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# FIGHTING FOR A HEALTH DIAGNOSIS: AN AUTOETHNOGRAPHIC JOURNEY INTO THE ROLE OF ACCESS AND LIMITATIONS OF RESILIENCE IN THE FACE OF POVERTY

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#### **Dedication**

To my father, who I just Lost less than ten days ago. To my father who Taught me it is never too late to change. To the one who told me over and over "Today, is the First Day of the Rest of Your Life".

-Josette 02/16/23

It was time for me to start crafting my dissertation. How could I manage the dedication section having so many people to thank, from the friends who stayed and showed me their unconditional love and support, Stuart, Isabelle, Eva, Robert, Diane, Vince B. and Vince C., Jehu, Fany, Linda, J.C., Muñequita. 'mom', and to those who have had their reasons to leave but showed me my own strength by doing so. How could I forget my aunt Nicole, who loves me beyond measure as if I had been her own child? How could I manage not to thank the many support services offered to me through UTEP, and my amazing mentors such as Dr. Ullman, Dr. Moya, Dr. Loza, Dr. Lusk, Darlene, and my Chair, Dr. Eggleston. How could I leave out those that inspire me by fighting immense challenges of abuse and poverty, in simply—as if it was simple—telling their stories?

Life, once again, made it relatively easy for me. It is only by stepping back that you can see the bigger picture. Somehow, I have not had/made time to cry over the loss of my father, and as I write this dedication section, tears roll down my face. Processing trauma. This is most certainly a big part of this autoethnography. There I am!

My father was a proud French man. We hardly ever agreed politically, and he constantly and passionately defended his viewpoints with me and the world. He showed me that we could love one another, and fervently disagreed. My father was a Secretive man. He said too much about History, and not enough about his Own history. Little is known about his relationship with my birth mother. Even less about his fraudulent encounters with the law. He did not trust the

government. Any governments, for that matter. Yet, he learned to accept his wrongs towards me, and thrived to mend a relationship I ardently rejected. He succeeded. That is his legacy.

In times of crisis, whether it was mental health, physical health, or broken hearts, he learned to be there to the best of his abilities. And when his abilities were lacking, he did his research, and he unlearned what he had once erroneously learned. He studied me through the internet. Learned how to talk to me. He showed me it was never too late, and that Love never gives up. Love can be messy, but it is Resilient.

Papa, although I still doubt, in writing these words, that you can still hear me, I know you would have been and were proud of me. I thank you for making me laugh when I was down, with good jokes you might have invented yourself, and for reminding me constantly that *Today*, *Is The First Day of The Rest of My Life*. To my father, the Wise in its Complex-Humanity, I dedicate this dissertation.

# FIGHTING FOR A HEALTH DIAGNOSIS: AN AUTOETHNOGRAPHIC JOURNEY INTO THE ROLE OF ACCESS AND LIMITATIONS OF RESILIENCE IN THE FACE OF POVERTY

by

## JOSETTE PELATAN, PhD

## **DISSERTATION**

Presented to the Faculty of the Graduate School of
The University of Texas at El Paso
In Partial Fulfillment
Of the Requirements
For the Degree of

## DOCTOR OF PHILOSOPHY

Interdisciplinary Health Sciences Program

THE UNIVERSITY OF TEXAS AT EL PASO

May 2024

## Acknowledgements

I am grateful to my family and friends for their love and encouragement in my academic and personal journey. I appreciate the insight and mentorship of my dissertation chair Dr. Eggleston, and my committee members, Dr. Moya, Dr. Loza, Dr. Lusk, and Dr. Ullman. I am thankful for the motivation from my peers and the continuous inspiration I receive from my students. Furthermore, I acknowledge the endless and unconditional support of my service dog, Milo. I appreciate all the feminists before me, who have fought for my rights and have opened the doors for me to obtain this education and occupy this academic space, and for those who dared to advocate for autoethnography, not only as a powerful healing tool, but also and especially as relevant research, widening our lens of academia to create a better future for us all. I hope my work inspires women, particularly those living with complex mental and physical health circumstances with juggling financial insecurities, to be strong and to arm themselves with the most powerful tool of all: education. Finally, *je remercie mon grand-père, André, qui m'a appris le courage, mon père, Aimé, qui m'a démontré qu'il n'est jamais trop tard pour s'améliorer, et ma tante Nicole, pour m'aimer comme ça propre fille, malgré toutes nos différences*.

#### **Preface**

This dissertation seeks to discover ways to cope with complex trauma while facing housing insecurity and financial challenges, in hopes to shed light on the limitation and power of resiliency. The umbrella of trauma-based research and resilience theory provides, in this dissertation, an overview of several intertwined theories for the collective use of qualitative-based methodologies' expansion in interdisciplinary health sciences. Within a larger autobiographical project, I embark on demonstrating several embodied autoethnographic reflections that are useful for research and dissemination of knowledge in the field of interdisciplinary health sciences.

The theory and methodology in this dissertation are founded in the discipline of interpretive methodology and greatly influenced by the works of Norman Denzin (2014), Raymond Carver (1997), Dwight Conquer good (2013), and based on these other foundational authors: Paulo Freire (2014), Laurel Richardson (2000), Johnny Saldaña (2011), and Augusto Boal (1998). Combined, these authors are exemplars as their theory, method, and overall approach/style are foundational to the production of the storytelling and reflections presented throughout this dissertation.

Autoethnographic dissertations in health sciences can serve to unpack health to highlight stories often excluded from research, leading to a better understanding of complex medical diagnoses and dissemination of social change. I argue that giving voice to diverse narratives and stories is key to learning about underserved populations generally excluded from research – such as my own. It is also essential for research interpretation to transition into community spaces in the sense that varied styles emphasize different ways of narrative writing to approach perceptions from various angles. This allows for different education and literacy levels for community and academia alike to engage in reflexivity and reduce the "othering" of participants in research studies. The interdisciplinary umbrella allows for an expanding understanding that no knowledge

is irrelevant and can contribute to bettering community settings and academic spaces as a means of community-engagement scholarship and allow for more comprehensive approaches to complex disease diagnoses, while providing adequate support and resources.

The work of this dissertation stems from personal experience. The unique contribution it makes is a re-envisioning of the autoethnographic methodology in providing a critique of the current limited community-based system that overlooks the lived experiences of some community members. I build from the notion that autoethnography has significant involvement in multifaceted connections that serve as a technique for developing within the dissertation as expansive to the field of Health Sciences, a way of producing multilayered community-engaged scholarship.

The production of "hidden" narratives from minority groups through oral or written storytelling often omitted from the Health Sciences can allow for systematic exposure of societal issues in-between spaces of community and academia, and to engage authentic qualitative research on new informed trauma-recovery methods. My personal experiences contextualize this project, and they situate the body as the site of trauma, memory, remembrance, and health. This is deeply relevant to my field of Interdisciplinary Health Sciences and community-engaged scholarship. I also argue that autoethnographies in Health Sciences can lead to significant transformational practices within communities of researchers, providers, scholars, and community-based settings. Autoethnographies can offer guidance on how to address issues such as the absence of financially and cognitively vulnerable patients' informed perspectives.

This autoethnography makes the case that individual voices are crucial to understanding societal and structural issues of housing insecurity and limited access to services. This scholarship is crucial to this current moment of qualitative research and is critical in the contribution to:

1) rejecting majoritarian ways of telling and experiencing stories,

- 2) evidencing and promoting a grounding for stories that are often untold, and
- 3) exemplifying autoethnography as a unique methodology to accomplish these goals.

I locate my study in relationship to the tentative future of autoethnographic writing as part of a purposeful contribution to the fields within Interdisciplinary Health Sciences.

#### Abstract

This research represents a highly personalized account of the complexities, interpretations, and reflections of the journey of a doctoral student navigating the challenges of health through access on a U.S.-Mexico border. Using myself as the subject and the researcher in the social context of schooling provided the impetus for this self-study. Through an insider's vantage point, I have chronicled and traced the experiences of my own identities' transitions and multilayered intersectionality using the qualitative methodology of autoethnography. This genre of qualitative research brings the reader closer to the subculture studied through the author's experiences.

While every story has its unique layers of complexities, the introspection, and evaluation provided by the methodology of autoethnography greatly facilitates an understanding of the processes of concepts constructions through a lens of the theory of resilience. The distinctive impact this dissertation makes on interdisciplinary health sciences is the aim to incorporate autoethnographic research into a popular narrative with cultural viewpoints of the lived understanding as praxis for public health. I am for this to be a new way of approaching community-engaged research. I contend that legitimizing social and individual elements of the lived experience is a way to comprehend the culture and the politics of dealing with hardships such as illness, violence, and residual effects of ongoing complex-trauma. The experiences I have encountered, the problems I have faced, and the interpretations derived from them will strengthen my own practices as a social justice activist and provide insight into the ever-changing positioning of nationality, gender, race, and social class perspectives within distinct geographical and political socio-contexts.

The themes that I address in this introspective journey revolve around the power of identity, utilization, and access. Concepts such as social class status, gender, and disability/different

abilities, in context, are mentioned through theories of resilience, with a greater focus on the redefining and role of education in fighting mental health and social class stigma, resisting "giving in," and "giving up," and forging a new path to survive and thrive in adversity. This qualitative autoethnographic study was the process by which I, a woman struggling with financial and health concerns, was able to evocatively and therapeutically write about the traumatic events I experienced. It was also the method by which I decided to disclose how I moved from being an atrisk Special Education student and high-school dropout to refusing to settle and concurrently strengthened my resilience.

This study demonstrated the basic tenets of autoethnography and how, by overcoming mental health concerns, thriving while facing financial struggles and housing insecurity, and refusing to abandon seeking a correct medical diagnosis, I was able to embrace the spirit of forgiveness and increase my resilience. Insights into the discourse of a dysfunctional family are shared, allowing me to offer a message of hope and shatter stereotypes. The study concludes that autoethnography, as a process, permits tapping into new-found autonomy. Autoethnographically, this study represents my life journey, but it can represent the life of many readers who have lived in the United States in disadvantaged conditions and/or have encountered physical, emotional, verbal, and sexual abuse. This study legitimized and validated my story as a survivor. Consequently, the plot of the story focuses on the long-term effect of trauma, how I coped, and how I am now, thriving through it all. Focusing on the acts and conditions while incorporating dialogue permitted me to involve the reader more closely in the story.

I leaned on my doctoral studies to expand my understanding of the abuse and financial disadvantages I experienced (Holt, 2003). I found that resilience was central to my life story. Embracing resiliency empowered me to discover new ways of thinking about my life experiences,

which included using an interdisciplinary approach or a positive model that offered "alternatives to the deficits-based explanatory models of environmental determinants of health that have dominated the literature" to accept the raw and cruel encounters I was exposed to and turn my thoughts into a healthier way of thinking (McWhirter, L., Ritchie, C., Stone, J., & Carson, A. (2020). Tugade and Fredrickson (2004, p. 320) would say that I obtained a psychological resilience to effectively cope and adapt, even though I faced "loss, hardship, or adversity." Ultimately, I discovered that resilience is a "state, a condition and a practice" (Knight, 2007, p. 544).

*Keywords*: Theory of resilience; Theory of identity; Gender; Social Class; Post-Traumatic Growth; Health Care Access; Resources; Reactive Attachment Disorder; Health Equity; Adverse Childhood Experiences (ACE); Mental Distress; Resilience; Stressful life events; Trauma & Healing; Complex Diagnosis; Recovery.

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#### 1. Chapter I: Introduction

#### 1.1 Statement of The Problem

Autoethnography is not designed for grand theorizing (typical to traditional research). Connections exist between autoethnography, interdisciplinary health research, and discounting the traditional nature of grand theorizing in general. Recast as problematic to research practice – among other authentic tensions (issues of participation and power).

Research exclusionary to women, medical patients, and diverse subgroups might not capture authentic truths/stories/narratives of those groups or fully inform theory. Furthermore, scholars began recognizing that different kinds of people possess different assumptions about the world—a multitude of ways of speaking, writing, valuing, and believing—and that conventional ways of doing and thinking about research were narrow, limiting, and parochial, due to differences. These differences can stem from race (Anzaldúa, 1987; Boylorn, 2006; Davis, 2009), gender (Blair, Brown, & Baxter, 1994; Keller, 1995), sexuality (Foster, 2008; Glave, 2005), age (Dossa, 1999; Paulson & Willig, 2008), ability (Couser, 1997; Gerber, 1996), class (Hooks, 2000; Callahan, 2008), education (Delpit, 1996; Valenzula, 1999), or religion (Droogsma, 2007; Minkowitz, 1995). Integration of autoethnographic research into interdisciplinary health sciences is an important research approach for community-engaged scholarship and to guide public health policy. It can inform/build a repertoire of knowledge within health sciences and communityengaged scholarship to be more inclusive to silenced voices, specifically, in this case, the voice of women and those who are financially, emotionally, and/or cognitively vulnerable. Such research engagement can more directly improve health and promote wellness (e.g., physical and mental) within spaces of vulnerability (poverty, incarceration, substandard housing, and violence against women). The "in-betweener" can serve as a bridge between community and academia and point

to hidden/forbidden narratives of financially vulnerable female patients. The active term 'in-betweener' admits that the researcher can make dynamic efforts to position themselves in-between instead of an insider-outsider continuum (Hellawell, 2006; Arthur, 2010), which implies an evident lack of agency from the researcher.

My positionality as a female scholar/medical patient and critic, provides a counternarrative that may highlight the voice of many other cognitively and/or financially vulnerable women and the challenges that often add up due to gender discrimination combined with their financial situations, should not go unvoiced. Contesting someone's life experience, trauma, and pain as is often done by researchers and society in general, historically has contributed to the oppression of many groups. The silencing of women's narratives is so embedded in our patriarchal culture where Women's movements like #MeToo have just recently become popularized (Mendez-Ringrose, 2017).

Spaces for oppressed women to share their truths are minimal and rare. It has always been taboo for oppressed women to share their truths and sometimes problematic in spaces of academia, popular culture, and within majoritarian narratives. Some women who share their stories are contested and questioned, yet still brave enough to share their truth. I strongly advocate for the composition of autoethnographic research as an intricate and crucial truth and for the dissemination of voices in all spaces as a basic human right (and, in my case, an academic woman's right) to share women's story and have it be of significant value in interdisciplinary spaces, health sciences, and overall research, without being contested or told that it does not have significance to new knowledge in research.

Dialectic perspectives can possibly function to expose relationships to cultural norms, values, and societal standards and their connections to potentially inform community health

research. Engaging the power of human activity and knowledge can help shape the world in positive ways (Bernhardt, 2018) and give meaning to the social and political world of our time that is shaped by community and cultural practices (Rossatto, Allen, & Pruyn, 2006). This research informs the autoethnographic topics of relational ethics, access, the body and mind, family and individual trauma, and with an emphasis on overall health. These topics should be recognized as a priority in interdisciplinary health sciences because of their effects on health, wellness, and engaged research practice, while providing the author a space for healing, closure and, ultimately, a way to reinvent oneself.

Through positioning several trauma-based events, the writing process details "coming undone" —the experiencing of unintended consequences (both positive and negative) on health and wellness. Within the method of autoethnography- the data, —new knowledge being generated comes directly from the source. However, the interpretation of the results and structure of the analysis is placed on the audience/viewer. The point is for the reader to bear witness to someone else's truth (in this case, a woman who "chose" adversity over Adversity, and therefore consciously "selected" trauma over Trauma, calling it "Resilience") and lived experiences, which by de-facto is new knowledge and important for overall community health of women, social justice advocacy, and population well-being.

By taking ownership of my health narrative because of trauma and socioeconomic status, I have already begun to craft this opportunity of rewriting past fractured narratives to make space for the designing of possible interventions for those facing similar challenges to those I have encountered. I intended that this dissertation serve as an example of the power and nuance of autoethnographic writing, for which I have made a call to be included in ways that the fields of

Interdisciplinary Health Sciences can disseminate as new knowledge and practices within community-engaged scholarships and to improve and inform policy change.

I want my dissertation to be a legacy of myself—that as readers in Interdisciplinary Health Sciences, community health, and other studies follow to propose new theories and guide better policies and outreach programs. Overall, as emphasized above, I intend for these varied and experimental works to serve as examples that may be included in public health research practice and the field of Interdisciplinary Health Science.

#### 1.2 Statement of Purpose

The overarching purpose of this dissertation is to identify the intricate relationship of resiliency in moving away from poverty through health challenges and to understand the implications and steps needed to overcome adverse childhood experiences (ACEs) in achieving "success" as defined in this autoethnography dissertation. The purpose of this study is to unveil personal life experiences that prompted me, from being a high school dropout, to seek higher educational degrees to escape poverty, get access to resources, find a greater purpose, and use my voice to spread awareness of the medical system and the boundaries it imposes on those with minimal financial resources. I will also disclose some challenging moments and ways that encouraged me to heal and discuss the sexual, physical, and verbal abuse I experienced and how it has shaped my relationship with the world around me. The intent of this narrative is to focus on risk factors of health and the interlinking of mental and physical health while addressing the role of resilience to overcome these adverse situations through a resiliency framework. This research will allow for better understanding of challenges often not addressed in literature.

#### 1.3 Research Questions

My narrative analysis of living in adverse situations and encountering abuse, overlapped with facing financial stressors, will revolve around the following questions:

- What factors hinder and contribute to resilience?
- What is the relationship between health, social class, and resilience in obtaining complex health diagnoses and treatment?

#### My sub-questions are:

- What is the role of resources in the development of resilience?
- How can education foster the development of resilience?

#### 1.4 Design of The Study

Being that this study is an autoethnographic piece of literature, I want readers to "keep in their minds and feel in their bodies the complexities of concrete moments of lived experience" (Ellis, 2004, p. 30). Furthermore, it is imperative that "the reader becomes an active participant in the meaning making" (Glesne, 1999, p.41). Autoethnography stems from an ethnographic philosophy that believes borrowing "the eyes of others to enhance our perspectives" is necessary; "at the same time, we should go on valuing our own" (Glesne, 1999, p. 43). The final chapter will offer concluding thoughts on what the story may mean for readers, patients, health practitioners, and scholars; although, "the focus will remain on the story" (Ellis, 2004, p. 198). It is the goal of this study to provide several perspectives. It concentrates on life's challenges playing positive roles rather than being viewed as deficits. Accordingly, I frame my writing using a resiliency

framework, choose autoethnography as my method of sharing my life story, and intersect my personal experiences with relevant research (Ellis, 2004; Holt, 2003; Wolin & Wolin, 1993).

#### 1.5 Definitions

<u>Analysis of Narrative</u>: The researcher takes content about the story and analyzes it (Rissman, 2003).

<u>Autoethnography:</u> Used as both a method and a text; "a form of self-narrative that places the self within a social context" (Buripakdi, 2013).

Cognitive Trauma Processing: This is the process of working on psychological distress by engaging in internal thinking processes and creating new meaning from the experience. In this study, cognitive trauma processing referred to the long-term strategies that survivors employed in dealing with the aftermath of an attack. They included regret, denial, acceptance, downward comparison, and positive cognitive restructuring.

Cope: to deal or struggle with events that have changed the "normal" sequence of life.

<u>Initial Trauma Processing:</u> This is the process of working on the painful psychological memories of traumatic events to make them acceptable without much distress. In the current study initial trauma processing refers to the immediate ways that survivors process an attack. These strategies

are synonymous with the with *The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-V), trauma clusters, avoidance, arousal, negative cognitive alteration, and intrusion.

<u>Narrative Analysis:</u> The researcher understands that "to think with a story is to experience it affecting one's own life and to find in that effect a certain truth of one's life" (Smith & Sparks, 2008).

Over-coming: gaining success over adversity, such as childhood trauma.

<u>Post-Traumatic Growth (PTG):</u> positive psychological change that some individuals experience after a life crisis or traumatic event. Post-traumatic growth doesn't deny deep distress, but rather posits that adversity can unintentionally yield changes in understanding oneself, others, and the world. Post-traumatic growth can, in fact, co-exist with post-traumatic stress disorder. (Dell'Osso, et al., 2022)

## \*\*\*Success is defined in this dissertation as PTG\*\*\*

<u>Post-Traumatic Stress Disorder (PTSD)</u>: diagnosis of a person who has been exposed to a traumatic event in which actual or threatened death or serious injury or threat to the physical integrity of self or others is present. The response involved is intense fear, 20 helplessness or horror; recurring dreams or thoughts of events; feelings of detachment from others; and cognitive, occupational, and social impairment (APA, 2000, pp. 218- 220).

<u>Poverty:</u> "A standard of living below the minimum needed for the maintenance of an adequate diet, health, and shelter" (Eitzen & Johnston, 2007).

<u>Poverty threshold:</u> "The poverty line established by the government based on the minimal amount of money required for a subsistence of level of life. The threshold varies with the size of the family" (Mercado-Garza, 2010).

<u>Reflexive Journal</u>: A written personalized diary account about any trauma a person may have experienced.

<u>Resilience</u>: A universal capacity of having "an awareness of the self-righting tendencies that move children toward normal adult development under all but the most adverse circumstances" (Henderson, 2012).

<u>Trauma</u>: generally defined by stress events that present extraordinary challenges to coping and adaptation; one or more blows, rendering helplessness, causing internal changes (Agaibi & Wilson, 2005, p. 196; Terr, 2003, p. 323).

<u>Trauma severity:</u> This refers to the degree of distress that trauma survivors experience after experiencing a traumatic event. In the current study trauma severity referred to the frequency of DSM V trauma symptoms survivors exhibited after traumatic events.

<u>Traumatic event</u>: Briere and Scott (2013) described a traumatic event as one that is "extremely upsetting, at least temporarily overwhelms the individual's internal resources, and produces lasting psychological symptoms" (p. 8). Traumatic events or stressors can be anything resulting in a person feeling that his/her life or another person's life is in danger.

#### 1.6 Theoretical Frameworks

The advantages of embracing the concept of resilience as a framework for assessment have been underlined in many separate scientific papers (Carpenter et al., 2001; Berkes et al., 2003; Gunderson & Folke, 2005; Walker et al., 2006). Undoubtedly, many would agree that one of the most valuable traits of resilience is its capacity to improve the framing of questions within a general methodology and to think in interdisciplinary ways. In circumstances where the susceptibility of persons is deepened by their communal and financial dependency on others also affected by trauma, the nature of resilience and its stress on the mutuality of different approach mechanisms is especially pertinent.

#### Organismic Valuing Theory of Growth through Adversity:

The organismic valuing theory was created by Svetina and Nastran (2012) and suggested that individuals have an instinctive capability to pursue evolution, know what is crucial for them and the guidance that will lead them to better health. The theory contends that the desire for growth can be hindered or driven by the social environment. It is a subliminal and biological process that leads individuals to assess new events to improve their growth or achieve actualization. The theory hypothesizes trauma as deceptiveness and contends that endeavoring in the direction of genuineness determines the incongruence developing from trauma. The qualitative standpoint of this study made it feasible to gain access to the posttraumatic growth assessment of shock survivors

in the context of societal ecological considerations. According to Joseph and Linely (2005) the organismic assessing theory has four fundamental principles that clarify how posttraumatic growth is achieved. These are achievement propensity, accommodation versus assimilation, meaning as comprehensibility and meaning as significance, and eudaimonia versus hedonistic wellbeing.

## Completion tendency:

The theory claims that confrontation with traumatic events destroys one's presumptuous world and calls for the incorporation of new trauma data. It is human nature to endeavor to alter the current worldview to clearly adjust to new trauma-associated knowledge. Managing the new trauma info fluctuates between invasive and avoidant conditions up until a new model is achieved, until conclusion. The course of completion tendency requires several approaches, but the existing research focused more on the trauma processing approaches that the survivors used in working out their trauma.

#### Accommodation versus assimilation:

After undergoing a traumatic experience, a person's psychological condition becomes insecure. A state of stability (assimilation) is achieved when traumatic recollection is cognitively understood to fit into the survivor's representations. When schemas continue intact after hardship, the survivor encounters short-term discharge but stays susceptible to ensuing traumatization. Accommodation, in contrast, requires the reorganization of pre-trauma schemas of the survivor to absolutely live with the traumatic items, leading to post-traumatic growth. This could be facilitated by intense cognitive processes within the minds of the survivors. Some studies have examined how participants accommodated the traumatic memory and the cognitive trauma processing strategies that might have aided that expansion.

#### Meaning as comprehensibility versus meaning as significance:

In the preliminary phases of traumatic incidents, the impacted entities seek out meaning to comprehend the event meticulously. This is followed by the process of assimilation or accommodation. Later, the organismic valuing process begins, where existential issues are asked with the intention of pursuing meaning to recognize the importance of the traumatic event. Meaning - seeking might lead to either negative accommodation through responses of despair, powerlessness, and pain or positive accommodation through enhanced relationships, change of personal philosophy, and change of self-view. The qualitative nature of the investigation into the type of posttraumatic markers demonstrated by some survivors assisted in bringing out the subjective meaning that survivors connected to the violence in different areas of their lives. This could also have been aided by the therapy mediations that were presented to survivors after the trauma. This advised the emphasis on the role of psychotherapy in the posttraumatic growth of survivors.

#### Eudaimonia versus hedonistic wellbeing:

Hedonistic wellbeing is achieved through the chase of enjoyment and dodging of distressing events while eudaimonia wellbeing strives for the quest of individual realization and recognizing one's ability. This theory contends that post-traumatic growth does not automatically make people happy but may make them gloomier but smarter. This suggests that the understanding of negative traumatic effects and posttraumatic growth are both related to the attainment of peace and healing in the aftershocks of traumatic experiences. Crucial positions that might have been performed by the excruciating events in sculpting the posttraumatic growth of people emphasize the harshness of the experiences. Harshness was investigated in terms of the urgency and pervasiveness of the trauma symptoms by survivors after the trauma. There are suggestions of self-

regulation amongst human beings (Geldhof, Fenn & Finders, 2017), a notion that this model emphasizes. Human beings can adjust themselves and make decisions in life without automatically relying on outside forces. The development of the discovery of meaning in life and the willpower to ascend out of the traumatic experience is an indication of self-regulation. The theory tries to clarify the reply to traumatic proceedings in both positive and negative scopes. The idea of assimilation discusses the illusionary and provisional trauma dispensation approaches, while accommodation clarifies the comparatively enduring trauma processing approaches that lead to post-traumatic growth as presented in my research questions.

#### Weaknesses of Organismic Valuing Theory

Opponents of this theory contend that it grants an overstated buoyancy to human nature. They contend that it is dubious to picture all humans as having an inborn ambition to be moral, given that some people follow violence and evil (Kensit, 2010). This theory tried to clarify the behavior of survivors as they struggled out of crises, but disregarded the communities and what provoked them to follow the misery of others as a goal. The theory is also perceived to over-depend on self-reports as a technique of data gathering. It is impractical to view people as continually positive in order to grasp a phase where they are fulfilled in life. In some situations, people might report optimistic moods when in the actual sense they are struggling with an adverse emotional state. There is consequently a call to expand the tools for research grounded on this theory to create more impartial results. The theory emphasizes an individual as the mediator of transformation in the healing process. Provisional trauma processing approaches, the progression of posttraumatic growth, and cognitive trauma processing approaches are all essential methods that entirely rest on the person according to this theory.

#### **Theoretical Framework: Transpersonal Lens**

After 100 years, traditional Western psychology was being challenged to deal with levels of consciousness that go beyond ego, and it was found lacking. What was needed was a new paradigm that would recognize legitimate spiritual or mystical experiences as attributes of the healthiest individual. – (Cowley, 1993, p.531). Transpersonal theory differs from Western psychological theories in that it is creative, whole-istic, multidimensional and integrative, as well as acknowledges intuition, and personal experiences and incorporates the spiritual nature of contemplative Eastern psychologies (Cowley and Derezotes, 2011).

Despite its continued marginality within the field of social work, there has been some movement to integrate transpersonal theory into social work literature and training (i.e. Cowley and Derezotes, 2011; Caroll, 2010; Derezotes, 2006; Canda and Smith, 2001), which "reflects a shift in reality perception within the field from an exclusively materialist-positivist view towards increasing openness to a metaphysical reality, which is not always amenable to research by traditional means" (Shahjahan, 2005 in Birnbaum and Birnbaum, 2008, p.88). Social workers now want "to know how to incorporate spirituality into their practice with specific populations and problems" (Derezotes, 2006, p.2). Therefore, this autoethnography about my experience working with a particular Amazonian shamanic wisdom tradition that uses a transpersonal lens to explore the possible benefits that a model of transpersonal therapy has to offer to my personal MS healing journey, as I undergo a spiritual process of individuation towards healing.

As the narrator, it is my experience that is at the core of the autoethnographical story, which allows one to "demonstrate the numerous layers of consciousness as a way to connect the personal to the cultural" through "action, dialogue, emotion, embodiment, spirituality, and a sense of self-consciousness" (Raab, 2013, p.2). Since transpersonal experiences usually occur during an altered

state of consciousness, which lead to "increased awareness, self-discovery, and ultimately transformation" (Raab, 2013, p.2), it is important to note that as you seek to understand my autoethnography through a transpersonal lens, a transrational shift in paradigm is required – a shift beyond the minds tendency to rationalize understanding. January 23, 2014 – I've finally located the source of the Achterberg quote I enjoyed reading in the article Ronald sent me prior to my departure. It was by a woman living with MS who shared her experience about her healing journey with Amazonian shamanic wisdom and rituals, one of which was Ayahuasca! The quote she began her article with was from Jeanne Achterberg (1988), who once stated that "soul loss is regarded as the gravest diagnosis in the shamanic nomenclature, being seen as a cause of disease and death. Yet it is not referred to at all in modern Western medical manuscripts.

Nevertheless, it is becoming increasingly clear that what the shaman refers to as soul loss – that is, injury to the inviolate core, which is the essence of a person's being – does manifest as despair, immunological damage, cancer, and a host of other very serious disorders. It seems to "follow the demise of relationships with loved ones, with careers or other significant attachments" (Achterberg, 1988, p.121-122). I can begin to see how this view of dis-ease relates to transpersonal theory, which views the spiritual void of our current paradigm as a "modern-day malaise of the soul," and is believed to possibly be at the root of many psychological problems and physical diseases (Cowley, 1996, p.668). Could this be the healing method for my Multiple Sclerosis experience? Why transpersonal theory?

The historical context and 'evolution' of transpersonal theory Transpersonal theory is an integral theory (Cowley and Derezotes, 2011; Almendro, 1994) that was born out of a reaction to the "decay of moral values evidenced in a drugged and violent society and the helplessness experienced by many in this age of nuclear threat, acquired immune deficiency syndrome,

homelessness, ecocide, and dis-spiritation [i.e., dispirited society]" (Bugental and Bugental, 1984 in Cowley, 1993, p. 528). The "dis-spiritation" of modern-day society that has been fueled by industrialization, is further disconnecting us from the "sacred meaning of existence" (translated from Almendro, 1994, p,187). And so, as proposed by Frances Vaughan (1991), the transpersonal movement can:

liberate us from the tendency towards destruction that prevails in our society, not by trying to impose a new system of beliefs or other metaphysics but rather to discover the relationship between existing worldviews, integrating both ancient and modern wisdoms (translated from Almendro, 1994, p,187).

Since the current neoliberal capitalist paradigm that we currently live in continues to further alienate us from one another as a collective species, from nature and the universe at large (e.g., cosmos), applying this multidimensional and integrative lens that views the micro-analytic lens and the macro-analytic lens as being interconnected seems appropriate to use as a theoretical framework for my transpersonal autoethnography. To understand how transpersonal theory links to my autoethnographic research, it is important to understand the four main western psychological theories that have emerged out of their own historical context – by doing so, important insight can be provided into the dimensions of human growth and development (Cowley and Derezotes, 2011).

Western psychology progressed through "successive stages emphasizing instincts and unconscious initiatives (psychoanalysis), environmental influences (behaviorism), self-determination and free choice (humanism), and transcendence and spirituality (transpersonal)," which also resembles "the stages of psychological growth and development a healthy person encounters" (Strohl, 1998, p.398). The Fourth Force 25 transpersonal theory differs from the other Western psychologies in that it is a creative, whole-istic, multidimensional and an integrative

theory that adds the spiritual nature of contemplative Eastern psychologies. What makes transpersonal theory an integral theory is its acknowledgement (vs. disapproval) of the importance – and inclusion – of the other three forces of psychology and their various models of intervention.

