Pragmatic truths about illness experience: Idioms of distress around Alzheimer’s disease in Oaxaca, Mexico

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Abstract
This article explores the pragmatic sensibilities that are implicit in idioms of distress among family caregivers for Alzheimer’s disease in Teotitlán del Valle, a rural Zapotec-speaking community in Oaxaca, Mexico. Through analysis of caregivers’ perceptions of progressive memory loss and related etiological understandings, this article emphasizes the pragmatism inherent to local health perspectives. In so doing, the article revisits Nichter’s earliest formulation of idioms of distress as providing an alternative epistemological framework to appreciate how illness is varyingly understood. Such a framework is useful for understanding how idioms of distress are not aimed towards attaining accuracy about what illness is in an objective sense, but rather put into focus how such descriptions are both constitutive of—and themselves pragmatic responses to—broader social circumstances. This article concludes with a consideration of how idioms of distress empower individuals as agents of action.

Keywords
Alzheimer’s disease, idioms of distress, pragmatism, Oaxaca, Zapotec

Introduction
Prevalence rates of dementia are roughly similar across global regions: for those aged 60 and older, rates range from 4–8%, but within this spectrum, Latin American settings score on the higher end (Prince et al., 2015). That is why, at the beginning of research for this study in rural Oaxaca, Mexico, it was telling that the individuals who had heard of Alzheimer’s disease (the most prevalent form of dementia) claimed that it simply did not exist. As one acquaintance said, “People...
do not have Alzheimer’s because they don’t need to worry about paying the rent and other [forms of] stress experienced over there [e.g., other metropolitan settings like Oaxaca City and the US].” Alzheimer’s was understood as a modern condition that occurred due to the stresses associated with non-traditional ways of living, experienced by migrants who jettison local ways of life, locals who embrace foreign values, and other individuals impacted by these social trends. In Teotitlán del Valle (hereafter “Teotitlán”), individuals maintained that Alzheimer’s did not exist and, of those who knew otherwise, there was strong reluctance to speak about it. It was evident that specific social issues were at stake with Alzheimer’s which rendered the experience, meaning, and treatment of it in Teotitlán unique compared to other settings.

Central to explaining this observation is the anthropological concept of idioms of distress, defined as “socially and culturally resonant means of experiencing and expressing distress in local worlds” (Nichter, 2010, p. 405). Simply put, some sociocultural settings foster a different expression and experience of illness than others. Nichter’s earliest formulation suggests that various experiences of illness are “culturally constituted” and that studying the particularities of distress is inexplicitly tied to studying broader cultural horizons (Nichter, 1981, p. 379). Idioms of distress thus serve as prisms through which to witness specific cultural worlds, indicative either of ways people encounter and negotiate broader social tensions, or, in other cases, culturally salient means of expressing personal difficulties.

Nichter’s (1981) original intent in developing this research agenda was to shift attention away from the content of cultural difference (e.g., that some cultures believe in spirit possession whereas others in biochemical changes to the brain) towards the function of those differences (e.g., how the experience of possession serves a social purpose). As Nichter (2010) later reformulates it, asking “Why this?” is instrumental in appreciating how idioms of distress are not just constitutive of—but also responses to—cultural surroundings. This type of questioning shifts attention away from an “objective” neo-Kraepelinian approach (i.e., a focus on symptomology and overlooking what underlies symptoms), towards appreciating how expressions of illness “serve adaptive functions” (Nichter, 2010, p. 402). This approach has produced a burst of global research regarding the social anxiety expressed in psychological and medical distress (Abramowitz, 2010; Yarris, 2017), the indicators of psychopathology across cultures (Hinton et al., 2010; Lewis-Fernández et al., 2010), the clinical utility of developing culturally sensitive assessment measures (Guarnaccia et al., 2003; Hinton et al., 2012; Kaiser et al., 2013; Kohrt et al., 2013), and the understanding of variances in help-seeking behavior (Hinton & Lewis-Fernández, 2010), to name but a few topics.

Yet little attention has been directed towards providing an epistemology that attends to the way idioms of distress serve culturally specific functions. Simply put, beyond how idioms of distress account for the varying ways people experience illness, how can one make sense of their impact and function in everyday life? This article seeks to address this question, exploring how idioms of distress
presuppose a specific epistemology best understood through philosophical pragmatism, and illustrates how this epistemology attends to their cultural function.

In this article, I draw upon the work of American pragmatists, represented by William James (2000 [1907]), John Dewey (1998 [1925]), and Charles Peirce (1905), and on the work of more recent scholars who illustrate how an underlying pragmatic epistemology accounts for the ways in which family caregivers’ talk about Alzheimer’s is not just meant to describe illness, but also meant to have a concrete impact in the social world. The pragmatists remind us that, when analyzing idioms of distress, it is not enough to merely observe that illness experience varies across time and place; we must also inquire into what function those differences locally serve and how such differences work toward the values at stake in everyday life. This focus differentiates pragmatism from social constructionism: while most research in anthropology is rooted in a social constructionist perspective that might attend to how idioms vary and are constituted within respective social worlds, pragmatism attends to the function of those idioms, and how such functions directly shape everyday life. This is to say, with a pragmatist lens, we not only appreciate how idioms are constructed within a given social world, but also how they are constructive of the world people want to furnish.

