

Spring 2011

Living for Two: Experiencing Alzheimer's Disease Through the Caregiver

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SIT
Brazil: Social Justice and Sustainability

Living For Two: Experiencing Alzheimer's Disease Through the Caregiver

An ISP Monograph Submitted in Partial Fulfillment of the Requirements
of:
ISPR 3000
14 June 2011

Submitted by:
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Abstract: This investigation focuses on the effects of Alzheimer's disease beyond the consequences it implicates for the patient. It must be recognized that this is a disease whose repercussions affect the family caregiver of the diseased with the same strength that it disturbs the principal carrier. The sporadic characteristics of Alzheimer's disease, externalized through mood swings, memory loss, the eventual loss of bodily functions, and, among other symptoms, the inability to communicate, create a category of instability and volatility experienced solely by the primary caregiver. This inconsistency that the primary family caregiver comes to know not only disturbs the patient-caregiver relationship, but also affects the caregiver's everyday, from stress levels to kinship ties. This study was realized in Fortaleza, Brazil, with a focus on the low-income neighborhood of Cristo Redentor. The socio-economic aspect plays a part in understanding the access to support where the government does not offer it. Through interviews with caregivers, discussions with health care workers, and participatory observation, the research found that the patient-caregiver relationship is reorganized in such a way that it does not mirror any other relationship that the patient maintains. Furthermore, due to the nature of Alzheimer's disease and its effects on the patient, the family caregiver must appropriate the patient's life narrative for it to continue. Lastly, the research emphasizes the caregiver's relationship with stress, noting that the experts' suggestions for reducing the overwhelming stress levels are by in large not heeded.

I would like to thank Maria, Maria Osmarina, Fabio, Lucas, Felipe, and Sabrina who graciously welcomed me into their home and treated me like a part of their family. While I could never have accomplished this research without them, I must add an extra amount of gratitude to the *palavras soltas da minha avó*, Maria Osmarina, without which, the idea for this research would never have occurred to me. I would also like to thank Deuciângela Carvalho, my project advisor, whose first words to me on the phone were, "My God, I don't understand anything this boy is saying," but who still had tremendous patience, and guided me through my struggles. Lastly, to the support network of the SIT Staff, without Bill, Emly, Neda, or Oélito, I simply would have been lost. *Obrigadão*.

I dedicate this research to all the people who quietly give care to family members, not due to obligation, but out of love; you all have bigger hearts than can ever be imagined.

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Methodology

This research was conducted over a three week period in two main locations in Fortaleza, Brazil: the neighborhood of Cristo Redentor and the Instituto de Geriatria e Gerontologia do Ceará. Cristo Redentor is a low-income area that makes up the larger conglomeration of Gran Pirambú, the second largest favela, or slum, in Brazil. Interviews were conducted with three caregivers in order to understand how their economic situations affect even more their everyday. Additionally, visits were made to a local non-governmental organization, Projeto 4 Varas, in conjunction with interviewing its co-founder in order to situate the culture of the neighborhood and understand its resources. At the second location, the Instituto de Geriatria e Gerontologia do Ceará, IGC, I conducted interviews with a social worker and with caregivers who volunteered to speak with me. The IGC is a geriatric clinic connected with the Hospital Valter Cantidio, a public hospital affiliated with the largest federal university in Fortaleza, Universidade Federal do Ceará. The interviews here in conjunction with the interviews with caregivers in Cristo Redentor allowed me to attain a deeper understanding of the patient-caregiver relationship, regardless of economic background. Finally, the social worker aided in contextualizing the caregivers' responses.

All interviews were carried out in Portuguese, which was then later transcribed. The questions throughout the interviews with the caregivers were semi-structured. Through this, I mean to say that I entered the interviews with an outline of major themes I wanted to discuss, but the caregiver was at liberty to simply talk about her¹ everyday. The questions that I posed were a means to direct the caregiver to focus on herself in relation to the disease and the patient, rather than explain the disease through the patient's symptoms.

¹ Author's Note: I elect to employ the female "she" and "her" when referring to the caregiver, as all caregivers in this research are women, a fact discussed later as a cultural nuance.

Statement of Social Relevance

The mindset of this research is to understand how the caregiver in Fortaleza is continually marginalized through a lack of support and a muted voice. As the research will demonstrate, this job, especially for those with basic economic means, is not one that is chosen by the caregiver, but is rather perceived as an obligation. These caregivers' narratives are not shared beyond their family networks or their support groups, if either exists for them. Through researching how their occupation affects their everyday and the relationships within which, one begins to understand how difficult the job actually is. Furthermore, as an increasingly aging population, caregivers will become progressively more vital to us as a society. Many of these future caregivers, like these participants, will enter the realm of giving care without true knowledge of how it will affect their relationship with the patient, the amount of added stress they are going to take on, and what instruments to use to handle all of it. This research, through the participants' narratives, discusses what the consequences of this are.

Introduction: Situating Alzheimer's Disease

“É que o cuidador é o despertador das lembranças. Lembram o que o outro esqueceu.”²

“Eu lembro que quando ela foi diagnosticada com a doença, ela falava sempre pra a gente, ‘você não vão falar pra as pessoas que tenho essa doença, não, porque essa doença é muito parecida à loucura.’”³

The pain and suffering Alzheimer's disease causes is grounded in a landscape of overlapping narratives. This research focuses on the principle family caregiver of an Alzheimer's disease patient, and investigates how the disease affects their everyday. In order to understand the caregiver's narrative, one must understand the relationship between the patient and the disease. The most recent theories on the cause of Alzheimer's disease, AD, suggest that the natural course of aging, without notice, may somehow trigger an amyloid-related mechanism that shrinks neuronal connections in the brain.⁴ However, only a few years ago, a different theory was prevailing, and furthermore, the National Institute of Health and the Alzheimer's Association disagree with each other on the root cause. In essence, although each new theory builds a greater understanding of the disease, the necessity of revising old ones emphasizes the fact that the cause is still a mystery.

Nevertheless, modern medicine has allowed us to understand, once active, what the disease does to the brain and the effects that it has on the patient suffering. In the neuron forest, signals travel forming the basis of memories, thoughts, and feelings. AD primarily targets neurons and the electric charges that travel within these cells. The activity of neurotransmitters,

²This and all subsequent translations from the Portuguese to English are done by the author. “It is such that the caregiver awakens memories. They remember what the other has forgotten,” see Field Journal, 49. Interview with Dr. Adalberto Barreto when he explains what the relationship is between caregiver and patient.

³“I remember that when she was diagnosed with the disease, she would always tell us, “Don't tell people that I have this disease, don't, because this disease is similar to going crazy,” see Field Journal, 16. Interview with Josélia when she explains her mother's reactions to her diagnosis.

⁴Anatoly Nikolaev, Dennis O'Leary, Todd McLaughlin, and Marc Tessier-Lavigne, *N-APP binds DR6 to cause axon pruning and neuron death via distinct caspases*, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2677572/?tool=pmcentrez> (August 2009).

tiny bursts of chemicals released when nerve cells connect to one another, is disrupted by the disease, and over time, causes nerve cell death and tissue loss. What this generates for the brain itself is a withered cortex, the area involved in thinking, planning, and remembering, a severe contraction in the hippocampus, where new memories are formed, and an augmentation of fluid-filled spaces known as ventricles.⁵

The disease's main victims are not limited to the bodies it inhabits. In other words, due to the pure nature of AD, the patient is not the only sufferer. Although everyone suffers when a family member goes through the fatal process of the disease, no one does more so than the primary family caregiver. The American Alzheimer's Association estimates that, in the United States, there are 15 million Alzheimer's and dementia caregivers providing 17 billion hours of unpaid care valued at US\$202 billion.⁶ The economic costs of caregiving do not stop at voluntary services. Beyond simply free hours, the toll of caregiving in 2010 created additional health care costs of US\$7.9 billion.⁷ These expenses were the result of high levels of stress, reported by 60% of caregivers in an Alzheimer's Association study, and symptoms of depression, asserted by 33% of caregivers in the same study.⁸ It is within these statistics that one begins to understand how intricately connected the life and disease of the patient is to their caregiver.

The stress that caregivers take on emanates from the uncertainty of their everyday caused by the inconsistency of the disease. Speaking of the disease, caregivers mention the "good" days and the "bad" days; however, there is no way of foretelling what kind of day it will be, and as a result, complete unpredictability. Clara Han, a medical anthropologist, in her study on the effects of the Chilean credit system on a low-income family defines "the possible" as "an indeterminacy

⁵ Alzheimer's Association. *Brain Tour*, <http://alz.org/brain/01.asp> (2011).

⁶ Alzheimer's Association. *Alzheimer's Facts and Figures*, http://www.alz.org/alzheimers_disease_facts_and_figures.asp (2011).

⁷ Ibid.

⁸ Ibid.

of lived relations within the present.”⁹ Along these lines, the sporadic nature of AD, externalized through patient’s dramatic mood swings, memory loss, and, among other symptoms, their inability to communicate, creates a type of instability experienced by the primary caregiver. In essence, the disease has the ability to dramatically alter a long-term relationship. This type of instability continues with the disease’s progression, and as this will play a major role in my findings, it must be noted here that Alzheimer’s disease is only terminated through death. The mean time of reaching that point is six to seven years where, along the way, confusion, aggression, communication breakdown, memory loss, and finally failure of bodily functions engender the loss of self.¹⁰ However, unlike in death where the chaos of one’s life ends organically, through AD, the chaos of one, and the burden with which it implicates, must be adopted by the other, the caregiver.¹¹

My findings explore the everyday of the caregiver in four aspects: the ability to accept the disease and the patient, the reorganization of the relationship with the patient, the effects on the physical and mental health of the caregiver, and the outlets available for support to the caregiver. Through this monograph, I posit that the shared narrative between the caregiver and the patient is no longer that; but rather, it is appropriated in an act of symbiosis to become a parallel narrative within the life of the caregiver. The locus of pain is situated in this dual narrative encompassing both the caregiver and the patient. It is here that one can perceive that while the patient unconsciously experiences the pain wrought by the disease, the caregiver consciously suffers *on behalf of* the patient. The caregiver lives the suffering that the disease has

⁹ Clara Han, “Symptoms of Another Life: Time, Possibility, and Domestic Relations in Chile’s Credit Economy,” in *Cultural Anthropology*, vol. 26, issue 1 (2011), 8.

¹⁰ Ron Brookmeyer, Elizabeth Johnson, Kathryn Ziegler-Graham, and H. Michael Arrighi. *Forecasting the Global Burden of Alzheimer’s Disease*, <http://works.bepress.com/cgi/viewcontent.cgi?article=1022&context=rbrookmeyer> (The Berkeley Electronic Press, 2007), 9.

¹¹ See Han, 2011 and Cavell, 2005.

made impossible for the patient to truly experience. Therefore, it cannot be a question of who suffers more because, in terms of a life history, the two can no longer be perceived as having separate narratives.

The research was carried out over a three-week period in two main locations in Fortaleza, Brazil, one being the low-income neighborhood of Cristo Redentor, and the other, the Instituto de Geriatria e Gerontologia do Ceará. The Instituto de Geriatria e Gerontologia do Ceará, IGC, is a peculiar place because of the patients there. The waiting room retains a special place in this research, as it was there where many of my critical observations occurred. During each visit, I was surrounded by a new group of people. At times, the stubbornness of the AD afflicted patients manifested itself in screams emanating from the various physician offices, similarly to what one would experience at a pediatric facility. Other times, for example, I was left sitting across from a man, in between his daughter and his wife, staring blankly at the floor. This man came to embody many of my encounters at the hospital. In this instance, a catheter soon became visible as the line traveled out of the left side of his shorts and into a plastic bag, which he aimlessly held. This begged the questions: Does he know the pain? Is he aware of where he is?¹² Yet, I could not ask him because of the nature of the disease.

In order to focus on the social aspect of the disease, I elected to interview various family caregivers in the Cristo Redentor neighborhood of Fortaleza, Brazil, which is part of the larger Gran Pirambú. To begin understanding this neighborhood, Projeto 4 Varas estimates that Gran Pirmabú houses over 250,000 inhabitants, marking it as the second largest “*favela*,” or slum, in Brazil.¹³ The government’s lack of presence in this neighborhood marginalizes the caregivers, as they have little knowledge of support groups where their situations would be truly

¹² See Field Journal, 51.

¹³ Projeto 4 Varas website.

understood. While my general thesis pertains to the restructuring of life narratives between the caregiver and the patient, I elected to execute this study with a focus on the Pirambú neighborhood, not as a way to assert that wealth diminishes the struggles to caring for an AD patient; but rather, to demonstrate that wealth can open the door to more resources to cope with those struggles. When a caregiver suffers stress levels to the point of damaging her¹⁴ mental and physical health because of a lack of access to coping mechanisms, this is structural violence.

¹⁴ Author's Note: I elect to employ the female "she" and "her" when referring to the caregiver, as all caregivers in this research are women, a fact discussed later as a cultural nuance.