#### **Spirituality in Transpersonal Theory**

To comprehend the spiritual nature of transpersonal theory, the conceptualization of spirituality is important. For instance, the spiritual nature that is included in transpersonal models to therapy is not to be mistaken with religion; however, if an individual prefers to work within the religious dimension, it can be included in a transpersonal approach. Several authors (i.e. Ortiz, 1991; Titone, 1991; Dudley & Helfgott, 1990; Hess, 1980; Joseph, 1988; Siporin, 1985) seem to have an overarching view of spirituality "as the human search for meaning in life or a purpose of life" (Carroll, 2010, p.7).

Meaning in life, which continuously changes throughout a lifetime exposure to belief and value systems, can be defined as "the cognizance of order, coherence, and purpose in one's existence, the pursuit and attainment of worthwhile goals, and an accompanying sense of fulfillment" (Recker and Wong, 1988, p.221). Specific to social work and spirituality, Canda (1988) found that the perspectives on spirituality shared seven recurrent themes. They are that spirituality is:

- (1) an intrinsic and irreducible aspect of the person;
- (2) is expressed through individual development and relationship with the environment;
- (3) integrates all aspects of the person;
- (4) involves the search for meaning and purpose;
- (5) involves a loving relationship with all which exists;

- (6) provides a way of understanding human suffering and alienation; and
- (7) integrates the everyday worldly aspects with the transcendent aspects.

Based on these findings, Canda (1990) went on to define spirituality as a "person's search for a sense of meaning and morally fulfilling relationships between oneself, other people, the encompassing universe, and the ontological ground of existence" (p.13). However, when social workers "partialize or deny the spirituality of their clients, the fulfillment of people's potential for wholeness and creative transformation is restricted" (Carroll, 2010, p.10). Transpersonal theory provides this space "to honour our most generous premises about spiritual potential" (Cowley & Derezotes, 2011).

Carroll (2010) contends that the meaning of spirituality "is best conceptualized as both the essence and a key dimension of human nature" (p. 11) and provides a clarification of social work's conceptualization of spirituality as having two different meanings: spirituality-as- essence and spirituality-as-one-dimension. The view of spirituality-as-essence refers to "a core nature which provides the motivating energy toward meeting the potential for self-development and self-transformation" and the view of spirituality-as-one-dimension refers "specifically to one's search for meaning and relationship with God, the transcendent, or ultimate reality" (p.11). For this research, a focus will be placed on the concept of spiritual healing, which will be conceptualized as an ongoing process of becoming whole and increasingly conscious of our interconnectedness (Peck, 1987) through a process of individuation towards "one's basic nature and the process of finding meaning and purpose" (Carroll, 2010, p. 2).

### **Models of Transpersonal Theory**

There are several transpersonal approaches that have emerged under the broad umbrella of Fourth Force theory. Even though Carl Jung was the first to use the term transpersonal to refer to the collective unconscious – and whose emphasis in analytic psychology was that of "the relationship between the individual and a higher self, which he referred to as "God within" or the "inner deity" (Campbell, 1975 in Cowley, 1993, p. 529) – the term transpersonal psychology was coined in 1968 by a group of psychologists and psychiatrists consisting of Abraham Maslow, Viktor Frankl, Stanislav Grof and James Fadiman (Guest, 1989). However, it is Maslow – an American psychologist who also read extensively in Eastern literature – who is the philosophical father of both humanistic and transpersonal theories (Cowley and Derezotes, 2011). In 1968, Maslow called transpersonal psychology the Fourth Force psychology, which emerged from mainstream psychology and religious studies (Strohl, 1996). Maslow believed that, as human beings, we have "a universal longing to transcend our aloneness and feel a connection to others and to the cosmos" (Cowley, 1993, p. 530), and that even if all our secular needs have been fulfilled, we want to feel and experience a cosmic connection (Bradshaw, 1988, p. 228).

Prior to his death, he had made a call for a fourth psychology that would be "transpersonal, transhuman, centered in the cosmos rather than in human needs and interests, going beyond humanness, identity, self-actualization, and the like" (Wittine, 1987, p. 53). Ever since, the definition of transpersonal theory has evolved to reflect its historical context. Some transpersonal Upon examining a rich variety of symbols in legends, myths, and folklore, Jung discovered universal themes from the personal and collective unconscious, which he called archetypes (Guest, 1989). models are Robert Assagioli's model of Psychosynthesis (1965); Jacquelyn Small's Self

Creation model (1982); Stanislav Grof's Holotropic Breathwork model (1985); Ken Wilber's Full Spectrum model (1986); and Au-Deane Cowley's Transpersonal Social Work model (1996).

# **Linking Transpersonal Theory and Autoethnography:**

The transpersonal paradigm entails highlighting the experiential facets of experiences, which can be easily documented in auto-ethnographical format through personal narrative, memoir, narrative poetry, or fiction. This form of communication can be therapeutic and healing in that the information presented by the autoethnographer involves self-discovery, self-awareness, and a sense of empowerment. – (Raab, 2013, p. 2) Transpersonal theory can expand research methods "in the two ways suggested by the prefix trans in transpersonal" (Braud, 1998, p. 9). Braud (1998) describes the first meaning as through in its emphasis on the "interconnections or tying together of what presently comprises us and our world," and the second meaning as beyond in that it "reminds us of the something else, the more of ourselves and of the world what we have not yet fully glimpsed, actualized, or understood" (p. 9).

The latter meaning "suggests other forms of knowing, being, and doing beyond those conventionally recognized – beyond what is available to us if we remain wedded solely to an egocentric view of our nature and possibilities." (p. 10). In addition, one of the main responsibilities of transpersonal psychology is the "democratization of knowledge" in that it charges "to take its findings directly to those who can most use them, rather than have these findings languish in dusty journals read only by professionals" (p. 16). Transpersonal studies honor the human experience of the researcher as a valid source of data, which can, in turn, have a transformative impact not only on the researcher but the reader as well. Autoethnographies have a similar intent and as claimed by Ellis (2004): people respond to it [autoethnographical study].

I can count on one hand how many people ever wrote to me about my more orthodox social science work, but I have gotten hundreds of responses to my autoethnographic stories. (p. 35). Similarly, Raab (2013) argues that in addition to the process of empowering the researcher, autoethnography – like memoir writing – can transcend a person's account by linking the story to broader social implications and contexts. For instance, in view of the recent surge in memoirs in the trade book market, it is apparent that the public enjoys reading about the personal lives of others. Getting up close and personal to a lived experience tends to move the reader emotionally, while helping the researcher to embody the experience. (p. 3)

Raab's (2013) autoethnographical study highlights that "for the most part, the transpersonal relevance of an auto-ethnographical study encompasses the idea of fostering self-awareness and self-discovery, which may lead to transformation" (p. 14). This study also addresses how an autoethnography can be performed using transpersonal psychology as a model. It demonstrates how an autoethnographical study could benefit from the use of transpersonal theory since it allows it to move beyond the walls of anthropological research and into the field of psychology and mental health. Raab's (2013) posits that there is "a natural blend between the autoethnographical method and the work of the transpersonal psychologist" given that "the core of transpersonal psychology is the concept of self-discovery and transformation – two benefits derived from sharing stories through narrative" (p. 17). Therefore, given that transpersonal theory is a comprehensive and inclusive approach that complements the healing potentials of sharing personal narratives – the use of this theory as a lens for exploring my inward subjective healing journey through an autoethnography is complementary.

# 1.7 Significance of The Study

The primary goal of this study is to consider how social class has played a controlling role in the attainment of early complex diagnoses. Through my journey, one will realize that some people are not given the chance to thrive due to expensive diagnoses often negated to those unable to pay for extremely costly treatments. By exposing my life story, I give a voice to many others who have been silenced, exposing the limiting and inhumane medical and service systems in the U.S. I offer insights on how I navigated through such challenges, using education as a platform for survival, purpose, advocacy, and hope to partake in policy changes to foster a better world for us all. Working through the complexity of my journey, I aim to reframe my mindset towards a transformative route in which one realizes we are all one together.

Secondly, this study is intended to reach readers who have been abused, moved from middle class to poverty, back to middle class, are educators, and/or scholars. Thirdly, I would like to acknowledge an audience of silent readers who are now bringing to the forefront their previous experiences of abuse or poverty within the current U.S. healthcare system. Consequently, this autoethnographic piece looks to share a personal narrative account of my experiences as a woman thriving for healing from an incurable aggressive disease on her own. Ultimately, this study will offer an analysis of what is considered financially vulnerable and lacking means for mental, emotional, and physical health (Bennett, 2004). There is a need to invest in psychological interventions as a way of addressing the challenges faced by complex trauma survivors, as well as by those not granted access to a diagnosis due to the burning cost they will lay on the system.

The focus on post-traumatic growth, the positive side of trauma, will open a new perspective of helping the survivors of trauma to approach the future with hope and optimism. This may help to counter the narrative of intimidation and hopelessness among survivors.

Exploring the positive outcomes after traumatic events among survivors creates awareness for other survivors to reexamine their growth experiences and begin to appreciate life in a new way.

In the field of counseling psychology, this study may help counseling practitioners incorporate posttraumatic growth knowledge as solution-focused strategies in trauma counseling instead of just concentrating on the current problem-focused critical incident debriefing. As universities continue designing and revising programs in response to emerging issues in society and remaining relevant, this study may be beneficial by availing knowledge on the positive outcomes of trauma. This may help them gain self-awareness, bring out their individual strengths, and develop new trauma-coping strategies as they introspect on the possible post-traumatic growth that may have developed within themselves.

#### 1.8 Contents of The Dissertation

Chapters I through III will use a traditional format when presenting the Introduction, Literature Review, and Methodology. In Chapter IV, I share early childhood experiences; to allow readers to understand their impact on adversity encountered in my adulthood. I will also address adversity encountered in adulthood and the Post-Traumatic Growth that followed. I share experiences of the adversity I encountered in my adulthood because of adverse childhood traumas. Also, I will impart how moving to the United States helped me embrace my resilience by "choosing" financial struggle and independence to escape a somewhat luxurious, yet extremely toxic environment. In this dissertation, I also address the role of "choice" as more perceptual than factual. I converse with my now expansive "adoptive family" and professionals who supported me at some point in my career spiritually, financially, or emotionally to attain the many personal and professional goals I had set for myself. I explore the lessons I learned throughout the lowest points

of my life regarding my finances, mental health, physical health, and emotional well-being (Eitzen & Eitzen Smith, 2009). I reflect upon my growth in relationships with others, the world around me, and myself. In some instances, I reflect on memories. I wrap up this chapter by exploring how trauma can be molded into a powerful tool for growth in the development of Post-Traumatic Growth (PTG), and I re-examine my relationship with Reactive Attachment Disorder (RAD), Complex PTSD, and the role of resilience in fighting for a complex and expensive physical diagnosis. In Chapter V, I offer general thoughts, reflections, and recommendations for creating a community more guiding in terms of public health policy aimed at helping people in need of complex healing, lacking the emotional, physical, and financial resources. I share concluding thoughts on the Role of Resiliency, and how autoethnographic studies can be powerful tools to offer contributions in interdisciplinary health science approaches.

### 2. Chapter II: Literature Review

# 2.1 Overview of The Chapter

Trauma affected my life in many areas as a child and teenager, such as social, emotional, and interpersonal areas, which all led to a less adjusted adulthood in which I struggled financially, emotionally, mentally, physically, and academically. Yet, against all odds, I went from being a high-school drop-out to becoming a doctoral student.

Although the onset of my physical symptoms appeared in 2008 when I was first diagnosed with the Epstein-Barr Virus, and although I have spent the past seven years fighting for a diagnosis, I am expected to get it this month (April 2023), I stand tall. Lucky enough to have been involved in social justice, I realized in 2017 during an excruciating episode of pain in the spine, loss of eyesight and balance, a drunken feeling, transient ischemic attack (TIA) symptoms, and unexplained tingling in my limbs worsened by slight inflammations, temperature, and barometric pressure changes, that what had been brushed off for severe PTSD for almost a decade, had been Multiple Sclerosis, Myelin Oligodendrocyte Glycoprotein Antibody-associated Disease (MOGAD) or NMO. Labels and degrees of the illness kept changing over the summer of 2023, though the only sure thing was that it was one of the three known demyelinating diseases. There started a long journey of self-advocacy, investigating a system that fervently denied a family-less, homeless woman the diagnosis of one of the most expensive treatments there is on earth for a so-called incurable disease.

Navigating a lack of support system, resources, energy, and strength, I have had to face countless coldhearted physicians, unwilling to help me obtain access to this diagnosis, most likely bought by the powerful pharma-industry – suspicions without "proper" evidence called upon from paranoia. Although I collected many other diagnoses, some accurate, and others to simply justify

MS symptoms in order avoid the diagnosis itself, I have been denied disability as I kept on working (for lack of any choice), juggling jobs as I struggled to keep them. My resilience at times felt like a double-edged sword. Yet, today, tired and struggling, I am ready to face and accept the uncertainty of a diagnosis that seemed to have been set in stone a few times over the past year and yet keeps on changing.

Beyond speculations and paranoia, I wabble with the fear of not ever seeing justice or finding peace. Yet, along this journey, my relationship with the Self has improved drastically, as I have had no other choice but to pick myself up from the streets, moments of cognitive impediments, gathering all the evidence of my obvious intentional dismissal by several practitioners and concurrently questioning myself on how much the obvious might just be paranoia. I am proud of the investigations I managed alone to put orders to and organize documents, seeking ways to get approved for my MRI scans, and just keeping track of it all. While this thirst for justice for all those whose voices were never heard has been driving me, I also find myself at a crossroads of exhaustion, where healing sounds more urgent than anything else. Here, I find the power that remains to influence therapies and policies in this autoethnographic research while healing the self, advocating for others, fighting for justice, and contributing to research all-in-one.

The body and mind are sometimes slowed down. Yet, I keep positive, watch my words and thoughts as I now believe they have power to work for or against me. With it, fear of uncertainty rises exponentially. I am learning to embrace what cannot be avoided while refusing to give up on hope and faith that one voice can make a difference. Though my choices may seem limited, I keep on trying to gain access to the most potentially accurate diagnosis and treatment. My studies are

an integral part of this complex journey as I strive to grow in faith that my contributions will bring about a humanistic present.

"Purpose is powerful. May I never lose purpose. May my words hold value and influence change."

- Josette Pelatan (2024)

I took some time to reflect deeply before I gathered my plan to face this illness with a research focus. In time, my decision to investigate the personal experience of this illness more formally required a way to organize my thoughts and feelings. I used to be quite fatalistic and negative. Survival has offered me the choice to change and choose different routes. Although I claimed to be an Atheist for over half of my life, I have always carried a deep spirituality and willingness to listen attentively to the many teachings of religions, philosophies, and peoples who crossed my path. Today, I am an Atheist with an outspoken spirituality that nurtures optimism, and that has more faith in anything that might help me, be a better me.

While I used to claim things were often coincidental, my heart never truly bought the words I often spoke to protect it from disappointment. A few years ago, feeling unwell, I sat in the cafeteria of the university where I studied. Although my eyesight was blurred and my head felt foggy, a booklet caught my eye. It was entitled, "Autoethnography." I have always been drawn by the things the mainstream seemed not to care for. Left alone on that table, it was waiting for me to rescue it. I read about the highlights of the works of exemplary scholars, such as Carolyn Ellis, Arthur Bochner, Gloria Marshall, Norman Denzin, and Clark Moustakas. I read about their passions and achievements in their contributions to ethnography, autoethnography, and heuristic research. In this vestibule, I also saw portraits of people I wanted to know more about, and I realized I was in a magical interdisciplinary House of Learning.

Serious illness is the loss of the destination and map that had previously guided the ill person's life: ill people have to learn to think differently.

- (Frank, 1995, p. 1)

Albrecht (2005) argues that "one's perspective on health is oriented by cultural values," and defines being healthy as a metaphor for well-being where one is "of sound mind and body; to be integrated; to be whole," while illness is referred to as an imbalance (p. 267). Such a definition works much better across cultures and various belief systems than when one links health to disease, which "technically, means simply a biomedical measurable lesion or anatomical or physiological irregularity" (Sobo, 2004, p. 3).

Illness is different from dis-ease since it is the "human experience of symptoms and suffering" (Kleinman, 1988, p. 3) and not "an alteration in biological structure or functioning" (p. 5). Dis-ease is anchored in the body and something that is either cured and or not, while illness "may be seen as anchored in the mind" and refers to a variety of conditions cross-culturally (Sobo, 2004, p. 3). Many cultures attribute illness "to a psycho-physiological disequilibrium in the human organism, which may include a social element" (Fotiou, 2012, p. 7). For instance, Holistic is referred to as whole-istic in this research to emphasize the wholeness element of the holistic 1 paradigm. *Curanderismo* – similar to Western transpersonal therapists – believes that "the root of diseases is in the spiritual as well as the social sphere. To treat illness, the curandero employs a variety of methods, such as prayers, *icaros*, messages, sucking, blowing smoke, incense oils, perfumes, and plant essences" (Fotiou, 2012, p. 7).

Illness is "the culturally structured, personal experience of being unwell and it entails the experience of suffering" (p. 3) – it is "the subjective state, which is experienced by an individual, a feeling of ill-being" while dis-ease is "a pathological condition recognized by indications agreed

among biomedical practitioners" (Stacey, 1988, p. 171). Therefore, culture shapes how we understand and treat illness, and dis-ease is what the biomedical practitioners "create in the recasting of illness in terms of theories and disorders... the practitioner reconfigures the patient's and family's illness problems as narrow technical issues, disease problems" (Kleinman, 1988, p. 5).

For this research, health is conceptualized as a "holistic notion of individual well-being" (Albrecht, 2005, p. 267) and illness as the result of imbalance (Albrecht, 2005; Brennan, 1988). More specifically, illness in this research is understood as "a signal that [I am] imbalanced because [I] have forgotten who [I am] ... a lesson [I] have given [my]self to help [me] remember who [I am]" (Brennan, 1988, p. 131). This view of illness is like the shamanic concept of "soul loss," which comes from an animistic causation perspective of disease and health that Murdock (1980) and Albrecht (2005) define as one of the three general types of theories of supernatural causation "Traditional folk healing practices," such as Ayahuasca shamanism (Fotiou, 2012, p. 26).

Theories of supernatural causation include "causes such as mystical retribution (punishment by the gods for violating rules), animistic causation (soul loss or spirit aggression for violating rules), and magical causation (witchcraft, "evil eye")" (Belgrave, 1998, p. 35). While the Indigenous medical system is whole-istic in its approach (Poonwassie & Charter, 2005), it also often "takes into account both natural and supernatural causation of illness and misfortune" (Wolff, 2004, p. 1033).

To understand this research, it is best to situate individual paradigm of understanding illness within "a creative and imaginative shift, suspending any logical, rational, and objective mode of thinking beyond the limits of science and into alchemy" (Moodley, 2005, p. 10). This will be included as a separate section as I will also clearly use logical, rational, and objective research

to trace my diagnoses journey. Whole-istic and Intuitive Hopeful Healing Whole-istic healing is a "synergetic approach which deals with the combined physical, mental, emotional and spiritual aspects of human health and illness" (Gerber, 1988, p. 536). Healing can be seen as the interweaving of both secular and spiritual teachings that include all aspects of life and can be understood as "the quest for balance and restoration of harmony," which includes either the body, mind, and spirit of a person or the physical, the emotional, the intellectual, and the spiritual (Poonwassie & Charter, 2005, p. 18). Healing has also been described as "the use of one or more of the following: intuition; presence, inspiration; psychic; shamanic; altered states; (spiritual) healing methods; subtle energy work; mediumship; channeling; use of spirit guides; and transpersonal work" (West, 2005, p. 39).

Given the complex nature of the incurable chronic dis-ease and illness of Multiple Sclerosis (MS) and other demyelinating diseases, I felt it was worth exploring how working with the community from a whole-istic perspective can support healing and provide the hope necessary when living with so many uncertainties that come along with the diagnosis. While there has been "an ongoing struggle in the sociology of health to understand the interrelationship of body, mind and spirit" (Albrecht, 2005, p. 273), the supernatural causations of disease are not recognized as valid by allopathic Western medicine.

In addition, given the reality of how knowledge is produced and marketed there is "a major problem of external validity and generalization," which exists with any knowledge of health, illness, and medicine that is generated outside of Western scholars (Albrecht, 2005, p. 270). While the status quo of Western medicine's knowledge, power and form of practice began to be challenged as of the later third of the twentieth century (Albrecht, 2005), those who are "interested in the spiritual dimensions of health and illness including belief in a higher being, ultimate

meanings of existence, hope and feelings of detachment and peace are regarded with suspicion by those grounded in the 'science' of the body" (Albrecht, 2005, p. 274).

While this research project draws on medical research, scholars and healers from around the world, it also speaks to the conversations that are currently happening in Western literature on the sociology of health (Albrecht, 2005; Bolaria and Dickinson, 2002; Stacey, 1988) and the importance of narrative when telling the stories of illness (Charon, 2006; Frank, 1995; Kleinman, 1988). Given that "discussions of pathology dominate the medical literature, social sciences point out that illness is culturally constructed and closely associated with the dominant social, political and moral orders" (Albrecht, 2005, p. 268). There are also concerns around the need for medicine to be practiced within a framework of "narrative competence to recognize, absorb, interpret, and be moved by the stories of illness" shared from patients who feel unheard (Charon, 2006, p. vii) so that "rich and accurate interpretations of these stories, and [...] the plights of patients in all their complexit[ies]" can be understood by doctors, nurses and social workers (Charon, 2006, p. 3). It is important to recognize the need for those diagnosed "to become storytellers in order to recover the voices that illness and its treatment often take away," allowing them to heal (Frank, 1995, p. xii).

It is important to include their judgements about "how best to cope with distress and with the practical problems in daily living [illness] creates" (Kleinman, 1988, p. 4). Not only does this narrative process heal; hope can often be an outcome of having our voices recognized when sharing the experience of illness because of the dis-ease diagnosis. While hope "is about finding a way to move through mourning and despair" it can be conceptualized as a "force which keeps us moving and changing – the renewal of life at each moment, or the 're-enchanting' of life and politics – so that the future may be about how we come to live and hope in the present" (Zournazi, 2003, p.

274-5). Hope remains a complex construct and the diversity of definitions and models "present a major research challenge" (Nekolaichuk et al., 1999, p. 591).

Barnard (1995) suggests that chronic illness brings forth "the very aspect of human existence that gives birth to hope, namely, that human beings are poised on the boundary between finitude and transcendence" (p. 38), and suggests that "people with chronic conditions are impelled at once to defy limitations in order to realize greater life possibilities and to accept limitations in order to avoid enervating struggles with immutable constraints" (p. 39). There are documented case studies that show a positive link between hope and health where the therapeutic value of hope is acknowledged, suggesting that "hope may promote healing, facilitate the coping process and enhance quality of life" (Nekolaichuk et al., 1999, p. 591).

When living with an incurable dis-ease such as MS, some individuals choose to use alternative treatments as a means of providing hope due to "the lack of effectiveness of traditional treatments in bringing relief from symptoms" and in curing MS (Berkman et al., 1999, p. 249). As an individual living with demyelinating disease, I believe that the incorporation of transpersonal therapy as a spiritual health care modality into the curative views of allopathic medicine is necessary when working with patients since it could provide the hope necessary to heal. Especially since there has been recent research linking spirituality to both emotional and physical well-being (Ironson et al., 2006; Laubmeier et al. 2004). While the fourth force psychology of transpersonal theory "does not attempt to supplant other psychological theories, but rather to complement and enrich them," it continues to challenge clinical minds "that are steeped in the first three forces to transcend traditional boundaries to include the spiritual dimension, to honor the intuitive and transrational elements of practice" (Cowley and Derezotes, 2011, p. 553).

Cowley and Derezotes (2011) provide a clear description of the four forces which consist of the First Force as the dynamic theory, which primarily focuses on pathology. This term will be used intermittently with conventional, modern and biomedical medicine and dynamics/past; the Second Force is the behavioral theory, which primarily focuses on social learning and the process of socialization; the Third Force is the humanistic, experiential and existential theories, which primarily focus on human growth (vs. cure); and the Fourth Force as the transpersonal theory, which primarily focuses on expanding thinking beyond traditional boundaries to include the phenomenological, the intuitive and the transrational.

Sadly, transpersonal therapy continues to live in the margins of mainstream Western psychologies (First, Second, and Third Forces), which lack spiritual and transrational dimensions. What brings me to this autoethnography? An interest of mine has always been to listen and work with all forms of silenced voices and experiences towards emancipation and a sense of self-worth. During this autoethnography, I will share my experiences of having my voice silenced by the mainstream biomedical healthcare system in regard to signs and symptoms of my illness that were often brushed off or discarded for severe PTSD. However, it was by shifting to what Frank (1995) calls a postmodern experience of illness, that I have been able to reclaim my voice and experience of living with this illness.

This shift allowed me to combine conventional modern medicine where the chart becomes the official story of the illness and the experience of thorough theory that includes the drive to seek and connect psychology, ego psychology, object relations, self-psychology to resilience theory, by including behavior modification, Cognitive Behavioral Therapy (CBT), Havening, and Eye Movement Desensitization Reprocessing (EMDR) therapy. "Overtaken by technical expertise, including complex organizations of treatment" (Frank, 1995, p. 5) the postmodern experience of

illness can be an empowering one since it allows for the honoring of individual voices as 'experts' and "begins when ill people recognize that more is involved in their experiences than the medical story can tell them when the capacity for telling one's own story is reclaimed" (Frank, 1995, p. 6-7). Voices have been silenced for decades (if not centuries) by cultural hegemony. For instance, there was a time when women healers who worshipped nature through the adoration of many gods were labeled as witches and burnt to death in the name of 'Enlightenment' and reason (A&E, 1996; Campbell, 1978).

While Western worldviews are based on "the physical, explicit, scientific, and objective journey for knowledge", other world-views are founded on a search for meaning from a metaphysical, implicit, subjective journey for knowledge based on the premise of skills that promote personal and social transformation; a vision of social change that leads to harmony with rather than control over the environment; and the attribution of a spiritual dimension to the environment" (Poonwassie & Charter, 2005, p. 16)

The 18th century 'Age of Enlightenment' marked a significant paradigm shift from traditional and mystical thought to rational and positivist insight (Honneth, 1987), which continues to be experienced not only through systemic racism but also within the biomedical model of treating dis-ease and illness that are based on anthropocentric, empirical, and unidimensional understandings of human health. In recent decades, Indigenous Peoples "have suffered from the consequences of some of the most destructive aspects of global "development" and these changes, because of colonization, have affected the present health practices of the dominant society (Solomon & Nathani Wane, 2005, p. 52). Conventional health care has much to learn from Indigenous ways of healing, which have often been silenced. While it is important to understand that Indigenous approaches to healing are not homogenous, there is a "communal ideology and

unique worldview" between and among Indigenous worldviews, and approaches to healing are similar in nature (Solomon & Wane, 2004, p. 54). They are whole-istic in their approach and quite often incorporate the use of spirituality in healing journeys (McCormick, 2005).

By incorporating spirituality as an integral element of my healing journey, I found a sense of hope and support for the healing process of an illness associated with a dis-ease that has no biomedical cure. It is important for me to heal so that I can be an effective social worker since, without health, it will be difficult for me to not only facilitate the healing process for others but also be an effective participant in social change. Thus, prior to fully engaging in any form of healing and advocacy work with others as a social worker and public health advocate, I recognize the importance of focusing on my health to have the strength and awareness to do so. This is what I call my healing journey, a journey where I can feel empowered as I reclaim my voice and thus heal by allowing myself to explore preventative health care and healing modalities that are rooted in a whole-istic paradigm. It is my hope that by shifting paradigms, I can not only heal but also prevent this autoimmune dis-ease from possibly attacking my nervous system any further, and perhaps even reverse it. As part of this journey, spirituality plays an important role in my healing. Spirituality is a component of human experience and can be understood as "a sense of meaning and morally fulfilling relationships between oneself, other people, the encompassing universe, and the ontological ground of existence" (Canda, 1988, p. 13).

To understand the healing benefits of spirituality – based on ancient wisdom, traditions, and rituals – it is necessary to shift one's process of understanding and explaining from our mainstream biomedical paradigm that is often based on a "mechanistic model of the human body," which operates according to individualists, logical inferential and causal scientific beliefs (Bolaria & Dickinson, 2002, p. 4). Instead, mainstream health care could move towards equally validating

individual intuitive meaning and honoring a causal and ancient wisdom that is based on a whole-istic approach to treating an individual. Intuition and spirituality are linked in that through the development of spirituality. Intuition is experienced as an outcome of increased awareness (Krishnakumar & Neck, 2002; Mauk, 1998). Intuition involves "not only the brain and its cognitive processes but also the whole body-mind-spirit" (Derezotes, 2006, p. 14). Not only is there a lack of research into the intuitive process, but what does exist does not seem to offer any consensus for the meaning of intuition (Shirley & LanganFox, 1996).

In both social and cognitive psychology, intuition has been extensively researched. For instance, Rea (2001) refers to it as "the ability for a rapid understanding of knowledge, or meaningful insight arrived at without the conscious use of reasoning or deliberation" (Ringel, 2008, p. 19). This is quite important to note, as I will also tackle reflections on how paranoia has affected my perception of certain events. In other fields, intuition has been conceptualized as knowledge (Fitz, 2002), a way of knowing connected with mysticism and spiritual matter (Vaughan, 2002), and a tool used for decision-making or problem-solving (Khatri & Ng, 2000), to name a few. A recent literature review by Jeffrey (2008) also found there to be no unified consensus in the postulated definitions; however, the literature seemed to point to intuition as "one main source of knowledge" (p. 30).

In the field of social work, there has been an evolving context for intuition as a critical tool – for both the social work professional and the recipient of professional assistance – to be found in the literature on the spiritual dimension in social work practice, transpersonal theory, and practice wisdom; however, intuition has not been elaborated upon in the social work practice literature and is rarely a direct focus in mainstream social work literature (Ringel, 2008; Luoma, 1998). For instance, Luoma (1998) believes that "intuition can become a critical tool in the process

of accessing more of the self to provide a more comprehensive approach to the issues being presented" (p. 37), and that a "larger transpersonal understanding of human nature needs to be incorporated into the practice of social work as well as into the educational process to be passed on to the next wave of future social workers" (Luoma, 1998, p. 36). Furthermore, intuition is often nonverbal and often experienced as spontaneous, immediate, sensed differently, and is as important as scientific ways of knowing in guiding and informing social work practice (Derezotes, 2006). Therefore, this study will help understand and incorporate intuition as a way of knowing that can provide a much deeper understanding of the situation/experience of illness. Intuition will be used as a way of knowing like any other psychological function such as sensation, feeling, and thinking (Vaughan, 1979) that is not contrary to reason, but rather as something outside the province of reason/ rational thought (Jung, 1934) since intuition involves "the ability to access thoughts and feelings that reflect an inner knowing or understanding" (Sollod, 2005, p. 275). Intuition is a valuable source of information that resides in our unconscious psyche, and thus outside of our conscious and rational awareness.

Throughout this personal journey, intuition will be used intermittently with the concept of the unconscious psyche, which consists of the unknown in our inner world (Jung, 1969). Since everything that does not pass through the ego is "unconscious" (i.e., not known to us), the ego will be referred to as "the subject of all personal acts of consciousness... to which all conscious contents are related... the empirical personality" (Jacobi, 1967, p.49). If you return to the initial conversation in this text between Luis and me when I had my first MS symptom in October 2006, you can see a disconnect between my rational ego and unconscious psyche/intuition. This marked a significant moment as I slowly began to expand my views of understanding and explaining life – and illness led to that shift (Frank, 1995). I started to tap into the world of the unconscious and

its psychic and intuitive content, including the supernatural causes of illness. As I began expanding my worldview and experiencing different ways of knowing and healing outside the cultural hegemony, I began to see the benefits of exploring the inner realm of my unconscious psyche as a means of changing my conscious ego's outlook, in turn supporting the healing of my diseases and disorders.