Pragmatism’s concern with function can be traced back to its philosophical foundations. Challenging the idea that truth corresponds to an abstract verifiable reality—a dominant assumption in much of philosophy since Plato—pragmatism instead suggests an alternative epistemology that focuses on how various truths are useful. Pragmatists hold that truth is not an abstract property waiting to be discovered, but rather a creative process wherein an idea is placed in relation to others held to be true. As James observed, “The truth of an idea is not a stagnant property inherent in it. Truth happens to an idea. It becomes true, is made true by events” (James, 2000 [1907], p. 88, emphasis in original).

Although rarely mentioned in the literature, pragmatism is a cornerstone of Nichter’s original focus on the communicative functionality of idioms of distress—what he at times refers to as a “transactional approach”—and also when he cites the work of semiotician Charles Morris (1971) for providing a theory of language that attends to how communication carries a concrete impact on social life (Nichter, 2010, p. 403, note 8). Inspired by the fact that Nichter explicitly references pragmatism in his early work, this article shows that returning to this philosophical origin helps account for why studying idioms of distress matters. It puts into focus not only the “metaphoricity” of how idioms are communicative of cultural parameters (Kirmayer, 1994), but also the social functions that such metaphors serve.

Pragmatism is an important theoretical development in Nichter’s conception of idioms of distress. It attends to how particular actors experience and respond to particular forms of distress, while being grounded in a view of truth that does not purport to assess the “objective” validity of those phenomena. This allows for studying the “truth” of idioms of distress insofar as truth is understood to be
a matter of social function. It allows idioms to be studied in their own right, without comparing them to descriptions of illness that might be taken as more valid. But more importantly, pragmatism also approximates the heart of the voices studied during this research in Oaxaca—caregivers who dynamically adopted multiple (and at times contradictory) strategies to deliver effective responses to manage the difficulties associated with dementia and attempt to maintain family cohesion.

In what follows, this article describes necessary background information to appreciate what is locally at stake in Oaxaca, methods used to acquire data, and presentation of data on caregivers’ perceptions and etiological understandings associated with what is termed Alzheimer’s disease. As this article will show, these data are expressive of an underlying pragmatic epistemology that serves to demonstrate the way idioms of distress are not only culturally constitutive but also responsive to social dynamics.

**Research setting**

Oaxaca is an important setting to study how social issues impact the experience of illness because questions pertaining to culture and its maintenance appear so salient in everyday life. The state is home to 16 indigenous groups and languages and has the highest proportion of indigenous language speakers (INEGI, 2014). But Mexico’s indigenous populations have been placed on the periphery of national agendas, and Oaxaca is one of the poorest states in Mexico (second to Chiapas), with over 60% of the state’s population living in poverty and 23% meeting criteria for extreme poverty (CONEVAL, 2012; for further discussion on causal factors contributing to this disparity, see Chance & Taylor, 1985; Knight, 1990; Lewis, 2006; Murphy & Stepick, 1991). Neoliberal policies have further intensified these social difficulties (Stephen, 2013; Worthen, 2015). The famous 1994 Zapatista uprising brought to the attention of many that, for the residents of Oaxaca, joining the global economy meant adopting international (non-indigenous) languages, adhering to foreign legal customs, migrating, and more generally replacing forms of life once centered on subsistence farming and communal solidarity with those premised on social independence and capital gain (see Stahler-Sholk, 2007). These macro-level changes have had significant impacts on local life. On countless occasions during research, participants stated that life has changed in Teotitlán primarily because people are now preoccupied about finances. “Before, the corn grew easily and you could always count on having a roof over your head,” one informant said. “Now, that’s just not enough—people are always worried about making enough money to survive.”

Teotitlán is interesting precisely because it is situated within these social tensions, while also being relatively distinct from the surrounding state poverty. Part of this stems from Teotitlán’s success in leveraging Oaxaca’s tourist industry. Teotitlán has gained fame both locally and globally for its weaving tradition, producing textiles that are touted as living vestiges of Zapotec culture (Stephen, 2005; Wood, 2008). Teotitlán has certainly capitalized on Oaxacan
tourism and is different from less economically advantaged neighbors, but the community continues to face economic hardship. The 5500-resident community receives federal subsidies and, at the time of this research, was designated a poor pueblo by national standards: 82% of residents met federal criteria for poverty, and 29% lived in extreme poverty (SEDESOL, 2014). As a result, Teotitecos are similar to other Oaxacans who have responded to economic hardship through migration (Cohen, 2004; Holmes, 2013; Kearney, 1995; Stephen, 2007). Apart from selling textiles, a significant amount of Teotitlán’s economy derives from remittances. This international dynamic is even reflected in the Zapotec word for the United States—*Stub Laad*—which literally means “the other side,” gesturing towards the perceived normality of crossing the international border. As Stephen (2007) has illustrated in her important work on “transborder lives,” such a lived experience shifts what local identity means: no longer constituted by the physical borders of Teotitlán, identity is now transnationally stretched and maintained.