Chapter 1: “Bereavement” and Acceptance

“E depois você se dá conta que essas coisas não vão curar a doença, e não pode resgatar sua mãe da doença; tem que aceitar.”¹⁵

“...e cinquenta e um anos depois de viver a tristeza e a alegria juntos, a gente acostuma à realidade.”¹⁶

Alzheimer’s disease is not death, and although it must end in death, the process of losing one’s self is not actual death. Due to the complications that AD causes for the patient, to an outsider, including the caregiver, the patient enters into this liminal state of the “living dead.”¹⁷ AD, in essence, forces the onlooker to enter into a negotiation of death, that is to say, for us to decide when we believe someone has passed, even though they may physically be there breathing. Anthropologists Sharon Kaufman and Lynn Morgan approach the end of life and claim that when dealing with the “almost-but-not-quite dead,” the problem arises from the question of “the nature of consciousness, the degree to which brain dead persons can be distinguished from corpses, and the moral ambiguity of bodies that are neither persons nor cadavers.”¹⁸ We cannot view such a hermeneutic disease as the termination of life, as it is distinct from that since one’s life narrative continues; however, even though the life narrative continues, one no longer has the express control over it. Although bereavement periods are usually contextualized within the realm of death, the intricacies of how AD affects the patient makes it so that their life narrative ends for *them*, thus making “bereavement” an appropriate term. The ending of a life narrative along with the disease’s symptoms causes a rupture of the

¹⁵ “And after you realize that these things are not going to cure the disease, and that you cannot rescue your mother from the disease, you have to accept it,” see Field Journal, 18. Josélia explains her process of understanding that her mother’s health was not going to improve.

¹⁶ “And after fifty-one years of living together through sadness and happiness, we become accustomed to reality,” see Field Journal, 42. Olga discusses how her long marriage with her husband aided her in accepting his Alzheimer’s disease.

¹⁷ See Desjarlais 2003 and Kaufman and Morgan 2005.

¹⁸ Sharon Kaufman and Lynn Morgan, “The Anthropology of the Beginnings and Ends of Life,” in *Annual Review of Anthropology*, vol. 34 (2005), 330.

past self. This chapter demonstrates how that breaking of the past self necessitates a “bereavement” period for the caregiver in order for her to accept her close loved one as ill. Furthermore, the caregiver must accept an alteration in the nature of her relationship because of the care her patient now requires.

We speak of the rupturing and reorganization of relationships during a bereavement period, in that during this time, we develop a new relationship to the deceased. Kaufman and Morgan emphasize the reordering of social relations during the end of life. They illustrate that this largely depends on the cultural understandings of indeterminacy and the transformation of a once living person to something else, “a corpse, nonperson, spirit, ancestor, etc.”¹⁹ I appropriate this term to apply it in this study because I view that Alzheimer’s disease has the ability to transform a living person into something else. In terms of the patient’s life narrative, the disease transforms the most active participant, the patient, into a passive role. Although they are still physically intact, they can no longer experience life for themselves; their life narratives are no longer in their own hands. What will be later discussed as the appropriated life narrative begins to arise here in the early stages. The patient begins to lose their ability to retain their own experiences, as they, along with their past, are forgotten. In other words, Alzheimer’s disease is akin to death in the sense that the patient can no longer retain their encounters. However, unlike in death where experiences are no longer created, here, experiences encompassing the patient as a central character continue to form but without the patient being able to preserve them. It is because of this inability to consciously continue one’s own life narrative that AD becomes similar to death, and requires mourning, or, “bereavement.”

What differentiates Alzheimer’s disease from other ailments is that it is the anticipation of death marked by the deterioration of the self. This knowledge that the caregiver has becomes

¹⁹ Ibid., 319.

the catalyst propelling her entrance into this “bereavement” period. These “bereavement” periods are described in various ways; however, all the explanations have common, central themes.

Maria Magalhães’ descriptions illuminate what is at the heart of this period. I first encountered her seated in the middle in the waiting room at the IGC with her 93-year-old mother, Belba. She spoke in a low, soft voice, as her unaware mother quietly sat behind us. The disease, like death, is not something Maria has ever been able to become *accustomed* to; she rather emphasizes the word “*aceitar*,” meaning to accept. Maria asserts, “*não, não é acostumar, é aceitar, né? Ninguém quer, ninguém quer isso. Mas aparece, e a gente tem que aceitar, pra ter uma vida melhor e cuidar melhor.*”²⁰ It is within this distinction between “becoming accustomed to” and “accepting” that Maria demonstrates the true process behind a bereavement period. To become accustomed is to maintain a continuous relationship with the sick, or the deceased; however, to accept is to reorder your relationship, which is precisely how Kauffman and Morgan convey a bereavement period to be.

This inability for the primary caregiver to become accustomed to the disease becomes a common theme throughout the interviews. Maria Magalhães verbalizes a sentiment that many others are unable to put into words. Maria Goret Guart, who cares for her 85-year-old mother, Maria Elce Rodrigues de Moraes, experiences the same trepidation in referring to her reorganized view of her mother’s illness as her having “become accustomed.” In discussing her process of acknowledging AD, Maria Goret Guart questions, “*Me acostumei? Não sei. Cuido da doença, cuido dela porque tá doente. Mas não me acostumei, acho que nenhum acostuma.*”²¹ Maria Goret Guart concludes that she rather has *accepted* the disease; for her, “to become accustomed”

²⁰ “It is not to become accustomed, it is to *accept*, right? Because no one wants, no one wants this. But it appears, and we have to accept, in order to have a better life and give better care,” see Field Journal, 22.

²¹ “Have I become accustomed? I don’t know. I give care to the disease; I take care of my mother because she’s sick. But I have not become accustomed, I don’t think anyone becomes accustomed,” see Field Journal, 26.

implies a different type of relationship than what she currently experiences. Maria's ability to accept the disease's transformative powers is noted in her responses to other questions.

Throughout the interview, she constantly employs the term "*normal*," never truly identifying what "*normal*" is until her final response. When "*normal*" is defined, it becomes evident that she has accepted her mother's disease and the reordered social aspects of their relationship. She proclaims, "*A gente teve que saber que agora isso é normal pra ela, que ela nao melhorará.*"²² Referring to her mother's present state as "normal for her," she asserts her acceptance. She does not resist against her mother's current condition. In her "bereavement" she has altered her perception of normalcy.

This alteration does not occur alongside the diagnosis, but rather is a process. All these primary caregivers had to come to terms with the disease through the "bereavement" period. These caregivers are speaking about the past that they have already lived. To give better care, accepting the disease through the "bereavement" period is necessary. Regina, who cares for her 72-year-old mother, Nanei Xavier, details this process: "*Quando soube da doença, eu fiquei triste e resisti, mas, tem que adaptar, tem que procurar tempo pra a adaptação, e eu aceitei. No inicio eu fiquei resistente, eu não disse nada, eu fiquei calada; realmente me afligiu.*"²³ Regina's first reactions center on her disbelief and, even more so, on her unwillingness to believe. Her emotions were manifested through silence and internal struggles. She highlights the necessity of the "bereavement" period when she discusses the need to find time to adapt. In order to care, one cannot be quiet and resistant, rather, one must accept, and this is the exact purpose that the "bereavement" period serves.

²² "We had to understand that now this is normal for her, that she will not get better," see Field Journal, 26.

²³ "When I found out about the disease, I was saddened and I resisted, but, you have to adapt, you have to find time to adapt, and I accepted. In the beginning I was resistant, I didn't say anything, I was quiet; it really affected me," see Field Journal, 41.

There were no instances where the primary caregiver was unable to eventually work through the process and come to accept the reordered social relationships; conversely, this is not the case for non-caregivers. Maria Magalhães, however, discusses her sister's predicament with accepting their mother's condition. She reveals that her sister "*não quer aceitar, de jeito nenhum. A gente agora fica conversando com ela tentando explicar pra ela que tem que aceitar pra ter uma vida melhor, tanto para nós como para ela. É que o Alzheimer não tem falta, cada vez vai piorando. Aceitar é saber que da pra pior, não vai ficar boa, realmente.*"²⁴ Her sister is not in constant contact with their mother's disease. Unlike Maria Magalhães, her sister does not *need* to accept, since she is not the caregiver. It is here that one begins to identify the special relationship between patient and caregiver. Her sister's inability to accept their mother's disease has hindered her sister's relationship with the family. Furthermore, Maria Magalhães worries for her sister because her lack of acceptance is also a lack of recognition that things are going to worsen, that there is no silver lining to the disease.

Accepting through the "bereavement" period does not mean letting go of the patient's past, but rather, accepting that that past is no longer the reality. This does not necessarily prompt that the past is no longer remembered. Josélia, whose mother, Maria Carmelita, was diagnosed with AD over a decade ago, contends, "*É o mesmo amor porque a gente vive das lembranças dela... As lembranças mostram que ela era muita alegre, muita comunicativa.*"²⁵ Even though her mother, twelve years after her diagnosis, is presently bedridden and uncommunicative, Josélia still finds a connection with her past. The previously discussed interviews demonstrate

²⁴ "[My sister] does not want to accept, at all. We now are talking with her, trying to explain to her that she has to accept in order to have a better life, as much for us as for her. It's that Alzheimer's disease doesn't skip anything, every day it worsens. Accepting means to know that it's going to get worse, that really, things won't get better" See Field Journal, 22.

²⁵ "It is the same love because we live through the memories of her... The memories show that she was very happy, very communicative" See Field Journal, 18.

that acceptance is the reordering of a relationship, it is creating a mental differentiation between the past patient's self and their current situation; yet, the past is not forgotten. This is done in order to understand and move forward. What caregivers come to accept through the "bereavement" period is that this is not death; death is the end, this is rather the expectation that things will deteriorate, but in the meanwhile, their loved one is still alive.

Alzheimer's disease propels the afflicted into a certain liminal state between the living and the dead, patients are identified as "almost-but-not-quite dead," and the disease becomes the anticipation of death. It is precisely because of this, that although "bereavement" is typically employed in conjunction with death, through using it here, I do not assert that AD patients are dead. Blieszner and Shifflett in their report on the effects of AD on close relationships emphatically underscore, "breakdown and decline in a relationship are psychologically distinct from dissolution and termination, and these processes have significantly different implications for the partners' future life styles and life satisfactions."²⁶ Although Blieszner and Shifflett are correct in describing the differences between the changes in relationships that ensue from death and those from AD, the "bereavement" period here underscores the immediate reordering of social relations as part of the process of relationship restructuring; yet, it only represents the beginning steps.

One participant's past experiences enabled her to detail the differences and similarities between approaching death and approaching AD. Olga Studart Roxa, who cares for her 77-year-old husband, brings an interesting point of view. Years ago, she suffered the death of two of her children before their respective fortieth birthdays. When questioned about the process of acknowledging and accepting her husband's disease, she was quick to compare it to her

²⁶ Rosemary Blieszner and Peggy Shifflett, "The Effects of Alzheimer's Disease on Close Relationships between Patients and Caregiver," in *Family Relations*, vol. 39, no. 1 (January, 1990), 57.

children's deaths. She describes, "*já me acostumei com os feios da vida. Dois dos meus filhos morreram ante dos quarenta anos. O meu filho morreu com trinta e oito anos e a minha filha morreu com trinta e nove anos. Quando a doença dele chegou, já estava acostumada. Então assim, quando meus dois filhos morreram, isso facilitou que eu aceitasse essa doença.*"²⁷ Olga likens the bereavement period she experienced through her children's deaths to the period where she accepted her husband's AD. For Olga, unlike the other interviewees, she feels comfortable describing her present state as being "accustomed." Olga understands the "ugliness of life" and the sorrows of burying her children, which has aided her in her process with her husband. Olga's situation offers juxtaposition between accepting death and accepting AD, and through this, it proves that the two processes are highly similar and can both be termed "bereavement" periods.

Olga's experiences with AD are distinct from the previously mentioned interviews because of her past; most notably, she does not take issue with the terminology of "being accustomed," but rather finds a connection with it. This introduces an important note that while many of the interviews have common themes, each caregiver internalizes and understands AD in a distinct manner. While the previous caregivers have utilized their "bereavement" periods to accept the disease and their new realities, others, such as Maria do Campo, utilize the period to begin to accept a new type of relationship.

Maria do Carmo, a caregiver living in the Cristo Redentor neighborhood, is the financial head of her household. She cares for her two children, two nephews, and her mother, Maria Osmarina, who was diagnosed with Alzheimer's disease five years ago. Similar to other participants, Maria expressed the difficulty in accepting the disease at first. What Maria emphasizes was even more difficult was, "*que me adaptasse que ela vai precisar mais de mim,*

²⁷ "I already became accustomed to the ugly side of life. Two of my children died before turning forty. My son died at thirty-eight years-old and my daughter died at thirty-nine years-old. When his sickness began, I was already accustomed. So, the deaths of my two children made it easier to accept the disease" See Field Journal, 43.