# **Overcoming Cultural Hegemony:** Reclaiming My Voice

In addition to my personal healing, I can also share my story with others living with MS as a way for them to vicariously experience the dis-ease through a whole-istic paradigm and to facilitate a sense of empowerment, an awareness of the powerful healing benefits of reclaiming our voices from the biomedical paradigm, and the sense of hope that can be generated by exploring models to 'treating' MS outside of cultural hegemonic practices. Please note that throughout this journey, I will not be referring to non-conventional healing practices as 'alternative medicine' since the concept of "alternative" implies the meaning of being secondary (Frank, 1995). This would imply that I support biomedical medicine as authoritative medical knowledge. Therefore, this work is situated within a cultural hegemony where the only hope of living a healthy life lies in finding a cure while - if accessible - treatment and prevention efforts may mitigate the progression. Multiple Sclerosis, an incurable dis-ease that causes the destruction of myelin and the protective sheet around the nervous system throughout the body, leading to progressive physical and cognitive disability (Ubelacker, 2013). The World Health Organization (2008) reports MS is the most common neurological dis-ease affecting young adults; that women are more than three times as likely to develop MS as men; and that very little is known about the causes of MS.

What is known about MS is that it is a chronic dis-ease with unpredictable progress, severity, and symptoms, and is "often [a] disabling disease" (National MS Society, 2012). And so,

since the goals of an autoethnography are both social change and personal healing (Tamas, 2011, p. 48), I decided to reclaim my voice/narrative in experiencing this illness through this methodology so that I could not only support my healing journey but also share my journey with others living a similar experience within a cultural context in which my dis-ease has often been silenced due to the modern (and normative) view of illness (Frank, 1995).

Due to the little hope that conventional medicine is providing my diagnosis, I am feeling an enormous sense of disillusionment and hopelessness. My neurologists have continuously reminded me that my only hope of living a healthy life lay in the hands of pharmaceuticals, even when I suggested my intuitive need to search for answers through more whole-istic modalities that recognize the mind-body connections of illness and auto-immune diseases. They viewed anything outside of the biomedical field as pseudoscience and quackery and that their knowledge was the only way to possible health. I was introduced to the mind-body connection hypothesis of dis-ease after reading that psychoneuroimmunology has found "scientific proof that thoughts affect your immune response...and over time, negative thought pattern create disease" (Boroch, 2007, p.84), I feel hope and am ready to embark on an MS healing journey.

It appears emotional and psychological stress can have a role to play in the onset and progression of MS. Structural social work views empowerment as being about taking charge and becoming an active player in our own lives; "a process that enables the transition from a state of passivity to one of activity and control over one's life... involv[ing] the psychological, education, cultural, and spiritual natures involved when individuals are helped to understand their oppression and to take steps to overcome it" (Mullaly, 2007, p.299). Therefore, it is by using a personal narratives approach to conducting an autoethnography that allowed me to be empowered as I reclaim my voice by moving into the postmodern experience of illness (Frank, 1995). In doing so,

the stories became about seeing myself as the phenomenon as I wrote in evocative narratives (Ellis et al. 2011), specifically focused on my personal life living with MS. This process of storytelling allowed me to understand myself living with MS as it intersects with the limitations of conventional allopathic medicine, and the hope that multidimensional whole-istic healing models provide. Therefore, doing and writing this autoethnography has been both a healing and an empowering process as I reflected on my own experience of living with the uncertainty of this disease within a conventional biomedical paradigm.

A study such as this holds significance for shifting the way trauma healing is approached when exploring my language use and the meaning of my life. While trauma is a core component of this study, healing is its main nascence and conversation. By exploring my traumas, healing, and showcasing why healing is needed, it is my intention to address the work necessary to create solutions to the problem of trauma, trauma recovery, and how trauma affects policy changes, and offer alternative ways of providing support and therapies. Burke (2018) stated that "Trauma is the absence of action." In my own experiences of trauma, I have found this to be very true. As a survivor of trauma, I was willing to review what I have been through and created disclosure to myself first to heal. This is a way to believe our own stories while coming back to the potential roots of trauma and the one thing that allows us to speak the truth without fear.

To "own" my story, I must be transparent with myself and others to share how much pain has been carried and how far I am willing to go with my healing process to become a better version of myself after being exposed to different traumatic experiences. It sometimes takes years to look at bad memories, but I am willing to unlock thoughts through writing with a purpose much greater than self- to bring light on my own darkness. This is where I began to discover that I do not need to be silent about my traumas. I need to own my story, so that I will be able to help others with

their trauma experiences and educate others on exposure to different life experiences, like post-traumatic stress disorder (PTSD).

#### 2.2 Resilience Framework

Resilience is used as a central framework in varied academic disciplines and is becoming prominently used by policy makers. The ability to foster an integrated approach as a positive element of Resilience does not prevent the theory from having important limitations. One of the main critics of Resilience Theory is that the term tends to be anti-poor as it certainly does not benefit them. Per se, resilience growth cannot substitute poverty lessening (Merriam et al., 2015). Since the 1960s, the notion of resilience has been acquiring critical attention in academia. It has now become a crucial model in disciplines such as ecology (Cote, M., & Nightingale, A. J., 2012), conceivably trading sustainability as the decisive goal of development (e.g., Folke et al., 2002). In areas where problems of shocks, susceptibility and risks are unavoidable, the upward stimulus of the notion of resilience is also obvious (e.g., Klein et al., 2003; Allison & Hobbs, 2004; Adger et al., 2005; Moser et al., 2010).

# 2.3 Background

Much attention has been focused on the nature of resilience and how to best evaluate it. A widespread line of research points to the historical and cultural development of the concept, which incorporated diverse shades of meaning over time.

Understanding why only certain people can react positively to adversity and use struggles as opportunities for growth and adaptation, was the focus of early studies on resilience. Adjustment struggles are statistically associated with living conditions often encompassing negative life

events. Moreover, the notion of adversity can be characterized as the state of distress and discomfort provoked by a hardship, challenge, or possibly traumatic experience. After the Second World War, interest in research started to spark an understanding of how people recover from traumatic encounters that caused them psychological anguish. The potentiality of altering a destabilizing experience into a positive transformation became one of the leading questions of our time, attempting to tackle questions of resources and susceptibility, suffering and courage, and the ability to challenge inner growth through hardships, herein remolding definitions of resilience. The primary focus of inquiry was targeted at offering a clearer grasp of the processes of resilience.

Descriptions of people's traits that had lived through traumatic events such as war and lived with post-traumatic stress disorder as well as other pathologies triggered by severe trauma, while demonstrating that a significant number of people encountering similar traumatic situations were able to successfully process trauma and avoid its long-term impact and mental health conditions' development. The analysis of risk and protective factors for mental health conditions started to focus, shortly after, on developmental psychology, leading to a better understanding of reasons why some cope, and others thrive. These studies on resilience shed light on the fact that resilience is much more complex than the ability to continue developing one's competencies in the face of misfortune or endure trauma by safeguarding oneself from the impact of external situations.

Some studies are aiming partially at the promotion of willpower in redirecting one's own mindset from a negative experience into an opportunity for a growth mindset. Psychological resilience, therefore, began to refer to the term as a dynamic process that takes shape as an alteration of the mind, allowing for positive evolution in search of and in the nurturing of a new healthy balance. During this growth, the person develops new aptitudes and revived feelings of personal value and self-enrichment. This spherical process helps to strengthen the resilience course

and its entire development. Consequently, a shift in an allostatic process is needed to adjust to fluctuations generated by the situation.

In their resilience model, Richardson et al. (1990) try to incorporate two viewpoints by contemplating them both as inherently established characteristics and as practices. According to the authors, we all have an instinctive tendency for resilience, which can permit us to confront struggles and the collapse of pre-existing stability. The concept of deterioration of an individual's life model offers the prospect for an in-depth self-reflection upon themselves and for a redefining of the self. From the understanding of perception and the quest for one's individual internal means comes the recognition and strengthening of resiliency characteristics. Therefore, I will allow approaches intended to help face unfavorable situations and restore balance.

This model accepts the circuitousness of the power of the self and the situation to that extent, as resilience is, at the same time, a component of the adjustment development and its result. Rutter (1985), drawing upon findings on children born to mothers with schizophrenia and showing that many of them had no atypical comportment as adults, suggested an initial definition of resilience as a 'positive' reaction of a subject to stress and unfavorable circumstances. Here, 'positive' indicates the non-existence of psychopathologic concerns such as conduct disorders and affective disorders. This research paved the way for a longitudinal study by Werner and Smith (2019), which took 30 years and was supervised on a model of 698 children born in Kauai, Hawaii.

These subjects had been registered in the research because they had been subjected to distinct pre-disposed mental health risk factors (e.g., difficult birth, poverty, families with problems with alcoholism, mental illness, aggression, etc.) that could have affected their progress in relation to the inception of mental illness. The assessment permitted the authors to examine the development of the sample's emotional and interpersonal malleability over time. Notwithstanding

the occurrence of these numerous pre-disposed mental health risk factors and the progression of severe symptoms of psychopathologic estrangement in numerous of these children, the research disclosed that 28% of subjects attained a respectable level of adaptation, becoming skilled and self-assured adults with a pleasing level of emotional and social functionality. Building on these data, Werner (1995) defined resilience as the strengthening of the subject's abilities in adverse circumstances.

With Werner's founding works, a major transformation started to take place in research on resilience. It was comprised of a change from the evaluation of risk and distress to the report of protective factors. Particularly, efforts were made to recognize what distinguishes resilient subjects and what considerations enable the activation of positive practices when critical or sensitively painful life situations are confronted. The findings of these first studies revealed the existence of subjects who were defined as 'resilient' because they showed adequate or positive evolutionary results in the face of an adverse situation. This data gave the theory of resilience essential visibility in the advancement of the salutogenic angle to the level that it is used as a broad-ranging concept from an investigative viewpoint for understanding typical health procedures.

Antonovsky (1987) contended that stress is an inevitable occurrence. However, a substantial proportion of people can find their equilibrium and can flourish and sustain a state of well-being regardless of misfortunes. The author highlighted the value of positioning research to the components that permit this growth and are at the source of health (e.g., salutogenetic components).

The consideration persisted among those who theorize resilience as a steady attribute of character (Sisto et al., 2019) and those who defined it as an active process that fluctuates in relation to circumstances (Southwick et al., 2014). Recently, those who regarded resilience in terms of an

attribute, in connection with the 'ego resiliency' perspective (Farkas & Orosz, 2015), contend that character traits are the primary protective factors against stressors. The authors who define resilience in terms of process (Fleming & Ledogar, 2008) regard it as a means by which the achievement of the matter between the person and their context alters. According to this approach, protective character traits towards stressors and pre-disposed mental health risk factors behave concurrently and energetically, and the impact is the consequence of their dealings. Consequently, being resilient requires constructing and reconstructing one's life route by refurbishing a new equilibrium and creating a transformation in oneself (Linkov et al., 2022).

## 2.4 Defining Resilience

In the 'Special report on managing the risks of extreme events and disasters,' the Intergovernmental Panel on Climate Change defines resilience as the 'ability of a system and its component parts to anticipate, absorb, accommodate, or recover from the effects of a hazardous event in a timely and efficient manner' (IPCC, 2012, p. 5). Many other practical definitions have been suggested in the literature, which reveals the broad array of disciplines that have welcomed the notion of resilience. Even though all these contemporary definitions fluctuate to some extent in their phraseology, most of them emphasize comparable features.

First, while resilience has occasionally been described in the past as a result that can be assessed and observed (e.g., Stow et al., 2007), a growing number of scholars and experts now acknowledge that a more practical way to theorize resilience is to comprehend it as an aptitude (Brown & Kulig, 1996; Pfefferbaum et al., 2008; Norris et al., 2008). To be more accurate, it is the 'ability to resist, recover from, or adapt to the effects of a shock or a change' (Mitchell &

Harris, 2012, p. 2). In that sense, the concept of resilience itself has progressed and is becoming like a traveling objective, that is continually being redefined.

Evolving in the ecological literature from a starting moderately slender definition derivative from system theory (i.e., the ability of a system to bounce back or return to equilibrium following disturbance what Holling (1973) referred to as 'engineering resilience') it then progressed into a more intricate idea where the 'resilience of complex adaptive systems is not simply about resistance to change and conservation of existing structures' (Folke, 2006, p. 7). As an alternative, it is an evolving property that unites various elements such as the ones highlighted below:

- (i) the extent of transformation that a structure can undertake and still preserve its purpose and form.
- (ii) the level to which the scheme is adept at self-regulation.
- (iii) the capability to develop and enhance the capability for learning, adjusting, and where needed, transforming (Berkes et al., 2003, p. 13). In this conceptualization, the capability to adjust and change is consequently acknowledged to be at the essence of resilience. Adaptability refers to the capacity of a system (or components of this system) "to learn, combine experience and knowledge, adjust its responses to changing external drivers and internal processes, and continue developing within the current stability domain or basin of attraction" (Berkes et al., 2003). By distinction, transformability is recognized as 'the capacity to create a fundamentally new system when ecological, economic, or social structures make the existing system untenable' (Walker et al., 2004, p. 5)

The extensive and interconnected research carried out on resilience has underlined the changeability of the concept and made the effort to reach a collective definition of the complex theory. Among the many definitions of the term 'resilience' the construct seems to share a common vision of being a complex phenomenon intertwined with the documentation of abundant interacting variables. To date, the literature approves that there are two required and sufficient requirements for characterizing the changing aspects of the resilience process: Exposure to a

substantial risk and positive development in terms of psychosocial well-being notwithstanding the hazard to which one is exposed (Sisto et al., 2019).

A 'significant or substantial risk' suggests any component of a situation that is understood as lacking an accessible solution and that can lead to dysfunctional modification and to a form of psychological hardship (Southwick et al., 2014). In this standpoint, resilient people would be able to revise their personal reality thanks to a 'positive evolution' of their life development despite the adjoining circumstances. They expand the capability to incorporate pain and emotional susceptibility with personal, family, relational, and existential means, operating to increase them in agreement with their own needs. Though there appears to be a conventional base in the work of research centering on the method of psychological resilience, the theory is used in many ways differing in part on the space of presentation, with various consequences from a theoretical and practical point of view. Subsequently, these inconsistencies impede a communal definition of the concept and limit comparisons between research outcomes, making factual measurement challenging. Thus, the importance of moving towards a conceptual unification of the term becomes evident.

Although resilience has been most recurrently defined as positive adaptation despite adversity, resilience research has gone through various phases. From an early emphasis on the impenetrable or unshakable child, psychologists began to identify that much of what appears to endorse resilience initiates externally from the individual. The expansion of research methods, combined with the complexity of the individual self, led to a search for resilience features at the individual, family, community, cultural, and structural level. Aside from the effects that community and culture have on resilience in persons, there is rising attention to resilience as a feature of whole groups and cultural communities. Researchers have found that resilience factors

diverge in diverse risk contexts, and this has underwritten the idea that resilience is a process. To illustrate the resilience process in a specific context, it is essential to recognize and measure the risk tangled and, in this respect, apparent discrimination and generational trauma shared by some communities. Researchers also try to comprehend how specific protective issues interrelate with risk factors and with other protective factors to sustain relative resistance. To facilitate the navigation of these complex issues, resilience models of three main types have been developed: "compensatory," "protective," and "challenge". Two added notions are resilient reintegration, in which a confrontation with hardship leads people to a new level of evolution, and the concept recognized by some scholars that resilience is an inborn quality that desires only to be correctly stimulated.

Amongst psychologists, Werner (1995) mentioned three conventional usages of resilience: decent progressive results, continuous proficiency under stress, and recovery from trauma. The most popular definition of resilience in the past few years is positive adaptation despite adversity (Luthar, 2006). Luthar described resilience as a concept with two separate elements: substantial adversity and positive adaptation. From this viewpoint, resilience is never immediately assessed but is ultimately understood from the evidence of these elements. This notion of a two-part theory is acknowledged by other researchers (Masten, 2001; Yates et al., 2003; Sroufe et al., 2005).

A key requirement for resilience is that it necessitates the existence of obvious significant risk or adversity. This distinguishes resilience from ordinary or normative growth (Luthar and Chichetti, 2000; Rutter, 1999, 2000a, 2005b). In fact, Fonagy and colleagues (1994) typified resilience as *normal* progress under challenging circumstances (see also Masten, 2001). In his more contemporary evaluations of the literature, Rutter defined resilience as relative resistance to psychosocial risk encounters (Rutter, 1999; 2000). This method aims to focus on a scale of results,

not just positive ones; it does not assume that protection lies in positive familiarity and does not presume that the solution lies in what the person does about the negative encounter in terms of coping (Rutter, 2000).

Luthar's and Rutter's definitions are nearer to one another than may perhaps seem at first. Luthar underscores that a child may show resilience in one sphere, but experience disorder in another realm. She depicts children who undergo considerable hardship and still show academic proficiency, as determined through a range of ways. However, some of these children also undergo a range of psychological and emotional disorders varying from anxiety to depression. Consequently, resilience in one sphere (learning) co-occurs in the same child with psychological/emotional condition (Luthar, 2006).

Hunter (1999) theorizes resilience in a scale with two stakes: less ideal resilience and ideal resilience. Less ideal resilience involves "survival tactics of violence, and social and emotional withdrawal" (Hunter, 1999, p. 246). Hunter's central argument is that teenagers who exhibit this type of resilience often are maladapted as adults. In his research he discusses psychological resilience, a multidisciplinary theoretical concept with significant applied suggestions for health sciences. Although numerous definitions have been proposed in various settings, an indispensable understanding of the concept is still missing up to now. This negatively disturbs contrasts amid research outcomes and makes the impartial dimension problematic. The aim of his analysis was to categorize communal foundations in defining the theory of resilience across the literature scrutinized to move to a theoretical fusion of the term.

The appraisal catalogs five macro-categories that recapitulate what has been stated in the current literature regarding the resilience phenomenon. They assist as an introductory and essential stage to a theoretical explanation of the concept. A suggested definition of psychological resilience

is the capability to uphold the perseverance of one's positioning for experiential purposes. It establishes a transverse boldness that can be comprehended as the aptitude to overcome the problems experienced in the diverse parts of one's life with persistence, as well as decent cognizance of oneself and one's inner logic by triggering a personal growth scheme.

The notional clarification presented can help better the accuracy of research on this subject by providing forthcoming routes of inquiry intended to help profoundly sightsee the issues surrounding the advancement of resilience funds of knowledge. Built on this idea, definitions of the term 'psychological resilience' are designed at distinguishing common components in describing the concept across the work in context. Outcomes are used for suggesting a comprehensive definition of psychological resilience that reflects the different theoretical and multidisciplinary backgrounds coupled with it and the distinct fields of practice. This theoretical merger can be a beneficial initial position for potential research focused on recognizing efficient coaching approaches to encourage and strengthen resilience supplies and therefore personal well-being.

## 2.5 Adverse Childhood Experiences (Aces) & Resilience

Childhood is a critical time for understanding and fostering resilience. Throughout these years, the foundations of self-effectiveness settle and many of the vital shielding practices for social development appear. Middle childhood is a vital phase to avoid and lessen risk, stimulate individual ingenuity, and develop a robust community resource center (Jenson & Fraser, 2016; Masten et al., 2013). Though, there is an indispensable difference, a child who develops alongside normative goals can be perceived as flexible or capable, but not automatically as resilient (Masten et al., 2013). The distinction is that resilience is a dynamic development in a considerably

unfavorable setting. There is a discrepancy in the manner individuals react to ecological threats, whether physical or psychological (Ungar, 2013; Masten et al., 2013).

According to the National Scientific Council on the Developing Child (2015), resilience can be pictured as a scale. On one hand, adverse experiences can lead to toxic stress, such as recurring exposure to aggression or poverty. On the other hand, the scale are aspects that can assist in molding substantial stress into a manageable one, such as prospects to build abilities and prepare working with challenges (Ungar, 2012).

A powerful connection between ACEs and diverse biological, behavioral, and mental health issues has also been observed (Purewal et al., 2016; Felitti & Anda., 2009; Logan-Greene et al., 2014; Felitti et al., 1998). People subjected to ACEs show greater levels of anxiety, depression, and suicide attempts, amongst other mental health disorders (Karatekin, 2018; Rosinski, Weiss, & Clatch, 2018). Mental health conditions have been correlated with long-term disability, addiction, and death (Prince et al., 2016). Nevertheless, only one out of three adults with mental health challenges are aided by their mental health conditions (Prochaska et al., 2012). The typical lag between first mental health concerns and treatment is 11 years (Wang et al., 2004). In 2018, only 43% of adults in the United States with a mental health condition gained access to the services they needed, whether due to stigma, finances, or other challenges associated with the medical system (NAMI., 2019). There is a disparity in the supply of mental health treatment for susceptible Hispanic populations (Villalobos & Bridges, 2018; Venta et al., 2018). The Behavioral Risk Factor Surveillance System (BRFSS) indicates that in El Paso, Texas, 23.5% have claimed mental anguish for more than four successive days and 22.8% are struggling to access essential health services (Healthy Paso del Norte, 2019).

Resilience is a protective element that aids people in overcoming the adversity encountered and the impacts of traumatic experiences (Venta et al., 2018; Hamby et al., 2018; Ungar, 2013). Nevertheless, hardly any empirical effort explores the connection between mental health and resilience (Roldan-Merino, 2016). Additionally, ACEs are understudied in the border area, as there is no literature to our knowledge investigating ACEs in the U.S.-Mexico border area. The negative mental health concerns triggered by ACE's are not tackled nor treated. Early detection of childhood trauma and proper mediation that focuses on resilience development can theoretically play an essential part in the avoidance of mental health conditions and chronic illness during a lifetime (Logan-Greene et al., 2014).

ACEs, mental health distress, and resilience are notions that have been explored independently, but few investigations have examined the connection amongst the three in a populace of Hispanics (for exceptions see Bellis et al., 2017; Logan Greene et al., 2014). Understanding resilience as it correlates to ACEs and mental health can promote trauma-informed interventions focused on resilience as a protective and adjustable risk factor to support the promotion of mental health, prevent chronic illnesses, and consequently lessen the impacts of ACEs. This is especially significant in the U.S.-Mexico frontier area, as ethnic minorities confront health inequalities due to prejudice, social persecution, and communal trauma (Estrada., 2009; Stanton-Salazar, & Spina., 2000). Therefore, trauma-centered interventions can be an effective instrument for minoritized people, families, and communities to avoid and remedy the negative health impacts of childhood adversity (Logan-Green et al., 2014; Purewal et al., 2016).

Resilience is the capability of people to steer through social, psychological, physical, and cultural assets that sustain their health, alongside with policing the funds accessible in evocative ways (Sciaraffa et al., 2018; Ungar & Liebenberg., 2011). People with tenacious resilience are

more prone to recover from adverse experiences (Bellis et al., 2017; Logan Greene et al., 2014). Preceding research discovered that the relationship between ACEs and adult mental anguish was significantly reduced among people who always had a reliable adult accessible as a child (Bellis et al., 2017). Moreover, the relationship between ACEs and inadequate mental health was worse among people with resilience sources of sufficient sleep, social support, and life enjoyment (Logan, Year; Greene et al., 2014). Therefore, resilience can lessen the correlation between ACEs and mental anguish.

## 2.6 Poverty & Resilience

A key element in the development of resilience and poverty is the recognition that, while it is crucial to strengthen households and communities' resilience, the understanding on how to do so with limited resources has yet to be accounted for. Interventions to consolidate resilience often fail at reducing poverty. Some of the most prominent questions that arise in resilience studies are whether poverty reduction and resilience building can and/or should be isolated, and otherwise, we must ultimately consider if what we are hoping provides some elements of an answer to the question: Is resilience valuable as an objective for development?

Proposing a new conceptualization of resilience, arguing that resilience results from the collaborations (trade-offs but also synergies) between three capacities: absorptive, adaptive, and transformative capacities, has been discussed, exposing potential benefits and limitations. Development perspectives have revisited some of the previously accepted pros and cons of resilience—particularly those found in the social-ecological system literature (e.g., Walker et al., 2006; Miller et al., 2010). Some new, not yet widely discussed, but critical arguments to the debate present critique of the approach, arguing that resilience is not a pro-poor concept and that too frequently, the probable negative rudiments/implications of resilience are overlooked (conceivably

intentionally) or softened. There is an urgent need to recognize that resilience is neither good nor bad, or more specifically, that it can be thought of as good while acknowledging the potential for it to be wrong. Re-emphasizing the central message that the concept of resilience might have been too uncritically—or too rapidly—recognized as a novel, leading paradigm by development interventions and that more work is needed to upsurge our understanding of how it relates to poverty reduction is crucial.

The resilience approach is helpful since it allows a systemic view of social-ecological connections, which seems required to grasp the networks between human systems, ecosystems, and distress and tendencies. The multi-scalar understanding that characterizes resilience can also aid in distinguishing the relation (and, if possible, complementarities) of diverse kinds of connections and the limits of distinct categories of approaches. It consequently helps identify some common properties of a resilient method in a framework of uncertainty and exposure to multiple modes of hazards. It can shed light on the numerous causes of susceptibility that can affect family circles or society at various scales (Wisner et al., 2004).

Instead of replacing the concept of helplessness, resilience should be coupled with vulnerability assessment analysis. A good illustration of this fused approach is the work on 'resilience in the context of poverty' guided by Béné and his collaborators in the Niger River Basin, where these sources use a vulnerability charting tool (Mills et al., 2011), which is linked with the resilience approach to enable the classification of generally defined system levels through hierarchy (Béné et al., 2011). Their joint resilience-vulnerability approach features influential alterations within groups regarding access to resources and privileges, which eventually influences single or group capabilities to recognize or adjust to changes. Subsequently, implementing a systemic approach also assists the justification for the statement that a substantial amount of the

methods and dynamics that impact people and/or their milieus are happening throughout scales, from local to global (Adger et al., 2005) and are regularly differentiated by criticisms (Folke, 2006).

In feasible terms, an understanding of resilience is hence presumed to allow players to competently estimate the probability and desirability of modifications or alterations among separate system formations. Carpenter et al. (2006) for example, in their reflections on research, remind us of the value of cross-scale influences, by citing the case of the loss of safeguarding seaside networks that ultimately uncovered widespread areas of the shoreline to disastrous damage such as repeated hurricanes in the Gulf of Mexico. In the context of rural livelihoods, resilience and its accent on system and holistic philosophy additionally uncover some significance in relation to natural funds and the surroundings. Poor people are known to depend more immensely on environmental resources (Reddy & Chakravarty, 1999; Beck & Nesmith, 2001; Béné et al., 2009b). It, therefore, implies that the resilience of a community is inseparably correlated to the state of the conditions and the standing of its resources.

Highlighting this social-ecological necessity helps redefine more satisfactorily the vulnerable groups (therefore, refining the leveling progression of interventions) but also, perhaps, help healthier scheming 'green' public works agendas intended for the environmental rehabilitation or natural reserve of conservation practices (e.g., replanting, and soil preservation measures) (Kuriakose et al., 2012). These points have been deliberated to several degrees in academic literature for years (Berkes & Folke, 1998; Carpenter et al., 2001; Folke et al., 2002). Nevertheless, in addition to these diverse raisons d'être of the concept of resilience, more current resilience initiatives are developing, in which the term is now used as a form of mixing discourse, a 'mobilizing metaphor' (Pain & Levine, 2012) that brings experts, policy makers, governments

with diverse agendas, and communities of practice from varied areas, together, around the same table, with the same objective: 'strengthening resilience' (notwithstanding of what this term means precisely).

Regardless of the benefits recorded, resilience has also been critiqued for its limitations. One of the most extensively argued constraints is its failure to properly capture and reflect social forces at work in general and specifically distributions of agency and power (Leach, 2008; Hornborg, 2009; Davidson, 2010). The concept of agency is usually employed to illustrate people as 'autonomous, purposive and creative actors, capable of a degree of choice' (Lister, 2004, p. 125), or the liberty people must negotiate their own lives (including their own resilience) in the face of difficult conditions.

In much of the examination on resilience, the agency of people is habitually obscure, concentrating instead on the aptitude of the 'system' to recuperate from traumas rather than on the choices applied by persons within the system who may or may not exercise regulation over the processes by which resilience is formed (Coulthard, 2012). Folke's (2006) observations on the increasing efforts made to join in the social dimension within resilience research (see also Adger, 2003; Gunderson & Holling, 2001) and a recentralization of agency within resilience discussions would be an imperative input to these expansions. Regardless of this advancement, several accept that resilience is still a bulky concept, at least when trying to speak of the resilience of social systems.

It is challenging to escape conflicts with keystone concepts such as power, democracy, and the right to self-determination when attempting to employ the concept of resilience to issues of politics and control because even though some parallels can be recognized, societies and ecosystems are also essentially dissimilar in many ways (Duit et al., 2010, p. 365). This worry

about the constraints of resilience to grant an apt analytical process to deal with power is also progressively present within the catastrophe and climate change convergence. Robust defensive statements have been made by the advocates of resilience: 'We know ... power has been problematic to integrate within the framework of social-ecological systems [but]... We are getting there.' (Galaz, 2009).

Curiously, notwithstanding these declarations, as well as the restated call to embrace a more individual-centered approach to resilience (Bohle et al., 2009; Pain & Levine, 2012), none of the definitions amongst the loads purported so far in the academic narrative cites the terms 'power' or 'agency.' From that perspective, it appears that the unease conveyed by social scientists, but also many others, concerning the failure of the concept of resilience to hold systematically or even more straightforwardly to capture concerns around power, endure validity. In relation to individuals or communities, resilience is not automatically absolutely linked with well-being: some family circles may have managed to reinforce their resilience but only at the detriment of their own well-being or self-esteem. In the field of development ethics, the perception that people can adjust to poverty and deficiency by 'learning to suppress their wants, hopes and aspirations' has obtained mounting attention (Nussbaum & Sen, 1993; Sen, 1999; Clark, 2007, p. 25).

The overlooked issue of adaptive inclination is the intentional or reflexive process by which people adapt their prospects and ambitions when attempting to deal with worsening changes in their living circumstances (Nussbaum, 2001; Teschl & Comim, 2005). Amartya Sen had previously emphasized this matter of adaptive predilection in his reflection on self-determination, well-being, and development. 'The deprived people tend to come to terms with their deprivation because of the sheer necessity of survival, and they may, as a result, (...) adjust their desires and expectations to what they unambitiously see as feasible' (Sen, 1999, p. 62). It is disputed that the

issue of adaptive liking does not only refer to well-being but also has some direct connections with the debate on resilience. Increasing resilience may occur in coincidence with the incidence of adaptive inclination. This argument should not come as a shock as the literature on coping strategies is filled with illustrations where family circles tend to 'absorb' the effect of a shock by engaging in harmful conduct, such as dropping the number of meals per day or number of times they extract their children from school (Corbett, 1988; Cekan, 1992; Roncoli et al., 2001). Without a doubt, these resilience strategies are impacting the well-being of these family units, even if they permit them to endure the bearing of the distress they are confronting. Levine and his contemporaries, in their fresh examination of the significance of resilience in the framework of climate change adaptation, made a parallel observation when they noted that 'the unacceptable trade-offs which people are sometimes forced to make to guarantee survival may too easily appear like resilience' (Levine et al., 2011, p. 4).

