitious intervention of broad scope was not required—but a listening ear was. Interventionist thinking prevails in research—particularly health-related research. Our own patient-

centric discretion regarding what, in Charmaz's terms, "should" or "ought" (2006, p. 207) to be done is at risk if we allow our passion and our subjectivity to speak louder than our participants do. In the case of social justice paradigms within constructivist grounded theory, we must, as we are told to do in our own work, co-construct with our participants. Although we can never be objective, a phenomena-based approach allows us to look critically at social justice and its implications, clearing away as much as we can that clouds the data, including our own biases, texts of power, and nebulous concepts that may unknowingly oppress. In honoring participants' realities as phenomena, we are able to see the fluid messiness of their interactions rather than statically categorizing and generalizing to overarching variables. We may not like what we hear, and we may not agree, but assuming we know better is a violence that pervades health care research, and such an attitude has not done much good thus far, as prevailing health disparities and consumer mistrust continue to show.

My discussion here should not be misconstrued as asserting that healthcare should become noninterventionist. What I am suggesting, however, is that a balance be attained and maintained—again, the holding-in-tension that has permeated this entire project. Here, at the close of Chapter 5, what I have found is that participant voices (those of caregivers and care recipients) must be the first to be heard. As the literature shows, we talk often about patient-centered care, but its implementation and proliferation remain incomplete. This situation must change. What we as researchers think is best (no matter how much we have done to lay our biases bare) may not be. Interventions, as the literature repeatedly tell us, are most effective when they are crafted according to patient needs. At this moment in healthcare's transformation, the paradigms that inform its shift can in turn inform our perspective here: It is time to design patient-centric approaches that see care the way participants do—plain and simple.

Nor in the course of my discussion am I implying that the insight gleaned from this study should not be re-used. It is my responsibility as a constructivist grounded researcher to be very clear about the fact that the story told by my participants and myself is a unique one, able to illuminate our co-construction of data. I am not claiming that others will come to the same conclusions that I did, but neither am I ruling out the possibility of similar conclusions. Instead, what I have sought to provide in these 300-odd pages is a map that can be used to chart caregiver processes. Others are free to pick up the map and take a different journey—or a similar one—as long as they determine it is befitting them and their participants.

Limitations

In Chapter 3 I explored three limitations to this project in terms of both their help and their hindrance: the opportunities and pitfalls of secondary analysis, the pros and cons of a small sample size, and the act of making the familiar strange/the strange familiar. As I bring the project to a close here in Chapter 5, having analyzed the data and explicated the findings, I continue to see these three elements as a balance of liberation and oppression for the study.

I do, however, believe that one limitation to the study remains, and by limitation in this sense, I mean a stone, unturned. In keeping with the co-construction of data required of constructivist grounded theory, I fully admit that this limitation is reflected in what I have been forthright about all long: the *idées fixes* that I referred to in Chapter 3 as "a near-obsession with texts, labels, preconceptions, binary oppositions, and presuppositions that inform realities and thus my work here." At the conclusion of Chapter 5, I add to this list the implications of freedom, anarchy, and philosophies that decry the state and other arbitrary cultural institutions of control that both oppress populations under examination and bias those who would seek to study them.

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The limitation to this study, then, and to other research that seeks to replicate or be informed by it, is an incomplete examination of the prevailing notions of the place of social justice in constructivist grounded theory and how these notions liberate and oppress constructivist grounded theory projects like my own. Specifically, the social justice of Charmaz, the liberation theories of Friere, and the feminist communitarianism of Denzin must be brought into dialogue with their exact opposites: Derridan hospitality/*pas de l'hopsitalite*, and the theories of individualism, anarcho-libertarianism, and anti-statism and economic philosophy of Hayek, Rothbard, and Von Mises. Without encouraging this dialectic, we are at risk of falling into what is similar to the limiting variable-based approach to the data lamented earlier. Instead, we must look at phenomena in all their manifestations, at the messy imperfections that plague our populations and ourselves as researchers, and question everything that we see and think, even "the common good." If we don't allow the other side of the conversation to tease these phenomena and questions out, silenced voices may never be heard.

Conclusion

Chapter 5 marked a move forward into the actualities of healthcare's transformation. The process and experience of a small group of caregivers was examined, and the data brought forth insight that, although not generalizable across larger populations, may stir to life additional studies that take a similar journey with this project as map. The caregiver's process, comprised of constellations of antecedents and drivers/tensions that informed her movement across health and healing sources, was laid bare. These constellations served as containers for complex phenomena that interacted with one another in ways that were not wholly predictable and were always emergent.

In charting caregiver processes, this project sought to clear a path for subsequent work that is grounded in the data and not afraid of its messiness. Above all, this project was fittingly courageous in the face of what may prove (must prove) to be the continued disintegration of the power dynamic between researcher and participant as participant voices are heard more and more clearly. As participant voices are heard more clearly, health and healing systems will be able to answer their needs. Health disparities and patient-centered care will both become obsolete vocabulary of the past. These words will no longer be relevant because health disparities will have disappeared and patient-centered care will be the norm, rather than, as Blaustein (2012) quipped in Chapter 3, a "malady [with] a diagnostic classification like 'patient-centric' in order to treat it" (para. 1).