*que eu tenho que estar mais disponível pra ela.*²⁸ I will later detail Maria do Carmo's restructured relationship with her mother in the next chapter; however, here I would like to emphasize that Maria was forced to enter into a process of relearning her relationship with her mother. At the beginning of the disease, she comments, "*Não foi fácil aceitar, foi bem difícil me acostumar que ela precisava de mim.*"²⁹ Although others lament that their struggles in acceptance were more grounded in acknowledging that their loved one was sick, Maria found trouble in understanding her transformed relationship of dependence. However, Maria's process of learning to accommodate her refigured relationship is part of the larger "bereavement" period.

I elected to open this research paper with a chapter on the "bereavement" period because it symbolizes the first step for these caregivers: acceptance. As Regina pointed out in her testimony, accepting means no longer resisting. One cannot give proper care if one resists or refuses to understand the power of the disease affecting their loved one. Acceptance for them allows their relationship with the patient to grow. The consequences of continuing to not accept are embodied in Maria Magalhães' sister. Her sister's inability to accept has triggered a decaying relationship not only with her sick mother, but also with her family in general. It can be observed here that a "bereavement" period is more than simply the time to acknowledge the disease; it is the time to mourn the loss of an old relationship and accept the new, reordered one. Whereas in death mourners utilize this period to understand the physical disappearance of their loved one, with AD, caregivers employ the time to divorce their loved one's past self from the present in order to for them to accept what they are about to embark on. The process is malleable; some caregivers use it to alter their perceptions of normalcy, others to acknowledge that their patient

²⁸ "to adapt that she was going to need more from me, that I have to be more available for her," see Field Journal, 34.

²⁹ "It was not easy to accept. It was very difficult to become accustomed to the fact that she needed me," see Field Journal, 33.

needs their help, while a few take this time to move beyond the initial shock of the diagnosis. Yet, the common denominator amongst the different uses of this period is that through “bereaving,” caregivers attain a level of acceptance that allows them to move forward, that allows them to create, as Josélia asserts, “*um novo jeito de conviver.*”³⁰ The idea of moving forward, or being able to do so, becomes a central theme in the next chapter, which focuses on, post-“bereavement,” the changes the kinship relations between patient and caregiver may suffer.

Chapter 2: Ruptured and Reorganized Relationships

*“Enquanto ela não pode me mostrar o amor, eu sei. Já sei embora ela não diga mais que me ama.”*³¹

*“Pra mim, todo dia é bom porque o sol nasce; pela alegria da criança. Eu tenho tristeza dessa doença porque ele não é o mesmo, mas eu sou forte.”*³²

³⁰ “A new way of existing together,” see Field Journal, 18.

³¹ “While she can’t show me love, I know that she does; I know it even though she may not be able to say it anymore” See Field Journal, 24. Maria Goret Guart discloses this while explaining what she considers a “good” day and a “bad” day.

³² “For me, every day is good because the sun rises; because children are happy. This disease makes me sad because he is not the same person, but I am strong” See Field Journal, 42. Olga Studart Roxa explaining why there are no bad days for her.

The “bereavement” period is utilized to surpass the first stages of the disease in order to come to terms with the disease’s presence. Moving forward from this period, the caregiver must create a relationship with the patient’s changed self. Maria do Campo, in the previous chapter, demonstrated how the relationship between patient and caregiver began to transform. In her case, she had to acclimate herself to the idea that her mother needed her, that there was an alteration in the relationship of dependence. This relationship of dependence fits into the larger realm of a transformed relationship of power. This becomes an influential aspect of the caregiver-patient relationship. The locus of power in the relationship between the caregiver and patient, wherever it was situated beforehand, now lies solely with the caregiver. It is here that one begins to recognize why the relationship must be reorganized. Furthermore, as the disease progresses, the patient becomes exceedingly more reliant on the caregiver, while simultaneously less present in their everyday. In essence, the patient experiences a series of transformations that ultimately leads them to becoming different.³³ This process causes a rupturing with the past relationship and triggers establishing a reordered one. Each caregiver, however, internalizes the change in their patient in a distinctive manner, and thus not all will have the same reorganized relationship. This chapter expands upon the root causes for restructured relationships within the realm of AD and how these relationships are then rearranged. However, it must be noted that there are cultural nuances that will also be discussed, which greatly influence these relationships’ transformations.

On May 26, 2011, I walked into the IGC in hopes of digging deeper into the lives of these caregivers and how they relate to their patient. However, what struck me that day was not what anyone revealed, but rather, what I had failed to observe thus far in my research. Joining me in the waiting room sat two patients in wheelchairs, and behind them, all women. I could not

³³ Author’s note: I purposefully utilize the vague term “different” here because the disease affects each patient in a distinctive manner.

distinguish which daughter or sister or mother belonged to which patient, but it finally struck me that I had only been interviewing female caregivers. This occurrence was not by choice, but rather because I had yet to meet a male caregiver.³⁴ This cultural discrepancies means that in this research, the changes in relationship that are discussed all involve a female caregiver.

To understand this cultural peculiarity, I elicited the help of Deuciângela Carvalho. Deuciângela is a social worker at the IGC whose main responsibility is to orient the family caregivers in relation to what they should expect from the disease. In discussing the topic, she, unsurprisingly, found it odd that this would strike me as abnormal. She conveys, “*Geralmente, cuidar cai nas costas da ultima filha que não casou, que ficou em casa.*”³⁵ Caregiving, in essence for these women, is not a choice that they were able to weigh. Conversely, these women were thrust into the role of caregiving as soon as their parent or husband fell ill without a choice of opting out. Simone, who cares for her 84-year-old mother, Maria Anika, when questioned how she became the primary caregiver, responds matter-of-factly, “*Todo mundo casou e foi embora, e eu fiquei.*”³⁶ I do not opine that these caregivers would have elected otherwise; yet, they were never presented the option. Similarly to Simone, Maria do Campo underscores the reason for her position, detailing, “*Os meus irmãos, eles já tinham casado, e então eu fiquei em casa... Eu trabalhei antes, mas eu deixei de trabalhar quando o meu pai ficou doente.*” Maria left her outside job to begin caring for her father full-time, and subsequently, when her father died and her mother fell ill, she simply continued caring. For Maria and Simone it seemed to them as the only logical solution.

³⁴ See Field Journal, 4.

³⁵ “Generally caregiving falls on the shoulder of the last daughter that has not married, that still lives at home” See Field Journal, 36.

³⁶ “Everyone got married and left, and I stayed,” see Field Journal, 27.

For whatever reason they are in their situation, as caregivers, these women enter into a negotiation of their relationship with the patient. A reorganized relationship with their patient is based on the disconnection between the patient's former self and their present. This divorce between the previous and current self is directly linked to AD. Due to the disease, the patient no longer has the same personality, and eventually, loses all ability to have, what I refer to as, an engaged presence. Arthur Kleinman defines "presence" using the terms "attentive" and "responsible."³⁷ He offers a unique perspective as an anthropologist who has taken it upon himself to chronicle his experiences of caring for his wife with AD. Kleinman focuses on the presence that is required from the caregiver. The inverse aspect to this argument is just as significant, which would focus on the lack of the *patient's* engaged presence. Without this engaged presence there is no longer a way for the two parties to further develop their past relationship.

A study executed by Chesla, Martinson, and Muwaswes aids in better understanding this concept of engaged presence. Here the authors illustrate that it is not the lack of desire to care for the loved one, but rather the lack of a sense of reciprocity that alters the relationship's stability.³⁸ What the authors refer to as "lack of reciprocity," I deem as a lack of engaged presence. It is because of this that a rupturing of the past relationship between caregiver and patient occurs, which thus spurs the development of a reorganized one.

Recognizing the level of engaged presence the patient displays allows the observer to understand the current relationship between them and the family caregiver. In a sense, the root cause of the rupturing of a relationship lies within this lack of engaged presence perceived in the

³⁷ Arthur Kleinman, "Caregiving: The Divided Meaning of Being Human and the Divided Self of the Caregiver," in *Rethinking the Human*, eds. J. Michelle Molina and Donald K Swearer (Cambridge: Harvard University Press, 2010), 23.

³⁸ Catherine Chesla, Ida Martinson, and Marilou Muwaswes, "Continuities and Discontinuities in Family Members' Relationships with Alzheimer's Patients," in *Family Relations*, vol. 43, no. 1(January, 1994), 4.

patient. The patient's engaged presence in their everyday can be measured through their inability to be an active participant in the relationship. That is to say, the relationship suffers because the disease disallows the patients from attaining any more than a passive role in their own life narrative. This came to light on May 19, 2011 as I found myself once more in the waiting room of the IGC. I sat next to a woman who appeared frail and uncommunicative. Her daughter, at an average height and weight, requested a wheelchair to move her mother to the taxi waiting outside. As it began to rain, the daughter disappointedly looked towards the wheelchair, then looked towards her mother. Forgoing the wheelchair, in one fluid motion, as if it were a daily activity, the daughter placed her mother's toothpick sized arms around her neck, lifted her off her chair, and *carried* her to the awaiting taxi. The mother's facial expression was constant; she did not smile, nor did her eyes widen from shock. She became a body in her daughter's arms. Quite literally, her daughter carries her mother on the weight of her shoulders.³⁹ The mother here is alive, she continues to create experiences for her daughter and for onlookers; however, she plays a passive role in her life narrative since she cannot be present; her experiences must be made *for* her.

Even though as I looked on and watched this daughter carry her mother out of the waiting room, I was able to visualize a lack of engaged presence, it was not until the interviews that I was able to detect how this affected the caregiver. Although the caregivers in their various interviews do not use the phrasing and language that I have elected here, their experiences and accounts create an understanding of what it signifies to lack this engaged presence. The key word here is "engaged," meaning an active participant, which must be seen as distinct from simple presence. Maria Goret Guart cements the difference between an engaged presence and simply being there. Referring to how she views her mother, she illustrates, "*Pra mim, ela tá viva, tá*

³⁹ See Field Journal, 1.

*aqui. Isso é meu modo de pensar.*⁴⁰ Maria's mother is physically there, and although the disease has transformed her, for Maria, her mother is still alive. Juxtaposing this response with the one in which she laments, "*Ela tá lá, mas não ri mais. A gente sempre fazia brincadeiras com ela, e ela sempre brincava com a gente, mas agora, não. Quando a gente faz brincadeiras com ela, ela não ri,*"⁴¹ one detects the difference between existing and being engaged. Although Maria's mother is there, Maria's second response demonstrates that her mother is not engaged in her experiences, she is not an active participant. It is within this absence of laughter, of joking, within the absence of the person, that the rupturing and reorganization of relationships begins.

The caregiver lives the absence more so than any other person connected to the patient. It is through their eyes that an outsider may comprehend why the relationship changes and how the disease affects the ability to participate and be engaged. For these caregivers, this is an everyday experience; they are reminded on a daily basis that their closed loved one may *be* there, but is not *engaged*. Maria Magalhães, describing her daily activities with her mother, highlights, "*Também passeio muito com ela, até muito durante o fim da semana. E eu fico pensando que queria conversar com ela, mas ela não está.*"⁴² Maria's diction here is noteworthy because she even emphasizes, "but she is not here," when alluding to her desire to converse with her mother. It is clear here that Maria is not speaking about the physicality of her mother, but rather, the lack of her mother's engaged presence. Her mother is not an active participant in their walks, as much as Maria would like to talk to her mother, her mother is simply not there.

Many caregivers found it difficult to admit that the patients were no longer there.

Although in their responses to various questions, one could recognize that they felt that way,

⁴⁰ "For me, she is alive, she is here. This is my mindset," see Field Journal, 26.

⁴¹ "She is there, but she doesn't laugh anymore. We always used to joke around with her, and she would always joke with us, but now, that doesn't happen. When we joke with her, she doesn't laugh," see Field Journal, 24.

⁴² "I also walk a lot with her, even more during the weekends. And I am there thinking that I want to converse with her, but she is not there," see Field Journal, 20.

they were hesitant to claim their patient had changed. This most frequently occurred between daughter-caregivers and their sick parent. Comparing two of Simone's responses highlights this point. When asked how she perceives her mother, she asserts, "*Ela é a mesma pessoa*"⁴³; however, when she begins to detail her relationship with her mother before the disease, she recalls, "*Antes da doença, a gente estava muito pegado, conversava muito, dançava, viajava muito; mas agora, não.*"⁴⁴ When asked directly, Simone refuses to accept that her mother is not the same; yet, when asked to describe their days together, one can clearly recognize how Simone's mother no longer has an engaged presence, and simply, can no longer be the same *person*. Simone is not the only child that has found difficulties in admitting the existence of a restructured relationship with their parent. As demanding as it is to accept reorganization in one's parent-child relationship, nuances in Brazilian culture complicates this process even more.