Adjustment to routine daily life might require these trade-offs between resilience and health. The points about these 'undesirable trade-offs' becoming resultant to adapt or to become more resilient portray quite a distinct picture from the optimistic sequence of events assumed by a compounding number of systems and plans. This probable negative side of resilience is consistent with the argument recently made by several authors in the social resilience literature (e.g., Davidson, 2010; Coulthard, 2012; Armitage et al., 2012), who emphasized the presence of a possible trade-off between resilience and health. One can be very poor and ill but very resilient. This point was plainly made by Wood (2003, p. 456) in his examination of the approaches implemented by the poorest and most impoverished when he observed that 'the deliberate strategy of choosing a coping level of poverty as the social condition of securing a sustained, albeit low

level, livelihood [also includes] ...the acceptance of truncated ambitions of self-improvement and advancement in order to secure basic welfare.' (Wood, 2003, p. 456)

Some authors therefore contend that a minimal and unreflecting function of the resilience concept in social and political matters will unavoidably run into considerable obstacles (Duit et al., 2010; Cannon & Muller-Mahn, 2010; Davidson, 2010) and call attention to the fact that other notions such as susceptibility, which have a sturdier 'social/actor' focus have been so far ahead of resilience in footings of accentuation issues around social justice or power distribution. By reframing climate change or catastrophe problems into a resilience framework, there is menace of 'moving back' to mechanical, apolitical interpretations with the peril that the social justice/transformative dimensions of these intercessions are overlooked or disremembered. While some resilience researchers have previously established some degree of understanding about these concerns (McLaughlin and Dietz, 2007; Miller et al., 2010), additional endeavor is required to make it more thoroughly established and prevent markedly 'romantic' and positivistic explanations of resilience.

The 'universal' innate significance of residence is what grants people to value it as an organizing symbol, joining together specialists and policy makers around the same metaphorical table. However, there is no established interpretation that has reached full consensus among these specialists and policy makers of what precisely resilience is. The label has been questioned and theorized substantially (Carpenter et al., 2001; Gallopin, 2006; Folke, 2006), yet there is no agreement on a single evident definition. Brand and Jax (2007, p. 9) Within the arena of sustainability science, it was determined that the 'meaning of resilience gets diluted and increasingly unclear. This is due to the use of the concept (a) with many different intentions and (b) with a very wide extension'.

Bahadur et al. (2010) assumes in their comparative analysis of various resilience definitions that there is a lack of conceptual clearness on the correlations between adaptation, adaptive capacity, and resilience. Others even claim that resilience per se cannot be calculated (Cutter et al., 2008). Yet, in the field, diverse groups or convergences of practice have attempted to foster resilience frameworks to analyze presented systems. Based on the classifications proposed by diverse subjects, they come up with catalogues of resilience attributes, which help estimate the resilience-building capability of accessible involvements. One could contend, though, that because no vibrant meaning or ways to quantify resilience exist, the list of features offered as resilience features cannot be verified meticulously (accepted or rejected) and thus will continually stay unverified theories (Béné, 2013).

### 2.7 Stress & Resilience

The conventional label "stress" might be best termed as the body and brain's reaction to inner and/or outer shifts, warnings, or tensions (often referred to as 'stressors') that one faces (Selye, 1950). McEwen (2008) proposes that the brain decides whether these alterations are stressful which, consecutively, are followed by the biological and psychosomatic rejoinders. Stress differs from stressors in that stressors are the incidents or events that trigger a reaction (stress) to the stressors.

A general range of illustrations in which stress might be generated involve tensions from traumatic experiences (e.g., illness, serious injuries, war), life incidents (e.g., death of a loved one), daily practices (e.g., work, school), and current traumatic occurrences (The National Institute of Mental Health [NIMH], 2019). Whereas stress is naturally identified negatively, stress is not simply natural but also a fundamental biological reaction. More precisely, the physiological

reaction permits adjustment to happen to restore a stabilized situation (Selye, 1950). Damaging or unmanaged stress could have devastating health concerns. Exploration signals gender variances in psychological stress such that women are more likely to have higher levels of stress compared to men (Matud, 2004). Consequently, it is worth identifying the factors that correlate with stress and the connection with health consequences. The biopsychosocial model of stress (Engel, 1977) has often been used as a probable theoretical framework to recognize the stress-substance use association.

The theoretical framework alludes that genetic features, mental factors (e.g., cognitions, behaviors), and social factors (e.g., environmental, cultural) are fundamental to identifying health results. Indeed, Garland and colleagues (2011) claim that stressful circumstances could strengthen concerns linked to stress when helpful funds are lacking. Sequentially, these stressful experiences may perhaps cause extended or constant stress stimulation reactions that aggravate the wear and tear of the body and brain experience due to the reoccurring stress reaction stimulation (Garland et al., 2011). When constructive means are not thought adequate, complementary channels are sought to decrease the consequences of stress, such as alcohol, hence establishing a negative strengthening circumstance (Garland et al., 2011).

Given the numerous mechanisms allied with the model, it is valuable to recognize the impacts of stress on the body and brain. From a biological outlook, stress has been correlated with affecting the performance of diverse physiological systems, such as the respirational system (Ritz et al., 2000), circulatory system (Torpy et al., 2007), neuroendocrine system (Miller & O'Callaghan, 2002), and procreant system (Kalantaridou et al., 2004). Unfettered stress has been linked with several health problems, such as

headaches, joint pain, chest pain, breathing issues, mood changes, sleeping issues, and several others (The American Institute of Stress, 2020).

Continued stress, also frequently referred to as chronic stress, has been shown to damage the immune system by impeding its aptitude to respond to external agents and snowballing one's vulnerability to catching a viral infection (Salleh, 2008). Salleh (2008) indicates that unmanaged stress can impede breathing, specifically amid asthmatics, can increase the possibility of diabetes amongst obese people, can create ulcers, and might trigger artery blockage in those with high-fat diets.

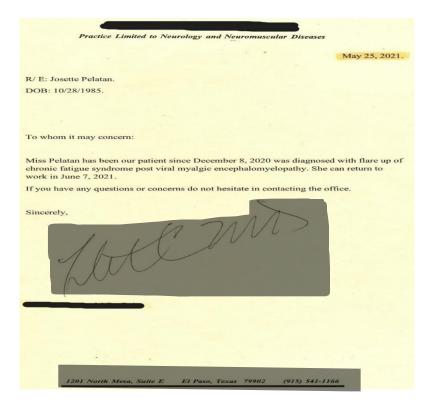


Illustration #1: Chronic Fatigue Syndrome Post Viral Encephalomyelopathy

Others indicate stress hormones can damagingly influence the heart, cause heart rate and blood pressure alterability, lead to heart failure, and cause a stroke (Torpy et al., 2007). The overrun of hormones, such as adrenalin and cortisol, can have an overabundance of impacts on

numerous systems. For example, De Vente and colleagues (2003) suggest these hormones (often in coincidence with other hormones) can increase heart rate (vascular system) and trigger blood vessels to widen (circulatory system). Hence, controlling stress is a fundamental function of avoiding diverse health challenges.

McEwen and Stellar (1993) first depicted the concept of allostatic load (AL) as the disposition to disease due to the dysregulating function of the body and brain that occurs due to perpetual stimulation in reaction to stressful experiences. To comprehend the paraphernalia of these stressful proceedings on the body and brain over time, McEwen (1993) theorized the AL model in which organic markers characteristic of several physical systems might offer insight into the possible bodily dysregulation (McEwen & Stellar, 1993). McEwen utilized the model using data from the MacArthur study of Successful Aging (see Berkman et al., 1993; Seeman et al., 1997). Explicitly, organic markers such as cortisol, norepinephrine, epinephrine, dehydroepiandrosterone, systolic and diastolic blood pressure interpretations, the relation of waistto-hip ratio, high density lipid (HDL) cholesterol, the relation of total-to-HDL cholesterol, and blood glycosylated hemoglobin were associated across partakers. The pertinence of the AL model has been extended to other health fields and has essentially supported compelling correlations. Increased records of AL have been correlated with obesity, physical dormancy, heightened substance use, and poor sleeping cleanness (Suvarna et al., 2020).

Like the examination of Seeman and colleagues (1997), Portillo (2021) directed a secondary data analysis of data from Zhang et al., (2020) observed natural processes of collective stress. These genetic markers were employed to produce an index of AL based on McEwen and Stellar's (1993) suggestions by utilizing a comparable method for generating the index labeled by Hampson et al. (2009). It was assumed that, given the remarkable contrasts in drinking displays

between the two groups, the average index scores of AL would be greater among males with an Alcohol Use Disorder (AUD) compared to the healthy male control group. Nevertheless, this theory was not verified as findings suggested there was no statistically substantial group mean variance between the two groups.

In contrast, a correlation study conducted by Zhang et al., (2020) and Portillo (2021) is striking for its widespread magnitude of natural degrees of cumulative stress and its use of a gold standard degree of alcohol intake and analysis of AUD. Whole, these results were outstanding and signal that, in the framework of AUD status or alcohol intake amid partakers identified with AUD, AL may not be sufficiently susceptible to differentiate group standing. Zhang and colleagues (2020) also examined the properties of mental stress on the hypothalamic-pituitary-adrenal (HPA) axis responsiveness.

Outcomes implied that greater emotional stress degrees were correlated with less responsiveness amid the control group but not amongst males with an AUD. Whilst granting validation for the correlation amongst the emotional stress directories, the indicators employed did not calculate the full scope of emotionally associated stress or systematically obtain emotional cumulative stress. Implementing a methodology like the parent study (Zhang et al., 2020) by utilizing the three indicators to generate a general guide, Portillo (2021) surveyed the connection of a guide of emotional stress depicted by instruments of psychological stress. Scores signaled that there were statistically substantial group mean differences in the catalog of emotional stress scores such that those identified with AUD had higher emotional stress scores paralleled to the healthy control partakers.

Crosswell and Lockwood (2020) contend that health investigation frequently ineffectively theorizes emotional stress as it connects to health consequences. Due to the multifaceted nature of

stress, which regularly results in the inexactness of mensuration of stress, Crosswell and Lockwood (2020) listed the forms of emotional stress (assessed by measures of mental health) and best practices for calculating stress response and emotional stress experience. The pair also contend that emotional stress is an ambiguous construct that depicts complexity in correctly rating it.

Five kinds of psychological stress are also designated, which involve chronic stress, acute stress, life events, traumatic life events, and daily worries. Furthermore, Crosswell and Lockwood (2020) explain crucial concerns to study when evaluating psychological stress, such as the time and life phase of a stressor, the time window the length refers to, and the stress reaction that appears. Although the label "stress" is generally used, research has made formidable developments in identifying the different forms of psychological stress (e.g., chronic stress, acute stress, life events, traumatic life events (a sub-type of life events), and daily hassles).

These abstract variations have been employed to rationalize time disparity relative to psychological stress as well as the scale as to how these contrasting varieties of psychological stress have been credited to contribute to diverse health outcomes. Crosswell and Lockwood (2020) assert that the period of the stressors is crucial to recognizing concerning forms of stress (e.g., ongoing stress [chronic stress], episodic events [life events]). Nevertheless, it is observed that numerous stressful occurrences seldom happen in a sole timescale. For instance, disputes with a significant other are normally considered to be an intense stressor.

Nevertheless, continual quarrels with one's significant other can result in a cause of chronic stress. Moreover, it is believed that the life stage at which the stressor suffered is significant to deem, as this can have consequences for long-term health effects (Crosswell & Lockwood, 2020). The writers suggest that calculating psychological stress related to identifiable life intervals can

notify routes concerning psychological stress undergone during a specific age (e.g., childhood, adulthood) and health consequences.

Correlated to a specific measure's assessment interval, Crosswell and Lockwood (2020) signal that inactivity is a fundamental piece to count as they relate to the descriptions of psychological stress. For instance, measures that limit one's reactions based on the previous day may possibly be indicative of everyday worries. Likewise, periodic experiences that have happened during the week may be more sharply correlated with acute stress.

Chronic stressors are extended frightening or challenging instances that upset everyday life and persist for a prolonged period (e.g., at least one month). Acute stress is generally short-term, event-based exposure to sinister or testing stimuli that induce a psychological and/or physiological stress reaction, such as giving a public speech. Life events are time-limited and intervallic proceedings that include substantial modification to one's present life plan, such as the diagnosis of a severe illness. Some life occurrences can be positive, such as getting married, and some become chronic, such as having to live with a disability after a car accident. Traumatic life events are a subclass of life events in which one's physical and/or psychological security is compromised. Daily Hassles are disturbances or hurdles that occur regularly in everyday life, such as small disputes, traffic, or work excess, and that can build up to eventually produce permanent hindrances.

### 2.8 Health & Resilience

Contemporary resilience studies started among psychologists and psychiatrists.

Researchers fascinated with psychological and social determinants of health harvested the concept and have progressively expanded its use from the domain of mental health to health in general.

Experimental work on resilience was concerned with the person, but more recently, scholars have become drawn to resilience as a characteristic of whole groups.

Besides the concept of absorbent ability or perseverance, meaning the different coping techniques by which people and/or groups negotiate or manage the effects of traumas. The three factors (absorptive capacity, adaptive capacity, and transformative capacity) are seen as three essential characteristics of resilience (Walker et al., 2004; Folke, 2006; Folke et al., 2010; Miller et al., 2010). The thought-provoking feature of this conceptualization is that it aids us in understanding that resilience arises as the outcome, not of one but all these three dimensions, each of them leading to diverse results: persistence, incremental adjustment, or transformational responses (Béné et al., 2012). It suggests that these distinct reactions can be connected (at least theoretically) to respective forces of shockwave or shift. The smaller the strength of the original distress, the more prone the family unit/group/structure will be to withstand it successfully, that is, to grip its effects without consequences for its function, status, or state.

As indicated by Norris et al. (2008, p. 132), 'the ideal outcome after [a] crisis is resistance, meaning that the resources have effectively blocked the stressor and, accordingly, there is virtually no dysfunction, no matter how temporary.' These sources reveal that people or systems depend on resistance tactics daily, suggesting the human immune system is one of the utmost efficient resistance approaches recognized to exist. Past our core resistance, resistance approaches are also suitable at an advanced magnitude for hazards that are probable to occur with some occurrence and can be prepared for.

People do not adjust to a single given chronic stressor but rather to a large amalgamation of transformations. Besides, it is hardly ever feasible to unscramble the various alterations to which people are reacting, and it makes little sense to try to do so (Levine et al., 2011; Hertel & Rosch,

2010). Ultimately, if the adjustments needed are so huge that they overthrow the adaptive capacity of the home, population or (eco)system, change will have to occur. What the developing body of literature that examines transformational shifts emphasizes is that the focal trials correlated with change are not of a methodical or scientific nature only. Instead, these changes might comprise a mixture of technical inventions, official reforms, communicative changes, and cultural fluctuations; they frequently encompass the enquiring of morals, the challenging of norms, and the ability to carefully inspect static theories, personalities, and labels, to challenge the status quo (e.g., Folke et al., 2009; Smith & Stirling, 2010; O'Brien, 2011).

The conceptualization of resilience often proposes that managements for resilience necessitates guiding a structure in a way that endorses resistance in a period of minor disorder, adaptation in a time of superior commotion, and transformability when circumstances are becoming unfeasible or unmaintainable. This rectilinear understanding is theoretically beneficial but practically too crude as it does not account suitably for the multi-stressor nature of susceptibility and the detail that numerous diverse shockwaves and stresses syndicate and happen together, each affecting the system with diverse relative concentrations at diverse scales, and each necessitating distinct or combined levels of resilience (O'Brien et al., 2004).

A significant note is the need to see these three dimensions of resilience as being altered perceptions of the same realism rather than three individual values that can be supplemented, with resilience as the center of them all. Nonetheless, we still have very little methodical identification of how diverse approaches vary in their capacity to manage, adapt, or transform with altered varieties of multifaceted change. An arising concept supports that this project appears to want both permanency and shift (Duit & Galaz, 2008) as well as linking multilevel connections within and across unique dimensions (Cash et al., 2006; Folke et al., 2005).

It seems that there is presently an inclination to present the three dimensions as challenging each other (resistance vs. adaptability, adaptation vs. transformability) or to stress the probable pressures between them. Heltberg et al. (2009, p. 91), for example, discusses the 'trade-offs between short-term coping and long-term productivity and adaptation ..., especially as the impacts of climate change accumulate over time'. Likewise, drawing on Dodman et al. (2009), resilience can be viewed 'as moving beyond coping strategies towards achieving longer-term development.'

Others judge resilience as a process of transformation (Cutter et al., 2008; Headey et al., 2012).

Pelling (2011) maintains this 'transformation' vision, claiming that abstracting resilience as shielding will strengthen surviving methods and uphold the status quo. Berman examines that "there is a risk that understanding resilience as 'buffering' may prevent necessary changes that would enable more sustainable development" (Berman et al., 2012, p. 89). This 'either-or' attitude that puts weight on one dimension of resilience (e.g., frequently to the impairment of the others) loses the correlation that occurs between these three dimensions of resilience. Even though there are undoubtedly trade-offs and conflicts between them. Enfors et al. (2011), for example, label resilience as 'deal[ing] with the tension between persistence and change', awarding these three dimensions as discounting developments leads to the peril of not just disregarding but hindering current (or possible) collaborations and complementarities.

This gamble is tangible markedly because the assessment of the literature discloses the developing inclination to recognize perseverance and permanence as negative, and to put importance as an alternative on change. Norris et al. (2008, p. 103), for example, see resilience as 'better conceptualized as adaptability than as stability'. Correspondingly, Miller et al. (2010, p. 5) assert that 'the challenge (...) is to learn to live with change and develop the capacity to deal with it, instead of trying to block it out'. What these declarations fail to see, in a growth framework, is

that the ability to sustain constancy is as essential as the aptitude to adapt or to change. Stability is required for adaptive or transformative function.

Stability is a vital state for property increase or for adaptation, consequently for some properties of poverty lessening (Zimmerman & Carter, 2003; Carter and Barrett, 2006). It is during episodes of political, economic, and institutional stability that homes and groups collect wealth, study, build affluence, and improve human health. But steadiness is not plainly a pre-requisite for the growth of properties and poverty lessening, it is similarly contributory for constructing effective establishments and for the development of corresponding movements, which are themselves required situations for adaptations. Stability is, therefore, a vital domain of adaptive function as well. Lacking stability, resources, and social and institutional capital that are required to upgrade adaptive capability cannot be increased.

Levine et al. (2011) point to numerous potential footings for the connection between augmented resources and strengthened adaptive ability. Initially, adaptation might have a financing expense obstacle, which more resources and higher income could eliminate. Another probable fundamental route stands on the notion that poorer families have, at least in some conditions, less adaptive capacity because they are more risk reluctant. Having a higher income could increase these risk prospects, opening novelty space. Adaptive capacity would hence be upgraded via a nexus between resources and improvement.

At a less perceptible level as well, past financial or physical resources, fruitful adaptation varies correspondingly to a great degree on social capitals, and the ability of persons, societies, or groups to organize verdict making, to act cooperatively, foster novelty and research, and exploit innovative prospects (Adger, 2003; Adger et al., 2009).

New research featured in the Journal of Neurology Neurosurgery & Psychiatry (JNNP) suggests a potential connection between childhood trauma and an elevated risk of multiple sclerosis (MS) in women later in life. Particularly, the study highlighted stronger links with experiences of sexual abuse and exposure to multiple categories of abuse. These findings propose that childhood trauma might influence the immune system and increase susceptibility to autoimmune diseases. Moreover, adverse childhood events such as abuse, neglect, and unstable home environments are associated with higher risks of both physical and mental health issues during adulthood. While it's not yet clear whether these events directly contribute to MS susceptibility, researchers examined data from the Norwegian Mother, Father, and Child cohort study to explore this possibility. The study involved nearly 78,000 pregnant women recruited between 1999 and 2008, with their health tracked until 2018. Childhood abuse data were collected via surveys, while MS diagnoses were confirmed using national health registry data and hospital records. Among the participants, approximately 14,477 reported childhood abuse, with 300 women diagnosed with MS during the study period. Among these 300 women, it was reported that approximately 1 in 4 (n=71; 24%) had been the victims of child abuse in contrast to the approximately 1 in 5 (n=14,406; 19%) who did not progress to the development of MS (n=77,697). After adjusting for various factors such as smoking, highest level of education achieved, financial state of household income, and obesity, women with a history of childhood abuse showed a higher likelihood of MS diagnosis. Notably, the association was most evident for sexual abuse (65% increased risk), followed by emotional (40% increased risk) and physical abuse (31% increased risk). Additionally, exposure to multiple categories of abuse displayed a dose-response relationship with MS risk. Even after excluding participants in the prodromal phase of MS and those diagnosed at the study's onset, the association persisted. While recognizing the limitations of the observational study, including the inability to establish causation and the absence of certain environmental factors, duration of the abuse inflicted, the age when the abuse began, and the type of support system that was afforded to the abused victims afterward, researchers proposed plausible biological mechanisms behind these associations. They suggested that childhood abuse might disrupt brain signaling pathways, leading to a proinflammatory state that could increase vulnerability to MS.

The researchers concluded that gaining a deeper comprehension of the risk elements and the timing of exposure to these risks could pave the way for preventive measures and provide additional understanding of the underlying mechanisms or biological plausibility of the disease. In this thorough examination of observational studies, the findings corroborated a substantial link between adverse childhood experiences (ACEs) and the emergence of multiple sclerosis (MS). Additionally, ACEs were shown to affect the well-being of MS patients, influencing the utilization of walking aids, increased anxiety, fatigue symptoms, and lower premorbid IQ. Furthermore, the analysis highlighted that exposure to multiple ACEs is tied to an earlier onset of MS, while the severity of ACEs is connected to the average relapse rates of MS.

Over the past twenty years, there has been a notable surge in scientific, media, and policy focus on ACEs. These experiences, as defined in various studies (Struck et al., 2021; Purtle et al., 2021a; Srivastav et al., 2021a; Crowley et al., 2021), involve the exploration of connections between exposures to various stressors within households and communities—such as caregiver substance use, physical abuse, and economic instability—during the formative years before reaching adulthood (Felitti et al., 1998; Ellis and Dietz, 2017).

Despite the extensive research conducted by clinical and public health experts regarding the outcomes of ACEs and their dissemination to the broader public (Srivastav et al., 2021a; Nixon et al., 2017), there remains a scarcity of studies examining public comprehension of ACEs or optimal communication strategies for conveying this scientific knowledge (Purtle et al., 2021b; Srivastav et al., 2021b)

A significant majority, approximately two-thirds (62%), of adults residing in the United States have encountered a minimum of one ACE (Merrick et al., 2018). Advocates advocating for necessary policy measures to prevent and alleviate the repercussions of this exposure strategically highlight various forms of scientific evidence. These encompass evidence pertaining to bodily health (Hughes et al., 2017; Sonu et al., 2019), social health (Afifi et al., 2008; Lee et al., 2020; Dube et al., 2003), disparities in health among racial and ethnic assemblies (LaBrenz et al., 2020), the economic burden of ACEs on society and public systems (Fang et al., 2012), and physiological impacts and epigenetic alterations (refer to Supplementary Appendix 2 for additional evidence) (McLaughlin et al., 2013; Lang et al., 2019).

### 2.9 Intervention Research

Intervention research is a dynamic process that involves researchers, groups, and specialists. The idea that physicians and most interventions do not have adequate time and funds to guide intervention research is a major issue addressed by Fraser (2009). It is via teamwork with researchers, whose work venues alter from universities to research to assessment organizations rooted in state government that additional involvements are proposed and extended. In depicting intervention research, Fraser (2009) is specifically sensible of the necessity to sponsor research

interests. Even though medical methods can occasionally be improved and tested with no substantial funding, the careful, scrupulous procedures necessitated in intermediation developments normally demand considerable state, federal, or organization funding. Hence, the route described guides not only the advancement of interventions but also grants necessary factors for developing research proposals.

The capacity to defeat or adjust to adversity is part of the swiftly expanding discipline of resilience (Bonanno et al., 2011; Kalisch et al., 2015; Masten, 2007; Ungar & Theron, 2020), and constructing resilience is now cheered in schools to help promote good mental health for comprehensive health (Public Health England, 2021; Public Health England and UCL Institute of Health Equity, 2014). In history, resilience was ascribed to the bearing of selected fixed temperament personalities (Southwick et al., 2014), but more current processual reports focal point on various adjustable components happening at separate systemic levels that help persons to reach positive aftermaths (Ungar & Theron, 2020). For instance, a review by Fritz et al. (2018) recognized influences at the individual (e.g., high self-esteem, low rumination), family (high family cohesion), and community (high social support) levels that differentiate those who are expected to experience better mental health subsequent to experiences of adversity.

## 2.10 ACEs Outcomes and Policies

Even with the array of evidence on different ACE outcomes, there remains uncertainty regarding which research findings are most compelling to both the public and policymakers (Purtle et al., 2019; Srivastav et al., 2020). However, public favorability, gauged by supportive public sentiment, can enhance the probability of policy adoption (Butler and Nickerson, 2011; Stimson, 2004; Burstein, 2003), particularly policies aimed at addressing ACEs.

Studies investigating framing have revealed that highlighting specific aspects of social issues, such as their origins, impacts, and the demographics they affect (Entman, 1993), can influence public perception (Gollust et al., 2013). Nevertheless, messaging strategies may inadvertently foster undesirable outcomes among the public, such as reinforcing stigmatizing beliefs (McGinty et al., 2018a).

Prior studies on childhood hardship provide valuable suggestions for public communication strategies. For instance, a report released by the Frameworks Institute in 2021 offers key guidance on discussing childhood adversity. This includes highlighting the influence of external factors on childhood adversity, acknowledging individuals' resilience, and integrating policy-driven solutions into the conversation (Sweetland, 2021).

Frameworks Institute embarked on a long-term initiative to enhance evidence-sponsored communication regarding toxic pressure, proposing efficient methods to address the biological mechanisms through which childhood adversity influences child development (Shonkoff & Bales, 2011). Similarly, the Berkeley Media Studies Group, building upon previous research on news portrayal of ACEs (Nixon et al., 2017), released recommendations on discussing childhood adversity in June 2021. They stressed the significance of presenting data on inequalities in childhood suffering through an operational perspective to prevent the perpetuation of individual culpability (Gehlert, 2021).

Despite the increasing volume of research on ACEs, it is imperative to acknowledge that scientific findings alone do not convey the message effectively. As emphasized by Shonkoff and Bales (2011), there is a need for research aimed at determining the most effective methods of communicating ACE science to the public. This is crucial in advancing ACEs as a priority on the policy agenda.

# 3. Chapter III: Methodology

## 3.1 Purpose of The Study

The goal of this study is to examine factors that hinder and contribute to resilience while considering the role of access to resources in health recovery and academic success. Based on preceding research, the *resilience conceptual model* theorizes how ACEs prevent individuals from having ideal health and how resilience can play a protecting role against the progression of poor mental health. The aim of the study is then to assess how access to resources contributes to the recovery of ongoing trauma and informs policy in providing new therapies to encourage societal well-being.

The purpose of this study is to share with readers the intricacy of my life encounters while uncovering inner thoughts, feelings, and views about children who come from an unhealthy environment, to display the long-term effects of traumatic experiences, and offer ways not only to cope but to thrive, by employing the qualitative research method of autoethnography. Ellis & Bochner (2000) have defined autoethnography as "autobiographies that self-consciously explore the interplay of the introspective, personally engaged self with cultural descriptions mediated through language, history, and ethnographic explanation" (p. 742). The method of critical autoethnography allows for the narrative of my journey in seeking a complex physical diagnosis while struggling with financial insecurity and mental health conditions often used to discard any potentially expensive complex physical diagnosis like Multiple Sclerosis, Neuromyelitis Optica (NMO), and Myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD) due to the nature of very costly treatments and the lack of cure.

An exclusive value that lies underneath the purpose of qualitative research is understanding that the study of naturally happening actions is best understood when experienced without the stimulus of exterior constrictions or controls and by bearing in mind the situational milieu in which actions happen (McMillan, 2004). Qualitative investigators study phenomena in their natural situations by endeavoring to make sense of the meaning that people assign to these proceedings (Lincoln, 1998). Moriarty, J. (2008), Ellis et al. (2008), and Lincoln & Guba (1985) denoted the qualitative investigation method to comprehend the meanings people give to their life understandings. Ellis (2004) stated that this goal is accomplished by probing the societal context and trying to comprehend "how we go about thinking, acting and making meaning in our lives" (p. 25). Qualitative research is an integral multi-method in focus and interpretations of the investigator's deductions (Denzin & Lincoln, 2005). Literature and postmodernist systems offer varied approaches to communication to speak to people undergoing therapies of different sorts.

As a patient often unable to afford the extensive therapies and lifestyle I have been needing, diving into therapy-development and investigation to learn how to better help myself, has been essential. My evolution as a teacher, student, and friend, but also as a patient, has allowed me to see relationships not only as a significant aspect of mental health but also as opportunities for exploration and transformation of the self. The notion of postmodernism meaningfully informed my alternate ways of thinking to process information and helps me, to this day, tackle life by identifying the connection of observance, body, and spirit. This is an opportunity to share deep insights that could help others undergoing similar challenges to not only cope but also thrive as community members.

Resilience Theory is the most appropriate emphasis given to my research, as I tackle not only a wide range of issues that have affected my life, but also post-traumatic growth and how resilience

played the key role in aiding me to advance and overcome challenges. My research is extensive given the nature of this method, yet all address resilience as the determinant factor in the complex defining of individual success. The purpose being, in the end, not only to heal, but also to inspire change, and partake in it more actively through educational recrafting, policy revolution, and public health advocacy.

## 3.2 Theoretical Framework

Resilience refers to the capacity to confront adversity with robust coping mechanisms and to sustain a consistent level of functioning (Kimhi, 2014, p.1). It embodies one's ability to adapt effectively amidst risk and challenges (Jenson and Fraser, 2006, p.8). As an inherent quality, resilience correlates with supportive environmental factors, including cohesive families, stable communities, economic opportunities, social networks, educational access, and community norms (Jenson and Fraser, 2006). Thus, resilience encompasses both individual and environmental dimensions. Moreover, research indicates that cultural backgrounds influence the experience of trauma (Silove, 1999; Mollica, 2006; Ungar, 2013). Culture serves as a mediator for trauma, offering frameworks for understanding hardship. Cultural narratives enable individuals to derive protective mechanisms from adversity, often expressed through rituals, ceremonies, familial bonds, and engagement with cultural communities. Cultural influences play a crucial role in understanding individuals' responses to adversity because resilience is not solely determined by inherent psychological traits but also by the ability of a person's social networks, both informal and formal, to foster positive development during stressful situations (Ungar, 2013). These social networks function as protective factors against adversity when individuals can access them, as argued by Ungar (2013). They constitute integral components of individuals' social ecology. These

networks encompass families and communities deeply rooted in the cultural norms of the individual. For refugees and displaced individuals, such networks may exist within other migrants who have previously relocated to the host country. These migrants may have migrated for reasons unrelated to trauma and victimization, such as economic opportunities or familial ties. Flores-Yeffal (2013) has highlighted the significance of Migration Trust Networks among Mexican migrants. As noted by Flores-Yeffal (2013), trust networks extend beyond being merely a collection of contacts of former migrants in the host country. They encompass a wide range of support provided to migrants without the expectation of immediate repayment. This support can include assistance in finding employment or housing, financial aid, support with cultural adaptation, and the sharing of cultural customs. Importantly, reciprocity within these networks is not in the form of direct repayment to the immediate network but rather entails a future obligation undertaken by the migrant to assist future migrants in a similar manner. These social obligations are rooted in trust-based relationships rather than expectations of monetary reimbursement. Thus, trust networks represent a form of social capital embedded within cultural connections and perceived obligations among newly arrived and vulnerable migrants. In our examination, we expanded the concept of resilience beyond an individual trait. Previous research in social sciences, often influenced by a Western cultural perspective emphasizing individualism, has tended to neglect the collective values of non-Anglo European migrants (Ungar, 2013). Drawing from our prior findings, which highlighted the robust protective elements within the culture of Mexican migrants, we actively sought to identify similar patterns within this sample (Lusk, McCallister & Villalobos, 2013).