This points to concern about local culture and its maintenance. High rates of migration mean that many households are fragmented, while migrants’ return to the community introduces global influences into local ways of life. Whereas all household members were once expected to support and care for dependent elders, now only those family members who remain physically present are assigned that task. Monolingual Zapotec elders stand in contrast to Spanish-speaking youths, and in general, locals are concerned with maintaining familial and communal solidarity in the face of larger social change.

**Methods**

This investigation took place during dissertation research that sought to understand caregiving for dementia in Oaxaca (Yahalom, 2016). Research was conducted in partnership with a local translator who led interviews in Zapotec and provided analysis for key Zapotec idioms; the majority of social life is carried out in Zapotec, and most elders experienced difficulty sustaining in-depth conversation in Spanish.¹

Through the course of a year of fieldwork in Teotitlán, 22 family caregivers across nine households were interviewed (comprising over 15 hours of recorded interviews in Zapotec). All recorded data were translated and transcribed in English, with detailed notes on original Zapotec idioms, and subsequently analyzed. These perspectives on the everyday experience of caregiving were supplemented by interviews with community doctors, *curanderas* (traditional healers), psychologists, state-employed individuals who work with elders, and others encountered in the course of this study. Data from government-sponsored wellness presentations (*pláticas*), *fiestas* and public celebrations, and encounters with other community members were also collected to gain information about life in Teotitlán. Lastly, the author also formally studied the Zapotec language to better understand local customs and concerns.
Perceiving forgetfulness in the context of modern change

The research included caregivers of elders in different stages of what would be called Alzheimer’s disease—that is, a spectrum of progressive forgetfulness ranging from those elders whose symptoms almost seemed benign, to a type of forgetfulness that was unquestionably pathological. Attending to caregivers’ perception of forgetfulness offers an important way to understand how it is talked about locally, but this analysis also illustrates how perception is constituted within broader, pragmatic concerns about how forgetfulness might be responded to. This is to say that the way forgetfulness is perceived is shaped by what can be done about it. This draws upon what Charles Goodwin (1994) terms a “practice-based theory of knowledge and action,” attending to how the very things people notice and take to be objective are not an act of cognitive transparency of the world, but are rather mediated by broader social practices that implicitly structure perception. Indeed, as Dewey (1998 [1925]) observed:

the function of intelligence is [...] not that of copying the objects of the environment, but rather of taking account of the way in which more effective and more profitable relations with these objects may be established in the future. (p. 10)

The following data show that caregivers’ perceptions of forgetful elders are not an unmediated depiction of “objective” symptoms, but an encounter with symptoms that is constituted by concern for the future in the context of social change.

To begin, consider Luis and Laura (pseudonyms here and throughout the article), a married couple in their mid-forties. They provide care for Laura’s mother, an elder in her mid-seventies who was recently widowed and deemed in need of help managing household affairs. At one point, they were asked to describe what sort of things they notice Laura’s mother forgetting, and their lighthearted tone was striking:

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

The levity of this exchange is perhaps best explained by Luis and Laura’s lack of concern. Laura laughs at her husband’s observation, but then supplements it with her own. Here, forgetting appears benign, ordinary, a simple instance of inattentiveness that most individuals can relate to. The elder’s forgetfulness poses no major hindrance to family functioning and can easily be overlooked. But there is more. Luis curiously says that the elder’s forgetfulness nevertheless strikes him as
strange. He is surprised about the frequency with which his mother-in-law forgets, the number of times she is confused about where her belongings are. Indeed, the fact that this household was being interviewed occurred because of information shared by the community about their recent difficulties managing the forgetfulness of Laura’s mother. Luis and Laura had told people about their experience—further indicating that they found this behavior “surprising.” In this way, minor forgetfulness is something caregivers are aware of, but nevertheless a condition they minimize.

Moving along from the most benign detection of forgetfulness to a case that presents with slightly greater severity, Alberto similarly described what he observed of his forgetful mother without concern:

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

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

Another household represents a further stage along this spectrum. Sergio is an unmarried man in his early thirties who cares for his demented father with the help of Manuel, his married brother in his mid-forties, and their mother Linda, in her mid-to-late sixties. These participants were asked to describe instances when they noticed forgetfulness. Precisely because the symptoms they described were more severe, it was surprising to note the remarkable similarity of their lighthearted demeanor in the context of other households discussed above:

Sergio: One time I was coming back home and he [my father] asked me, “Who’s your dad?”

[Linda laughs in unison.]