Returning to the two paradigms explored at the outset of this project, patient-centrism and postmodernism, and having followed their convergence and divergence throughout the last five chapters, it is at this moment in Chapter 5 that their roles are clear. Alongside complexity, social justice, and my own *idées fixes* about metanarratives, binary oppositions, texts of power, gender, culture, and even liberation, they serve to remind us, researcher and participant alike, that everything is in dialectic, and our task is to critique the boundaries and question them.

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METHODOLOGICAL APPENDIX

Seneca's words rang out in the preface to this dissertation: "It is pleasant at times to play the madman." His ancient tongue-in-cheek sentiment is freshly applicable at this late juncture. It *is* pleasant.

What is "madness," exactly? Foucault's explanation is this: simply looking into the brightest of days and seeing *nothing*. A bright day on which to everyone else, everything looks to be well-illuminated, well-understood, *clear*. Madness questions that clarity and, peering through its garish illumination, seeks what it is actually hiding. Madness contends that what is hidden is a space full of assumptions, binary oppositions, presuppositions, and metanarratives situated within cultural contexts informed by time, place, perspective, and texts of all kinds.

Foucault's articulation falls neatly into step with the core conversation of this project itself: recognizing the façade of juxtaposition, converging and diverging paradigms, meta- versus localized narratives, critiquing the prevailing boundaries in health and healing systems. And sounding the alarm. Only those possessed of Foucalt's *unreason* see prevailing structures for what they are—disintegrating and arbitrary.

And, the greatest irony for a project whose foundational *idees fixes* are bent on questioning the "clarity" to reveal that which is hidden in prevailing medical and cultural paradigms: *Who determines who is mad and who is not?* Foucault would contend the judge and jury are none other than prevailing medical and cultural paradigms. So, those of us who seek what is hidden under the assumed clarity of these paradigms place their metanarratives in danger, and thus, to safely secure the perpetuation of those metanarratives, are labeled mad.

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Is this the madness Seneca extolled? I believe it is. Seneca also said that there

is no genius without some touch of madness, and I admit that the critique presented in

this dissertation, while intelligent, does have a bit of the *provocateuse* in it. My task

throughout this project has been one of "critique and renewal" (Charmaz, 2006, p. 133).

I have toed many a line, pushed many a limit, chosen, decided, defended, and

eschewed boundaries, structures, and prevailing notions of all kinds. And why?

Because I am mad?

Maybe.

My experience has been that it is not only pleasant to play the madman, it is also

illuminating. I contend that it is in taking on this role that I have been able to arrive at

some very well-founded and provocative conclusions.

And with that, what follows is a brief tracing of my philosophical lineage, because

even in madness there is, as in chaos, some pattern, albeit unpredictable and

unanticipatable. I begin by presenting my general assumptions about epistemology and

ontology and conclude with those theories and philosophies that I believe have been

essential in shaping and refining my views.

General Assumptions About Epistemology and Ontology

I hold pro-empiricist, antirationalist philosophical assumptions about

epistemology and ontology: An individual's epistemology is shaped by experience,

perception, and language.[33] No two epistemologies are exactly alike. There is no

universal ontology—no absolute truths or relationships that exist objectively. Ontology is

dependent solely upon epistemology, and no two ontologies are alike. I do not believe in

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[33] See Lévinas (2003) and Merleau-Ponty (1945).

the existence of a universal metanarrative.[34] The idea of freedom and localized reality

underpins everything I live and breathe.

Essential Factors Shaping My Research

Because of my primary academic background as a student of political science

and international relations, much of my grounding, as I've mentioned in the preceding

chapters, lies in political and free-market economic philosophy. I am versed as well in

continental, analytic, and critical philosophy, as well as cultural and medical

anthropology, religious studies, and linguistics. This varied disciplinary training, as well

as time spent attending university in France and later traveling in the Sahara Desert in

Tunisia and living in China, has exposed me to a spectrum of worldviews, psychologies

of language, and differing degrees of freedom and oppression. Because of what I've

experienced and how I perceive what I've experienced, I believe strongly in individual

freedom, the retention of one's personal worldview and possessions, and the option to

work together only when free to choose to. This fundamental belief has shaped my

epistemological and ontological foundations and has colored my research.