The primary theoretical framework I intend to employ in addressing my research inquiries is resilience theory, as it offers a lens through which to engage with several other pertinent theories

essential for navigating the complexities inherent in my critical autoethnography (CAE) research. I've opted for CAE as my methodological approach because it provides avenues for "cultural analysis through personal narrative that scrutinizes interpersonal and cultural understandings of identity from the inside out" (Boylorn & Orbe, 2014; Hughes & Pennington, 2017). The term "critical autoethnography" serves to distinguish between autoethnography primarily focused on the researcher's self and autoethnography that encompasses the reflexive methodology of "self-analysis" advocated by Pierre Bourdieu (2008a). Exploring resilience within the framework of this dissertation also provides an opportunity to delve into Crenshaw's theory of intersectionality. My personal journey as a financially vulnerable woman has exposed me to additional challenges that men, especially those with financial security, are less likely to face. Crenshaw conceptualized intersectionality as "a metaphor for understanding the ways that multiple forms of inequality or disadvantage sometimes compound themselves and create obstacles that often are not understood among conventional ways of thinking" (Aiston et al., 2024).

In this study, Positive Psychology theory serves as a foundational framework, emphasizing the positive facets of human existence such as happiness, strengths, and fulfillment rather than solely focusing on pathology and mental illness. This theory offers therapists a unique perspective and toolkit for enhancing their clients' mental health and overall well-being. Despite its rapid expansion over the last two decades, Positive Psychology (PP) is not exempt from scrutiny regarding its credibility, relevance, and impact as a scientific discipline. Various criticisms have been raised regarding the paradigm's distinctive contributions, as well as the validity of its underlying philosophy, theories, methodologies, and interventions (Van Zyl et al., 2022) provided a synthesis of critics' arguments, pointing out several key critiques. These include assertions that positive psychology rests on weak metatheoretical foundations, suffers from the jingle-jangle

fallacy concerning constructs, employs inadequate methodologies and simplistic assessment tools, exhibits cultural biases, utilizes complex statistical analyses to address simple issues, and fails to demonstrate the sustainability of its interventions. While not all these criticisms are unique to positive psychology, they have ignited discussions regarding the discipline's future and strategies to enhance its sophistication (Lomas et al., 2021; Wong, 2011).

Building on these initial critiques, Lomas et al. (2021) introduced the notion of waves or stages that positive psychology has undergone as it has evolved. According to Lomas and Ivtzan (2016), the first wave marked the field's inception, characterized by a relatively simplistic incorporation of positive approaches to understanding flourishing and well-being. Subsequently, Lomas and Ivtzan (2016) propose a second wave, termed Positive Psychology 2.0 by Wong (Citation 2011), which embraced a more dialectical perspective on flourishing, acknowledging the intricate and dynamic interplay between positive and negative experiences. They illustrate that not all ostensibly 'positive' approaches lead to positive outcomes (e.g., optimism), nor do all 'negative' approaches result in negative outcomes (e.g., posttraumatic growth). More recently, Lomas et al. (2021) noted the emergence of a third wave in positive psychology research, aimed at expanding beyond the individual to encompass systems, contexts, and cultures, employing a broader array of methodologies, and taking a more interdisciplinary approach. Like with any paradigmatic shift within a discipline, each successive wave represents a response to criticisms of the preceding one. This evolutionary process fosters a more nuanced, sophisticated, and well-informed body of literature. While it might be premature to declare positive psychology as on the cusp of a revolution (Kuhn, 1970), the growing complexity and scholarly refinement, influenced by critiques of earlier waves, are undeniably enhancing the field.

Hence, it's beneficial to ponder over the criticisms and appraisals directed at the field to foster its advancement and maturation as a scientific discipline. These critiques may unearth novel opportunities that could bolster the scientific credibility of the field and usher in a fresh wave of groundbreaking concepts. However, there is no cohesive perspective on the contemporary criticisms and appraisals of positive psychology. A comprehensive understanding is imperative to pave the way for the third wave of research in positive psychology (Van Zyl et al., 2022).

Resilience is one of the most reflective theories across disciplines. Nevertheless, the essentially atheoretical nature of the research on resilience persists to make it vague. A new theory of stress and resilience, the Theory of Resilience and Relational Load (TRRL), is working towards this space in literature. The theory connects communicative, perceptual, and physiological aspects of stress within the context of social interactions to rationalize individual/interpersonal risk, resilience, and thriving. The TRRL investigates how relational partners' and family members' collective coordination and preservation of their relationships daily impact their message during stressful events, as well as their considerations of the stress. The theory also points to how these exchange models and assessments shape individual and relational health and adaptation. The theory of relational weight is presented as the wear and tear that chronic stress and exhaustion of one's emotional, psychological, and relational reserves through reiterated stress-related exchanges can have on connections. Eventually, people need to persistently invest in their relationships to avoid relational load and foster resilience and potential growth.

Furthermore, resilience theory grants a useful framework for research that links the micromacro division, which could make influential contributions to heightening social development theory (Patel, 2015). This is accomplished by identifying the necessity for micro, meso and macro

social services access, safeguarding that all access promotes the integration of service delivery across all levels by all service contributors.

Resilience theory has been challenged by the conflict relating to agency and structure, which is occasionally denoted in sociological literature as micro and macro. As contended by Van Breda (2016), resilience theory, predominantly resilience informed by person-in-environment, transactional environmental, and social ecological theories, is adequately placed to lead researchers in joining this gap in the research by recognizing a full range of resilience properties that subsidize to human flourishing. The rising literature on social justice in resilience offers especially appealing prospects for new research that critical autoethnographic research could spark.

This research will make a case that it is crucial to acknowledge the contested nature of concepts such as the self or identity and its fluctuation as one navigates different positions and statuses, languages, as well as countries. Autoethnographic research grants the introspective space to interrogate social positionings. The term "critical autoethnography" has been gradually evident in academic circles and labelled by Boylorn and Orbe (2014) as including three aspects of critical theory: "to understand the lived experiences of real people in context (navigating the system in different countries, through different languages and level of access), to examine social conditions and uncover oppressive power arrangements (medical system under a capitalist umbrella, for my case), and to fuse theory and action to challenge processes of domination" (p. 20).

Because resilience is recognized, not only as an individual emotional attribute, but also as a social phenomenon that is reconciled by the person's culture and social ecology (Ungar, 2013), it is best appropriate to address my research questions. Resiliency, the capacity to overcome harsh circumstances and to react to trauma, is also a role of a person's social networks and the resources

they use to sustain individual health. Consequently, surveying the resources and access in the individual's setting and culture can be retrieved to facilitate adversity. These involve family networks, informal networks, and cultural norms, as well as faith which provide a link to transpersonal theory, which together help navigate adversity.

The theory of resilience is at the core nucleus of my research but can and is undoubtedly intertwined with the theory of identity, which provides the fluctuating inspection of interpersonal and cultural experiences of identity from the inside out (Hughes, Pennington & Makris, 2012; Boylorn & Orbe, 2014; Hughes & Pennington, 2016). Ongoing critiques of my personal experiences and research revolve around resilience theory but extend to affect theory to bring to light aspects of cultural life (Ellis et al., 2010; Ellis et al., 2011), that might not be well-reflected if isolated by a single theory. The nucleus of this interdisciplinary research methodology is the Theory of Resilience as it sheds light into the interconnectedness of the theory of identity, affect theory, and transpires into post-traumatic growth (PTG) and transpersonal theory. Only a few mentions of those theories will be included throughout the research as inseparable progressions of the inner-outer world and evolution, to highlight crucial aspects that are relevant to both the critical autoethnography and fused with the theory of resilience.

The purpose of this research is to understand the intricate and inseparable relationships of certain experiences, and how to use these understandings to overcome certain challenges that are again indivisible. Addressing mental, emotional, physical, financial struggles withing specific contexts (e.g., family settings, countries, institutions) separately might not allow one to shed light into the bigger picture one might need to bring about enough awareness of the complexities of the self and of the repercussions of mitigating and sometimes conflicting identities. The primary goal is to expose the intricacies and spread an awareness of these issues (e.g., n class, gender,

sociocultural context, concurrently with mental health, physical health, financial standing, and the role of access throughout), but the purpose then becomes greater as it can extend to the development of new theories and therapies and might even contribute to public health policy changes and new ways to advocate for certain causes (emphasizing the role of access in overcoming challenges, questioning meritocracy, while nurturing and finding better ways to develop resilience and growth mindset).

The paradox of resilience and stages of traumas do not allow me to overlook the foundations, and progression of events. Protective and risk factors must be well-understood to rise towards an impactful storyline that moves from traumas to resilience, victimization to advocacy for societal change, further nurturing the purpose to make a significant and perhaps even daring contribution to the field.

For my data analysis, I construct categories of experiences (e.g., abandonment and instability leading to Reactive Attachment Disorder; abuse and assault leading to Post-Traumatic Stress Disorder; stigma and codependency; therapies and survival leading to Post-Traumatic Growth) and identify emerging themes (safety, trust, power, control, self-esteem, intimacy).

To mediate my time, I will attempt to write vignettes of experiences first and will then include relevant literature to justify correlations of happenings, feelings, and outcomes. I will allow my writing to be both evocative and analytical and will use research and knowledge intentionally, with texts, pictures, critical reflections, and legal and medical documents. I will eventually allow for those I deem to be closest to me to read and contribute to the confirmation of or different perspectives of specific events.

Critical autoethnography gives me space to tell counternarratives, witness lives with more empathy, recognize my positions in existing structures of power, and learn to navigate institutional

and societal structures while pondering upon my privileges (mostly in terms of race, linguistic background, and legal status) and sense of oppression under the medical capitalist umbrella of a US-Mexico border city (mostly in terms of economic standing).

This specific methodology allows me to address intersecting aspects of my socio-cultural experiences in terms of race, sexuality, language background, socio-economic status, and nationality while situated in an academic and social context. Some of the vignettes I plan to write about describe my identity fluctuation as a student and teacher. A story in which I represent myself in a particular social context and some reflection on the story will help me craft elements typically associated with narrative or memoir including but not limited to developed characters, dialogue, poetry, and thick description because "in critical auto-interviewing, autoethnographers can use their reconstructed life histories to explore and facilitate insight into their evolving worldviews" as internal data source (Hughes & Pennington, 2017, p. 65).

For external data source, I will use observation of self and others in cultural contexts (France, United States, Mexico), interviews of friends, artifacts such as medical and legal documents, poems, conversations screenshots, and audio/video transcripts. For the analysis, I will use interviews, facts correlations (data/diagnosis-based), member checking, and I will maintain "self" at the center of the analysis and report. To legitimize and problematize data (Hughes & Pennington, 2017), I will constantly have to ask myself if my writing is an accurate representation of the critical incidents from my life, from my perspective and the one of those that shared theirs.

By combining critical and evocative autoethnographic perspectives I will be able to move beyond the insider/outsider dualism, better understand the ways in which stories of personal experience are "strategic," and interrogate the broader contexts and processes of social inequality that shape life trajectories. The potential contributions to critical autoethnography of the reflexive approach of "self-analysis" will draw upon my usage of critical autoethnography in research (in France, United States, and Mexico, in the social context of schooling, navigating my identities as students versus instructor, nationalities in context, and gender/socioeconomic standing vulnerabilities, because critical autoethnography, when viewed as a genre of research and writing that both takes into account personal experience and becomes an "anthropology as cultural critique" (Marcus & Fischer, 1986), can contribute to knowledge of power and social inequality.

I plan to situate my stories in methodological literature and in a chronological manner so readers can better understand what theories are influencing my reflections within and concurrently with the theory of resilience. I will share analysis, connecting my stories to relevant literature so readers can understand how the personal stories relate to the larger sociocultural context, and offer social critiques that can encourage the expenditure of narrowed definitions, theories, therapies and/or policy possibilities. This methodology allows me the flexibility to evolve with my research in a non-linear confining manner while using an interpretative approach to writing and advocate a narrative form that "shows struggle, passion, embodied life, and the collaborative creation of sense-making in situations in which people have to cope with dire circumstances and loss of meaning" (Ellis and Bochner 2006: 433).

I believe that analytic/critical autoethnography will place me at a vantage point that facilitates deeper analytical understandings of the context where events are determined by complex intersections of class status and gender. From this angle, critical analytic autoethnography in such a research context can capture the perspectives of the unvoiced and powerless. As a female patient with mental health diagnoses seeing a physical diagnosis struggling with a lack of financial resources, my voice has felt undermined. Critical autoethnographic research is a change-orientated

methodology that seeks to contextualize an auto-ethnographer's experience and critique power and privilege that can elevate silenced voices such as mine.

A suggested approach in critical autoethnographic research is to first "over-include" information in the data collection stage of research, which allows to be more intentional about what to highlight during the analysis and writing of the story/final presentation, and then narrow down the scope to better address the focus of each excerpt. After collecting my data –in the form of journal entries, medical and legal documents, field notes, and/or interviews, video/audio transcripts, receipts – I will prepare the data for analysis. This will involve recording and transcribing interviews or recorded reflections. It will also require organizing artifacts and/or documents into categories or chronological order to prepare for further analysis. Like the challenge identified in data collection section, there is a challenge of "seeing" when analyzing one's own data (what I wrote, what I experienced, etc.). This is both a strength and weakness to this model, and a skill that can be developed to help me navigate this challenge as a critical autoethnographic researcher.

Given that I will have multiple forms of data and may utilize several different approaches to data analysis – chronological analysis, and thematic analysis – it will be important to synthesize the results of my analysis. There is no single right way to do this, but one approach I would like to use is to layer the themes arising out of my thematic analysis over the timeline, which may provide deeper insights into how each personal event aligns with the broader context. It can also deepen analysis to then utilize an arts-based technique as a form of summarizing your results; for example, writing a poem that brings together the key themes identified, or drawing an image that reflects the overall journey I am reporting. The possibilities are unlimited, but the idea is to bring the analysis together into a rational set of conclusions.

In addition to enriching my eventual research findings, these various sources of data also afford a process of quality control in the research design, such as triangulation. For instance, aligning a journal entry in which I reflect on an experience with a photograph dated during that time illustrating the experience presents evidence external to my own recollection. Interrogating friends about an experience will provide backing for my own recollections. Documents will offer objective data to give credibility to the details of my accounts. These are approaches in which the value of my conclusions will be augmented and rendered more reliable using an alternative source.

It may seem that autoethnography would be "easy" in terms of ethics since I am focused on my own life, however, since no one lives in isolation, my life includes others, and my choice of depictions of them and/or of events shared has the potential to impact the lives around me. Whereas in most research accounts, I will try to shield the privacy of those depicted by keeping their identities confidential, and although, everyone knows the story is about the life of the researcher, there are unique ethical issues that must be taken into consideration. I will consider how the publishing of this autoethnography may reflect upon family members and friends that may be referenced in my story and keep in check my responsibility as the researcher to obtain the consent of some key players to be identified in my story. My responsibility as researcher is to minimize the risk to others by protecting them from harm, and I will therefore reflect upon how to manage protecting the privacy, image, and/or confidentiality of those in my research.

I will use a combination of pseudonyms where possible, obtaining permission from individuals identified, and receiving confirmation from individuals of the accuracy of written stories sent to them for their review. In some cases, a pseudonym, composite figure, or obscured identity may effectively protect the identity of people in my life. I plan to obtain informed consent and interview others as part of my data collection. I will also attempt to rely on public data so that I will be

sharing information which is already in the public sphere. I will attempt to describe bystanders in a manner that will be ethical and focused on my own feelings and experiences, avoid personal characterizations, and rely on court filings and other public documents regarding words and actions. Both a relational ethic and an ethic of personal care are essential through the autoethnographic practice, which includes the design, development, and distribution of the research.

Since there is no one "right" way to write autoethnographic research, the style of writing that supports the readers in learning more about how to conduct autoethnography as I concurrently read, reread, analyze, reanalyze, and enjoy the report, will allow me to grow as a researcher during the process itself, and adapt to the dilemmas encountered on the go. While the report may not follow precisely the traditional format of a qualitative research report, I have incorporated standard elements including an introduction to the context and purpose of the study, a review of literature that frames the key concepts of analysis explored in the study and highlights prior research in this area, a description of the procedures followed to collect and analyze the autoethnographic data, a presentation of results (the story), and a discussion of those findings and how they contribute new understanding. While this style of broadcasting can be poignant, persuasive, and lead to important insights for the readers, it does not provide for a one perspective-fits-all. Two results are, however, important: an understanding of the research process, and a means to assess the trustworthiness of the findings. My peers and committee members contributed to the growth of this project by sharing their views on potential dilemmas.

Sharing the research method explicitly allows for added objectivity and replicability which also has the potential to lead to meta-studies of autoethnographies, thus creating critical generalizability. Including the literature will allow the discussion portion to knot the story back to

the literature review, which feeds the analysis with a greater chance to compare, contrast, and situate my story within the literature or identify how can fills the gaps, and help the research advocate for inclusion of those technical specifics that help see how I have arrived at this story lay out, with explicit analysis that credits the components of this methodology. The research will incorporate the traditional elements in the customary chronological sequence and may present some unconventional formatting through the inclusion of more artistic features such as poems. I have chosen to begin with the stories in chapter-like layouts and then follow with the explanation of the context, procedures, and discussion of the related literature. Elements of the stories will be laced throughout the review of the literature and discussion of the results.

## 3.3 History of Autoethnography

Because autoethnography is a relatively new research paradigm that negotiates reflective accounts to illuminate the researcher's personal experiences to analyze cultural beliefs, practices, and the social experiences that influence our identities (Wall, 2008), it is widely criticized, but also embraced as a pipeline for change. Throughout autoethnographic studies, researchers offer personal stories to demonstrate their own understanding of and the importance of autoethnography as a valid and important research tool. Eventually, they assert that the research method's goal is to create a symmetry between "intellectual and methodological rigor, emotion, and creativity" as well as seeking "social justice and to make life better" (p. 2). Due to the intimidating nature of selecting a theoretical framework for any area of research, researchers must always take great care in deciding which framework will best suit the ultimate aims of what they hope their research will accomplish. Intrinsically, these authors provided a list of contentions aiming at demonstrating

autoethnography as a valid and constructive tool to investigate how to acknowledge how their own identities, lives, beliefs, feelings, and relationships influenced their approach and their reporting.

A researcher utilizes canons of autobiography and ethnography to create and write autoethnography. Autoethnographic research is self-reflective ethnography (fieldwork, study, and the dissemination of first-hand research in a particular place, time, and community/group of people) positioned on the first-hand assessment of the researcher/self. Ellis (2004), Ellis, Adam, and Bochner (2011), and Jones (2005) further dissect the label by specifying the source of the word autoethnography as both a product and a process. "Autoethnography is an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) to understand cultural experience (ethno) (Ellis, 2004, p. 10). Some of the leading pioneers of autoethnographic theory and method, continue to write widely on the topic, and describe the objective nature of the method as one where autoethnographic writing resists grand theorizing which can frequently decontextualize the theme and pursue to feature only one remarkable truth.

As mentioned by Spry (2001, p. 710) uses Crawford (1996); Denzin (1997); Ellis & Bochner (1996); Ellis & Flaherty (1992); Goodall (1991a, 1991b; 1998); Neumann (1996); Reed-Danahay (1997); Secklin (1997), autoethnography removes the widespread façade that research should only be objective. In this manner, the method demeans the researcher and adds an exceptional nuanced impact to conclusions. The "truth" is progressing with the "research subject" or in this case, the auto-ethnographer as a researcher. It can evolve into auto-ethnographer and researcher involved engagement and learning creating a process which contributes to identifying cultural practices, lived experience, behavior, needs, and health of individual community members.

A researcher employs theories of autobiography and ethnography to generate and author autoethnography. Autoethnography, includes the influence of ethnography (fieldwork, study, and the dissemination of first-hand research in a particular place, time, and community/group of people) focused on the first-hand viewpoint of the author/self. Ellis (2004), Holman Jones (2005) and Ellis, Adams, & Bochner (2017) additionally scrutinize the method by noting the basis of the word autoethnography as both a product and a process. "Autoethnography is an approach to research and writing that seeks to describe and systematically analyze (graphy), personal experience (auto), to understand cultural experience (ethno)" (Ellis, 2004, p. 10).

Some of the prominent theories about autoethnography as illustrated by those who founded autoethnographic theory and method and continue to write extensively on the topic: Castaneda, (2019) portrays the factual nature of the method, as one where autoethnographic writing defies grand theorizing, which can frequently decontextualize the subject, and seek to emphasize only one peculiar truth. Autoethnography removes the conventional façade that research should only be impartial. Thus, the method demeans the researcher and includes a unique nuanced impact to conclusions. The "truth" grows with the "research subject", or in this instance, the autoethnographer. It can progress into auto-ethnographer participating position and learning. This generates a research method which contributes to understanding cultural practices, lived experiences, behaviors, needs, and health of individual community members. The design of autoethnography finds choice in its partiality, constructing a standpoint unique from one of the traditional research analysis methodologies. Ellis, Adams, & Bochner (2010 p. 273) explain that "this approach challenges canonical ways of doing research and representing others." Intrinsically, the auto-ethnographer offers circumstantial knowledge that is more than a plain data fact. Ellis, Adams, and Bochner (2010, p. 276-277) pinpointed that Ellis and Ellingson (2000), Couser (1997),

Goodall (2001), Maso (2011) vibrantly depict autoethnography as: "evocative, engage readers, and use conventions of storytelling such as character, scene, and plot development—by finding and filing a 'gap' in existing, related storylines." This focuses on the unique perception of those involved in the research course and aims at a better understanding of stories and experiences.

The exercise of producing autoethnography exposes bits and pieces of lived experiences leading to effectiveness in spreading understanding, while contributing to the nurturing of a healing process. Spry (2010) reminds Gramsci's (1971) concept of the whole intellectual being used in autoethnographic research, seen through self-narrative and broad interrogation. Spry (2001 p. 710) expands this through Reed-Danahay (1997), Behar & Gordon (1995), Clifford (1988), Clifford & Marcus (1986), Conquergood (1985, 1991, 1998), Geertz (1973, 1988) Marcus & Fischer (1986), Myerhoff (1979, 1982), Trihn (1989, 1991), Turner & Turner (1982), Turner (1987), and Denzin (1992, p. 20) affirming that autoethnography can be described as a self-chronicle that analyses the situatedness of self with others in social contexts. Autoethnography is both a method and a script of various interdisciplinary praxes. Its origins trace the postmodern 'crisis of representation' in anthropological text where autoethnography is a fundamental rejoinder into pragmatist schemas "in ethnography and sociology 'which privilege' the researcher over subject, method over subject matter, and maintain commitments to outmoded conceptions of validity, truth, and generalizability".

Ellis, Adams, and Bochner (2010, p. 276) add up to the nature of the attributes cited above and inform autoethnography as critical to bridging the gap between people in the culture and the people examining the culture. The individual who is the researcher is similarly assisting as the human being researched. This can provide an essential cultural contribution beyond making evident "relational practices, common values and beliefs, and shared experiences for the purpose

of helping insiders (cultural members) and outsiders (cultural strangers) better understand the culture." The "subjects" from an immediate viewpoint, the auto-ethnographer, allows for an interdisciplinary understanding excluded in most other types of the research, by connecting elements of the individual's life and cultural distinctiveness which have had substantial influence on the lived experience (Bochner & Ellis, 1992; Couser, 1997; Denzin, 1989; see also Ellis, Adams, & Bochner, 2011 p. 275), and disputably on health. The auto-ethnographer is compelled to analyze a predicament and attend to that understanding (Zaner, 2004) which can lead to awareness and then to healing, where life after might not feel the same (Ellis, Adams, & Bochner, 2011 p. 275).

Autoethnography is an important form of critical pedagogy, which can be a vigorous theory-method interdisciplinary setting. Saldaña mentions Denzin, who presents the notion of compounding and positioning auto-ethnographic narrative/research, placing the modern and meditative work which upholds "close allegiance to the lived experiences of real people" (Saldaña, 2005). As a strategy that questions and challenges observable societal incidents through methods of analysis, autoethnographic research touches on moral and political discourse (Denzin, 2004).

Elements of credibility and acceptance are current throughout this research process. Through critical pedagogy and interdisciplinary lenses, autoethnographic research maintains that coming to this method is founded on a coalition from "ethnography, personal narrative, pedagogy" (Denzin, 2003 p. 2014), and can contribute to growth through resistance of set-limiting structures by an expansion of exploration, therefore making research more manageable to community spaces. Autoethnographic research situates and informs the reader on recommendations and descriptions of importance of giving voice and power to hidden narratives.

### 3.4 Methodology

Autoethnography is the study of one's own culture and oneself as a part of that culture in many variations (Patton, 2002). This study will allow the readers to picture my experiences of lacking emotional stability due to childhood traumas. It will include conversations with my "chosen" family, friends along the way who accepted me as such in El Paso, as well as conversations with childhood friends back in France and with counselors and therapists about my journey and life philosophies. I will also describe stigmas, dependencies, educational goals, strategies to cope with poverty, and dealing with complex physical diagnoses.

The flow of the stories will remain continuous throughout Chapters IV through IX. If there are any interruptions to the flow of the story, it may be due to the use of French (in italics). I want to honor the legitimacy of the dialogs with my childhood friends. Consequently, at the start of a sentence when conversing with my French friends, I start with a word, phrase, or sentence in French to prompt the reader that I used the language the receiver felt more at ease with. An English translation of the French word, phrase, or sentence follows soon after.

Ultimately, I am an educator in search of the betterment of self as an individual, as a facilitator in the classroom environment. As a social justice activist in the world, we all share. While many still argue the congruency of autoethnographic studies as a major scientific contribution, I demonstrate, through my story, that the complexity of histories in specific sociocultural contexts enriches the understanding of what this world at large needs.

Social structures that allow for individual complex healing can provide spaces and understandings of what is needed to allow for community healing. Thus, at this level of research, it is advantageous to scrutinize my own experiences alongside my role as an educator with a financially vulnerable population who has experienced trauma and share experiences to give a

critical vision on how to heal the self so that community members can better support the healing of others.

Autoethnographies unite a vision of interdisciplinary studies by allowing for individual voices to provide meaningful evaluative material to craft new theories and mold better policies. Telling analytically explores matters that support the approach to engage readers in their imaginative relationship with the text (Muncey, 2010, p. xiii). This genre of writing research demonstrates numerous coatings of consciousness, joining the personal to the cultural (Ellis & Bochner, 2000, p. 739). To better explain the idea of the multi-layered nature of this method, Reed-Danahay recommended the alternative definition that "an ethnography includes the researcher's vulnerable self, emotions, body and spirit and produces evocative stories that create the effect of reality and seeks fusion between social science and literature" (Reed-Danahay, 1997). Muncey highlights the significance of considering the type of filter that the researcher will use to distinguish personal understanding from the issue of analysis. It is impractical to isolate the power of individual experience; thus, it is vital to acknowledge oneself as the focal point of research. Autoethnography is research that benefits the person by "attempting to portray an individual experience in a way that evokes the imagination of the reader" (Muncey, 2010, p. 2), while depending on "Participant Observation Strategies" (Wolcott, 2001, p. 90). The auto-ethnographer is, therefore, the contributor in the social context of their experience, but also an observer of their own story and its social setting (Muncey, 2010, p. 2),

Autoethnography as a methodology allows for a better understanding of complex feelings and experiences that cannot be shared in conventional ways. Phenomenology intimately resonates as it holds a comparable objective of depicting a lived experience. Phenomenologists imply that the distinction between the meaning of life and obtaining meaning in life goes deeper as the

investigator must identify there is no discrepancy between leading research and living life when the auto-ethnographer is both the researcher and participant of the research (Muncey, 2010).

The practice of self-reflexivity is vital for the betterment of self as human beings. This idea of identity encompasses biology, social context, and consciousness. An essential part of this challenge is the self-suppressed personal beliefs, feelings, and perceptions conveyed only when preferred. Reliability and validity are therefore questionable, as concerns over reflexivity. However, part of the integral human experience, cannot be properly assessed and may partake in the relationship-blurring of the researchers and participants of the research (Borbasi, 1994). Nonetheless, self-reflectiveness grants the prospect to see the self in our understanding and the self as others view us.

Distinct viewpoints become apparent as we contemplate our private humanity as if it were somebody else's and someone else's world as our own. This offers the space for empathy and sincerity (Muncey, 2010). To truly grasp oneself, we must be concerned about how others look at us. According to Mead, the idea of self-changing our relationship with the world rewards us with exceptional strength. In seeing ourselves as an entity, we can understand others and intermingle with ourselves, which generates an impact on the world (Mead, 1934). This encourages the self to turn into a reflexive process. Romanyshyn (1982) expands this notion that consciousness in not experienced in our minds, but that it is instead created by reflections of thoughts, feelings through the individuals and things who make up our world.

Muncey (2010) emphasizes the need to contemplate subjective awareness, which offers a framework for examining the qualities of the personal world assembled by the investigator. When the individual world is blended with physical experiences, it makes our experiences appear

susceptible and translucent. This justifies why people prefer suppression over outward communicative observations. This casts light on the concealment of traumatic recollections.

Utilizing an autoethnographic lens helps to expand and strengthen ongoing conversations relevant to educating students who have faced trauma by providing my role as a student and then as a teacher. Spry (2001) reminds us that human experience is complicated and tumultuous and that what divides autoethnography from typical autobiographies is the researcher's intent to destabilize a prevalent discourse, by becoming "a self-narrative that critiques the situations of self with others in social contexts" (Spry, 2001, p. 710). While I acknowledge the shortcomings of this very personal qualitative method, I believe that the strengths of this method offer further advantages, especially in interdisciplinary settings. I therefore also triangulate personal reflections with document analysis of ACEs and ALSUP scores, aside from other medical/personal documents, to support and question current theories such as cognitive-behavioral theory, traumatheory, and resilience theory. I intend to address the construct of deficit, problem-solving skills, and self-regulation, and foresee that this amalgamation of autoethnography and content analysis will allow me to reflect on which elements of protective factors and therapies were the most effective, while incorporating a constant self-reflexive conversation of my own experiences.

This methodology's strengths and weaknesses both draw from the fact that the heart of autoethnography is my understanding as a researcher, teacher, and student. This places substantial stress on myself as the researcher, the process of my examination, and my capacity to locate and decipher meaning (Reda, 2007). This research will be examined through the lens of my practice; thus, it is critical that I draw on record analysis, ACEs, and ALSUP scores to position my autoethnography in events beyond my own. Nevertheless, largely, the capacity to correctly read the culture and understand patterns all rides on my shoulders. In the analysis of the narrative, I

offered suggestions that may lead to policy change, new theories, informed theory, and contributions to policy. I present my life story with pieces of research within that narrative and have provided pseudonyms for some of my friends who have requested it.

In *History of Autoethnography*, (Preissle, 2006, pp. 686 & 687) began describing objectives of qualitative investigation in the following manner. First, it stresses an explanation of immediate understanding and significance. Second, it identifies conceptual framing while leaving open the 'what and why' of experience and meaning that fluctuates by the philosophical, theoretical, and disciplinary inclinations that investigators bring to their analyses. Third, it is an active part of theory—practice nexus where theory and practice are collaborative and symbiotic in the sense that Dewey (1939) advocated.

While we have collected data for many years, the practices of gathering and understanding have been less comprehensive (Preissle, 2006). Preissel (2006) found that it was not until the 1980s that qualitative research became accessible in more disciplines and theorized that in some studies, the research is significant and obvious, like in ethnographies or oral histories. Nevertheless, there are components of the investigation design that can mix as found in autoethnographies (Ellis, 2004). Hence, this autoethnographic study draws "across boundaries of methods, disciplines and fields" to create this piece of literature (Preissle, 2006, p. 688).

Holt (2003, p. 2) penned that an "emergent ethnographic writing practice involves highly personalized accounts where authors draw on their own experiences to extend understanding of a particular discipline or culture" is autoethnography. Ellis (2004, p. 37) referred to autoethnography as a comprehensive lens that zooms out to make observable social and cultural facets of individual experience and then zooms in to uncover a susceptible self that "may move through, refract and resist cultural interpretations." Ellis added that "Feminism has played a role in the

narrative/autoethnography movement" (Ellis, 2004, p. 37). Female investigators combined their intimate experiences by starting with themselves, and by making a personal connection with the research and using their own experience to support the process (Ellis, 2004).