Linda: Oh, last year one of my daughters came back home, and when she arrived at the house she was very happy. And then my husband asked her, “Who are you?” And my daughter told him, “I’m your daughter.” And he said that he didn’t believe her, and he laughed. So he forgets. Even now he confuses his children. He will switch their names and he would call Sergio “Manuel,” and Manuel “Sergio.” And he always confuses them.
Forgetfulness here means more than just misplacing objects or forgetting ordinary events. It involves difficulty remembering basic information. Family members are forgotten, names are confused, and there is a more serious threat to the elder’s coherence and to the life around him. These caregivers’ responses are very similar, despite encountering different levels of severity. Sergio and his family continue to laugh and thus demonstrate that this lighthearted perspective is maintained even when basic family exchanges appear more jeopardized.

Readers are invited to pause and consider how curious this phenomenon is. At once, this household talks about an experience as disrupting normal exchanges while saying that it is something they overlook. The anthropologist Michael Jackson (2017) writes that “laughter springs from an ambiguous situation” (p. 137) of interpersonal relating where contradictory understandings or perspectives collide. Here, laughter is expressive of the juxtaposition of elders as they have historically been known, i.e., as figures of authority, and as persons who now display symptoms of forgetfulness. Elders’ forgetfulness stands in contrast to their authority. So, caregivers laugh. Yet one must also consider the nature of language and the way in which talk about forgetfulness shapes caregivers’ experience of it. Semioticians influenced by pragmatism (e.g., Morris, 1971), and social scientists influenced by Michel Foucault (e.g., Kendall & Wickham, 1998; Packer, 2010; Potter, 2003), all point to how language has constitutive power in the social world. Each of these researchers is at least implicitly influenced by Austin’s (1975) perspective that language does not merely describe, but has performative functions—it does things—and these functions have concrete effects on the surrounding world (see also Laugier, 2013, pp. 97–109). Caregivers’ talk about forgetfulness as something that is normal changes their worldview; it constructs a perspective that at once acknowledges symptoms while simultaneously minimizing their importance. It follows, then, that caregivers’ behavior overlooking forgetfulness is founded in part on their talk about forgetfulness as benign.

Although appealing to the nature of language helps explain how caregivers are able to experience forgetfulness as normal, it does not address Nichter’s question about why they do it. This question is especially pertinent to readers in the US, where age-related forgetfulness is noted with much hyper-acuity and alarm (for a history of how Alzheimer’s in the US has been varyingly understood, see Ballenger, 2006). By contrast, Teotitecos’ view of forgetfulness as normal makes sense in context. In the most general sense, a major part of social interactions is premised on overlooking peculiarities of another person’s speech in order to establish a sense of common understanding. Drawing on pragmatism’s emphasis on function, all language is designed to have a particular effect. We tend to find meaning in what other people say despite the ambiguity, irrationality, and opaqueness that surround language. This is because, in the words of Donald Davidson (1984), we maintain a “principle of charity” (pp.155–170), an assumption that other people are intentional agents and that it is our responsibility as listener to decipher the meaning they seek to convey.

But the fact that even caregivers who deal with more severe symptoms view forgetfulness as normal moves this idea beyond a general statement about the
nature of language towards an observation specific to Teotitlán. Why do caregivers like Sergio, Manuel, and Linda state that their father’s inability to recall members of the family is normal when it is so clearly a divergence from prior life experiences? Although there are many ways to account for this stance, the most compelling is found by taking on Kleinman’s (1998) consideration about what is “at stake” if they risk claiming that these instances of forgetfulness are aberrant. At stake is not only caregivers’ relationships with elders, but more broadly how their relationships implicate a view of local tradition. Similar to Lawrence Cohen’s (1998) observation about how elders with dementia in India were perceived to have a “hot voice” that suggested they lived in a “bad family” that failed to uphold normative expectations, instances of forgetfulness in Teotitlán also carry broader social meanings. Both in the privacy of their own homes and their visibility in public settings, forgetful elders appeared to represent how local values are viewed to be endangered. As forgetfulness is held to occur only in stressful environments, the presence of forgetfulness in Teotitlán signifies how the community has begun to change. The larger community understands that elders forget because elders have jettisoned local values in the course of their own lives, or because elders live in family environments that have forgotten how to embody local values about social cohesion through practices of care. These perceptions are maintained as members of households migrate to pursue economic opportunities and broader globalizing influences are introduced from the outside. In this context, these caregivers’ statements are efforts to bolster what every Teotiteco implicitly knows to be endangered—the integrity of the family unit and the cohesion of the larger community. Talk about forgetfulness as normal promotes certain ideals centering on social cohesion in the context of “modern” social change that is perceived to undermine those ideals (see also Ochs & Kremer-Sadlik, 2015).