The parent-child bond in Brazilian culture can be recognized in various aspects, even from the mere fact that a son or daughter often lives with their parents until marriage. There exists a strong cultural bond in the parent-child relationship, which binds the two, especially in relation to the mother. For this reason, Maria Magalhães expresses frustration as she explains that even though her mother recognizes her, "*me chama 'minha amiga.' E digo, 'não, sou a sua filha,' e ela me diz, 'você não, você é minha amiga.' E realmente, isso não sente muito bem.*"⁴⁵ Even though her mother is influenced by AD, Maria finds it extremely difficult in having her mother mistake her for just a friend, instead of seeing her as her daughter. In the interview, Maria even verbally stresses "*amiga*" to demonstrate her disdain. For Maria it is not enough that her mother recognizes that she knows her, which does not occur with other relatives and friends.

⁴³ "She is the same person," see Field Journal, 28.

⁴⁴ "Before the disease, we were very close, we used to converse a lot, we used to dance, we used to travel a lot; but now, no," see Field Journal, 28.

⁴⁵ "she calls me, 'my friend.'" And I say, 'no, I am your daughter,' and she says to me, 'you are not, you are my friend.' And really, this hurts my feelings," see Field Journal, 22.

Maria cannot bear to see that kinship relation broken. Similarly to Simone, Maria Magalhães hesitates in pronouncing that her mother has changed, because for her, that would mean a rupturing of that sacred bond.

Conversely, the same cultural imposition is not influential with regards to a wife caring for her husband. Although the sanctity of marriage in Brazil retains the same value as in any other culture, there is not this same impasse for married couples dealing with AD that exists for the parent-child scenario. It may be because of the different nature of the relationship, yet, wives caring for their sick husbands are less reluctant in proposing that their husbands no longer have an engaged presence. Olga Studart Roxa has been married to her husband for fifty-one years and she frequently asserts that their relationship has always been on good terms. They raised a family together, and she never suspected him of infidelity. Olga's bond with her husband, Fernando, can be perceived as unwavering, and when asked to describe the changes in their relationship, she concludes, "*A relação entre a gente mudou. Ele me beijava muito, mas ele não se lembra assim, tipo sexo, não se lembra.*"⁴⁶ Even though Olga has maintained a strong bond, she, like other wives, finds it easier to accept and discuss her changed patient. Olga's statement also serves to underscore how her husband's lack of engaged presence, manifested through his inability to intimately demonstrate his love for her, has restructured her relationship with him. The present relationship between Fernando and Olga is different from their relationship before the disease, yet still connected to it. AD did not dissolve their relationship, but rather caused a rupture in it, and it continues as transformed.

The idea of a transformed relationship is one of the three modes I employ in my research to understand how AD affects the primary family caregiver's relationship to the patient. For a

⁴⁶ "Our relationship changed. He used to kiss me a lot, but he doesn't remember how, things like sex, he doesn't remember," see Field Journal, 42.

guideline of approaching the variations in relationships between the primary family caregiver and the patient, I utilize a study executed by Chesla, Martinson, and Muwaswes. The authors categorize three main outcomes from AD in relation to the relationship between family caregiver and patient: a continuous relationship, a transformed relationship, and a discontinuous relationship.⁴⁷ Although I employ a theoretical framework from other anthropologists who have focused on the relationship between caregiver and patient, this study is particular from the rest because of the Brazilian cultural influences on that relationship.

The previously discussed “parent-child bond” is culturally important to this research, and furthermore, proved to be an obstacle in applying Chesla et al’s definitions. This cultural relationship is so engrained that it psychologically prohibits the child caregivers from answering direct questions in relation to the existence of a different type of relationship. The child caregivers are hesitant in admitting that the relationship has changed because they believe that a changed relationship is equal to a changed person. A changed person to these caregivers signals a loss of the patient.

Briefly, for Chesla, et al, a continuous relationship is one where “family members continued to define themselves ‘in relation to’ the patient in ways that paralleled their relations prior to the disease.”⁴⁸ A transformed relationship arises from family caregivers perceiving the patient as *lost* to them; however, they remain connected “to maintaining contact with the person that the patient had *become* in the disease.”⁴⁹ Finally, the discontinuous relationship is formed through the interpretation that “the spouse or parent was lost in the disease, and therefore the family member could not continue a truly personal relationship.”⁵⁰

⁴⁷ Catherine Chesla, et al., “Continuities and Discontinuities,” 3.

⁴⁸ *Ibid.*, 5.

⁴⁹ *Ibid.*, 6.

⁵⁰ *Ibid.*, 7

Although this is the basic framework for analyzing the restructured relationship, their study, as illustrated, does not fit culturally within Brazil. Due to this, I redefine these terms with more weight on if and how these relationships were reorganized after the diagnosis, rather than on the perception of the patient as being lost. For this study, a continuous relationship is one where the caregiver attempts to maintain the same relationship with the patient's past self, unwilling to accept a change in the patient's engaged presence. A transformed relationship is one where the caregiver develops a relationship to the patient through accepting their lack of engaged presence, while still maintaining continuity with the previous relationship. A discontinuous relationship is one where the relationship after the diagnosis has no real connection to the relationship before AD, but is not limited to relationships where caregivers believe their patient to be lost in the disease. In other words, in a discontinuous relationship, a relationship may be established after the diagnosis, but it has no continuity with the relationship that existed beforehand. As such, when I apply these terms, it is with the understanding that the majority of the primary child caregivers identify their parents as the same person, and furthermore, that even a discontinuous relationship does not refer to the caregiver perceiving their patient as lost.

Discussing engaged presence made it possible to locate the catalyst that causes the relationship's change. Nevertheless, the lack of engaged presence was not the actual change in the relationship. It is within how the caregiver describes her patient's lack of engaged presence that we can recognize the type of reordered relationship. When Maria Goret Guart was questioned directly if she believed her mother was the same person, she answered straightforwardly declaring, "*Ela é. Ela é a mesma mãe.*"⁵¹ However, continuing with the interview, when solicited to describe her relationship with her mother before the disease, Maria mourned, "*Éramos amigas, nem pra mim existia só uma mãe. Não é fácil agora, ela conversa,*

⁵¹ "She is. She is the same mother," see Field Journal, 25.

mas conversa das coisas que não têm nada que ver.”⁵² Maria lost a mother who was also her friend because of AD. However, mentally, she does not differentiate her present mother from her mother before the diagnosis. In her explanation of how things used to be, one can recognize that her mother is altered now. This relationship that Maria maintains can be identified as continuous. Maria refuses to accept that her mother lacks engaged presence. Although she comments on it, for her, the relationship’s continuity has not experienced a rupture. Maria will not admit to herself that her mother has changed, and thus, sustains a relationship largely based on the relationship before the diagnosis.

Where as continuous relationships view the patient as the person they were before the diagnosis, relationships between husband and wife, when faced with AD, are more likely to integrate the new patient’s self into the already established relationship. Sabrina’s relationship with her husband, Raimundo, transformed along with the onset of the disease. When asked if he was the same person to her, she explains, “*É muito difícil, porque ele mudou muito. Mas quando ele olha pra mim, é a mesma pessoa. Depois de cinquenta e seis anos, é a mesma pessoa.*”⁵³ In her response, Sabrina demonstrates that she accepts that her husband has changed, however, she remains unwilling to believe that he is lost in the disease. In those moments for her when she looks at him and sees the man she married fifty-six years ago, she forges a connection between her present, reorganized relationship with her husband and the one they shared before. In further discussing her relationship with her husband, Sabrina asserts, “*Quando eu saio pra medico ou pra banco, e quando volto, ele sempre me diz, ‘Não sai mais.’ O problema que ele tem tá na*

⁵² “We were friends, for me she was not just my mother. It isn’t easy now, she talks, but she talks about things that have nothing to do with anything,” see Field Journal, 26.

⁵³ “It is very difficult, because he has changed a lot. But when he looks at me, he’s the same person. After fifty-six years, he’s the same person,” see Field Journal, 14.

cabeça dele, mas as vezes ele tá ligado em uma forma.”⁵⁴ Sabrina reiterates here that she understands that he may not have the engaged presence to actually say “I love you,” but she has learned in her new relationship with him how to perceive that same sentiment. Additionally, Sabrina is able to acknowledge the disease, and divorce it from her husband. Sabrina contends at one point, “*Pra a gente, depois de tantos anos, é só parte da relação.*”⁵⁵ It becomes clear here that the even though the relationship has changed, it still maintains continuity with the past. Sabrina’s restructured relationship with her husband defines a transformed relationship, and because of that, she is able to continue to grow with her husband along the same trajectory as before.

The third outcome, a discontinuous relationship, creates a completely new relationship that resembles very little the previous one. In this instance, the caregiver does not have difficulties in accepting the new patient’s self; however, because that self is radically altered, the caregiver elects to construct a relationship with the patient’s new self, leaving little continuity between the restructured relationship and the one that existed before the diagnosis. Maria do Carmo, as was discussed in Chapter 1, found trouble in accepting that her mother, Maria Osmarina, because of her AD, was going to necessitate her help. This anxiety emanated from Maria’s relationship with her mother before her AD began. Maria highlights, “*Ela sempre foi mais ligada com meus irmãos, ela sempre só falva deles.*”⁵⁶ Their relationship, unlike the previously mentioned mother-daughter relationship, never had solid grounding. When the disease began to truly affect her mother, her mother changed. Maria’s perception of her present mother compared to that with her mother’s past self is not like Simone’s experience with her

⁵⁴ When I leave to go to the doctors or the bank, and then when I return, he always says to me, ‘Don’t leave anymore.’ The problem he has is in his head, but at times, somehow he becomes aware,” see Field Journal, 14.

⁵⁵ “For us, after so many years, it’s just part of the relationship,” see Field Journal, 13.

⁵⁶ “She was always more connected with my siblings, she would only speak about them,” see Field Journal, 33.

husband. Maria stresses that after her mother began to change, “*Ela ficou mais próxima. Antes era mais distanciada de mim. Eu sempre senti minha mãe distanciada de mim. Nunca senti ela do meu lado. Agora, eu sinto mais ela do meu lado.*”⁵⁷ Maria’s relationship with her transformed mother has been reorganized in a completely different manner, bearing little resemblance to how Maria describes their relationship in the past. That is not to claim that Maria is no longer aware of their previous qualms and issues with each other. Maria, rather, has decided to allow this new relationship to grow separate from their previous relationship. If she were not to permit this to occur, the grudges from the past relationship would hinder her ability to care for her mother.

Maria do Carmo ultimately learned how to accept that her mother needed her care, thus leading to her eventual restructured relationship with her. Regina, who cares for her 74-year-old mother, Nanei Xavier, experienced the same type of reordered relationship. Regina describes that her mother, before the onset of AD, “*era uma pessoa muita vocal, sempre cheia de opiniões, e por isso a gente tinha muitas discordâncias.*”⁵⁸ She then details how, in contrast to her previous self, “*Hoje ela tá mais passiva, e pra mim isso facilita tudo. As limitações que tinha no passado, agora não existe.*”⁵⁹ Regina, like Maria do Carmo, acknowledged her new mother’s self in order to accept a different kind of relationship with her. Although both daughters are aware of their past struggles, they move beyond them in order to care. Even though Regina’s new relationship with her mother is not as close as Maria’s is with hers, neither of the two view their mothers as “lost” in the disease and no longer present. The relationships between the two daughters and their

⁵⁷ “She became closer to me. Before, she distanced herself from me. I always felt like there was a wall between us. I never felt like she was on my side. Now, I feel much more like she is on my side,” see Field Journal, 33.

⁵⁸ [My mother] “was a very vocal person, always opinionated, and because of this, we had a lot of disagreements,” see Field Journal, 40.

⁵⁹ Today she’s more passive, and for me, this made everything easier. The limitations that we had in the past, now don’t exist,” see Field Journal, 40.

respective mothers presently have little in common with their relationships before AD, and for this reason, they can be termed as discontinuous.

Among the primary caregivers, Maria do Carmo and Regina are the only ones that expressed tension and resentment in their previous relationships with their mothers, and furthermore, they are the only ones to have subsequently entered into a discontinuous relationship with their patients. Josélia, a **former** primary caregiver, has entered, as well, into a discontinuous relationship; however, hers is vastly different than those previously discussed. On the other hand, her sister, Joselina, the current primary caregiver, has entered into a transformed relationship with their mother, Maria Carmelita. The juxtaposition of the two sisters' narratives highlight that even though the caregiver-patient relationship is restructured, it is still unique from any other relationship the patient maintains. It must be noted that their interviews were carried out on separate occasions, without the presence of the other, and that none of their responses were revealed.