### 3.5 Self-Reflexivity

As a process, reflexivity entails motion whereby the act of self-consciousness is decided or suggested. Self-reflexivity is a notable form of self-activity in which self-consciousness is generated, and it is continued in any form of self-consciousness. 'Self-reflexivity' or 'reflexivity' is a method to deal with the problem related to objectivity and is meticulously connected to empathy. Researchers attempt to view diverse ideas of the people in an unbiased or neutral manner. The definition of self-reflexive is someone searching for and analyzing their own deceit.

Critiques of autoethnographic research are concerned that the researcher being the subject unavoidably leads to the selective avoidance of controversial facts and feelings that may be relevant in contributing to an understanding of the biggest picture, whether for self-preservation of guilt, judgment from others, safety, attempting to protect others from harm, and so-on. While it is unquestionable that some autoethnographic researchers may be reflective of some situations but might not examine how theory, culture, and communication shapes and moves through their actions and their words or how theory, culture, and communication influence the experiences they research, it still illuminates the power and privilege of self-reflexivity in research.

By working towards and in self-reflexivity, researchers submit evidence of the power and limitation of the method, as there is in any research that considers time for incubation, examination into existing research, and revision of the final product. This self-reflexivity was found to be present in all phases of this research, including in the final stage of revision, which must consider

that autoethnographic research is truly never-ending if fully embraced and is impossible to externally regulate. The idea of intersubjectivity is key here, as sharing autoethnographic research makes it possible to analyze this phenomenon.

In *Autoethnography: Understanding Qualitative Research*, creators Tony E. Adams, Stacy Jones, and Carolyn Ellis justify how autoethnographic research "enable us to live and to live better" and contend that "stories allow us to lead more reflective, more meaningful, and more just lives" (Adams et al., 2014, p. 1). Adams, Jones, and Ellis assert that through cautious self-examination, one can understand, empathize, and connect personal experiences to others. Consequently, one's lived experiences subsidize the increasing social narratives at play in society. While autoethnographic research can be fallible in the examination of some theories and not have transpired precisely the way they were written, it works through emotions and stories analysis, provides a powerful and in-depth examination of situations leading to new mindsets and theories, therapeutic applications, and major guidance for policy change.

### 3.6 Ethical Dilemma

One of the main ethical dilemmas that arise from conducting autoethnographic research, is validity. It might be human nature to merely exhibit positive edges of the self to the outside world. Furthermore, it is still culturally not welcome to discuss private matters with the world at the cost of hurting people's reputations. It is even more shameful when it exposes the negative sides of beloved family members. But, left hidden, the unseen messy parts of us and others, cannot contribute to a qualified interpretive autoethnography.

Ethical encounters ascending in directing and bestowing autoethnographic research must be discussed to improve the ethic of respect in autoethnography. To address potential privacy concerns, (Ellis, 2007) acknowledged two well-known ethical elements— technical ethics and located ethics—and depicted a third as interpersonal ethics. She suggested that process approval, verifying with the individual that they have grasped how their exchanges will be embodied, is needed (Ellis, 2007). However, Tolich (2010) mentioned with worry that (Ellis, 2007) had not used this recommendation about broadcasting an autoethnography about her mother, which she did not show her and read quotes of a further autoethnography to her mother but omitted parts she thought could hurt her. At the same time, it must be recognized that Ellis (2007) expressed her discomfort, along with the intricacy of concerns that occurred for her, as she wrestled with her choices about what needed to be done to guarantee observance of a relational ethic. How consent is negotiated and additional practices of fair procedure are circumstantial and cultural, thus challenging the guidance process for ethical oversight in autoethnography, as reported by Ellis (2007) and Tolich (2010).

Autoethnography cannot be one static and incontrovertible method but instead needs to be a theoretically messy, fluid, and highly contextual approach to exploring and understanding self-experience in context. The relentless examination of the right to speak about or even for others, as illustrated by Bishop (2020), demands self-questioning deep contemplation, and a duty of honesty. Research affecting human participants is also constrained by organized or nationwide research ethics obligations, and this may not be over-ridden by autoethnography's aim to concentrate on self-experience. Lee (2018) suggested that without support from new researchers, the ethics of autoethnography can uncover a hazard, what Dilger (2017) more pleasingly depicted as needing fumbling through. There is continually the opportunity in writing autoethnography that "people in narratives become fixed ... which can have serious and far-reaching consequences for the author and their characters" (Lee, 2018). Some have explained this depiction of others in

autoethnographic narratives as treachery (Tolich, 2010). When writing about others, "all others have rights over how they are represented regardless of any apparent consents they may have given at the outset" (Andrew & Le Rossignol, 2017, p. 245).

It could be alleged that the principal concern for the ethical oversight of the research—whether a retrospective or simultaneous autoethnography—rests with the auto-ethnographer. Nevertheless, even with the permission of those described, the auto-ethnographer may encounter a comparable challenge as in ethnography, whereby, as mentioned by Fine (1993) the investigator assumes that contributors understand what they are getting themselves into. It is nearly impossible to predict how one's autoethnographic research will be received and/or how, if individuals identify themselves in the descriptions, they will feel and respond to it, if at all. This is mainly worrisome with concerns to retrospective autoethnography, available with no authorization or understanding of those depicted. In turn, the publication takes control out of the author's hands (Lapadat, 2017). Yet, the method of accounting for challenging impractical positions and the actors within them is a course by which organizational autoethnography can be the heart of disclosure, particularly with respect to problematic workplace systems needing remediation.

The investigator has a duty to illustrate and explore their own experience authentically. Though it can be agonizing to remember complicated past experiences, with allusion to an ethic of the self, prospects to think about whether the damage can be triggered by in-depth private disclosure is revelatory. Hazard to the reputation of self and bystanders could similarly be deemed as a potentiality to mental health risk due to unforeseen encounters occurring from in-depth introspection about events, which may perhaps lead to contemplation. Lee (2018) suggested that introspection in autoethnography is interminable. How these facets are routed in autoethnographic composing is theoretically tricky, negotiated afresh every time we move towards themes with this

method. The experiences recounted through autoethnography occurred in day-to-day enduring years, and do not take place in some independently situated area of research, like in interview-based research where one seeks to understand participants' experiences through a specific lens, with deep-listening in a narrow context. These encounters shared by others in interviews can move us, but they are not our personal experiences lived in our bodies and minds or re-lived in recollection through retrospective autoethnography. Through autoethnography, numerous interpersonal encounters between the self and others and frictions between professional and academic roles, expose aspects of a power dynamic. When illustrating and revealing encounters besides collaborators or in relations with family members and friends, unintentional harm to self-reputation and others may occur.

Important concerns and goals contained by an ethic of autoethnographic research involve granting the opinion of the researcher to be heard. To quiet this voice because of others' potential liability reports in triggering the writer's uneasiness or anguish, could uncover these others to a kind of detriment. Though tricky, the claims pertaining to the rival assertions of the right to be heard and oppressive silencing (Lee, 2018) outweigh the risks of autoethnographic research. Practices such as masking may be deemed valuable to safeguard identity (Jerolmack & Murphy, 2019), but in some cases, it might be impossible to accomplish this. Rambo (2016) reported how an autoethnographic seminar that earned a prize was not able to be circulated because of possible hazards to those she depicted. She was recommended to generate an adaptation as a story or play instead of an academic peer-reviewed paper. In an associated experience of publishing an extremely personal account, she could not use her name as the author of her autoethnography described encounters of her parents, who would lose their privacy by publication of her name.

Another downside is that autoethnography can be considered a deceitful production intended to "represent the author in a particular way" (Walford, 2021, p. 5). Armstrong-Gibbs (2019) pondered whether this prospect of self-disclosure may encourage a culture of exaggerated self-status of the researcher, analogous to Walford's prerogative of autoethnography as unadulterated self-sympathy (2021), conceivably where the researcher's self-images are not predominantly thought-provoking, or at vilest disclose a shallow account whereby an individual uses the method to whine about their situations. As Hackley (2020) depicted concerning structural autoethnography, when the researcher's statement of perception of experiences uncovers incessant self-immersion, it cannot be concealed from the reader.

There are well-recorded practices of ethnographers hiding participants where the privacy of their communities could not be preserved post-publication. Arlene Stein's research was described in *The Stranger Next Door* (Stein, 2010), Nancy Scheper-Hughes' research focused on mental illness in a rustic Irish community (Scheper-Hughes, 2001), and Carolyn Ellis' book informed her research over many years in a fishing community in Chesapeake Bay (Ellis, 1986). Stein (2010) indicated the consequent flap in reaction to Ellis' book drove her to focus on local and personal events in successive research analyses, ultimately resulting in the marketing and development of the autoethnographic method. The three researchers published later reflections on what transpired and what they may perhaps have done in a different way (Ellis, 1995; Scheper-Hughes, 2001; Stein, 2010). All expressed the treachery that communities and their participants faced when reading critical reports of themselves and their behavior in ethnographic aspects. Scheper-Hughe's (2001) participants appeared especially bothered by her account, asserting they had not been granted recognition for the assets, magnificence, and resiliency of the community but somewhat perceived she had criticized them as regressive, out of touch, and foolish.

The executive auto-ethnographer does not have the ethnographer's challenge of gaining access to the public. They write and research from the position of entry and social context, where they hold several positions, never merely as a researcher. Nevertheless, retrospective structural autoethnography has an extra ethical facet as it is generally not likely to attain retrospective ethical consent for such work. An ethnography denotes various voices with whom the researcher examines and relates (Lester & Anders, 2018). In writing an autoethnographic research, the researcher is at the center. Instead of representing events of others, they write about themselves, and their encounters in dealings with those who were present when the incidents happened. It is here that (Lee, 2018) the assertion that "[t]he auto-ethnographer strives to achieve a version of the self and an account of events that is consistent and acceptable to their own conscience" (p. 313) does have to be considered.

Wood & Liebenberg (2019) underscored the significance of courteous relationships and the prudent usage of phrases to show this respect in remembering experiences to construct a retroactive structural autoethnography (Herrmann, 2017). Lee (2018) recognized several resources retrieved to authenticate their account. Using her partner as a witness helped her with credibility issues. Her partner was implicated in portions of the dilemma summarized in the autoethnography and/or had heard the author's report soon after the incidents happened. Lee additionally retrieved medical and court/police documents to confirm specifics. She showed the support of her doctoral supervisor. These elements of authentication are crucial to maintaining the reliability of the research. Researchers are accountable to communities of practice, culture, and impact, in which self-knowledge is lived and elaborately narrated through autoethnography. In all research, we need to be attentive to safeguard the rigor, liability, and truthfulness of our work. We ought to come across a selection of adequate practices to make sure that individuals mentioned in

autoethnography should be notified, and where feasible, their recollection as to what transpired should be pursued for interpretation. If this is not conceivable, a choice of alternative possibilities could find reasonable ethical limits, such as masking the others broadly. There is a difficult stabilizing act concerned in getting this right, and what might appear to be prudent in one position may not be suitable in another. The challenges occurring from the friction between the social ethic and the ethic of the self in autoethnography are real and ongoing.

To submit an autoethnographic dissertation or autoethnographic research at large, one must apply for review and exemption from the Chair of the applicable Human Research Ethics Committee. This is granted on the basis that the experiences depicted are documented in the public sphere.

# 3.7 Autoethnographies are Transdisciplinary and Interdisciplinary Research Methods

As the literature review highlights, autoethnographies are both interdisciplinary and transdisciplinary in nature. Transdisciplinary research is defined as research efforts conducted by investigators from different disciplines working jointly to create new conceptual, theoretical, methodological, and translational innovations that integrate and move beyond discipline-specific approaches to address a common problem. Interdisciplinary research integrates information, data, techniques, tools, perspectives, concepts, or theories from two or more disciplines or bodies of specialized knowledge. Interdisciplinarity analyzes, synthesizes, and harmonizes links between disciplines into a coordinated and coherent whole. Transdisciplinary research integrates the natural, social, and health sciences in a humanities context, and transcends their traditional boundaries.

As an autoethnographic researcher, one is both the researcher and the subject. While the research uses reflexivity to analyze the self, they can also share data to provide a better picture of analyzed assumptions about systems and others. Analyzing the self cannot be done without analyzing the world behind the self. Being human is being complex. The complexity of this interdisciplinary and transdisciplinary method is well highlighted by Levy (2015) that states that "The inter- or transdisciplinary nature of human bodies suggests the yet untapped power of the body as an instrument of arts-based transdisciplinary research" (p. 153). Autoethnographic research is knowledge-based analysis of life experiences of inseparable inner and outer worlds.

Transdisciplinary is holistically organized, and advocates of it accept that this is the only way problems can be solved (Leavy, 2011). It welcomes distinct perceptions and, by doing so, helps expose the limitations of the historically structured, independent disciplinary borders; it focuses on the problem itself and requires meaningful collaboration, modernization, ingenuity, and flexibility. By encompassing such nonlinearity, connection, and complexity, it offers the great challenge of pondering upon the criticism of autoethnographic limitations, as a mirror. In other words, allowing for traditional criticism of its limitations to be seen instead as a limitation of traditional methods unable, or perhaps unwilling to welcome change, especially with the complexity of transdisciplinary and interdisciplinarity pushing for the full collaboration and acceptance of all-knowledge based value, of a world that feels the need always to see to believe, but not feel to understand. The interwovenness of autoethnographies tapping into so many different fields of studies and theories, can offer new perspectives and offer new conceptual frameworks that have yet to be explored. As mentioned by John Muir (1911) "When we try to pick out anything by itself, we find it hitched to everything else in the universe" (para. 11).

#### 3.8 Limitations

While defining the constraints of autoethnographic method lays around things beyond control, delimitations and boundaries can purposefully be set. The method imposes obvious limitations of inquiry revolving around the researchers' own biases and integrity questioning of shared perceived facts. The perception of the same event viewed and experienced by several people will be felt wildly differently by each one of them. This goes beyond the simple concern of the research telling his/her/their truth, therefore opening a challenging debate of unpredictability of findings (Reeves, Peller, Goldman, & Kitto, 2013).

Randomness can be recognized as an all-comprehensive element of chaos; and chaos is a fundamental property of life and in nature. Consequently, the variable nature of autoethnographic research, allowing for a wide range of unconventional layouts, data, and analysis, makes it a limitation. Furthermore, because of its interdisciplinary and transdisciplinary nature, autoethnographic research mostly revolves around the researchers' perspectives and lived experiences, alone. It is the researcher's voice that presents and understands the phenomenon(s) they seek to explore. Using mostly and sometimes solely oneself as a research site, dis-allows other voices to be heard and is therefore a limit to this study. Another obvious limitation of autoethnographic research is that cultural perspectives tend to largely be biased, especially since this method exclusively rests on self-lived experience of encountered phenomenon(s) which occurs only within the complexities of the Self.

German theologian Meister Eckhart once wrote "A human being has so many skins inside, covering the depths of the heart. We know so many things, but we don't know ourselves." If this assertion is to be taken plainly, the grasp of ourselves is controlled by the fact that we create layers that veil our true natures. The supposed lack of credibility and generalizability among non-

endorsed research paradigms holds similar statements that can be found in quantitative and qualitative journals in which the notion that self-reflection cannot be considered as valid, in research. Accordingly, autobiographical, and auto-ethnographical studies elicit little support in certain academic circles. However, since the 1970s, some researchers have begun to dispute the status quo by employing personal narratives as a rich primary source to advise investigation (Chang, 2008).

#### 3.9 Delimitations

While this method can encompass and include several disciplines and fields of study, the responsibility of a full analysis of either one is well beyond the focus of an autoethnographic dissertation. It should therefore be considered a delimitation. Another delimitation is not considering specific aspects of one's life, whether to avoid judgements from readers, or to protect someone's identity and/or well-being. Autoethnographic research can be limited in scope to discussing general terms as well, as the purpose lies elsewhere.

The use of narrative analysis as part of the framework should also be understood as a delimitation. It could be argued that an autoethnographic research inquiry is by its very nature narrative. While narrative research is not limited to a specific methodology, it is a major component of Autoethnographic research as a method, adding to the list of delimitations. Additional delimits include the works of philosophers or theorists that may have bodies of composition. Similarly, autoethnographic investigation can be focused on vague, overall understanding of specific archetypes. An exploration into the various fields, theories, and disciplines it touches on, is well beyond the scope of autoethnographic investigation. While it is

important to briefly include the presence of varied and distinct multifaceted aspects of the research, the inquiry itself does not have to offer set answers to thorough discussions.

## 3.10 Validity

Although the validity of autoethnographic studies is high in the list of debates, a collective rise in consciousness seems to successfully advocate that, while remaining vigilant to the reflexivity process, aids in uncovering biases as an integral part of validity itself. Utilizing autoethnographic research to nurture the practice of questioning the self thoroughly and constantly is yet another way to achieve validity. Constancy throughout the process can be developed in the making of the final, yet never-fully-final, product of the research. (Leavy, 2015).

This process encourages the acceptance and succeeding conviction of Perception of Truth by the researcher as a researcher, by the subject that is concurrently the researcher, and by the readers of the study that must embrace hearing, feeling, and understanding one's truth as one describes having experienced it while finding validity and contribution to the field. While this seems to be a heavy challenge many might not agree to tackle, the possibilities for growth in That field (whichever that may be) can be very vast. First, aspects of stigma should be considered valued knowledge, must be analyzed, and removed from the list of boundaries.

Acknowledging the authenticity of lived experiences as valid knowledge that can lead to the proposal of new theories, perspectives on valued knowledge, and substantiated awareness and understanding of reality, and interconnectedness of fields of study as powerful spaces for growth, rather than limiting factors, allows for evolution in research.

While validating the self is crucial for self-healing, validation of the research process as valuable and legitimate must equally partake space as a criterion that supports the truth, when it

comes to the researcher (Denzin, 2014, p. 59). Consequently, knowing and trusting one's truth as the subject and the researcher is a critical element of the validation process. Validation is also achieved using multiple theories, methods, and sources—known as triangulation—which also provided a standard for academic rigor in this inquiry (Merriam & Tisdell, 2016). Triangulation refers to the use of multiple methods or data sources in qualitative research to develop a comprehensive understanding of phenomena (Patton, 1999). Triangulation has also been viewed as a qualitative research strategy to test validity through the convergence of information from different sources.

Autoethnographic methods and theories that support its use often provide a framework that adds to further validity. It is fundamental to stay open to what may progressively and, ostensibly without endeavor, come forward. While validity calls for determining the truth of phenomena, it is sensible not to deem that one has discovered a definitive truth. When we become "certain about what is real, we seal ourselves off from 99 other possibilities" (Gergen, 2009, p. 161). Sealing ourselves off can be grasped as an alternative phrase for compartmentalization or duality, issues that this investigation does not support. As mentioned, the various methods and theories that can be interwoven in autoethnographic research provide multiple—and other—ways of knowing, thus creating a nondual framework. Reactions from those interacting with this research can "contribute important indicators of validity" (Braud & Anderson, 1998, p. 219).

Those quantitative and qualitative "purists" are likely to have much to say about the use of personal narratives as a valid tool to conduct research. Understandingly, the authors assign substantial attention to responding to autoethnography's critics while developing a sound litigation for its validity. Autoethnography fills a valuable space in the field of interdisciplinary research.

While some may reject autoethnography as an invalid theoretical framework, the authors have shown its capacity to relate one's personal experiences to the broader social experiences of others and open space to broaden complex understandings of self and structures. This can undoubtedly lead to new theories and applications, if the world continues to dare open to the idea that the chaotic, unstructured and unknown, is equally important that the well-arranged traditional array of layouts, research offers, to unwrap complex mysteries of health sciences, social justices, academia, and all that is interconnected.

### 3.11 Data Analysis and Theory Nexus

The place where data and theory meet are the most useful to help us understand the phenomena we witness. It is a place where the micro meets the macro, and we can see accurately how these ideas affect us and how they are constant through our interaction connections. Autoethnography is one of the qualitative research methodologies that remains somewhat mysterious to many scholars. While the use of autoethnographic research has expanded across numerous fields and is becoming increasingly accepted as academia now embraces interdisciplinary studies, it can be difficult to find much guidance about the procedures involved in directing autoethnographic research because of its intentional disregard for formatting control and one-size fits all publishing processes.

Recognizing both the flexibility and originality inherent in autoethnographic study, as well as the need for rigor in attaining meaningful research results, encompasses extensive reflections regarding the process of conducting the research itself – from developing the research questions with an understanding that several research questions may follow up with sub-research questions to fit the interwoven nature of the study, that aims at reporting the findings that may potentially

offer suggestions for future research. Recommendations drawn from both narrative and ethnographic research methodologies highlight that, as with any qualitative research project, the first step is to compose research questions, which reflect the focus of your study. It is important that the research question reflects the focus of the autoethnographic study, which is studying a cultural issue through one's personal story. Autoethnographic research is a form of cultural analysis, that nurtures the pondering of the original research questions throughout the process and contributes to the birth of sub-research questions. The cultural multifaceted features allowed by autoethnographic research seen through self-reflexive lens of lived experiences, might contribute to the reformulation of research questions and/or how the researcher may perceive the final contribution of their work.

While autoethnographic reports may not always overtly state the research question in publications, having one or several uttered can aid direct the research process and keep the researcher on track in terms of the focus, which, as Chang (2008) states, "transcends mere narration of self to engage in cultural analysis and interpretation" (p. 43). One of the key questions that researchers ask when handling autoethnographic research is what establishes their data. Since one's own life is the primary source of data, there are numerous avenues to gather information. One may simply share one's remarks. Yehuda Silverman (2017), in his dissertation entitled Uncertain Peace: An Autoethnographic Analysis of Intrapersonal Conflicts from Chabad-Lubavitch Origins, utilized his observations of self-and surroundings. Silverman applied various techniques of data collection, including self-observation, in which he chronicled notes of his observations of his internal conflicts throughout the day on a smartphone and then relocated them later to a worksheet log of observations. Self-reflective data can contain journals, notes, pictures and drawings, and reflections about your experience and perceptions related to the topic. Lai

(2012) asked himself a series of queries related to the death of his grandmother and documented and transcribed his answers to those questions for later analysis.

McIntyre (2016), who conducted an autoethnography about her involvement of being in the World Trade Center on 9/11, describes writing in her journal daily, noting thoughts, feelings, memories, and questions about her experience with the goal of having an entry every day, no matter how small (though at times she needed to pause to manage and process the emotions that arose from the data collection process). Additionally, there is the point of when the reflections are made, if they were made with likely research in mind, and if it is helpful to deliberately address factual, social, and emotional elements rather than letting these develop later.

One's reflections in the instant are probable to be distinct than reflections at a later point. One may have access to outward data, such as photographs, letters, diaries, reports, and other documents or artifacts that are pertinent to your study. Moynihan (2018) integrated files such as court motions, judicial decisions, letters, and emails pertaining to her topic, which was *Structural Violence in the New Hampshire Family Court System: An Autoethnographic Exploration*. Others have used bills, doctor's appointments, or other similar items, such as artifacts, to determine timeframes and kindle recalls. (Emerson, Fretz, & Shaw, 2011)

Another technique for data collection is to chronologically list major events or experiences from one's life that pertain to the research topic. Chang (2008) suggests this as a data creation exercise, in which one describes these events and how they contributed to cultural self-discovery, designates the instances of these events, and justifies why they are important to the analysis of the research. While autoethnographic research may not solely draw on memory, it is likely to be heavily based on personal data reminiscence. There are some trials related to using memory as a data source. It can be complicated to know what is "true." Some memories may be ambiguous

while others are vibrant. It can be favorable to ask, do we "color" our recollections for diverse purposes? How might one's emotions affect memory and event remembrance?

Since the researcher investigates one's topics through the lens of their own life story, they must consider how family rituals, or other substantial involvements through their developmental years may have informed their view of the topic. Outlooks and perceptions we hold are frequently due in part to what might be described as the "acculturation" process experienced growing up in extended families. In keeping with such writing, sensory data can be included to achieve verisimilitude so that the reader can see and feel what it was like to have that experience or be in that setting.

What we might consider "basic" qualitative research – qualitative research that is not tied to one of the major traditions such as grounded theory, ethnography, phenomenology, and so forth – has several characteristics that are applicable and beneficial to autoethnographic data analysis, such as a descriptive focus, exploring human experience, and acknowledging subjective meaning-making. These characteristics can be incorporated into autoethnographic analysis using general, qualitative coding methods such as descriptive, in vivo, emotional, and initial coding (Saldaña, 2016).

It is common to use several forms of data in an autoethnographic study. While this may lead to some intricacy in terms of data gathering and data analysis, it also has its advantages. Besides enhancing the subsequent research outcomes, these compounded wells of data also offer a tool of quality control in the research design, such as triangulation. For example, positioning a journal note in which one reflects on an experience with a photograph dated during that time portraying the experience presents evidence outside of that specific memory. Interviewing a relative about an occurrence may grant backing for one's own remembrances.

### 3.12 Researcher Bias

Self-examination, at the core of this method, typically presents opportunities to receive both self- criticism and world-judgement. This never-ending process and practice can take a toll on a researcher and subject analyzing self-bias appearing firmly in place. This personal challenge must be furthered in its complexity of being – to the self, by the self, for the self, and contributing to general knowledge and within academics.

As an autoethnographic researcher, one must remain open-minded while securing oneself within the study. Doing so primarily helps identify one's bias and preconceived notions not usually present or foreseeable. Because autoethnographic research strives to remain "open to ongoing examination, modification, and critique, [the researcher] requires a high tolerance for uncertainty, and the courage to revise, modify, and abandon ... most cherished beliefs" (Bernstein, 2005, pp. 28–29). This is to say that while the researcher may be aware of their own biases, they remain open to changing them.

An essential bias to point out is the expectancy of outcomes. Human beings tend to be biased in their own belief. Autoethnographic research predisposes encounters of biases throughout the process because of the intimate connection it has between the relationship of self as a subject and self as a researcher. Additionally, this research methodology requires the researcher to biasedly believe in her/his/their ability to (a) establish a mindful, embodied state of being before they begin the process or protocol and (b) be actively engaged with this somatic procedure. Another bias held is that the subject and researcher, being two-in-one, may experience a shift in awareness—including somatic ones. These interior shifts may likely be a result of trauma lessening its grip on my body. Offering information that may help shift the paradigm so that one does not have a

maintainable and prosperous future, chapters may lay out possible scenarios of healing beginning with the individual and moving outward from there through the ripple effect.

### 3.13 More Than a Method

Autoethnography has become more than a method; it is also a perspective that calls into question the readers' own influences, morals (both scholarly and political), and ideally the readers' own power and privilege. Unlike most other research methods, autoethnography intentionally calls upon the readers' emotions and personal experiences and thoughts to analyze ideas (Goodall, 2000). This makes autoethnography a suitable method for interdisciplinary studies.

Autoethnography allows us to see how theories through our cultural practices, and at-large experiences. Autoethnographic narratives are used by researchers and scholars as evidence and are themselves the subject of interpretation and analysis. Often, it is the researcher's own experiences that endure analysis as opposed to pieces or notes of the experience of anonymous subjects. This can be difficult for scholars and researchers since there is no margin of error, statistical significance, or even description of participants, therefore allowing for IRB exemptions. Reading autoethnographic research requires a shift from the positivist and postpositivist paradigms to the interpretive and critical paradigms. Many would say that autoethnographic research is part of the interpretive paradigm, as a means of understanding people's experiences with greater depth and degree.

Though some scholars may not give much weight to the revelatory critical paradigms, it is essential to embrace (at least) some values from these paradigms to consume autoethnographic work; otherwise, autoethnographic research appears as useless ramblings and emotional babble. Readers must be disposed to challenge conditions where emotion is central to examined ideas.

Readers must also be ready to embrace their own emotional and intuitive responses (positive or negative) to autoethnographic research. These emotions are what tie scholarly experience to human experience, though some argue that these two should never professionally meet as part of the ongoing ethical debate.

The connection between scholarship and humanity is what makes empirical, scholarly knowledge worth knowing. If what we know does not benefit or thwart harm to the human condition in some way, it is not worth knowing, studying, or interrogating. Autoethnographic inquiry is beneficial to readers and scholars as it co-exists in the intricacy of research. Scholars, especially in interdisciplinary settings, have the power to help others around us in everyday interactions. Autoethnography not only allows us to see how culture and theory influence us, but it also allows us to understand ways in which they can help others around us. It is the applied effort of theory and the encouragement to make better situations for our students, colleagues, and strangers we network with every day.

Autoethnographic research can foster growth by allowing calls for social change through interdisciplinary and/or transdisciplinary spaces. Social Justice cannot happen without the knowing of stories and understanding of content and context. Whether in Health Sciences or in Social Sciences, progress is limited if it excludes [perspectives and experiences of individual voices that may, can, and do shed light on complex structures that hinder access to the betterment of the self and of our communities. Here lays a major forefront argument to not only defend, but also expose the validity and power of autoethnographic research, as it can lead to extensive branching of other rigorous research of systems, theories, conceptual frameworks, and expansion of data analysis, all working collaboratively.

We need to hear from those who are suffering, downtrodden, marginalized, and silenced. If no legitimate place in higher education and interdisciplinary published research is accepted, exposed, voiced, and discussed, controlling political factors affecting vulnerable masses will remain protected and in place, gatekeeping boundaries of awareness, stratification of and for change, and de-structuring/restructuring control towards equity. Assuming autoethnographic research has no place in higher education or is even to be considered valid research, is a means of control, that must be dismantled to expose the power it can hold in impacting other research.

Through autoethnography, I link years of medical, financial, and contextual data, filled with assumptions of the systemic issues I faced, to documents that will eventually validate my previous assumptions. This exhaustive search, and research, in the fight for a complex costly diagnosis constrained by social class and social support limitations, demonstrates a throughout knowledge of self-acquired facts through extensive peer-reviewed research correlated to personal medical documents, and careful self-advocacy in jotting down detailed information, extending to a higher purpose fearlessly and unapologetically focused on the interdisciplinarity of health sciences, social justice, and resilience and as resistance.

## 4. Chapter IV: From Resilience to Post-Traumatic Growth

## 4.1 Childhood Adversity

### 4.1.1 Introduction

I was born on October 28<sup>th</sup> of 1985, in Miami, Florida, over 2 months premature, and with Jaunice. My Birth mother lived with alcoholism and several drug addictions. Although "Birth mother" sounds redundant, I have yet to let go of it, as I still struggle greatly in being associated with her further than the simple fact that she birthed me. I have carried, for as long as I can recall, a deep, uncontrollable, and partially inexplicable hate towards her. That engrained feeling drained me even further throughout my life, due to the guilt attached to it.

Messages all over, at church, from home, at school, on televisions, all stressed the importance of extending constant gratefulness towards mothers, often putting them on pedestals. Akerlof and Kranton (2000) describe identity as a person's perception of self or self-image, and mention that their identity is attached to social groups; individuals identify with people in some groups and distinguish themselves from those in others. Identity for me is quite complex. I suppose that it must be so for many, if not most others, as it is inherently attached to national origin, ethnic background, gendered experiences, social class, family dynamics, and so much more.

Born in a country I have a hard time identifying with, yet aware of the massive privilege of having dual-nationality in first-world countries, I tend to settle for answering "I am French" to those asking where I am from. Perhaps due to the fact that my name could not be more French. Or maybe because of my "accent" ... the one most people pose the question for. Maybe also because

of certain political issues I agree with France over the United States upon, such as socialized health care... coincidently enough, is a major part of this dissertation.

It is undeniable that identifying as French in the United States has also fed my ego due to unfortunate stereotypes of intellectual capacity, among others. The flawed assumption that national origin determines certain traits, such as a classification within "the construct of smartness", has certainly been beneficial in motivating me to "prove Them right". In France, the only "exotic" thing about me, is not without a negative connotation. One that I undoubtedly have tried to hide. In France, I am the American. The high school dropout, who failed two grades. Both, quite unusual in France.

I pause to ponder upon some advice from one of my committee members as I write these terms. Highschool dropout, and Failure, are harsh words. I was told to consider using "did not finish/complete high-school" and "had to retake two grades-levels", instead. This committee member took the time to explain the power words had on our self-esteem and well-being. The timing of this welcomed guidance was perfect as I had started observing my words and thoughts carefully, in an attempt to rewire my brain for reasons I will dive in in the adequate section of this dissertation.