Hence, claiming that forgetfulness is normal is not due to some abstract notion of normalcy—not positing a theory of what normal means in an abstract Platonic form—but something Teotitecos want affirmed. Pragmatism is so relevant to caregivers’ experience and talk about distress because it puts into focus how perception of illness occurs within larger concerns about what it is perceived to threaten. As James (2000 [1907]) reminds us, “The really vital question for us all is, What is this world going to be?” (p. 57). This question stands not only at the heart of how individuals make sense of the world, but of their very perception of it, a question that constitutes the nature of experience itself. In the case of the caregivers exhibited above, to take on this question implies an affirmation of family relationships, continuing to view elders as they have traditionally been viewed, and is a broader means to uphold social practices representative of local culture through the maintenance of expectations to care for elders.

Though caregivers appeared to minimize elders’ forgetfulness to maintain respect and social cohesion throughout most of the fieldwork, this approach proved untenable in the most severe case. Carlos, an elder in his mid-seventies, cared for his wife who was diagnosed with Alzheimer’s disease but more accurately would be described as meeting late-stage disease criteria. Carlos describes his wife
as forgetting members of the family and stated that his wife’s memory was “com-
pletely lost.” Carlos further elaborated:

She doesn’t remember anything anymore. And if you talk to her she won’t listen. And even
if she listens she won’t answer . . . And when she answers she answers completely off topic.
That’s how I realize that she’s not aware anymore. You can’t hold a conversation with her.

Importantly, in these descriptions, Carlos does not laugh or attempt to normalize
his wife’s forgetfulness. Carlos’ use of the world “completely” points to how his
wife not only fails to recollect information, but no longer functions on a basic
cognitive level. (It perhaps also sheds light on what Alberto meant above when he
contrasted his mother’s perceived benign forgetfulness with “true forgetting.”) Members of the family are not recognized, distant memories are not recalled,
and even basic speech is compromised. Both the charity and the pragmatic func-
tionality of language described above appear to have collapsed. Through this
household we gain insight about caregivers’ view that forgetfulness is normal
has a firm limit.

Taken as a whole, each of the caregivers featured above illustrates a
moment along the spectrum of progressive forgetfulness. On the one hand, this
spectrum is congruent with how Alzheimer’s disease is classified on a spectrum
according to early-, mid-, and late-stage symptoms in the US and other biomedi-
ically-oriented settings. In Teotitlán as elsewhere, these forms of forgetfulness are
progressive: memory problems become more problematic with time. On the other
hand, this spectrum highlights location-specific meanings. Compared to a US set-
ting, where early signs of forgetfulness are considered a grave forecast of one’s loss
of autonomy, in Teotitlán, forgetfulness is minimized and considered normal.
Appreciating the functionality of these perceptions and considering how speech
has constructive power, pragmatism’s notion of truth helps account for how these
perspectives are constitutive of and responsive to broader social changes in the
community.

Etiological understandings render a space for action

Participants also expressed varying perspectives on the causes of progressive for-
getfulness. As Kaja Finkler writes of her own study in Mexico, “to know the cause
of a sickness is to make sense of one’s suffering . . . [Etiologies] furnish a window to
people’s ideologies, morality, social interaction, and relations to themselves, their
bodies, and their environment” (Finkler, 2001, p. 31). Indeed, the etiological under-
standings noted among caregivers provide a similar prism onto their lives. What
follows is a selection of etiologies noted by caregivers to make sense of progressive
forgetfulness they observed among elders. Each of these etiologies is situated within
a medically pluralistic landscape that implicitly references pre-Hispanic health per-
spectives focused on ecological harmony (Somolinos D’Ardois, 1973), the humoral
and folk beliefs introduced by Spaniards (Hernández Sáenz & Foster, 2001), and bio-psychiatric understandings of the body and mind associated with global influence (Duncan, 2017).

The point in highlighting these etiologies is to further demonstrate that they are pragmatic in nature, not based on opinions about what is “objectively” occurring to account for forgetfulness, but rather oriented towards responding to social challenges. Studying etiological perspectives helps highlight what Dewey (1998 [1925]) terms pragmatism’s “metaphysical implication” (p. 8). Being attentive to concrete, lived experience (over abstract theoretical propositions) inherently fosters concern about how various ideas about illness impact everyday life. Similarly, such a focus draws upon Peirce’s observation that, “the rational meaning of every proposition lies in the future” (Peirce 1905, p. 173). In this way, the following etiologies are not mere explanations about forgetfulness, but statements and social projects to build a better future in the context of it. Analysis of etiologies shows how they open a space for caregivers to become agents that do something in response to forgetfulness and associated distress.