Maria Carmelita lives with her husband and her daughter, Joselina, in their second floor apartment overlooking Avenida Theberge, the main commercial street in the Cristo Redentor neighborhood. I first met Maria Carmelita when I went to have lunch with Joselina and converse with her about caregiving. I walked up the stairs and Joselina showed me around. There is a makeshift dining room consisting of a table and four chairs in the hallway between the entrance and the kitchen. Where the architect had originally planned the dining room, there is now a hospital bed on which Maria Carmelita lies motionless in the fetal position. The dining room is reminiscent of a geriatric ward. There are post-it notes on the dresser where Maria Carmelita's medication is kept, serving as reminders to Joselina when to administer it. Joselina explains to me that her mother rarely opens her eyes anymore. She simply lies on the bed curled up much

like a small child. Maria Carmelita cannot eat on her own, and nearby her is the equipment necessary to administer her nutrients through a feeding tube.⁶⁰

Maria Carmelita, after battling Alzheimer's disease for twelve years, can now only wait for death to come. For ten of those twelve years, her daughter, Joselina, has been her sole primary caregiver. During the first two years, Joselina and Josélia shared the responsibility until Josélia left after finding a husband. Josélia, who has not spent the last ten years caregiving, describes how she currently perceives her mother, and asserts, "*Ela tá aqui, o físico, mas já não fala mais. Já já é outra pessoa. A mulher que está lá não é a mulher que era a minha mãe.*"⁶¹ Josélia maintains a discontinuous relationship with her mother in the radical sense that her mother is more than just not the same person. For Josélia, Maria Carmelita is lost in the disease, and the woman before her bears no resemblance to the woman she knew twelve years ago.

Josélia is no longer the primary caregiver, and has not been for a decade, and as such will not directly factor into theories pertaining to the primary caregiver; however, her juxtaposition with Joselina serves a greater purpose. Joselina, while discussing her perception of her mother in her current state, bluntly admits, "*Pra [meus irmãos], a mãe já tá morta!*"⁶² Her disdain towards her siblings for thinking this way illustrates that Joselina sustains a sort of continued relationship with mother. While for Josélia, her mother's uncommunicative, bedridden condition makes it impossible for her to identify the woman as her mother, Joselina, has been able to preserve a relationship with her throughout all the years. While explaining how her mother's degenerative condition has affected her in the past, Joselina, in relation to visitors seeing her mother, confesses that years ago she decided, "*A não ser que seja da familia, mas assim... todo mundo tem essa*

⁶⁰ See Field Journal, 6.

⁶¹ "She's there, physically, but she doesn't speak anymore. She's simply a different person. The woman that is there is not the woman that was my mother," see Field Journal, 17.

⁶² "For [my siblings], mom is already dead!" see Field Journal, 44.

idéia da minha mãe alegre, simpática, uma pessoa muito boa, aí quero que continue essa imagem. Não quero que as pessoas vejam...”⁶³ It is within this confession that Joselina demonstrates that long ago, she acknowledged that the illness had changed her mother. Furthermore, she proves here that she understands that visitors who knew Maria Carmelita in the past, upon seeing her, would develop the same type of discontinuous relationship with her mother that her siblings have forged. Yet, for her, it is still her mother there, and it is because of this transformed relationship, that Joselina has been able to move forward with her mother and not perceive her as lost. Josélia is unable to see this, not because she does not love her mother, but because she has not been caring for her daily throughout the disease. Josélia and Joselina’s experiences emphasize that although the caregiver’s relationship with the patient is reorganized because of the disease, it will always be stronger than the patient’s bond to a non-caregiver.

It is within this same idea that the patient-caregiver relationship is distinct from any other that one understands why and how this relationship is restructured. Our understanding centers on the lack of engaged presence, which catalyzes the restructuring of the relationship into one of three modes distinct to Brazilian culture. The caregiver endures this lack of engaged presence on a daily basis, and in order to continue caring for the patient even with that, they must come to a new understanding of their relationship. Whereas an outsider may see the patient as already lost, these Brazilian women who live the absence of the patient and continue to care for them, never reach the point where they no longer recognize their patient. This concept remains unchanged no matter whether the primary caregiver sustains a continuous, a transformed, or a discontinuous relationship. Nevertheless, simply because this new relationship is established with the patient, does not eliminate all stresses the caregivers feel in their everyday. While these previous

⁶³ “Unless it was family, well it’s like this, everyone has this idea about my mother being full of joy, being nice, being a very good person, and I just want this image to continue. I don’t want people to see...” see Field Journal, 43-4.

chapters have focused solely on the relationship between caregiver and patient, the next chapter will continue to discuss the role of the caregiver, while taking into account the external influences on her. In other words, we will come to the understanding that caregiving does not occur in a vacuum isolated from the outside world.

Chapter 3: Understanding the Caregiver's Stress

“Não, não, não acontecem dias bons. Espero que acontecer um dia bom. Mas agora não acontece um dia bom.”⁶⁴

“É, é difícil. Muito difícil. Me faz chorar, e choro, nunca em frente dela porque ela não sabe, e quando ela me olha chorando, ela fica emocionada e me pergunta, ‘Por que tá chorando?’ E não quero dizer por que.”⁶⁵

The previous chapter serves to prove that with AD, a certain type of relationship continues even after the patient's loss of self begins. Akin to relationships with the deceased, those with the AD patient continue in an altered form. For this reason, it becomes difficult to differentiate relationships post-mortem from relationships post-diagnosis; however, the main distinction lies within the fact that unlike in death, relationships with the AD victim continues to grow in different ways. This must be stressed because although AD may provoke similar feelings of sorrow and grief that death would, it is not the same. As discussed, it is peculiar from death, as

⁶⁴ “No, no, good days do not occur. I hope to have a good day, but now they don't happen,” see Field Journal, 12. Sabrina, when asked what she considers a good day or bad day, clarifies that for her, her husband's AD has eliminated the possibility of a “good” day.

⁶⁵ “It is, it is difficult. Very hard. It makes me cry, and I cry, never in front of her because she doesn't know why, and when she sees me crying, she gets anxious and asks me, ‘Why are you crying?’ And I don't want to tell her why,” see Field Journal, 26. Simone explains how the stress she feels from her mother's AD affects her.

that state terminates the victim's narrative. Alzheimer's disease, rather, is the inability for the patient to further his or her own narrative, yet that narrative still continues. The narrative's ability to persist is due to the primary caregiver's appropriation of it. In a broad sense, this chapter defines what it means for the primary caregiver to appropriate their patient's narrative. As a way to further our understanding of the stresses the caregiver endures on a daily basis, I will investigate how this appropriation is not limited to the life narrative of the patient, but also to the anxieties of that patient. Yet, the tension brought on from caring is not the only stress the caregiver confronts on a daily basis. In this vein, this chapter, in order to fully comprehend the caregiver's stress, will also explore the caregiver's world outside of their relationship with the patient.

A common occurrence in Maria do Campo's household may help in contextualizing the idea of what it means to appropriate the patient's narrative. As Maria and I are leaving the house to run an errand, Maria Osmarina, Maria's mother, stands up. Unable to form sounds other than a constant muttering of "sha," she points towards the living room and continues "speaking." Maria refers to this as "*palavras soltas*," unfinished words. Maria Osmarina understands what you say. She may forget it shortly thereafter, but she understands it nonetheless. Maria asks her what she wants as she continues to point. Thus begins the omnipresent game of twenty questions. Questions are deconstructed to their simplest form so that a shake of the head or a certain look can indicate "*sim ou não*," yes or no. Every time Maria Osmarina speaks, it is like a puzzle, and her daughter has become accustomed to putting the pieces together. Maria tries with, "*Quer Felipe* [Maria's youngest son]?" No. "*Quer assistir um programa*?" No. Fine. Maria is not in the mood; she turns to me and repeats that ubiquitous Brazilian phrase, "*Vamos lá*," let's go. We

leave never knowing what the mother actually desired. Closing the door behind us, Maria screams back to her youngest son to take care of Maria Osmarina: “*Felipe, olha avó!*”⁶⁶

Maria and her mother had been communicating fluently for decades before the onset of the disease, yet through the progression of AD, they can no longer converse. All of a sudden, understanding becomes a guessing game; one in which no matter how high your score reaches, it will never be perfect. Maria experiences her mother’s life for her, she remembers all her actions, she speaks for her, discerning to best of her ability what is hidden behind the *palavras soltas*, the unfinished words. The appropriated life narrative extends to this scenario because Maria never can truly know what her mother wants to say with the exact diction, the same syntax, or the same tone. Maria appropriates the ingredients that form the soul of the phrase, those insignificant nuances that empower the words. Maria takes on her mother’s communication.

The ability to communicate, whether verbally or through gestures, is a part of developing the life narrative; however, it is not the most important facet. What is truly at the heart of a life narrative is the ability to create and maintain experiences. Desjarlais, an American anthropologist, posits that being alive is intricately connected to maintaining experiences, which, for him, are the basis of the self.⁶⁷ In an ethnography of a homeless shelter in Boston, he stresses, “The phenomenal plane of experience is a thoroughly reflexive one: to experience is to engage in a process of perception, action, and reflection couched in *mindful introspection*.”⁶⁸ Note that the italicized words are in an effort by me to call attention to Desjarlais’ idea of reflexivity exceedingly associated with experience. In the Desjarlais sense, the AD patient no longer experiences. Rather, the patient continues to create experiences and play an active role in *others’*

⁶⁶ See Field Journal, 3.

⁶⁷ See Desjarlais 1997 and Desjarlais 2003

⁶⁸ Robert Desjarlais, *Shelter Blues: Sanity and Selfhood Among the Homeless*, (Philadelphia: University of Pennsylvania Press, 2003), 22.

life narratives, especially that of the primary caregiver; yet, when it comes to the focus of the patient's own life narrative, the position of it has transferred away from the owner. This becomes clearer turning to the metaphor Desjarlais employs when discussing the body: "The body is often held to be one container, with the skin as an 'envelope' within which, as William Faulkner writes, 'the sum of experience' resides."⁶⁹ The process of AD forces the envelope to undo itself, and in this way, it is not as though experiences cease to be made, but rather, that there is no longer an "envelope" to retain them or maintain the past ones. Nevertheless, these experiences still exist and are predominately retained through the primary family caregiver. It is because of this that we can only see the experience of AD through the eyes of the caregiver. This connects back to how Maria Osmarina is only ever understood through the words of her daughter, Maria do Carmo. It is in this way that it can be perceived how the caregiver simultaneously continues her life narrative while also appropriating that of the patient. Furthermore, quite simply, this illustrates why caregiving is being present for two.

An appropriated life narrative is not something that can be expressed directly through the caregiver's words. It is because the caregiver maintains the memories and experiences the patient is no longer able to retain that the locus of the patient's life narrative shifts towards the caregiver. Dr. Adalberto Barreto, an anthropologist and psychologist, as well as the co-founder of the Projeto 4 Varas, a mental health NGO in Cristo Redentor, works with caregivers. In discussing the unique relationship between caregiver and patient, he highlights, "[São] *coleguinhas, o cuidador e o paciente*."⁷⁰ While Dr. Barreto does not go as far to say that the caregiver is the holder of the patient's experiences, he does touch on the notion. His phrasing, "intimate colleagues," conjures the idea that they are bound together, with one unable to exist without the

⁶⁹ Ibid., 16.

⁷⁰ "[They are] intimate colleagues, the caregiver and the patient," see Field Journal, 49.

other. Although the caregiver would exist without the patient, the caregiver is the sole reason for the patient's experiences continuing to be retained, and in this sense, for their life narrative to be remembered.

The idea of "intimate colleagues," is created through the recognition that the caregiver has symbiotically absorbed the patient. This is a process that is quickened by the degenerative nature of AD. The disease creates greater dependence on the caregiver with each subsequent symptom. The caregiver arrives to the point, like Simone has with her mother, where there no longer exists a separation. Simone, describing what it means to be the principal caregiver, explains, "*Agora, ela tá vinte e quatro horas comigo; minha vida já é vinte e quatro horas da vida dela.*"⁷¹ Simone simply through discussing her everyday, verbalizes the notion of the appropriated life narrative. In her description, she emphasize that her life is now her mother's life. The two are no longer separate narratives, but rather, have become parallel narratives both encompassed by Simone.

Simone is the only caregiver that was able to directly articulate this notion. In order to identify the same idea with the other participants, one must alternatively look towards how this idea is externalized in the caregiver's everyday. The appropriated life narrative in the everyday is perceived through the ability for the caregiver to become conscious for the patient. Dr. Barreto succinctly describes this consciousness when he details what the role of the caregiver is:

*"Lembram o que o outro esqueceu. Se o outro fica triste, e não tem sentido pra ele, você se lembra depois de quantos anos por que ele fica assim."*⁷² Dr. Barreto points out here that beyond administering medication, going to doctor appoints, or feeding the patient, part of the caregiver's role is to contextualize the patient through sustaining their life history. The caregiver not only

⁷¹ "Now, she is with me twenty-four hours a day; my life is already twenty-four hours of hers," see Field Journal, 27.

⁷² "They remember what the other has forgotten. If the other becomes sad, and doesn't know why, you remember after so many years why he is like this," see Field Journal, 49.

maintains the new experiences that are formed, but also preserves the patient's past, their life narrative. In assuring that the patient "makes sense," or in other words, that the patient upholds certain continuity with their former self, the caregiver becomes conscious for the patient. The primary family caregiver is able to accomplish this feat because they know that patient. In this same vein, Joselina pronounces quite simply, "*Eu sei das coisas da minha mãe que os outros não.*"⁷³ It is because the primary caregivers are wholly aware of their patient's life narrative that they are able to continue it on behalf of them.