I am first and foremost an anarcho-libertarian. I am wary of prevailing structures

of control, including all forms of "rights-granting" or "peace keeping" organizations like

government, nation-states, and international organizations like the United Nations. By

nature, "rights-granting" in itself belies a power dynamic of who can grant and who

cannot, and "peace-keeping" assumes a universal opinion of when conflict should or

should not be undertaken. I believe such overarching organizations are built upon and

sustained by arbitrary and oppressive realities replete with texts of power, gender, and

the Other, and thus should be abolished to ensure that those who would otherwise be

under their rule are instead free. If a governing body is permitted to exist at all within

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[34] See Foucalt (1976), Lyotard (1979), Derrida (1982), and Derrida and Defourmantelle (1997).

those arbitrary borders it enforces, it must be severely restricted to, as I stated in an earlier chapter, "protection of persons and property within [those] borders."

I subscribe to Austrian Economics, an extreme laissez-faire noninterventionist, and antistatist philosophy. Bastiat, Rand, Von Mises, Rothbard, and von Hayek inform my thinking about market forces, and my antistate and thus antiwar views. Philosophically, I am a postmodernist and a cultural relativist. As a scientist, I subscribe to a Feyerabendian (1975, 1996) epistemology.

Feyerabend (1975)[35] did not believe in the existence of a metanarrative shared by all people and denounced the writings and actions of many scholars who gave credence to Western rationalism as the only way of knowing. He decried what he felt was the ethnocentric condescension of scientists and scholars in their discussions of alternative/indigenous healing traditions. In his opinion, science, originally intended to liberate, has become instead a repressing epistemology examining a universal truth to which only it has access, and a free society should be protected from science's over-influence; it should not be held in higher esteem than other ideologies such as religion or myth. Feyerabend advocated the end of methodological restraint and suggested "a dose of anarchy," asserting that it is the most humane treatment of scientists and scholars to let each create his or her own rules and work from a paradigm that welcomes pluralism and dialogue. Indeed, imposing a single way of knowing in any area of life inhibits freedom and, according to White (1995), silences voices that should not be silenced.

Certainly, Feyerabend's methodological restraint, or more simply, his support for rules that are unique to each person, is not without problems, but it does provide a jumping-off point for inquiry.

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[35] Paul Feyerabend was influenced by physicist Felix Ehrenhaft, economic philosopher and philosopher of science Karl Popper, and philosopher Ludwig Wittgenstein.

My Ontology

My ontology happily suffers from what Lyotard (1979) calls "the postmodern condition" and tends toward *poststructuralism*. Poststructuralism, as understood by such scholars as Foucalt (1976), is an awareness of the falling-away of old, overarching ways of understanding the world and the emergence, instead, of local and unique dialogues and narratives. These narratives are best understood as those truths that were oppressed or subjugated by power structures and often by Western thought. The grand theories that disregarded the heterogeneity of truths have not spoken adequately for all people; as a result, more personalized and localized narratives are emerging.

I believe an assumption of objective truth disregards the complex nature of the world as well as the inherent freedom to think and perceive of truth that should be granted all people. My grounding in complexity science runs contrary to subscribing to any ontology that ignores the heterogeneity of truth—the result of variations in culture, experience, and existence found the world over. Further, like Foucalt (1975), I firmly believe that ontologies prescribing metanarratives for entire populations consciously oppress and assert control over those populations.

As a poststructuralist, instead of an ontology allowing for one objective reality, I would offer Lyotard's (1979) "petit récits" as an alternative to a single truth. *Petits récits*, literally "small recountings" or "small recipes," are understood by Lyotard as localized worldviews. They are marked by diversity, unique and varied viewpoints, and are specific to smaller groups of people. Peters (2001) calls them a "multiplicity of theoretical standpoints" (p. 7) as opposed to metanarratives or grand theories. Poststructuralism speaks to the importance I place on freedom, to my understanding of truth (or, more appropriately, truths) as well as to the foci of my scholarship in complexity science (multiple truths interacting with one another) and interdisciplinary healthcare (the

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truths of many disciplines) and as I wrote of caregivers in Chapter 5, "her process in her terms."

Conclusion

My epistemological and ontological foundation draws from the spectrum of my own experience and from myriad scholars in a variety of disciplines. My epistemology is Feyerabendian. My ontology is poststructuralist, comprised of Lyotard's (1979) *petit récits* and Foucalt's (1976) suspicion of the metanarrative as a tool used to oppress. Lévinas's (2003) assertion of the importance of language as a creator of reality and Merleau-Ponty's (1945) "primacy of perception" further affirms for me the existence of multiple realities and the inadequacy of a single metanarrative. I echo Parse (1992): Health is defined by the individual. And I conclude with Von Mises's stance against the power of those who would govern: *Tu ne cede malis sed contra audentior ito* (Do not give into evil but proceed ever more against it).

In providing my philosophical pedigree, I sought to demonstrate that there is, simply, a "method to my madness." By engaging critical and postcritical philosophy and the scholarship of those economists, philosophers, and writers who eschew the prevailing metanarratives, I believe I am Seneca's madman. It *is* pleasant, but do not let the pleasantness of the exercise fool you. It is, I believe, the only non-violent way to navigate healthcare's transformative shift as more and more localized narratives emerge, needing to be heard above the din of those who would silence them.