**Soul loss and fright**

A common way to explain forgetfulness occurred in reference to traditional notions about soul loss and fright. For example, Beatrice and Alberto described the case of another family who refused to believe a doctor’s diagnosis that their mother had Alzheimer’s disease.³ When asked about this family’s encounter with the doctor, they reflected on whether they thought the doctor could have helped the situation:

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

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

What is so striking in this excerpt is that the doctor’s diagnosis of Alzheimer’s disease is contested through the family’s understanding of bianan, a traditional illness category. In Teotitlán this illness occurs when an individual is abruptly taken away from a place—or experiences a shock or trauma—and subsequently becomes irritable. Typically associated with vulnerable individuals (children and older adults), the affected person is said to have lost his or her soul. It is a condition where the person is physically alive, but, in a subtle way, is different. In this story, the elder was in the field letting his livestock graze and, after being shocked due to an unknown cause, forgot where he put his donkey. He returned home to be perceived by his family as impatient, forgetful, and no longer the same person.
A related illness category, *xhibi* (Spanish: *susto*; “fright” or “fear”), was similarly employed to make sense of forgetfulness. The idea behind *susto* is that a sudden shock or traumatic event causes part of the self to leave the body. *Susto* has been researched in Teotitlán (Fitzsimmons, 1972) and is more widely recognized as an illness category across Latino cultures (APA, 2013; Rubel, 1960). Locally, *susto* and soul loss are treated as two separate illness categories, but they are conceptually related. *Susto* (a shock) is understood to be one of the causes of soul loss—though not all cases of *susto* cause soul loss, and there are also other circumstances (like spirit intrusion) where a person may lose his or her soul. Additional information was gained through Linda’s account of a case of *susto* that she speculated occurred to her husband during his twenties:

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

This exchange provides insight into how past incidents of *susto* are used to explain forgetfulness in the present. Linda recalls an event she knows happened to her husband decades ago. She cites this incident to speculate on a possible cause of her husband’s current forgetfulness, implying that these past injuries may have resurfaced to cause her husband to forget.

Both of the above “traditional” etiological understandings illustrate how they are functionally communicative in the sense Nichter originally outlined: expressive of modern social parameters that open up a pragmatic space for action. As in many other rural settings, the caregivers studied in this project faced the challenge of being educated about Alzheimer’s by physicians, but told that there was little to be done to reverse, arrest, or mitigate disease progress. In the entire state of Oaxaca there exist three nursing homes, few geriatric specialists, and hardly any mention of related pharmaceutical options. Hence, in contrast to the new forms of social life that are described of persons with Alzheimer’s in biomedically-oriented settings, such as participation in caregiver support groups, consultation with physicians, and study of caregiving best practices (see Lock, 2007; Rabinow, 1996), in Oaxaca, the same diagnosis paired with limited relevant social arenas forecloses meaningful social roles and related action. Appealing to soul loss thus opens up a new possibility to do something—to seek medical treatment from local healers and to engage with the community by adhering to local medical tradition. As an illustration of how this perspective on forgetfulness provides alternative modes of action, Sophia,
a wife and caregiver, described how it allowed her to provide care for her husband in a way that her allopathic physician could not. She said:

I took water, flowers, and food for us to eat there. I also took a blanket so he could sleep there . . . so he could get his soul back . . . And I sat next to him. I took bread, and sprinkled it all around . . . So I did that, and he fell asleep there. I also took holy water and a bamboo reed to use to call his name [and entice his soul to return].

Indeed, this approach would not be possible had she maintained an alternative biomedical understanding of forgetfulness. This is also in the spirit of pragmatism as James describes it: “the attitude of looking away from first things, principles, ‘categories,’ supposed necessities; and of looking towards last things, fruits, consequences, and facts” (James, 2000 [1907], p. 29). Etiologies are furnished not in reference to some abstract, underlying idea of cause; they are not deduced from an abstract understanding of biomedicine or another medical framework. Rather, those frameworks are appealed to because caregivers intuit that they might have a function—in this case, appealing to soul loss furnishes hope for other medical systems to respond to the symptoms that cannot be treated by current local biomedical options.

**Thinking too much and sadness**

This pragmatic sensibility can equally be detected in caregivers’ understanding of sadness and related ruminative symptoms. Indeed, “thinking too much” has been a widely studied construct across cultural groups and appears as a cultural concept of distress in the DSM-5 (APA, 2013, p. 858; Kaiser et al., 2015). Mexican immigrants commonly cite thinking too much as a symptom of depression associated with migration and nostalgia for home communities (Martinez Tyson et al., 2011) and, inversely, in a similar Nicaraguan setting, grandmothers who remain in their communities experience it in relation to the insufficient social support they experienced while caring for their migrant daughters’ children (Yarris, 2014, 2017). In Teotitlán, the Zapotec word to refer to sadness is nabang and is used as a conditional state of being in sentences like naban yuan, meaning “She is sad.” Caregivers viewed sadness not only as a symptom but also as an etiology to furnish an explanation of forgetfulness that opened up functional possibilities.

Carlos is one such example, and he speculated on how his wife’s finger amputation due to diabetes limited her ability to weave. Common throughout Oaxaca, diabetes is an important medical symbol of social change and is locally associated with non-traditional lifestyles. In Carlos’ case, he observed that his wife’s inability to weave foreclosed a meaningful social role, causing her to ruminate (Zapotec original: riqiuilá’áź; literally “to think a lot from the heart”), which in turn led her to forget. Such an explanation was an attempt to empathize with and understand his wife’s forgetfulness as an underlying expression of her social pain.
As caregivers endorsed this etiological justification to explain forgetfulness, it was also interesting to witness elders do the same to explain their own. This was most salient during an interview with Pablo and Vanessa, a married couple who reflected on the family member they cared for, and how this elder made efforts to be understood by expressing her own sadness:

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

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

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

This excerpt reads remarkably similar to observations made about Carlos, only it is the elder who is making her sadness known. The elder in this household left her community to migrate to Mexico City, only to feel alone once her husband passed away. Despite having returned to Teotitlán, migration is perceived as the center of the elder’s own pain while she continues to feel isolated and removed from the larger community. This further situates her sadness and forgetfulness as being located within Teotiteco cultural parameters.