As discussed, being conscious for the other requires the understanding of the patient's life narrative before the onset of the disease. This is so that while the patient may forget a substantial event in their life, you, as the caregiver, still retain it. Maria do Carmo speaks to that concept when asked about her mother's relationship to her dead father. Maria surmises that although Maria Osmarina, her mother, never asks for her dead husband, "*Ela sente falta, mas ela não tem consciência. A mente dela apagou das lembranças dele, acho que pra não sofrer.*"⁷⁴ Maria understands her mother's past, she preserve her mother's life narrative because her mother no longer can. Maria here also acknowledges that her mother lacks conscious of past events, and as such, recognizes that she must be conscious on behalf of her. This "conscious on behalf of" can also force the caregiver to relive stressful moments. Unlike Maria Osmarina, Maria Goret Guart's mother does frequently ask where her husband is, and even more, where her father is. It is within these questions for dead relatives that Maria Goret Guart admits, "*E tenho que explicar outra vez que não vai vir, e é difícil. Tenho que viver o morto do meu pai toda vez que lhe*

⁷³ "I know things about my mother that others don't," see Field Journal, 43.

⁷⁴ "She misses her, but she is not conscious of it. Her mind has shut him out of her memories, I think so that she doesn't suffer," see Field Journal, 31.

explico.”⁷⁵ Maria Goret Guart, because she is conscious on behalf of her mother and understands for whom she is asking, is forced into a tense situation where she must recall her father’s death. It is here that an outsider can begin to recognize the stressful components related to being conscious for an other.

This idea of being conscious on behalf of the patient extends beyond the realm of the life narrative. An even more stressful situation is that the caregiver, in being conscious on behalf of the patient, finds herself constantly thinking about her patient. Josélia recalls her two years as the primary caregiver, and underscores, “*É assim, quando a pessoa é cuidador, você pensa pra os dois. Você sempre tá pensando em o que pode ser perigoso pra ela, ou coisas assim, você não pode desliga, você tem que estar ali sempre.*”⁷⁶ She elects “*os dois*” here to refer to the patient and the caregiver. Josélia admits that, like the other caregivers, she always used to find herself thinking about the patient because she acknowledged that her mother could not be conscious for herself. Furthermore, she demonstrates that the caregiver must always be present and engaged for the patient. However, what must be remembered is that the caregiver also maintains her own life narrative, her own stresses, and her own consciousness. The caregiver is not an empty container to be filled with the patient’s life. The extreme stress and depression the caregiver may endure is born out of the fact that she is being conscious for both herself and her patient, that she is continuing both life narratives, and that she is, quite simply, living for two.

Arthur Kleinman, in his writings based on caring for an AD patient, focuses on the need for the caregiver’s “presence,” and how this requires a divided self. I identify this “divided self” as a reference to one taking on the narrative of the patient while also maintaining one’s own. He

⁷⁵ “And I have to explain again that he’s not going to come, and it’s difficult. I have to experience my father’s death every time that I explain this to her,” see Field Journal, 25.

⁷⁶ “It’s like this, when someone is a caregiver, you think for both people. You always are thinking about what could be dangerous for her, or things like that, you can never disconnect, you have to always be there,” see Field Journal, 17.

succinctly describes that through becoming a primary caregiver, “we become aware of our incompleteness and the limits of our selfhood.”⁷⁷ It is within this “incompleteness” and the inability to continuously lead a divided life that leads to caregivers expressing feelings of entrapment or depression. Dividing one’s self in order to take on the narrative of another, while simultaneously continuing one’s own is part of the locus of stress.

Maria do Carmo, like all primary caregivers, experiences stress in her everyday unrelated to her mother’s illness. One night, over potato and carrot soup, Maria began relaying her day’s activities. She explained to me how she had to ask a friend to come to the house and watch over her mother for a couple hours while she went to the local courthouse. The courthouse visit was to resolve “*algumas problemas*,” some problems. The courthouse has failed to send Maria her finalized divorce papers, which she is more than willing to sign, in the nine months since she first requested them. However, there is another motive for the trip. The court sends representatives to houses to verify claims of caring for a sick person in order for the household to receive federal aid. Maria scheduled the appointment to have a representative come to her house one year ago; yet, no one ever followed up. She recounted to me how she once again that day provided them with her address and phone numbers, only to be told that a representative should be coming shortly. Maria thought this situation to be stressful, however, she could do nothing besides shrug her shoulders in acceptance.⁷⁸ This her everyday; however, what would have been a trip to finalize a divorce is complicated by the court system’s lag time in approving additional funds for the household.

While Maria was able to handle this situation in a controlled manner, other caregivers find their daily stresses in conjunction with caring overwhelming. Their anxieties about caring

⁷⁷ Arthur Kleinman, “Caregiving: The Divided Meaning of Being Human ,” 18.

⁷⁸ See Field Journal, 2.

manifest themselves in various ways, from feelings of loneliness to depression. Many caregivers lament over the lack of sleep they receive, as they lie awake thinking about the patient. In this vein, Joselina admits, “*Eu não durmo bem mais, porque antes eu dormia super bem, agora não. O meu sonho é muito leve e não consigo dormir direito mais porque eu fico com medo toda hora que ela vá morrer, sabe?*”⁷⁹ Joselina, similarly to the other caregivers, is unable to ever stop being conscious for her mother; she is constantly thinking both about herself and about her mother. This extreme sleep deprivation that she experiences is only one of the ways in which the added stress of caring is able to affect the caregiver’s health.

The caregiver’s health is paramount in her ability to continue to give care to her patient and endure her everyday. Whether through sleep deprivation or through placing added stress on other relationships, caregiving takes its toll on the caregiver; yet, in its most developed form, stress from caregiving is able to manifest itself in low self-esteem and depression. While many caregivers recall extreme stress and a constant feeling of anxiety, Joselina, along with others, dejectedly admits, “*Ultimamente eu não estou gostando de mim, muito não.*”⁸⁰ Her low self-esteem is exacerbated by the feelings of loneliness and the weight of the world on her shoulders. It is also the root cause for her various battles with depression. On this theme, Dr. Barreto emphasizes, “*O maior patrimônio numa pessoa é a confiança em si.*”⁸¹ In relation to caregivers, Dr. Barreto believes a vital component is solid self-esteem. The stress of caring and of being conscious for the patient, while the patient’s disease continues to deteriorate, leads to the caregiver expressing sentiments of failure and inadequacy.

⁷⁹ “I don’t sleep well anymore, because before I used to sleep really well, now I don’t. My sleep is very light and I can’t go straight to bed anymore because I’m always scared that she is going to die, you know?” see Field Journal, 44.

⁸⁰ “Lately, I haven’t been liking myself, not very much,” see Field Journal, 45.

⁸¹ “A persons’ best asset is confidence in themselves,” see Field Journal, 48.

The patient's outbursts are also sources of feelings of defectiveness and stress. When AD causes the patient to "act out" and become aggressive, it creates stress for the caregiver. It is here that one can recognize the contagious characteristics of stress. These caregivers describe their days through not only their own stresses and anxieties, but also through their patients. Maria Magalhães illustrates how connected her mother's stress is to her own, describing, "*quando ela tá muita gritada e não fica calma e em vez de conversar, ela grita ou bate, eu fico nervosa, como qualquer pessoa, mas é que eu tenho que controlar.*"⁸² Although it is not an easy task, Maria recognizes that it is the disease causing her mother to act in this manner, and the situation would only worsen if Maria did not remain calm and unstressed. A good day for the caregiver is when the patient is not stressed or anxious. The caregivers' days are frequently recalled *in relation to* the patient, and it is in this notion that one can perceive how stress enters into the appropriated life narrative.

As previously mentioned, caregiving does not occur in a vacuum, and as such, the relationship between the caregiver and the patient is not the only one that may be affected. The stress that the caregiver endures because of her relationship with the patient also affects other relationships. Simone, while discussing the stress she feels from caring for her mother, laments, "*E não tenho mais tempo pra meu marido. Sair, diversão, é difícil, agora ele não gosta mais de mim {laughs}, mas é difícil. Quando ele quer sair, é difícil, eu tenho que ficar com ela. Esse cria um grau de stress bem alto, porque a doença está afetando tudo.*"⁸³ Simone finds it difficult to divorce her role as caregiver from her outside life. Having to be conscious for herself and her mother, Simone's relationship with her husband suffers because she cannot be present for him. In

⁸² "when she shouts and doesn't stay calm and instead of talking, she screams or hits, I get nervous, like any other person, but I have to stay controlled," see Field Journal, 20.

⁸³ And I don't have any more time for my husband. Going out, having fun, it's difficult, now he no longer likes me {laughs}. When he wants to go out, it's hard; I have to stay with her. This creates a high level of stress because the disease is affecting everything," see Field Journal, 28.

the previous chapters, I have focused purely on the relationship between caregiver and patient; however, here it is recognized that caregiving, for Simone and the other participants, has become their lives, the stresses of which reach far beyond solely the patient-caregiver relationship.

Many of the stresses of caregiving are born out of the notion of an appropriated life narrative, in that the caregiver is not only preserving and maintaining her patient's life history, but also her patient's stress. The caregiver begins to constantly think about the other to the point that her divided self is split between her worries about herself and her worries about the patient. In this equation, there is little room for relationships outside of the patient. It is within attempting to maintain her own self while also her patient's self that the caregiver quickly becomes overwhelmed. Additionally, this highlights how fundamental support is to the well-being of the caregiver. The next chapter will explore how these caregivers tolerate the discussed stresses, placing particular emphasis to those living in the low-income neighborhood of Cristo Redentor.

Chapter 4: Outlets for Stress

“Pra cuidar bem, o cuidador tem que estar bem!”⁸⁴

“É ingressado, e dá pra rir, e só posso rir, porque se não, o que é, né? Tem que rir.”⁸⁵

For some caregivers, as was discussed, stress manifests itself in feelings of inadequacy, low self-esteem, and depression. However, there exist healthier options so that the stress build up does not transform itself into a debilitating issue for the caregiver. Utilizing the expertise of the IGC social worker, Deuciângela Carvalho, and that of psychologist and co-founder of Projeto 4 Varas, Dr. Adalberto Barreto, we can understand to what caregivers should commit in order to endure the stresses of caregiving, and furthermore, why these outlets are appropriate. However, what is proposed is not always carried out. In this vein, this chapter will ask the caregivers how they incorporate the suggestions into their everyday and how they maintain their stress. Particular attention will be placed on the three caregivers in Cristo Redentor in order to understand what is available to them in their neighborhood and if they take advantage of it. Additionally, this information will be employed to comprehend how caregivers in a low-income neighborhood are further marginalized.

⁸⁴ “In order to care well, the caregiver has to be well,” see Field Journal, 36. Deuciângela emphasizes here the necessity for the caregiver to find time to take care of herself in order to take care of her patient.

⁸⁵ “It’s funny, and it’s worth laughing at, and the only thing I can do is laugh, because if I don’t, what else is there to do, right?” see Field Journal, 25. Maria Goret Guart explains that sometimes when her mother does things that stress her out, she simply has to stop, and laugh, because there is no better remedy.

Whenever the caregivers cried during the interviews it would be during one of two themes: seeing a loved one go through AD or feeling a lack of support. Support can be perceived financially, which becomes more of an issue among the caregivers in Cristo Redentor, or as someone to converse with so as not to feel so alone in one's struggles. Deuciângela explains that she separately meets with the woman who will be the primary caregiver and then with that woman's family. In these orientation meetings, one of Deuciângela's main objectives is to make the caregiver understand that she also has to take care of herself. In order to emphasize this point, when she speaks to the family of the patient and caregiver, she asserts, "*Olha, não dá pra ficar só uma pessoa cuidando essa pessoa; não vai agüentar,*" she goes on to explain, "*Pra que isso não ocorra, a cuidadora tem que se cuidar. Tem que ter momentos de lazer...*"⁸⁶ The first section demonstrates how Deuciângela attempts to convey to the families that a support network amongst them must exist. In Deuciângela's solution to stress, although there may be one primary caregiver, the other family members help, especially in creating time for the caregiver to relax. For the caregiver to endure the stresses and anxieties of caring, Deuciângela warns, she must take care of herself and have free time.

Apart from the leisure time that Deuciângela prescribes to help maintain the caregiver's stability, there is also an emphasis placed on support groups where the caregiver can voice her concerns and talk about her everyday. Through the IGC, Deuciângela organizes meetings every Thursday for the caregiver and her family. Although at the moment these meetings have been suspended due to construction, she urges the caregivers to attend.⁸⁷ Support groups are places where one can go to be understood, where others have experiences that relate. Dr. Barreto explains that when he leads these types of groups he highlights, "*Eu tenho o saber da*

⁸⁶ "Look, it won't work if only one person is caring for this person; they won't be able to handle it"... "So that this doesn't happen, the caregiver has to take care of herself. She has to find leisure time..." see Field Journal, 36.