Knowing that words have power and that these terms are and have been detrimental to my self-esteem for most of my life, I still chose to use them in this written work and make a note for my oral defense. My justification for this is that Because words are so powerful, I feel the necessity to use them in hopes to inspire others. Many students who do not finish high-school and have failed several grades assume that they are not capable of graduating from college. Even less so from a PhD. Most of these students are labelled "dropouts" and therefore also internalized this

term as an inherent part of their identity. I feel that using words they could identify themselves with might have a greater chance of catching their attention.

With this dissertation, I do not simply aspire to graduate. I aspire to inspire many others in their pursuit of academic and/or professional endeavors. I aim to demonstrate that one person can certainly have a significant impact on the redesigning of policies. I seek to contribute to a spout of awareness of our current medical system, while demonstrating that one person, without necessarily having financial, familial support, specific knowledge, and understanding of intricate and limiting self-advocacy routes, can still succeed in all and every way. The "against all odds" is no longer a boundary to this story, but an empowering one, to help others reach heights they might not yet know are attainable.

Adversity being the sub-title of this section, I realize that I am, somewhat unconsciously, trying to avoid diving into it fully. But there is no avoiding vulnerability to successfully write a critical autoethnography. Triggers must and will be faced. It is an intrinsic part of this work. I suppose that Adversity, as per this section, is due to the fact I never felt fully French, nor fully American. It is undoubtedly why I found myself in texts of Gloria Anzaldua; *Ni de aquí, Ni de allá*.

Identity was built from the core of my adversity. I was a sad child. I found comfort with animals and plants but felt out of place amongst my peers. I was quite shy and quiet in kindergarten and elementary school. I fondly recall my 1<sup>st</sup>-grade teacher, Monsieur Cohen, who noticed my fascination for birds as I always sat by the window to watch them. School was not my forte. I found no point in it. Meur Cohen made me feel seen, acknowledged, and loved as he one day brought milk cardboard boxes and scissors to school for us to create bird houses, stating today was a day he knew "la petite Josette" (the little Josette) would love. He smiled at me tenderly. Joyful

emotions I wish to never forget, and a story I still tell when presenting Parents & Teachers as Allies, one of the NAMI programs for our community, to emphasize the lifelong impact teachers can have on students.

Looking back, there is no doubt in my mind that I lived with depression from a very young age. Was it due to the fact I did not have a mother and father? Or maybe because of the impact drugs and alcohol had had on my premature birth and/or brain development? Or perhaps because of abusive circumstances, I was too young to have been able to create a memory out of? Was it because I was pulled out of class early to go with a few other kids, knowing we were the "slow" kids? No labels had to be given for me to understand WHY I was part of that group. At six years old, every school day, I watched the classroom clock nervously waiting for 3:30 pm... the time they would call my name to go to a separate classroom. A deep shame invaded my little self. Although my classmates did not seem to have a care in the world, this felt like a public humiliation every single time. The goal was "to help me," of course. To help me be "normal, and better". This could only mean one thing, and it made perfect sense to me. I was abnormal and deficient, which must have been why my parents had left me. My inner child has yet to heal from many wounds inflicted by societal well-intentioned errors, such as the separation from my peers to join special aid programs.

Adversity also took the form of bullying. My bullying experiences started with my name. What a powerful statement. So simple, yet so deep. Josette was my grand-mother name. My father, after years of absence and silence, had contacted my grandparents, his parents, with "wonderful news". Named after his beloved mother (sarcastic tone), his first and last, to my knowledge, child, had been born over a year ago, in the United States. After the unexpected phone call topped off by the surprise of my birth, my paternal grandparents also had to process the fact that I was born, in

the United States, from a person with drug addiction and alcoholism, conceived not from love, but from pure lust, with a prostitute that had failed to mention there was a charge.

To this day, I do not know why my father and his parents were not on speaking terms for so long. What I do know is that he reached out because he needed their help to assure me of a safe environment for me, away from the woman who had accidentally conceived, yet refused to abort. My father had to marry my birth mother eventually in order to obtain my guardianship. A knowledgeable international lawyer, he knew exactly what had to be done and how in order to give me the best possible life. In 1986 he married my birth mother. In 1987 he divorced her. In 1988, he became my sole legal guardian. CPS involvement was ongoing. Luckily, my grandparents stepped in with lawyers, and brought me back to France safely. Looking at medical records, I must have been around three years old.



Illustration 2: Baby Josette

My bullying experiences started with my name. What a powerful statement that feels like it needs to be repeated. Josette was the name of my paternal grandmother, assigned to me by my father most likely to try making amends with his parents. Josette is a very old-fashioned name in France. There is no equivalent in English. However, there is one in Spanish. For those readers fluent in the Spanish language, no Josette is not French for Josefina. Josefina is Josephine. Josette

is not Josefa. The closest translation to Josette in Spanish is Pepita... which is used in the Spanish language as a nickname, not a name in itself (also means little seed in Spanish). In French, it simply means "the little Joseph-feminine, and I cannot insist enough how bad it was growing up with this name. From day one in elementary school, the class burst out laughing during attendance when my name was called. Songs were improvised with denigrating words that rhymed with mine. "Josette, la chaussette, la quequette, les toilettes" (...the sock, the (childish) penis/willy, the toilet). The friends I managed to make along the way, called me Jo, Jojo, Josie... a simple gesture of kindness granted as empathy to make life more bearable.

Little did I know that later on in life in adulthood, I would finally welcome and embrace my first name. In the United States, it was foreign and exotic (positively perceived). It took me 20 years hearing the positive to finally cancel out the 16 years of negative I had internalized. Oh, the power of words, names and experiences! Just a snippet of how deeply they can scar, shield or garland one's identity.

Not having had a mother was heavy. Not knowing why, was heavier. My family was always very secretive. I grew up not knowing much about my birth mother. What I knew could be summed up to the following:

- She was American
- She was a bad person, dangerous, and "stupid"
- She hurt the family a lot
- I looked/was like her (never meant in a positive light)

What I knew about my father growing up was, although much more extensive, still quite limited.

The highlights were as followed:

- He spoke 7 languages

- He graduated from *Science Politiques* with a prestigious degree
- He had been an international lawyer, a journalist, and a brilliant businessman
- He was a "genius" that also happened to be concurrently stupid in having procreated with my birth mother, had conflicts with the law (tax frauds), yet still managed to always struggle for basic needs.



Illustration 3: Picture of my father. Unknown. County Record Local Newspaper Allsportrating

VP Joe Francis Interview. ALLSPORTRATING. <a href="https://baseballrating.itgo.com/page4.html">https://baseballrating.itgo.com/page4.html</a>

https://avis-deces.midilibre.fr/avis/2023/02/07/aime-pelatan-954796.html

In my earliest memories, I was already in France. I recall being loved by my grandfather, Andre, most of all, yet lacking a deep sense of belonging and happiness that seemed so natural to peers my age. It is unclear how old I was when I first arrived, but judging by my first vaccines, assumed to have been done at my arrival in France, I was three years old. I do recall the first and last visit to France, from my birth mother. I believe I was 4 or 5 years old. Told incessantly to be kind to this so-called mother of mine, I was reluctantly polite and felt forced to accept her hugs (without hugging her back). The sound and tone of her voice, her smell... inexplicable instant hate. I recall clearly crying one evening, as I had refused to let her put my pajamas on. I was sort of offended that she thought I could not do it myself, and this stranger putting clothes on me was a boundary I refused to cross.

I wonder if hate can develop in the womb, perhaps due to self-inflected emotional and physical abuse... drugs and depression. I wonder if, and if so how, such strong feeling of hate can develop so young. I had not yet had a major reason to hate her so much, prior to her departure from France, aside from perhaps abuse and abandonment I did not recall. Whatever was stored might have been stored in a memory that went beyond the consciousness level. I know depression and trauma can be passed on through genes. But hate was an emotion, and it made it so much harder to comprehend it.

About a year later, a reason for hating her, as I already did, arose. Papi and Mamie rushed me to the laundry room. They looked very concerned, and Mamie had tears in her eyes. She told me people would soon come ask me if I had been raped. I asked what this meant, unfamiliar with the term. She put her head on my grandfather's shoulder and let out a distressed sigh I could not read well. My grandfather took over, with a little smile determined to lighten up the process. He told me in French "c'est comme quand les garçons te soulevant la jupe a l'école", meaning "It's like when boys lift your skirt at school". I replied I understood and had been raped many times... at school. I am sure they might have explained further, but do not recall the rest of this conversation. What I do recall, though, were the people observing me at school and taking notes. Hyperaware this had something to do with the laundry room discussion, I pretended to act/be/feel "normal", whatever that meant at the time in my mind. But still, I had failed. Whatever I had done or said was not enough or perhaps even encouraged them to take Papi away. Mamie cried a lot. My aunts tried to reassure her everything would be okay. I spent most of my time in my room or playing outside as I was pressured not to be around the family as they had serious things to discuss.

Papi eventually came back home. I do not recall how long he was gone. Days? Weeks? It certainly felt like months. I was overjoyed to have him back, yet something had changed.

Everything had changed. Papi no longer held me. He no longer kissed me lovingly as he so perfectly did before. My innocent, pure, perfect love that I needed so much, was forever gone, taken away by horrible accusations coming from my birth mother, that his heart could not bear. He was there, yet he was gone. She took away my greatest joy. My emotional lifeline. The only genuine love I felt.

Whether or not this was just my perception, I felt my aunt Martine (the youngest) and my grandmother, both grew bitter. Perhaps towards my father's life choices consequences and repercussions on our family. My father being absent under suspicions of fraudulent activities, I felt that the bitterness and blame was turned to me. "After all we have done for you" are words carved on my heart for they were repeated to me throughout my childhood, and into adulthood, even to this day. I was only a child. I did not ask to be born, nor to be cared for. I believe the codependency that I let rule a great part of my life was rooted in those words.

I do not recall when the nightmares and night terrors started. They might have been there all along, and therefore were somewhat normalized by my little self. But I recall some of them very clearly as they were recurrent throughout my life. A dark shadow floated above me, soaking my energy out. I could not breathe or move. Prisoner of my own dreams, feeling overpowered, did not fit the script, as it felt I was fully unable to offer any type of resistance. What I know now is that the amount of trauma I am unable to recall because I was an infant, might be living in me in ways science is starting to better understand. Some stories told by my father, one day, on Bruce's balcony, marked me. My father always avoided discussing anything related to my mother, how he had met my mother, and the circumstances of my childhood in Miami. The few times I had asked, he always started developing sudden headaches, and annoyingly started walking away, saying he would tell me "When he felt better". The thing is that he never felt better.

One day, when he was visiting El Paso and staying at Bruce's house, sitting on the balcony, he gave Bruce glimpses of a story I had never been told myself. I do not recall how he started, nor why he might have told him such a thing. Here is what I do recall. "I had to beat him. I left him paralyzed, and in a wheelchair. But I had to. He was selling drugs to my wife. Maybe, I would have done things differently knowing what I know now. Although, maybe not, because months later, even in his wheelchair, he was still selling drugs." I recall feeling Manly Pride in his voice, talking about having beaten up another man. My father perhaps had a bit of a Napoleon complex as he was short and unathletic. I recall feeling that he might have felt a bit of shame right after, mentioning he might have done things differently knowing what he had learned after. Perhaps because he knew that Bruce, just like I, was anti-violence of any kind. I felt he might have bounced back to his original stand, having found, what in his mind, was justification enough. More than anything, I felt shocked that he had called my birth mother "His Wife". Never had my father mentioned anything positive about her.

Many years later, during my last visit to France prior to his death, in 2017, my father revealed something that I did not recall having been told, yet somehow felt I already knew. Over coffee, at the village café, and again, without recalling what led us to this conversation, he mentioned my mother had been "an accident". He revealed with what seemed to me like clumsy shame and discomfort that he had just slept with a woman, who afterwards asked him for money... her rates. Realizing this had been a prostitute, he supposedly paid and avoided her as they lived in the same neighborhood. I could not tell you what my father was doing in Miami. The enigma will remain for us all. Weeks later, she supposedly "hunted him down" claiming she was pregnant, and that the child was his. According to my father, he offered to pay for an abortion, stressing the fact that it would have been cruel and unreasonable to have a child from and under such circumstances,

and that he doubted the child was his, either way. He claims my mother was not willing to abort as she lived with addiction and thought that was a way for her to get/keep a roof, and some kind of basic needs support. She supposedly threatened him, leaving him little to no options as he was not a citizen of the United States.

My father also explained that, given that I was born prematurely of two months and ill with jaundice due to my mother's drug uses, he knew he had to marry her in order to have a chance at becoming my legal guardian so that he could get me out of this mess. Stories of having had to run away from my mother with me several times, who accused him of abuse of all kinds on us both, seemed credible to me. My father, supposedly having been an international lawyer at some point, knew how to work the system. I was born in 1985. He married her in 1986 and divorced her in 1987, earning my full custody in 1988. Shortly after, I was brought to France to live with his parents.

In fact, the traumas inflicted to my developing brain while I was still in the womb, through the injection of many illegal substances and of alcohol, are undoubtedly responsible for some mental and emotional damage. Yet, it seemed to me while growing up, that this was not evident to my family who often said very loudly (screamed), and in third person while addressing me: "Mais, elle n'est pas normale! Elle est folle!". This would translate to "But, she is not normal! She is crazy!". These harsh damaging statements were recurrent, and usually prompted because I spent my time playing in dirt, with reptiles and rodents, or sitting up high in trees to better observe birds and clouds. I indeed found little to no interest playing with other kids, dolls, or toys. I did, however, have two items very dear to me. A baby doll with a body made of tissue that I had named Nicolas-Francois, and my baby blanket that I had named "Mequette". While Nicolas-Francois was regrettably handed to a child during one of my nervous breakdowns when I was 18 years old, living

in a motel on Mesa Street, I still have what remains of my 38-year-old baby blanket, highlighting incoherent reactive attachment disorder (RAD), perhaps. I will dive into this disorder in the appropriate section.

Taking it a step further, although the little description above might be plenty to justify childhood trauma, we also now know that trauma can be passed on through genes. That being said, we also know that people living with addictions are often inseparable from mental illnesses, face such challenges due to lived or traumas passed on to them. Born from an absent father, with avoidance issues, and potential undiagnosed depression and anxiety somewhat obvious to me, AND from a woman living off criminal activity to feed legal and illegal drug habits, it leaves me little to no doubt that I carried many predispositions and traumas within my DNA prior to experiencing any types of abuse and trauma.

Despite the limitation of the current literature, there seems to be a buildup of evidence to suggest the transgenerational transmission of DNA methylation alterations from parents to children. Told that my maternal heritage is divided into Cajun French and Native American from the Black Foot Tribe of North Dakota, if that information is indeed accurate, I wonder how much of it has influenced my mental health. Regardless of the validity of these claims, if trauma is indeed passed on through genes, the mere fact that my maternal grandfather lived with alcoholism, and that my mother lived with drug addiction, a history of physical and emotional abuse, but have impacted me. Future studies should clarify the timing of the trauma (of whether it occurred prior to pregnancy or during pregnancy), and if there are further differences based on the trimester of pregnancy, correlated with its propensity of impact. The chronicity versus acuity of the transgenerational trauma needs to be considered and studied. Future research of this topic may

lead to the identification of biomarkers of trauma and PTSD risk and to important developments in the prevention and treatment of PTSD.

Understanding specific childhood traumas and their timeline is crucial to grasp the interconnectedness of this journey. My current fascination for brain science and attachment research led me to comprehend the powerful relationship mental, cognitive, and emotional health, had with public and physical health. In the book "The Body Keeps the Score" (Van der Kolk, 2013) therapists and scientists introduced me to brain rewiring, the idea that through natural neuroplasticity one could rewire disturbed functioning and rebuild certain abilities to counteract the helplessness and invisibility associated with trauma that literally reshapes both brain and body. The title emphasizes the book's central idea that exposing the "abuse and violence fosters the development of a hyperactive alarm system and molds a body that gets stuck in fight/flight, and freeze. Trauma interferes with the brain circuits that involve focusing, flexibility, and being able to stay in emotional control. A constant sense of danger and helplessness promotes the continuous secretion of stress hormones, which wreaks havoc with the immune system and the functioning of the body's organs. Only making it safe for trauma victims to inhabit their bodies, and to tolerate feeling what they feel, and knowing what they know, can lead to lasting healing."

This book came into my life curiously enough when I was experiencing quite severe cognitive issues. Whether I was not looking for it unconsciously, or whether it found me from fate, might be irrelevant, nonetheless, the timing of having encountered this book with an awe at human resilience and at the power of human connections to hurt and heal, insighted a new found passion for health sciences, particularly focused in brain rewiring, and with it, hope for a future I yet did not know would lead me into the Interdisciplinary Health Sciences PhD Program.

Shortly after joining the program and seeking advice from one of my committee members specialized in Resilience, I was advised to read several works from Dr. Bruce Perry. Once again, timing and having followed the path to intuition, had led me to better understand the multilayered complexities of trauma on the brain, through stories of humanity, transformation, courage, lessons and hope, alongside insightful strategies for rehabilitation to long-term extreme stress exposure. Through the readings of this author alongside others, my hope of healing my inner wounded child grew. A greater understanding of the power of love to mold and redirect the mind allowed me to grow in strength, dedication, and in purpose.

For children in particular, the most traumatic aspect of all disasters is the fragmentation of human relations. When the people who are supposed to love you rob you of the safe and valued relationships that make you feel human, it is a very destructive experience. Because people are social beings, the worst disaster that can happen to us is always the loss of relationships. As a result, recovery from trauma always has to do with rebuilding and having faith in relationships. In addition to medication and therapy, healing is impossible without lasting, caring, and loving relationships with others. Abused and traumatized children need a healthy community around them. Dr. Perry believes that "we are at a transition point in history in which people come to see that modern society has lost many of the essential elements needed for optimal mental health". Children must be protected from poor childcare practices and other injustices. They must grow up in a healthy and loving environment, where their needs are respected, by a strong and non-fragmented community.

While there is hope in the future through educating the masses and providing better community support systems, one may wonder if there is any hope for adults. As we know, learning new skills such as acquiring new languages, becomes more challenging as we grow. When it comes

to cognitive abilities, challenges become necessary to slow down the decline. While these statements may sound frightening and counterproductive in spreading hope, I feel empowered to share some of my successes in this research. Through hard work and a wide range of therapies and voluntary exposure and intentional practices, I genuinely feel that I am currently feeling better emotionally than I have ever been in my entire life.

### **4.1.2** Reactive Attachment Disorder (RAD)

Kindergarten seems to be hard for most kids. I still have not been able to assess if my experience was any different than the norm in facing the first "drop off" at school from Papi. Now looking back on my childhood in chronological order, there were evident signs of attachment disorders. When thinking about the past, the timeframe I address usually revolves around "who I was dating at that time", prioritizing the whom over the what.

First grade was the first time I recalled feeling loved by someone else than Papi. Julien, a boy from my class, had chosen me as his girlfriend. The word "chosen" now really feels misplaced... Nonetheless, I recall feeling surprised and honored. Julien became my best friend. We "dated" for the next 6 or 7 years. I occasionally went to his house to play. His family had many animals. Nothing made me as happy as spending time with animals and plants.

After failing the last grade of elementary school (the educational system is a bit different in France), Julien broke up with me. To this day, when I think about it, it still hurts. The incoherence of a childhood romance affecting me over 25 years ago, is nonetheless very real to me. The fact that it is such an illogical thing to experience makes it perhaps just that much harder for I feel like an emotional misfit, at times.

First grade was also the start of afterschool tutoring for me. Papi had told me he would come pick me up an hour later than usual. By the time the bell rang, and perhaps due to obvious abandonment issues I was unable to understand at that age, my mind had forgotten. While most kids were being picked up, I still anxiously looked for him. The teacher, Mr. Cohen, Kindly asked me if I was sure I did not have to stay for tutoring, and I confidently replied negatively. After all the kids had gone home, and the few others were ready for tutoring, I decided I could simply walk home. After all, I was a big girl, and Papi must have forgotten about me.

Vergèze is a small town in south of France. Most people stuck to riding bicycles during my childhood because the distance from one end of the town to the other is quite small. The town must be the size of UTEP. While walking confidently with my little pink backpack (cartable), I thought of how proud Papi and Mami would be when seeing me cross the town and streets all by myself. Little did I know that I, and my teacher, would both get big scoldings instead. But what was I to do? Papi MIGHT have forgotten about me. What if he had just left me there forever?!

This memory and the feelings of abandonment attached to it are perhaps the initial hint to a reactive attachment disorder I have lived with, most of my life. As the years passed, this felt confirmed through the heartaches of breakups, loss of plants, animals, and human being friends, very early on. The betrayal of adults, especially when it came to plants and animals, taught me that They were not to be trusted. Too soon, I realized this transcended age groups, as even kids my age or younger proved to be cruel towards each other, animals, and plants. Oh! How the world felt lonely in that little head of mine, and how it was painful to crave a sense of belonging yet feeling like an unachievable goal.

Reactive Attachment Disorder (RAD) originates from traumatic experiences, particularly severe emotional neglect prevalent in institutional environments like overcrowded orphanages,

foster care systems, or households with mentally or physically unwell caregivers. It would absolutely make sense for me to experience the world in such a way due to early on disturbances.

## 4.1.3 Hypersensitivity

To this day, I sometimes wonder if hypersensitivity is a gift or a curse. Lately, I am prone to embracing what might be potentially good, over what might be potentially bad, primarily for my mental health. Ever since I can remember, I have felt deep pain over the suffering of all living things. I recall crying and yelling about kids burning ants in the school yard, feeling my spine hurt and my heart ache every time someone cut a tree. I was unbearably dramatic with my grandmother who often bought bouquets to the cemetery. Why couldn't she buy potted plants instead? Why were adults insistently cutting flowers, who would therefore obviously die, to show respect towards another lost life?

My frustration at jokes, bullying, the news, some movies, adults' way of being, only worsened as I grew up. I felt unfit for the world. Extreme. But I could not help it. Something deeply engrained in me could not contain the flow of emotions I experienced at such an incoherent level. Poverty baffled me. Consumerism did too. Still too young to even know the terms, I found ways to express those violent emotions. Always in conflicts with myself, divided into shouting and kicking to try saving or defending the lives at stake, versus running away to the river to scream and cry because I felt unable to change a thing, I often fell asleep exhausted. While other kids resisted nap time, I, on the other hand, could not wait for it. Constantly exhausted from the overstimulation I felt from sceneries, sounds, and emotions, I often fell asleep in inadequate settings just as much. I was/am not just hypersensitive to the horrors of the world and to suffering, but also to climatic changes, colors, smells, lights, music. Atmospheric pressure changes have

affected me potently throughout my life, like a sixth sense in feeling the weather changes before seeing them.

Motion sickness has gotten a bit better into adulthood, but as a child, a simple car ride to the city nearby would get me to throw up most of the time. It fascinates me to think how different we all are. The theories and mysteries behind why some people have motion sickness and/or why they are affected differently by climatic changes, have always prompted deep curiosity within me. Theory and research suggest that people with sensory processing sensitivity (SPS), observed in approximately one-fifth of humans as well as in more than a hundred other species, have a higher sensitivity and are more receptive to environmental and social cues. Studies based on self-reported data suggest that high SPS individuals are particularly affected by others' emotions, but little research has been done on the neural mechanisms that activate in response to others' feelings.

In all scenarios examined throughout the articles I have read, heightened scores on the HSP scale are correlated with increased brain activity in regions associated with attention and planning of action, particularly in the cingulate and premotor areas (PMA). Notably, during exposure to photographs depicting joy and sorrow, SPS demonstrated a correlation with activation of brain regions implicated in sensory information integration, empathy, and planning of action. These regions include the cingulate cortex, insula, inferior frontal gyrus (IFG), middle temporal gyrus (MTG), and Progressive Muscular Atrophy (PMA). I hold little to no doubt, that there is a correlation between my hypersensitivity to the weather, people, lights, music, colors... one that correlated with motion sickness and my reaction to emotional and physical pain experienced by plants, animals, and people. While science has yet to conduct studies to assess all of these relationships, I have no doubt that my intuition, paired up with the simple self-observation of my sensorial experiences, might perhaps provide some guidance for brain-heart research of that nature.

Elevated HSP scores corresponded with heightened activation in brain regions linked to awareness, empathy, and self-other processing when presented with images of partners or happy facial expressions. These outcomes furnish evidence supporting the assertion that awareness and responsiveness constitute foundational aspects of SPS and elucidate the potential neural substrates of these characteristics.

Visual perspective taking, as defined by Michelon and Zacks (2006), involves the capacity to anticipate the viewpoint of another individual. The ability to process information more efficiently from a first-person perspective compared to a third-person perspective, as suggested by Jeannerod and Anquetil (2008), underscores the significance of visual perspective in shaping both self-representation and representation of others.

These findings in brain research had me question diagnoses of autism-spectrum and labels I had been associated with since effective social engagement necessitates the ability to infer both the visual and mental viewpoints of peers. Such inference implies the ability to detach from one's own visual perspective and adopt that of another, as outlined by Samson et al. (2010). While I was never diagnosed on paper for Autism (as far as I know), I was placed in special aid in first grade, pulled out of class early for tutoring. A few years later, I also went to specialized therapy mixed with kids that had "obvious" forms of autism. My memory of these times tends to have a close link, to feeling the pain of these other kids, and carrying the frustration of the adults around them, supposedly trying, and according to my little mind, failing at helping them.

Self-perspective is commonly perceived as an inherent egocentric bias, which is adjusted or restrained during efforts to comprehend others, as proposed by Keysar and Henly (2002). Studies have indicated variations in individuals' abilities to suppress self-perspective, implying differences in the propensity to adopt others' perspectives, as highlighted by Epley et al. (2004)

and Samson et al. (2005). It is postulated that individuals identified as pain responders who experience pain upon witnessing others' injuries may encounter fewer cognitive barriers when transitioning between first and third-person perspectives. Consequently, pain responders are expected to navigate visual perspectives more swiftly and seamlessly compared to non-pain responders, who do not report similar reactions when observing others' injuries. I most certainly identify myself as a pain responder. Ever since I can recall, I have felt the pain I witnessed in people and animals, both emotional and physical. Yet, people on the autistic spectrum tend to be desensitized and/or unable to misinterpret the pain in others.

It appears that the sensation of pain triggered by witnessing another person's injury stems from a misinterpretation, attributing the perceived threat from the observed injury to the corresponding location of the observer, as suggested by Osborn and Derbyshire (2010). Consequently, it is theorized that individuals who exhibit pain responses upon witnessing others' injuries will experience a more pronounced illusory sensation. It is postulated that shared pain encompasses the seamless integration of observed pain from others into one's personal historical narrative. I wonder if having lived through countless instances of physical and emotional abuse from birth into early childhood (i.e., to discard the complexity of my pre-birth damage), has played a role in my extreme hypersensitivity. To a certain extent, this feels like a curse as much as a gift.

Taken together, these discoveries imply that individuals classified as responders demonstrate a heightened propensity to embrace the perspectives of others, assimilate external body components into their personal bodily framework, and undergo pain more readily upon witnessing behaviors that have previously elicited pain in themselves.

Engaging in visual perspective taking, as noted by Newcombe (1989) and Aichhorn et al. (2006), does not inherently involve deciphering the inner thoughts of another individual. However,

empathizing—where one infers and shares the other's mental state—entails subjectively adopting their cognitive perspective to grasp their thoughts or feelings. Distinguishing between shifting visual perspectives, a fundamental skill, and empathizing by understanding another's thoughts or emotions underscores the hierarchical nature of these abilities. It is conceivable that lower-level processes like automatic visual perspective taking contribute to more advanced abilities, such as empathy, as proposed by Samson et al. (2010). These mechanisms may converge when empathizing with someone experiencing pain, as proposed by Singer et al. (2004) and Banissy and Ward (2007). Nonetheless, specific aspects of empathy may function autonomously from vicarious sensations.

This discovery lends credence to the notion that experiencing pain ourselves heightens our capacity to empathize with others' pain, suggesting a fusion of personal and observed pain experiences. Furthermore, the shared experience of pain correlated with an elevation in state empathy but not trait empathy. Although it is widely acknowledged that empathy involves an overlap of self and other representations, the precise mechanism of self/other amalgamation remains ambiguous. Empathizing may involve either understanding another's pain as we would our own or understanding their pain as distinct from our own, as posited by Decety and Sommerville (2003). The former relies less on self-representations of pain and more on empathic processes oriented towards the other. In contrast, the latter leans towards self-oriented representations of pain and may be less reliant on empathic processes directed towards others. I wonder how much my passion for social justice, which seemed so innate, might be related to all this. The question of nature versus nurture, for me, does not seem well balanced, for I feel my family certainly did not share most of my feelings. I have, however, considered whether my innate need to advocate fiercely for others might have been driven by my rebellious nature at not wanting

to assimilate myself with my family members. After a long analysis over scrutinizing my feelings, I have concluded that this was not the case, at least, not for the most part.

The experience of pain while witnessing another's suffering may hinge upon the amalgamation of the other person into a self-centric framework of injury or pain representation. Previous investigations have indicated that undergoing pain diminishes the sense of culpability for prior transgressions. I have indeed questioned myself, incessantly, over whether my good deeds, seen and unseen, were perhaps ways for me to deal with the guilt of being an inadequate burden to those I loved, and or attempt at "making up" for the uncontrollable hate I have always felt towards my birth mother. Taken together, these outcomes imply that the assuaging impact of guilt through pain may manifest even in the absence of actual physical distress. Through a systematic examination of whether witnessing others in pain alleviates feelings of guilt, this study offers further reinforcement to the theories positing that guilt necessitates suffering. The findings of this study suggest that the palliative influence of pain on guilt persists even without direct physical discomfort. Merely observing others in pain is adequate to alleviate our sense of guilt. Perhaps, this is a way to manage a sense of worthiness, in order to cope with my own mind.

#### 4.1.4 Confusion between R.A.D. & Other Disorders

Numerous symptoms associated with Reactive Attachment Disorder (RAD) exhibit similarities with those of other disorders, often leading to comorbidity or confusion with RAD. This complexity poses challenges in assessment, underscoring the importance for clinicians to thoroughly eliminate any alternative disorders that could account for the child's symptoms prior to confirming a diagnosis of RAD. Whether or not I do fall under the Autistic spectrum and/or RAD, I tend to think that all of my "differences" are simply perhaps due to complex PTSD and ACEs.

Labels have given me a sense of belonging in the past, which sometimes extended to empathizing with my own self as I felt I lacked understanding and empathy from others. Nowadays, however, and perhaps thankfully due to the lengthy therapeutic process of this dissertation, I feel unattached to these labels. Freedom and individuality come to mind, instead. This, I call healing!

### 4.1.5 High School Bullying

While I moved from being a shy child in elementary school to being the class clown and class president in high school, some things did not change.

Having spent four years of middle school observing why the popular kids were popular, I was ready to apply my gained knowledge in high school. The high school was not in my town, but in a city nearby. It was an agricultural boarding school, mostly composed of boys wanting to become farmers. The majority of girls went back home after school every day. I was the only girl in my class to remain at school overnight.

Being new and "far away" from my town meant that I had the opportunity to recreate myself to avoid bullying. There were things I could not control. For instance, my clothing. But I had learned that there was a way around getting bullied by making sure to overtly make fun of my own self to make others laugh. This was indeed infallible.

This agricultural boarding school felt amazing. Far away from my family, and from school kids who had bullied me through elementary school for being shy, being named Josette, and being awkward, slow, and voted the ugliest of the class two years in a row in middle school, I was determined to fit in while avoiding becoming cruel in nature myself. Making fun of myself was effective and efficient in avoiding making fun of others and worked wonders in gaining the

approval of my peers. The recognition of being voted class president... for "someone like me," was definitely the ego-boost I needed.