Appealing to rumination and sadness as a cause of forgetfulness shows how adverse life circumstances—what Finkler (2001) calls “life’s lesions” (p. 35)—become inscribed on the body and expressed through illness. Focusing on these circumstances helps caregivers make sense of elders’ symptoms, attributing the cause of forgetfulness to something they can understand. But it also provides for a common language—a means to engage—between caregivers and forgetful elders. Understanding forgetfulness through this perspective establishes a common understanding and, more importantly, a means of social engagement. Teotitecos’ experiences of sadness, loneliness, and loss were expressive of a broader social setting where notions of family and social unity were changing. Forgetfulness can be challenged by contesting the loneliness associated with social change and integrating elders back into the family.

**Stress**

Stress is another etiological understanding that imputes social and pragmatic significance to forgetfulness. Informed by the influential descriptions of stress in the work of Hans Selye (1956), most readers take it as a given that the experience of stress leads to illness. This Euro-American idea also circulates in Oaxaca, as indicated by the fact that Alzheimer’s disease is widely held by locals not to exist
because of the purported absence of modern stress associated with capitalistic lifestyles. In Teotitlán, the Zapotec expression associated with stress points to the anxiety that a person endures—rak garlien—which literally describes “a distressed heart.” This view implicitly points to a concomitant experience of modernity: the abandonment of traditional modes of living in pursuit of non-traditional capitalistic ends. Caregivers continue to adhere to this understanding as they explain the cause of forgetfulness—now claiming that elders forget because they experience stress in a social setting that has begun to change.

This was perhaps best articulated by Juanita, who reflected on her husband’s forgetfulness due to a stroke after a recent family dispute about the inheritance of a property. In Teotitlán, there are specific customs about how property is allocated among family, and it is perceived to be against tradition to dispute it. Yet in her husband’s case, he experienced an instance when these norms were not followed, which she explained signified larger changes within the community. Juanita interprets her husband’s forgetfulness as rooted in the stress of this conflict. “Well I believed it was due to a lot of stress and the anger that he had,” she said.

As we grew up and as we grew older, there was a lot of stress [we experienced] throughout our lives...[But a major source came from] a [family] dispute when we first got married. We got kicked out of his father’s house, and until now he [my husband] still talks about it. But I tell him to forget about it. Because we already have worked our way through, anyway. So we didn’t need them.

Juanita ultimately encourages her husband to forgo family ties. She told her husband that they “didn’t need them,” which helped foster peace at home, but was a significant diversion from normative expectations in Teotitlán to prioritize family cohesion. Though Juanita was reflecting on her husband’s sudden onset of symptoms due to a stroke, her perspective about her husband’s stress is illustrative of other caregivers who all viewed stress (or conditions related to stress) as a cause of forgetfulness.

Stress was at once viewed as a phenomenon that arises in settings that contrast to local lifestyle (such as in Oaxaca City or the US), and where individuals attempt to contest foreign influence of those changes in the community. This is a setting where family and social cohesion matter, but are put into tension by migration, pursuits of capital gain, and other modern modes of being. In this way, understanding forgetfulness as caused by stress serves a similar pragmatic function, as noted above: it clads progressive forgetfulness in a social fabric that engenders caregivers’ ability to note what is at stake as the community faces social change, and it furnishes a meaningful response to come together in the context of it.

As a whole, attending to the pragmatic function of etiologies moves beyond an understanding of etiology as mere theoretical explanation of illness. Here, it is a type of explanation that constructs a vision of the world based on desired action. As Dewey’s (1998 [1925]) point on metaphysics shows, the whole purpose of thinking is not to make sense of the world in an abstract sense, but to change it.
Pragmatism reveals how etiological explanations of illness are not merely constituted within social parameters, but also function to achieve the world caregivers want to live in. In Teotitlán, etiologies are aimed towards social cohesion, and are a means to continue engaging with elders by responding to their needs in the context of an ever-shifting social landscape.

Conclusion

Attending to perceptions and etiological explanations of Alzheimer’s in Oaxaca helps put into focus how talk about illness performs culturally specific functions. Idioms of distress are not simply constructed within social parameters, but are also constructive of the world people want to live in. Congruent with Nichter’s original formulation, this article has approached idioms of distress not just by studying their perceptible “whatness” (i.e., cultural differences) but also by pragmatically asking “why this?” (i.e., inquiring into their cultural functions). Idioms are not merely constituted within and expressive of cultural parameters, but are also dynamically responsive to those social surroundings. This is the larger significance of Nichter’s suggestion that researchers question why people express distress in a particular way, reminding us of the inherent agency of individuals as they encounter, respond to, and attempt to ameliorate distress surrounding illness.