⁸⁷ See Field Journal, 36.

universidade que me permite prescrever os remédios controlados. Mas, cada um de vocês tem um saber... O que nós vamos fazer aqui é compartilhar saberes.”⁸⁸ Through this explanation, one begins to grasp the theoretical foundation of a support group. It becomes a place where the caregiver is reminded that she has wisdom and knowledge already, which empowers her and assists with her self-esteem. Additionally, this is a place where caregivers converse amongst themselves, and through helping others in similar situations, the caregiver can help herself.

Deuciângela’s advice, if followed, would help to inhibit stress from overwhelming the caregiver; however, through the interviews, a noticeable disconnect arises between Deuciângela’s scenarios and what truly occurs. Through analyzing how Deuciângela orients the caregiver, one can identify the three central aspects to creating a less stressful environment: leisure time, familial support, and support groups. Focusing on the caregivers’ responses in relation to these three elements, one begins to understand how the reality of the situation does not mirror the clinical suggestions.

Leisure time for the caregiver is when she is able to unwind. Even if in this time she is thinking about the patient, she is separate from the patient and can breathe on her own. The lack of leisure time in the caregiver’s everyday was noted in each interview. Regina can recognize the importance of leisure time, nevertheless, when questioned about her free time, she answers with a smile, “*Eu?! Pessoalmente, não,*” she goes on to qualify, “*Eu trabalho de manhã, de tarde e praticamente toda a noite. Eu tô tratando de relaxar... O relaxamento que a gente precisa, não tenho.*”⁸⁹ She finds it comical that I would ask about her leisure time, because she does not truly have any. Additionally, Regina understands that she is not taking care of herself; but for her, like

⁸⁸ “I have university knowledge that permits me to prescribe controlled medication. But, each one of you has wisdom... What we are going to do here is share knowledge,” see Field Journal, 46.

⁸⁹ “Me?! Personally, no.”... “I work in the morning, in the afternoon, and practically all night. I am trying to relax... The relaxation that we need, I don’t have,” see Field Journal, 40.

the other caregivers, she simply does not have the time. Maria Goret Guart speaks on the same issue of time. While explaining the nonexistence of her free time, she stresses, “...só *cuido dela. Não tenho lazer assim. É difícil quando meus filhos vêm pra casa e dizem, ‘vamos à praia nós três,’ é difícil.*”⁹⁰ As was discussed in Chapter 3, the caregiver and patient are not the only actors involved in AD. While they may be the protagonists, there are other people that are affected. Maria highlights here that not only is she not finding time for herself, but also in her constant caring for her mother, she neglects her two children. Maria and Regina serve to demonstrate that what Deuciângela points out to be a key component in reducing stress, many caregivers simply do not exercise.

Regina, in her narrative, proves that it is not the fact that these caregivers do not recognize the basic elements they are missing from their everyday that would reduce their stress, but rather, that they simply do not have them. This notion extends beyond just leisure time, and in fact, enters into each facet. Deuciângela emphasizes the need for kinship support, even to the point of meeting with the caregiver’s families and explaining how important they are to the *caregiver*. It is within these long established relationships that the caregiver should be able to find acceptance and understanding. Even though this may be the case, Joselina, in relation to her familial network, laments, “*Me dá raiva mesmo. Ela tá acamada, e ela já tem doze anos com essa doença e pode durar mais porque eu cuida dela com amor, não por obrigação. Eu queria que os meus irmãos ajudassem, nem eles ajudam financeiramente.*”⁹¹ It is noteworthy that this response was not prompted. During the course of the interview, familial relations had yet to arise when she stopped in order to tell me what she refers to as “*a coisa mais importante,*” the most

⁹⁰ “I only take care of her. I don’t have free time. It’s hard when my kids come home and say, ‘Let’s go to the beach, us three,’ it’s hard,” see Field Journal, 25.

⁹¹ “I get so angry. She is bedridden, and has had this disease for the past 12 years and it could go longer because I take care of her with love, not out of obligation. I would like my siblings to help, they don’t even help financially,” see Field Journal, 44.

important thing. For her, the lack of support from her family is what most affects her outlook and her everyday. Similarly to many in Cristo Redentor, Joselina does not have the financial liquidity to burden all the costs of caring. Without her siblings' aid, she and her father decided to take money out of his salary and dwindling retirement fund. Additionally, the kinship ties that Joselina perceives as unsupportive and absent have thus eliminated the group of people that are supposed to aid in maintaining self-esteem. Her siblings' lack of presence manifests itself in Joselina through her low-self esteem and, as was discussed in the previous chapter, her bouts with depression. However, one must bear in mind that each caregiver has a different situation, so while Joselina, like others, may not be able to form a family support network, some find that network to be vital.

It should be noted here that through discussing Deuciângela's elements to reducing stress individually, it allows for the breakdown of how each one relates to the caregiver. However, this same organization diminishes the components' interconnectivity. That is to say, it erroneously makes it seem as though the three facets exist independently of each other. For example, Joselina connects her family's lack of support with her incapability to have free time away from her mother. Her familial network should give her room to breathe, however, Joselina admits, "*Todo mundo faz algumas coisas pra minha mãe... mas ninguém faz nada pra mim. Se eu quero ir à igreja, ao shopping, ao cinema, ninguém tem tempo pra ficar com a mãe.*"⁹² Joselina is not the only caregiver to express the interrelatedness of the three keys to reduced stress, and even more, has no remedy other than wishing it were different.

In identifying that their everyday lacks these stress reducers, the caregivers' narratives prove Deuciângela's correct in naming them paramount to controlling anxiety levels. What

⁹² "Everyone does something's for my mom... but no one does anything for me. If I want to go to Church, to the mall, to the movies, no one has time to stay with Mom," see Field Journal, 44.

remains, however, is that they also demonstrate that attaining these components is not as simple as it may first appear. Only one participant admitted to ever attending the support meetings at the hospital. Maria Magalhães expresses their importance to her as she describes, “*Lá no começo, isso aí ajudou muito. Porque ao principio, ninguém tem essa idéia de como a doença vai, como é, como cuida, né? Então, uma colega mia que já tinha sua mãe com o Alzheimer, me levou à reunião e participei varias vezes.*”⁹³ The meetings oriented her and made her feel prepared to handle caregiving. For her, they contextualized through other participants’ stories what she had been told about the disease, but had yet to experience. Maria’s overall experiences at the support groups demonstrate their effectiveness; however, for reasons unexplained, she has since stopped frequenting the meetings. Maria being the only participant to have attended such a meeting is not to say that the other caregivers do not engage in the same conversations found in a support group. Interestingly, the other caregivers create informal support groups without realizing it.

Informal support groups appear without any real cause. One occurred while sitting in the packed waiting room about to leave the IGC. There, I overheard the various caregivers discussing with each other their patients’ symptoms and woes. These family care-providers respond to each other declaring, “*sim, mas a minha mãe também faz...*” (yes, but my mom also does...) ⁹⁴ I do not opine that they do this in an effort to make it seem that one situation is worse; but rather, that in a demonstration of solidarity, they are relaying to each other that they are not alone, that others are experiencing the same difficulties. Using the same terminology Dr. Barreto uses to describe what occurs within support groups, these care providers share with each other

⁹³ “At the start of it, it helped a lot. Because in the beginning, no one has an idea of how the disease progresses, how it works, how to give care, right? So, one of my colleagues, whose mother already had Alzheimer’s, took me to the meeting, and I went various times,” see Field Journal, 21.

⁹⁴ See Field Journal, 4.

their own “*saberes*,” wisdom from experience. In a way, these thirty to forty-five minutes of waiting to see the physician become these caregivers’ organically formed support groups.

These informal support groups are much more common amongst the caregivers than their participation in formally organized ones. This same notion extends beyond the IGC waiting room and enters into Cristo Redentor, where conversing on the street is the neighborhood pastime. In one episode, Maria do Carmo accompanied me to Josélia’s store four blocks from her house on Rua Dois. My research acted as a catalyst to induce a discussion about AD and the experiences with caring. In an incident not unlike the one described above, they recount their mothers’ battles into depression. One asserts that her mother talks to strangers, while the other rebuts that hers can no longer communicate, and the other then explains how hers has a feeding tube. Maria even jokes, “*A única coisa que a minha mãe não esquece é comer*,”⁹⁵ referring to her mother’s insatiable appetite. They laugh together, and for those few moments, Maria finds comfort in a kindred soul. Through this back and forth banter, I could perceive that there was this sense of relief that others are affected in the same ways.⁹⁶

In front of that store, standing with Josélia’s husband and brother, watching them converse with Maria, I saw two families struggling with the same illness share their experiences. This disease has consumed their lives. Maria carries the weight of her mother, her two children, and her two nephews on her shoulders. She worries on behalf of her mother because her mother no longer has the capacity to worry. Even if there is therapy available in her community, who is going to let her know? Who is going to watch her mother while she busses to Hospital Valter Cantidio for a support group meeting? It must be amongst her neighbors and within her neighborhood that she finds comfort.

⁹⁵ “The only thing my mother doesn’t forget is to eat,” see Field Journal, 9.

⁹⁶ See Field Journal, 11.

Cristo Redentor's residents are indoctrinated into the prevailing culture of their neighborhood. They are marginalized to such an extent that they have issues believing in themselves. Dr. Barreto contextualizes Cristo Redentor, and largely *favaleiro*, culture in stating, "...a pior miséria na favela não é a miséria material, do lixo ou da casa caindo, mas é a interiorização da miséria das pessoas que não aceditam mais em se. É um problema de fé, mas não é fé em Deus, é fé do homem."⁹⁷ Believing in oneself is the foundation of self-esteem, which is both a required ingredient for caregiving, as well as a characteristic that Dr. Barreto, through his work, has found people in this neighborhood to lack. In an effort to build self-esteem, residents not only seek support from neighbors, but also from the main institutions within Cristo Redentor offering help, those being the Church and NGO's, most notably, Projeto 4 Varas. It is significant that among the entities listed, the government does not appear. Generally, these people do not perceive the government as a supportive body, and furthermore, the government does not offer any support for these caregivers.

In relation to the Church, the two predominant religious groups in Cristo Redentor are Evangelicals and Catholics. While I did not request for the participants to reveal their religious background, I utilized these interviews to identify what type of support these institutions presented to their communities. In speaking with Carini, who is involved with the local Evangelical church, I attempted to assess the church's offerings. She became confused as to what I was referring to when I asked about "*grupos do apoio*," support groups. She concluded that those do not exist and conveyed, "*Geralmente, quando uma pessoa queria conversar, vai ao*

⁹⁷ "...the worst misery in the slum isn't material misery, from the trash or the house falling apart, but it's the internalization of the misery by people who don't believe in themselves. It is a problem of faith, but not faith in God, it's faith in man," see Field Journal, 48.

*'aconselhamento' nos sábados às oito horas da manhã pra conversar com o pastor.'*⁹⁸ While speaking with a pastor can be helpful, many of them cannot offer an understanding of their everyday like another caregiver could. Additionally, I found the same type system in place at the neighborhood Catholic church.

The caregivers who conveyed that they find respite within the church did so without mentioning support groups. In other words, for them, although the Church helps them, it is not through a formal support group. Maria do Carmo, who brings her mother to mass every Sunday afternoon, considers church to be a place where she can transcend her everyday and simply think. Maria admits that she is not one to open up and talk to people, but rather, for her to alleviate her stress and tension, she cries and then moves on. Her uneasiness in confiding in other extends to how she utilizes church, stating, *"...lá eu me desligo um pouco, tento rezar, tento entregar minha semana, tento aliviar um pouquinho que as vezes eu fico mais chata. As vezes eu fico até mais áspera com ela, que ela me fala a mesma coisa dez vezes, e eu não entendo."*⁹⁹ My objective was to understand the programs offered through church in relation to the caregivers, yet none truly exist. Instead, what Maria do Campo emphasizes, along with other caregivers, is that the church becomes an escape where they can breathe. In a way, the church becomes their leisure time, instead of what I had imagined to be a place of group support.

Unlike the church, none of the caregivers encountered in Cristo Redentor attended the community therapy sessions at the Projeto 4 Varas. However, knowing what this organization attempts to accomplish is necessary for understanding what is at least available to the caregivers in their community. Dr. Barreto, the co-founder of this NGO, explains that the mentality of the

⁹⁸ "Generally, when a person would like to converse, they go to 'advising' on Saturdays at eight o'clock in the morning to talk with the pastor," see Field Journal, 9.

⁹⁹ "...there I disconnect a little bit, I try to pray, I try to go through my week, I try to de-stress a little because sometimes I become really monotonous. Sometimes I become even rude because she says the same thing ten times, and I don't understand," see Field Journal, 33.

organization was first established as a backlash against the prevailing “*salvador da patria*”: “*A nossa proposta é você tem problema, você tem solução, vamos procurar, vamos. O ‘salvador da patria’ é clientalista; a solução vem da fora [da comunidade].*”¹⁰⁰ In this model, the community therapy sessions at the organization strive to teach the community that they are capable of finding their own solutions within themselves, that they have personal value. Through this, the objective is to guide them through their issues while also building their self-esteem.

Attending a community therapy session one Thursday afternoon, I quickly understood how such a place would assist the caregiver. The therapy circle is housed in a pagoda on the organization’s grounds overlooking the ocean. Inside, the chairs are positioned around a web painted on the ground. The web is constructed from the rays of a half-sun-half-moon figure at its origin, with each ray terminating at a chair. The symbolism is obvious; here we are all connected and part of a network. In these sessions, many of the attendees require as much visual evidence as possible to affirm for them that in their sufferings, they are not alone, that they have a connection to another human being, and that they have support. Continuing this vital theme, the participants are reminded at the end of the session, “*As pessoas precisam dos outros, a gente não viver sozinho. Nós temos as pessoas pra nos ajudar, pra nos balançar.*”¹⁰¹ Through a community grounded support network and a calming place to talk, Projeto 4 Varas offers to the caregivers much of what Deuciângela believes to be critical stress reducers. However, the caregivers in the area that were interviewed did not attend these sessions.

The caregivers confront their stresses on a daily basis, each finding their own particular way of handling them. While Deuciângela proposes three essential elements in combating stress,

¹⁰⁰ “Our proposal is that you have a problem, *you* have the solution, let’s find it together, let’s go. The ‘salvador da pátria’ is clientilistic; the solution comes from outside [the community],” see Field Journal, 47.

¹⁰¹ “People need others, we are not alone in our existence. We need people to help us, to balance us,” see Field Journal, 6.

what becomes obvious through the caregivers' narratives is that the everyday cannot mirror the textbook. Although the caregivers, even those who had never met Deuciângela, identified these three components in their varied responses, they simply acknowledged that they lacked one or more of them without offering a solution. Even though they agree that these suggestions would ease the daily stress they endure, they do not foresee a period where they would be able to incorporate them. In other words, they place their family's and patient's well-beings before theirs, and in the meantime, cry to relieve the overwhelming tension and savor the few moments that they can actually breathe. Yet, these sporadic occasions of unwinding are not enough to maintain mental stability, and some will continue to feel lonely and depressed.

Conclusion: The Caregiver's Everyday

*"Agradeço todo dia que Deus deixe ela comigo."*¹⁰²

*"Como dizemos na favela, academia não tem a hegemonia da produção do conhecimento."*¹⁰³

These women agree to enter this realm of extreme stress and endure it because the call to care comes from a loved one. The responses in the interviews help in understanding the caregiver's difficulties in accepting her loved one's Alzheimer's disease. Through this acceptance however, the caregiver learns how to alter her perception of normalcy so that she continues a relationship with her patient and can begin to understand her new everyday. The caregiver must dedicate herself to the patient, retaining and maintaining all of the patient's former and future selves. It is because of this that the relationship between the caregiver and the patient becomes restructured, and distinct from the one that existed before the onset of AD. Although the mode of this reorganization depends on how the caregiver internalizes her new reality, what becomes the common denominator between all participants is the extraordinary caregiver-patient relationship in to which all have entered. This relationship can be characterized as such because even though the stress that it brings may sometimes be insurmountable, in no

¹⁰² "I give thanks everyday that God leaves her with me," see Field Journal, 20. Maria Magalhães expresses that even through all the stresses of caregiving, the disease, and her mother's altered self, she still is thankful to have her alive.

¹⁰³ "As we say in the ghetto, school doesn't have the hegemony over producing knowledge," see Field Journal, 50. Dr. Barreto underscores that simply by virtue of living one's everyday, one gains wisdom and experiences.

other relationship, does one person envelope the other, which is to say that one entity appropriates the life narrative of an other in order for it to continue.

In general, this monograph conveys that all caregivers lament sentiments of being marginalized, of being not heard or understood by others; however, particular attention is paid to the narratives of Maria do Campo, Josélina, and Josélia in order to demonstrate the lack of support offered to women in Cristo Redentor. In this vein, the marginalization of the caregiver is furthered by a lack of economic means. While all caregivers deserve a higher degree of support, these women do in particular because, with the exception of Projeto 4 Varas, the resources for support in their neighborhood are seemingly inexistent.

While this research aims to expand upon the central theme of how caring affects the caregiver, it also raises numerous questions. On this topic, I would like to further my research through probing why more caregivers in Cristo Redentor do not elect to attend the group meetings at this organization. Additionally, I would like to investigate the government's role in order to understand why it has no role in providing support for caregivers, regardless of neighborhood. While I chose to conduct an array of interviews, other researchers on this topic may elect to focus on one specific stage of the disease. Finally, in this vein, with less time constraint, I would hope to be able to follow individual families for the first few years of the disease starting from the diagnosis in order to gain a deeper understanding of the beginning stages of reorganized relationships and the progression of appropriated life narratives.

Work Cited

Primary Sources

Barreto, Adalberto. Personal Interview. 7 June 2011.

Carvalho, Deuciângela. Personal Interview. 1 June 2011.

Do Carmo, Maria. Personal Interview. 30 May 2011.

Guart, Maria Goret. Personal Interview. 26 May 2011.

Josélia. Personal Interview. 25 May 2011.

Joselina. Personal Interview. 6 June 2011.

Magalhães, Maria. Personal Interview. 26 May 2011.

Regina. Personal Interview. 2 June 2011.

Rosa, Olga Studart. Personal Interview. 2 June 2011.

Sabrina. Personal Interview. 25 May 2011.

Simone. Personal Interview. 26 May 2011.

Secondary Sources

Alzheimer's Association. *Alzheimer's Facts and Figures*. Alzheimer's Association. 20 April 2011. Web. 2011. <http://www.alz.org/alzheimers_disease_facts_and_figures.asp>.

Alzheimer's Association. *Brain Tour*. Alzheimer's Association. 20 April 2011. Web. 2011. <<http://alz.org/brain/01.asp>>.

Blieszner, Rosemary and Peggy Shiflett. "The Effects of Alzheimer's Disease on Close Relationships between Patients and Caregiver." *Family Relations*, vol. 39, no. 1, January, 1990: 57-62. Print.

Brookmeyer, Ron, Elizabeth Johnson, Kathryn Ziegler-Graham, and H. Michael Arrighi. *Forecasting the Global Burden of Alzheimer's Disease*. The Berkley Electronic Press. 20 April 2011. Web. 2007. <<http://works.bepress.com/cgi/viewcontent.cgi?article=1022&context=rbrookmeyer>>.

Chesla, Catherine, Ida Martinson, and Marilou Muwaswes, "Continuities and Discontinuities in Family Members' Relationships with Alzheimer's Patients." *Family Relations*, vol. 43, no. 1, January, 1994: 3-9. Print.

Desjarlais, Robert. *Shelter Blues: Sanity and Selfhood Among the Homeless*. Philadelphia: University of Pennsylvania Press, 2003. Print.

Han, Clara. "Symptoms of Another Life: Time, Possibility, and Domestic Relations in Chile's Credit Economy." *Cultural Anthropology*, vol. 26, issue 1, 2011: 7-32. Print.

Kaufman, Sharon and Lynn Morgan. "The Anthropology of the Beginnings and Ends of Life." *Annual Review of Anthropology*, vol. 34, 2005: 317-341. Print.

Kleinman, Arthur, "Caregiving: The Divided Meaning of Being Human and the Divided Self of the Caregiver." *Rethinking the Human*. Eds. J. Michelle Molina and Donald K Swearer. Cambridge: Harvard University Press, 2010. 17-29. Print.

Nikolaev, Anatoly, Dennis O’Leary, Todd McLaughlin, and Marc Tessier-Lavigne. *N-APP binds DR6 to cause axon pruning and neuron death via distinct casases*, National Institute of Health. 24 April 2011. Web. August 2009.
<<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2677572/?tool=pmcentrez>>.

Appendix

1. Could you have done this project in the USA? What data or sources were unique to the culture in which you did the project?

I could have completed a similar project in the USA, however the Brazilian cultural nuances made this research unique from what would have been accomplished in the USA. The parent-child relationship, which affects how daughters care for their parents, influenced the outcome of my theory on how AD affects relationships.

2. Could you have done any part of it in the USA? Would the results have been different? How?

I could have carried out a project with AD caregivers in a low-income neighborhood in the USA, however the cultural peculiarities here made the results different. As noted in my research, a study carried out by Chesla et al on the subject of AD’s effects on relationships was not appropriate here because Brazil, culturally, is different than the USA.

3. Did the process of doing the ISP modify your learning style? How was this different from your previous style and approaches to learning?

No, I had previously conducted independent research projects where I had to write a formal proposal and then carry it out as stated in that proposal. I was already accustomed to this “hands-on” learning approach.

4. How much of the final monograph is primary data? How much is from secondary sources?

The majority of the monograph is primary data; the secondary data was utilized to ground my theories.

5. What criteria did you use to evaluate your data for inclusion in the final monograph? Or how did you decide to exclude certain data?

I approached my data with certain theories on relationships and life narratives. I examined the interviews with this lens, and attempted to exclude the data where participants spoke of the disease in relation to the patient instead of to themselves.

6. How did the "drop-off's" or field exercises contribute to the process and completion of the ISP?

The "drop-off" made me feel more comfortable navigating the city and understanding how to arrive at certain locations where, from there, I would already know how to get home. This facilitated the process of the ISP as I was not nervous to be alone. The community project, the excursion to Aracati, and the interview aspect of the response papers all made it easier for me, when it came time for the ISP, to understand how to correctly formulate interview questions and made me feel more comfortable conducting interviews in Portuguese. Furthermore, these exercises taught me the importance of the field journal, without which, I would have experienced difficulties in completing this monograph.

7. What part of the FSS most significantly influenced the ISP process?

Being forced to define our research question, which then narrowed the scope of the ISP and made it easier to plan and propose.

8. What were the principal problems you encountered while doing the ISP? Were you able to resolve these and how?

I was unable to find a solid number of families dealing with AD in Cristo Redentor. Although more than two existed, no one really knew of others or felt comfortable in introducing them to me. In order to resolve this issue, I focused more on the caregiver in general, thus being able to use more participants regardless of their neighborhood, and only placed emphasis on those from Cristo Redentor for one theme of the paper.

9. Did you experience any time constraints? How could these have been resolved?

I did not experience any time constraints in the sense that I was not able to complete all my interviews, but rather, I would have liked to follow the caregivers over an extended period of time rather than having obtained a snapshot of their everyday.

10. Did your original topic change and evolved as you discovered or did not discover new and different resources? Did the resources available modify or determine the topic?

My original topic changed as the availability to families changed, as discussed in question 8. However, I then discovered new resources at the Instituto Geriatri e Gerontologia do Ceará. These resources modified my proposed topic, but certainly did not determine it.

11. How did you go about finding resources: institutions, interviewees, publications, etc.?

I was put into contact with the IGC and all the participants there through my project advisor. I found the families in Cristo Redentor and Projeto 4 Varas, an NGO, through my host family. I was then put into contact with the co-founder of that NGO through the SIT staff.

12. What method(s) did you use? How did you decide to use such method(s)?

The overall method I used to conduct this research project was the personal interview. As I was attempting to understand the caregiver's narrative, I felt there was no better way than to sit down and converse with the caregiver.

13. Comment on your relations with your advisor: indispensable? Occasionally helpful? Not very helpful? At what point was he/she most helpful? Were there cultural differences, which influenced your relationship? A different understanding of educational processes and goals? Was working with the advisor instructional?

My relations with my advisor were indispensable. She introduced me to various contacts who later become participants in my interviews. Furthermore, she was available to sit down with me and discuss so as to contextualize the responses from the interviews. The cultural differences that we experienced together did not affect our relationship, I simply learned that when she gave me a time to show up somewhere, she would not show up until 30-45 minutes afterwards. Working with her was very instructional, as we met every Wednesday and Thursday morning of each week.

14. Did you reach any dead ends? Hypotheses which turned out to be not useful? Interviews or visits that had no application?

I reached dead ends with a few interviews, as the participants had just learned of the patient's AD and were rather in a state of shock than in a position to detail how it changed their relationship. One hypothesis that I found to be false was that there were no resources available to caregivers in Cristo Redentor. On the other hand, that knowledge then prompted me to ask why these caregivers were not utilizing the resources available to them.

15. What insights did you gain into the culture as a result of doing the ISP, which you might not otherwise have gained?

I came to understand how engrained the parent-child relationship is within Brazilian culture. Additionally, I learned that in Brazil, the caregiver is chosen because she is the last daughter to not have married.

16. Did the ISP process assist your adjustment to the culture? Integration?

The ISP process assisted in a greater understanding of the culture, and in that way, aided in helping me adjust.

17. What were the principal lessons you learned from the ISP process?

I learned to be more flexible when it comes to interviewing, that although I may arrive with questions in hand, the interviewee should be able to speak freely, with me only there rather to direct the themes of the conversation.

18. If you met a future student who wanted to do this same project, what would be your recommendations to him/her?

You must understand that some caregivers are going to hide their true emotions because they do not want to confront them either.

19. Given what you know now, would you undertake this, or a similar project again?

Yes.