While this sense of functionality has been implicit in the years since Nichter’s original project, it is important to provide a coherent epistemology to account for it. By shifting focus from thinking of truth as something objective, towards seeing it as created and based on usefulness, philosophical pragmatism attends to the functionality of idioms of distress without being sidetracked by questions of whether some health perspectives are more valid than others. According to pragmatists, claims about the causes of illness are valid insofar as they are useful. This helps us to appreciate the cultural differences noted in the symptoms and the perspectives about the cause of Alzheimer’s disease in their own right, and to become attuned to how those differences represent important strategies to live in the context of illness. Pragmatism at once helps appreciate the way idioms of distress are constituted within cultural parameters and, more important to this article, are expressive of human agency within them.

As we often assess beliefs for their validity, pragmatists are correct to show that this leads us to neglect due recognition that the types of truths we adopt impact broader spheres of life. Pragmatists remind us that studying idioms of distress has never been about achieving an ultimate truth about illness, but rather about studying how individuals work collectively with the best available information to pursue dignified lives. As Richard Rorty writes on this point:

Our identification with our community – our society, our political tradition, our intellectual heritage – is heightened when we see this community as ours rather than nature’s, shaped rather than found, one among many which men have made. In the end, the pragmatists tell us, what matters is our loyalty to other human beings clinging
together against the dark, not our hope of getting things right. (Rorty, 1982, p. 166, emphasis in original)

The voices gathered in this article speak to this sensibility. They reveal how perceptions and understandings of illness are not passively based on claims about underlying “objectivity,” but rather, are active efforts to make sense of the world in order to carry out meaningful social ends. In the case of Oaxaca, perspectives about Alzheimer’s disease demonstrate that what matters is bringing individuals closer together in a setting marked by social change and fragmentation. Such perspectives represent truth in a plural sense; for clinicians and social scientists who strive to understand illness experience, the truth of a given idea depends on the possibilities it opens for meaningful action.

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Notes
1. Many anthropologists might take objection to this approach. It is commonly expected that investigators fluently speak the language of those with whom they study to reduce interpersonal distance. Yet having a local spark conversation among household members fostered rich data—not between primary researcher and participants, but more importantly among participants as they talked amongst themselves. Having a research assistant to create a space for conversation—and subsequently having access to him to explain subtle differences (for example, during the transcription process)—unquestionably gave rise to more intimate data than if interviews had been conducted by the author himself in Spanish or Zapotec.

As Temple and Edwards (2008) rightly point out, translators are rarely employed to merely communicate ideas across languages. More importantly, they play the implicit
role of “border crossing” from one cultural outlook to another. Responding to the fact that many elders felt more comfortable and “at home” speaking in Zapotec, the research assistant and author identified the most salient questions in order for the translator himself to carry out discussions with household members in Zapotec. The translator waited for basic inquiries or prompts from this author and subsequently held in-depth conversations with members of households to learn about their experiences. This strategy was also informed by methods used in focus group discussions and attempted to maximize discussion among families while minimizing the researcher’s voice (Carey & Smith, 1994).

2. Indeed, the very fact that there exists no Zapotec word for “caregiver” or a related concept is expressive of the fact that providing care for members of the household is a presupposed feature of everyday life. In Teotitlán as in most other Oaxacan settings, taking care of one’s parents or one’s spouse is simply what one does. Caregivers adhered to relative social values about household and family cohesion, and they said that these efforts helped promote the larger family unit. Yet the Zapotec term for an elder, bengul, does help provide further insight: this word literally means “person who is mature in age.” As there are no gender pronouns in Zapotec, this word refers to the aged maturity found among both men and women. Most often, the word connotes a sense of prestige and respect on the basis of elders’ accumulation of life experience, much like the word “president” does. Such perceptions coalesce around the Zapotec notion of respet (“respect,” a Spanish cognate from the word respeto). Respet is a concept that refers to the amount of authority and honor a person is endowed by other members of the community. Respected individuals are greeted with a distinct handshake and spoken to with different pronouns and verb conjugations. As one adult explained, “Elders have more experience than we have had... In our community, they’re the ones that are respected the most. Because of our customs and you perhaps know it because in a fiesta they’re the first ones to be called on. So they’re the most important part of the community. And they deserve respect.”

3. There exist inherent difficulties in using the term “belief” to discuss people’s perspectives of health conditions (see Good, 1994). Yet the following pages deliberately use this term not only because it is the best translation for how caregivers described certain opinions about medicine and underlying etiology, but also because it situated the implicit power dynamics when it was compared to caregivers’ “knowledge” about biomedicine. This dichotomy is further explored in the author’s recent book (Yahalom, 2019).

References


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