While I was able to build friendships and gain the illusion of love and attention I had craved so much from peers, teachers were not my fans, as I was soon addicted to the attention I got from clowning around. An insatiable thirst for attention soon became out of control, and I spent most of my evenings in detention. In contrast, I spent many classes hiding in the trees of our agriculture wonderland.

The subject matter taught in class was of no importance or relevance to me, and my grades were much lower than anyone I knew. I was well aware of that, being the class president, and fiercely advocating for my peers during reunions over students' grades and behavior. Yet, when it came to advocating for myself, I was quiet and ashamed, perhaps feeling unworthy or unwilling to change focus.

Although I should have been worried about my academic future, my mind had other things to wrestle with. There was one girl in my school (luckily, not in my class) from my hometown, who had bullied me for years.

I had hoped that I would stay under the radar by simply avoiding her, but the universe had other plans, and since there were few girls staying over at night, I was paired up with her and her two friends. Much like the famous movie *Mean Girls*, they seemed dedicated to hurting me. The bullying started, as in previous grade levels, by simple name-calling and laughing at my demeanor, clothing, grades, and looks. I ignored them, hoping this would come to pass, focusing on the love and positive attention I felt from my classmates. When my girlfriends went home after school, I stayed with boys from my class and always felt protected in a brotherly way by them.

But the dorms separated boys and girls, and this was a stressful time as I endured physical

bullying on top of the emotional/verbal bullying every day.

Unwilling to compromise my fun during daytime, by speaking up about this, partially due to shame or fear that my peers might follow the bullying, I endured. Luckily, my bullies made that same mistake to assume that, if they shared "their cruel ways of having fun with me", the crowd would follow, and they bragged about it to some of the boys in their class, who then told the boys in mine. Shortly after that, the boys in my class collected proof by breaking the rules and going to the girls' dorms, catching them in the act by filming on a cell phone. Right after, I was escorted against my will, begging them not to tell the surveillants of the school. My panic had me forget the details soon after. All that is left is the letter below, sent to my grandfather a week or so later.

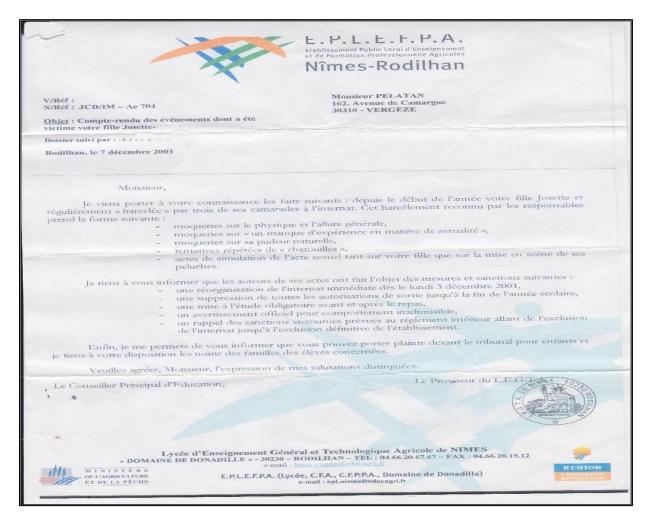


Illustration 4: High School letter

Dear Sir,

I would like to bring to your attention the following facts: since the beginning of the school year, your daughter Josette has been regularly <<harassed>> by three of her classmates at boarding school. This harassment, acknowledged by those in charge, takes the following form:

- Teasing about looks and general appearance.
- *Teasing about <<a lack of experience in sexual matters>>*
- Teasing about her natural modesty
- Repeated attempts at <<tickling>>
- Acts of simulation of the sexual act both on your daughter and on the staging of her stuffed animals

I would like to inform you that the perpetrators of these acts have been subject to the following measures and sanctions:

- A reorganization of the boarding school, effective Monday, December 3, 2001
- Suspension of all outings until the end of the school year
- Compulsory study before and after lunch
- An official warning for unacceptable behavior
- A reminder of the sanctions provided for in the school rules, which range from exclusion from boarding school to permanent exclusion from the school.

Finally, I take the liberty of informing you that you can file a complaint with the juvenile court, and I can provide you with the names of the families of the pupils concerned.

Yours sincerely,

*The Principle of Education* 

## <u>UNCONTROLLABLE EXPLOSION</u>

I do not recall what was said to me to make me so mad. But, as usual, I exploded and lost control over all emotions. I threw my plate and my glass. I threw the chair. I scratched my face and hit the wall with my right foot. Aaaaaaaaaahhhhh. So much anger! Why couldn't they see? What had I done?!!!

The shards of glass multiplying on the floor tingled like a calling whisper of far diner bells.

Thoughts of killing myself rushed through my mind uncontrollably, with the desirable sound of "rest" that I hadn't found in my waking moments.

To add to that, my aunt's reaction was to become as hysterical as me, throwing things occasionally as well, screaming louder than I could stand... screaming about how abnormal and stupid I was.

Screaming about how alike my birth mother I was.

Nothing could drive me more nuts than these words that I couldn't help but to internalize for having been told so, so many times, by my family members.

#### Crash.

My bed is cold. It makes noises every time I move, and the sound startles me. I try not to move in my sleep. Sometimes, I wake up in tears, with a fast heartbeat, and shiver back to sleep. My bedroom is upstairs. No one knows or hears. I am as silent as the untouchable walls that divide myself and who I pretend to be.

-2013 moving towards

healing.

"Molded Memories"
Josette Pelatan

That year, blamed by some of my family members for acting abnormally on purpose to seek attention, I failed my first year of high school. The devasting feeling of losing my friends, so incoherent because they remained in the same school, though in another grade, left me unable to cope with the guilt, shame, and pain. Soon after, my grandfather passed away. After he passed, I learned he had had prostate cancer for several years. As usual, because it was important and because I was known to want attention that my family felt I neither needed nor deserved, I had no knowledge of his health condition until after he passed.

Having lost the only adult who made me feel loved and the only one I trusted, now facing concerns of being returned to be placed again with my aunt Martine and my two cousins, my mental health took a turn for the worst, and I became threatening, aggressive, and more rebellious than ever towards any authoritative figure. My father came back for my grandfather's funeral, supposedly to stay, yet unable to care for me. Defiant of his return, unwilling to welcome him as my father, he took on the difficult decision to take my side, no matter how detrimental it was to his reputation. Being the only one who seemed to realize that I was not bluffing with my threats of running away if placed with my aunt or anyone else other than my grandmother labeled unfit at caring for a minor, he took charge, helped me drop out of high school, and move to the United States, alone, at barely 16 years old, without knowing anyone there, and with very little money at hand. This resulted in the start of a growing friendship that lasted up to his death in 2023.

#### 4.2 Adulthood Adversity

#### 4.2.1 Dallas, Texas

When I first arrived in the United States, I was barely sixteen years old, with not much in my pockets but some pouches of anger that pulled me forward. I landed in Dallas, Texas. Three

planes visited, and an ocean crossed. My life had changed drastically once again. I was now in the shoes of an adult and needed to sustain my needs by myself. A sense of freedom that screamed at me was finally invading my insides and drove me to quickly learn how to communicate, get around in this big city, find places to stay, find people that seemed trustworthy, find a job that meagerly paid but offered a roof and some food, aside from an incredible experience that no drama could make me deny.

My actual arrival in Dallas is blurred and my memories of so many things seem unsure. I believe my father had purchased the flight for me to land in Dallas because he had some contacts there, in case I needed someone. I vaguely recall spending the first night or two at the airport, exhausted by the fatigue of the lengthy trip, paired up with the anxiety of having made such an impulsive decision of leaving, to avoid saying fleeing, France, on my own.

I also vaguely recall that a gentleman who worked in the airport noticed I seemed lost, perhaps obviously squatting on the premises, and approached me. I am unsure how we communicated as my English was near-to-inexistent, but he ended up bringing me to his home with his wife. They were an old Mormon couple that seemed kind and well-intentioned. Either way, the fatigue prevented me from thinking straight. I was never great at handling stress and lack of sleep. I do not recall how long I stayed with them. Was it days? Weeks?

The weather in Dallas was humid and hot. It was the middle of summer. I began working on a Longhorn Ranch. How did I get that opportunity? Did I find it? Did those people find it for me? Was it my father? More importantly, is it normal that I do not recall such details because they were over 20 years ago, even though I have some clear childhood memories? What determines what one remembers and what one does not?

My second job was as a babysitter living in Irvin. The couple that hired me helped me a great deal. Aside from paying me well and treating me like family, they also enrolled me in ESL classes at Richland College at the tender age of 17 and helped me pass the GED. My wild and untamed soul soon moved to Houston and College Station. In College Station, I met a man from Chihuahua, and this first love brought me to the first place I ever felt I belonged to, up to this day... El Paso, Texas.

### Francesa, "-Chicana-DE CORAZON"

I Love the Plants that Grow
En el diserto de El Paso
Resilient
Creciendo en las Heridas
De Esta Tierra TAN seca,
Con falta de agua,
Y, aun así,
¡Con tanta vida! ¡Vida Maravillosa!

This misunderstood soil
Reflejando el sol como aluminum foil,
One border
Una gente
Accepted me, De repente.

I found myself in the words of Gloria Anzaldua

¿Como? ¿Que tu no eras francesa?

Identity is a Funny Thing. Isn't it?

Pocha Francesa Chicana de Corazón... Because it feels right So, it must be where I belong?!

I found myself in words from Sandra Cisneros. But How could I? "Ni de aquí, ni de allá" ... Tampoco Me. ¡Menos yo Era!

It might be Time

To Find a Word
To best describe
This conflicted identity of mine

Porque "-De Corazon"
Might create conflict on the Horizon
Between Appreciation & Appropriation?!

Quien Quiero Ser? Quien PIENSO ser?

## DIRECTION- Diversión- DirecciónES nuevas creadas

Pertenezco a un mundo En cual batallo pertenecer.

I suppose most people, if not all, Struggle with this?

¿O Seré Yo?

Soy un conflicto caótico
De heridas superadas
Where the resilient, diverse, strong, and beautiful seeds,
De mi alma soleada,
Sprouted into magical Fauna & Flaura,
Sin banderas,
Y con un solo idioma
El del Amor....
Porque es lo único
Que todo aguanta.

-Josette Pelatan



## MY SUN CITY

I was ready to follow him across the globe. El Paso was about fifteen hours driving from where we were. Only a backpack at hand, I helped him load his white pick-up truck with his belongings. Someone loved me enough to bring me along... I smiled all trip long. I had no doubt that he was a good man. No fear of the unknown since it was going to be by his side. New adventures... a new landscape was ahead, with mountains and acres of desert that I loved instantly.

El Paso was known as 'The Sun City'... and it was indeed. Never bothered by the heat, and always happy to almost never face rain and cloudy weather, I felt at home for the first time. The city was mostly Hispanic, and I connected right away with the people.

College with Aaron. I loved it. Aaron's family. I loved it. His mother was loving and funny. His father was kind and tender. They had three sons from which Aaron was the youngest. I was spoiled and felt loved. What a family! I loved my new family. Him, his parents, his brothers, their language (Spanish), their house, their street, this city...

"Molded Memories"

- Josette Pelatan

After my chapter with Aaron ended, adulthood proved to have its own set of challenges, mostly due to the fact that I was a young woman, that struggled financially to keep afloat. Diving into the stories of sexual harassment from employers, customers, instructors, classmates, landlords, roommates, students, so-called trusted friends, and strangers would make it seem like the too-familiar "I could have written the MeToo Movement, all by myself" statement.

I often have questioned myself how much of these recurrent happenings were due to my behavior and how many women lived through the same accounts and recurrence of challenges while perhaps never speaking up about it by fear of judgement or shame. The most troubling thing for me was the most unexpected players. How could I ever envision a serious relationship if even the most respected and "respectable" older men, highly educated, who seemed so in love and caring for their wives, children, and grandchildren, would behave as predators with me after having gained my trust many years ago? Furthermore, why would I bother sharing such experiences that are unlikely to be believed?

Survival in itself was hard enough. Some might argue that I chose adversity as I would have never struggled for basic needs had I chosen to stay in France. Others, mostly but not only predatory men, have also pointed out that Adversity was indeed my choice as I could have lived quite well had I accepted lucrative offers of "letting myself be cared for." But at what cost? What is not said is easily read between the lines. The prideful and stubborn feminist in me most definitely chose certain hardships over others. I do have to admit that codependency, perhaps as another form of survival, did take over for a big chunk of my story. My type of codependency was hiding my financial vulnerability by paying for others, as well as for myself when in a relationship, no matter the means of my partner. This was my way of asserting indirectly that I could not be bought, granting a level of illusion of the control I craved.

Relationships were quite tough due to my need for control. I replicated, in some relationships, the emotional abuse I endured from my paternal family. In all relationships, I used money as a form of control. I did so by compulsively paying for whatever I could or denying any type of financial help to assert my value. After years of analysis of myself, I also came to the conclusion that I used sex as a form of control. Never engaging in participation or demonstrating

pleasure, I limited myself to being extra-affectionate under any circumstances other than intimacy. After all, if men "only wanted one thing", I knew there had to be more attached to it. The reciprocity craving was one of the things I had heard men sought. Since I expected my partners to leave me at some point, this was one thing they would not take away from me.

My heart was indeed shattered over each failed relationship I have had, and I carried the idea that I did not heal from "losing them" as others seemed to. Heartbreaks affected me so deeply, that, to this day, my elementary school break up still hurts. I suppose this extreme is due to a level of reactive attachment disorder, paired up with the complexity of codependency, punishing them for leaving me in the future. While this may sound incoherent, it makes sense to me to this day. Since they were evidently going to take pieces of my broken heart, never to be returned, they would at least not walk out with the satisfaction of intimate reciprocity or true stories of participation from my end.

## 4.2.2 The Role of Support

### **Introduction**

My paternal family was not very supportive of my education. I was reminded that school was never my thing and that I had never been good at it. There was also the constant reminder when contact was maintained that I was just drowning myself under mountains of student loans I would never be able to pay back. Interestingly enough, to this day, I believe that student loans and the many support services provided by the university are what have kept me off the streets, and finally reach some kind of medical treatment.

While I was always careful in choosing my romantic partners and friends to avoid any type of abuse, as I was well aware that these choices were going to influence me for the better or for

the worse, I still had to endure housing insecurity, amongst other financial stressors, as I was not willing to accept their financial help for most of my life. Repercussion of codependency from "after all we did for you" words told to me as a child, demonstrates the power words can have.

### **Incident 1**

## RAPE ATTEMPT

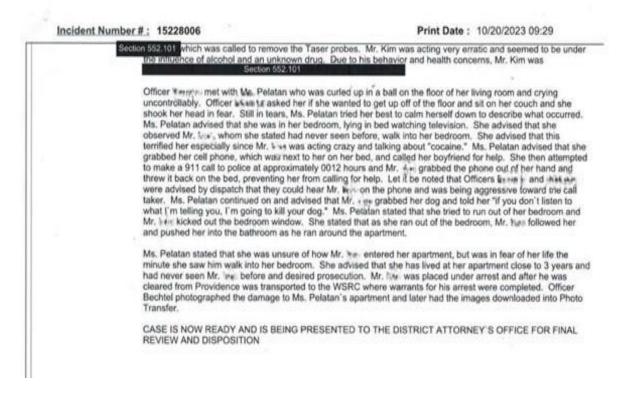
In 2015, I finally started seeking help for my codependency by joining a Co-Dependents Anonymous (CoDa) support group, that followed the 12 step-program. Traumatic incidents seem to have been key to creating major changes in my life. At that time, it was an attempted rape. I was followed from the pizza place Nona's on Mesa Street to my apartment on the same parking lot, I was unaware of the danger. After locking my door and greeting my cats, foster dog, and service dog Milo, I went to my bedroom and turned on the TV. The dogs would not stop barking, but I ignored them and assumed people were just passing by. The man who had followed me tried opening my front door, but when his attempts failed, he climbed to my balcony, broke into the kitchen, and opened my bedroom door.

With my phone in hand, I called my boyfriend Bruce and told him "There is a man in my bedroom" and then dialed 911, gave them my address, and told them the same thing. The man then took the phone away from me and told the police they would not get there on time. In a state of panic, I tried escaping, but he blocked the door, grabbed me, kicked and broke my window, grabbed a piece of glass, and said that if I did not cooperate, he would kill my dogs.

I do not recall all the details, but I found myself rushing from the bathroom to the front door, and him grabbing me again. Then, a Special Weapons and Tactics (SWAT) team broke down my door and tased him. Bruce had arrived at the same time as the SWAT team. I genuinely believe that had I not had my phone at hand, I would have been raped and would be dead. The next day, Bruce drove by the man's house and came back telling me I would never see justice because this man, or his family, had a lot of money. He was sadly right. From 2015 to 2023, they kept dropping

charges. He only had 67 days in jail, while I was granted 10 hours of free counseling and one month of free rent.

Because my memory still struggles so very much, for the purpose of this dissertation, I went to request copies of this case at the police station. "Attempts to commit a felony" is the wording used in the report, and I wonder if this is meant to lessen the gravity of his intentions as bail bonds were paid. My intuition leads me to believe that loads of money was involved in protecting him. Whether or not this is simple paranoia or justified by my few meetings with his lawyer regarding this case, money is known to make a difference in judicial outcomes. He had money, and I did not. Furthermore, my emotional exhaustion might have been evidence enough that I would not cause a commotion, as my mental health could both be blamed on paranoia or, in the best-case scenario, I was too concerned about making ends meet and staying afloat to get involved further than I had to. And this was indeed the case.



*Illustration 5:* Police Report

## Witness Testimony- Bruce



Illustration 6: Picture of Bruce

- In 2015, Josette mentioned that you and she were dating, and that one evening, a man broke in her apartment. Describe what you recall, starting with her phone call. How did you feel?

Received the call. It was late so I got dressed and drove over. Police were already there when I arrived. I knocked on the door and the guy opened it but quickly shut it again. Police managed to get inside. I was mainly standing aside watching. I was concerned but it was over quickly once the police got inside.

- Josette believes that, had she not had her cell phone at hand, she would have been raped and would be dead. Do you believe she might be exaggerating and/or that perhaps her complex PTSD had her sticking to unrealistic paranoia for all these years. If so, why? If not, why not?

Not sure about dead but understand why there was that concern. She was being overpowered by a strange man in her own home.

- Do you believe Josette had justice in this case. The man went to jail for 67 days, and paid bail bonds. Charges kept on being dropped, and court dates kept on being postponed. Case was closed without Josette's involvement in 2023. From the little that you know, what would your assumptions be.

No justice. No victim statement? Then what is the justification for minimal punishment? What is the confidence level this would not happen again to someone else? Doesn't seem to have been taken seriously.

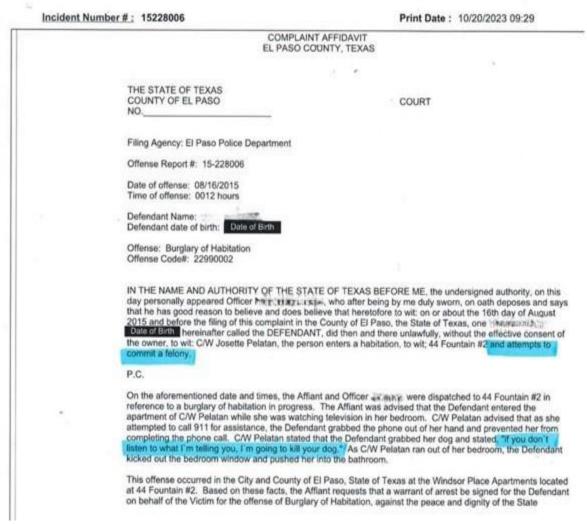


Illustration 7: Police Report 2

Soon after the incident, the nightmares got worse. This was most certainly complex-PTSD. Bruce had not only been my best friend since I was 17, but he was now my romantic partner, and the most stable person I know to this day. I did not want to mess up by adding more chaos to his life, yet I knew that I had certainly been the most stressful thing in his life. I therefore did not share much about my uprising of anxiety, increase of nightmares, paranoia of being followed. This is

when I decided to join a CoDa support group, which helped me... unfortunately, much later, to ask for help.

# Reflection over witness testimony & documents pertaining to incident #1:

Although I have known Bruce for over 20 years now, it is still quite hard for me to pinpoint his emotions. Communication was never his forte, and I assume this is because he is an extremely private person. I, on the other hand, tend to be unfiltered to a fault, which might not help him open up, knowing that my unintentional clumsiness might put him in a delicate situation. I would like to think that because he has been there throughout the entirety of my adulthood, that he genuinely cares about my wellbeing and is perhaps simply reluctant not to put distance in between us for self-preservation as I would not doubt having been the chaos in his mostly stable life journey. Yet, while he is still the person, I trust the most on this earth as far as honesty and reliability go, it is hard for me at times to accept him not being like me. I suppose that the fact that I need to share everything I think and feel with him and know that I would fiercely advocate for him had he been in some type of trouble, has me craving reciprocity of some sort. Yet, I know this feeling is a "toxic" trait shared by one of my paternal aunts, who would undoubtedly die for me, while I heartbreakingly choose distance for self-preservation.

# **Incident 2**

## DEFINING RAPE IN TEXAS

Financial insecurity had me struggle to keep a roof over my head throughout adulthood. Worsening mental health due to financial insecurity contributed to financial insecurity since I struggled more and more to keep a job. I have moved so many times, and the timeline details are blurred, but I do recall living in a garage twice, reaching out to shelters, some who would be ready to take me in, and then making up excuses when they realized I had a service dog. I have stayed in motels when I had the luxury of having earned enough money that week, all while trying to hide my circumstances by fear of judgement, shame, or to simply avoid the frustration of my partners and friends who knew I was the first one to pay for people around me, and the last to accept any type of help.

In 2016, my father helped me go back to France so I could get some type of medical help for my declining mental health, for which all of my physical symptoms were blamed. Unfortunately, France is perhaps the second worst trigger of all for me, closely followed by the thought of my birth mother. Unable to deal with the proximity of my paternal family, I threatened my way out of France. My uncle paid for my flight.

In 2017, my father, once again, brought me to France to attempt to get me treated for mental health, as I found myself unable to hold a job and sustain myself. I was no longer at UTEP, and support services were, therefore, much more limited. Furthermore, I was absolutely exhausted from financial stress and lacked rest due to constant nightmares. Once in France, to the greatest disappointment of my father, my psychiatrist told him that, to help me, he needed to support me moving back to El Paso. And so, he did.

On my arrival in El Paso, I stayed in a lady's garage in Canutillo. She was a friend of my friend Mike. Bruce broke up with me but assured me we would still be friends. I was unsure of how much I could take, but I had to move forward. I found a job in a daycare, cleaned houses, I did some pet sitting and babysitting. I eventually found a room for rent in downtown El Paso, with two men, cheap enough for me to afford. On my birthday, I got drugged, raped, or taken advantage of and went homeless again. Rape is a big word (I was told when testifying at the police station)! That is true, I suppose... I do not recall the details, so how could I be sure how much did or did not happen. What I am sure of is that I was unconscious.

It was my birthday, and I was dealing with very severe depression. I had seen Bruce earlier that day, desperately trying to make him jealous, as I was looking for signs he might still care about me. I realize how sad it is to feel the need to be loved by an ex-boyfriend, being a grown woman. While attempting to gain his attention, I recall carrying the guilt and shame of "being that way". Why was I so childish? Why did I feel unable to redirect my mind while being so conscious of it all concurrently? How frustrating.

On my return "home", my roommates offered me beers to celebrate my birthday. This was also my first day to accept smoking marijuana. I am unsure exactly what happened, but after my second beer, I blanked out. Snapshots in my head of my landlord over me are all I can recall. It must have been around 4 am when I gained back enough consciousness to stand up, go grab my purse and keys, and walk off to my car. Walking off feeling so unwell, blanking out so often, I could not recall some of my steps, as if I had been part of a broken movie. Somehow, I made it driving to Bruce's house. I waited in my car until 6 am for him to step out of his house to go to work, but he seemed stressed and upset, and I therefore denied his offer to go ahead and stay at his house.

There were not many people I trusted, but I was desperate. At the time, I had a job picking up a few kids from school and driving them home while waiting for the parents to get back from work. Because it was still so early, I planned to wait until early afternoon and use their bathroom to "clean up" before getting the kids. The car was hot, but I was too unkept to go to a public place to use a bathroom. I felt so very unwell. At 1pm or so, I headed over to the house of the people I worked for to use their bathroom before it was time to go get the kids. I knew it was not reasonable for me to go get the kids in such a state, but I was hoping that after a shower and loads of water, I would be okay by then. I really needed the work. I desperately needed the money. I had to try. This could work. Somehow, it had to be okay.

As I walked into their house, the teenager who was going to Franklin High School at walking distance from her home stepped into the hallway, asking me what I was doing there. In a state of panic, I explained I was driving nearby and had to rush to use a restroom. Once in the bathroom, I recalled that she had a half-day that day. Devastated that she had seen me in such a state, my hair extremely unkept and smelling like marijuana, I took a deep breath, washed my hands and face quickly, flushed the toilet, said thank you, and rushed out as if I had an urgent matter to go attend. I do not recall for certain, but I seem to recall the mom contacted me to let me know she would not need my services for that day (or a few days). It was obviously because the teenager must have described my unexpected and unapproved visit, and my state. I was crushed. What would be the odd that this was a half-day? What must these people think of me?

In the parking lot of a gas station, I sobbed, fighting off a very large number of intrusive thoughts, with blurred flashbacks and extremely uncomfortable black outs. I went back to park my car at Bruce's house. He had been "my safe place" in El Paso since I was 17. Someone I looked up to in many ways. Once there, I called my Japanese teacher. I do not recall what I said, but she

came for me and took me to her home. I laid in her bathroom after a long shower and recalled having some sort of episode. At some point, I think she sent a nurse to get me checked out... I think. I must have slept for 12 hours or so. This was, I believe, the last time I saw her. Oh, how I wish I could see her again and try to explain. But life goes on, and survival always took priority.

Somehow, within a few days of that incident, I found myself driving off with my cats, thinking that I could start over, far away from El Paso, sitting on street corners begging for money, where no one would know me. In a motel where I smuggled my cats and service dog while considering begging for survival, suicidal thoughts took over. How was I going to handle this amount of piled-up trauma I had no luxury of time and means to address?! It all felt so impossible... and trying to keep faith in miracles, felt unworthy. I no longer wanted to be resilient. I wanted to rest in peace, forever. But I looked at cats, Tornado and Fleur, and my service dog Milo. They deserved a good life. A stable life. I owed it to them. After calling the suicide line, which did not help much aside from reminding me there was still resilience left in me, proved by the fact that I had chosen to dial this number, I contacted Mike, another best friend of mine.

Mike told me to go to a police station to request a drug kit. I am not sure if this was the night of the incident. It seems that must be it. I vaguely recall picking up that drug kit, reading it, going back in to request a date-rape drug kit, and being told there was no such thing. I was advised to go to a hospital to get examined, and go to Las Palmas, asking for one at the front desk. While waiting for my turn or forms, I panicked at the idea of being touched again. I felt so very alone and tired, and it was just easier to leave and "let it be". It was way too much for me alone.

I have Mike to thank for flying me to his place in Wisconsin to watch over me while exhausted and highly suicidal. I drove back to El Paso and left my pets with Bruce, who then drove them to Paul and Nancy, an older couple I loved and trusted as well. My flight was scheduled in

the morning the next day, and I did not want to be more of a burden to Bruce than I already was. I waited at the airport, but by 8 pm, I was too exhausted again to care much. I contacted my exhusband Daniel, who came to pick me up, allowed me to shower, and fed me. At that time, he was engaged, and I, therefore, could not stay the night, so he eventually drove me back to the airport. Once at the airport, one of my ex-students named Flor, contacted me. I do not recall her motive, but I took the opportunity to vent. She picked me up from the airport, let me sleep at her house, and drove me back in the morning for my flight.



Illustration 8: Picture of Mike

# Witness Testimony - Mike

- When living downtown on California street with two men, Josette put herself at risk and got date raped. She does not recall the year, but vaguely recalls having gone to vote at a westside library with you, the day prior to the incident. She also vaguely remembers it having been her birthday. What do you recall of this incident, if anything at all?

I do recall Josette shared with me something to the effect that she woke up feeling as though she was raped. She stated she did smoke some weed and felt nauseated afterwards. I think she stated some clothing items were loose or opened. Now, I am not sure if this was the time when she was so filled with guilt and embarrassment and too afraid to contact the police, but I do believe she contacted me and was driving with no destination in mind other than enroute to California through New Mexico. I invited her to come stay with me, temporarily, because she was not in a stable mental state. I purchased her a ticket to Wisconsin, and she stayed with me for a few days. When I picked her up from the airport, she was completely disheveled, unbathed, hair unkept

and looked as if she had been through a mental nightmare. While with me, I convinced her to contact the El Paso police to address the allegation. She eventually shared her story with the authorities. She decided to leave my place after a few days, even though I tried to convince her to stay. She thought she was interfering in my life and didn't want to disrupt it.

After coming back to El Paso and going to report the incident, I was told I could be placed in a women's shelter for up to 6 months, and I certainly could have used a place to stay, and support from women who had dealt with potentially much worse circumstances. Unfortunately, my cats could not come along. My cats, "just cats" for most people, were my children. Writing these words, I know that I have yet to heal fully from this, as I am tearing up. How is it possible that writing about both incidents above does not have me tear up, but that thinking of having failed my sweet furr-babies does? The brain is indeed fascinating.

Because I could not take my cats, I turned down the shelter option. When the officer told me that I would have to retell everything I recalled several times, and eventually in front of a judge, but that in the end, it was going to be my word against his if no evidence were found, I felt unable to picture myself going through this, especially alone. I gave up. I had to worry about survival and about my animals. I had to find work and side gigs for I knew I could not hold a job for long. I always needed backup and backup for my backup. And a plan B, C, D, and more for my pets, in case this or that went wrong.

Public research underscores the critical importance of social support and access to social capital resources for the academic success of students from diverse backgrounds, including those with experiences of homelessness or foster care (Skobba, Myers, & Tiller, 2018). Examining academic achievement through the lens of college student identity development highlights the need for targeted efforts to integrate experiences and identities into the broader context of collegiate life while addressing associated mental health challenges. Without Mike's support, I believe I would

have ended my life. I hope this study advocates for tailored support programs, including enhanced mental health services on campus to cope with emotional stressors, fostering self-reliance alongside help-seeking behaviors, and fostering inclusive interpersonal relationships to combat feelings of isolation. The Campus Advocacy, Resources and Education (CARE) Program at UTEP was instrumental in addressing some of these traumas, but the suicide line did not provide the help I truly needed at that time. The call receiver did his best, but what I needed was a connection I did not feel with a stranger. Had I not been a student, access to support would have been much harder to acquire as well. Moreover, I stressed the importance of raising awareness about individual experiences to foster a supportive environment conducive to social, emotional, and academic triumphs despite the unique challenges posed by personal backgrounds and mental health issues.

Exploring our own situations and acknowledging the influence of both social and biological ties on their sense of belonging and identity formation. In response to calls from scholars like Herrick and Piccus (2005), one of my aims is to address the dearth of studies examining self-awareness, specifically concerning their understanding of family ties and relationships and their significance in shaping individual experiences. Everyone requires a feeling of belonging and a distinct identity, which are shaped by a combination of biological and social connections. This necessity holds true even for children who have resided in multiple households, although their experiences in diverse home environments may result in more intricate configurations of biological and social relationships.

# **Incident 3**

## JO'S DEATH

The year 2020 was a tough year for most people due to the pandemic. After having come back from yet another trip to France in 2017, yet another attempt by my father to me a potential suicide or reckless behavior prompted by survival instinct, I had concluded that France was not an option for recovery. My wounds were too deep.

Although I once again had found a way to return to El Paso, my family "had" to keep my two cats, Fleur and Tornado. Was it control? Punishment? It certainly felt that way and was indeed very devastating as I had promised my cats and myself that I would never fail them as a mother. That was confirmation I needed to never have children myself. If I had failed my cats, leaving them behind, I decided I was not fit to ever have children. Animals and children deserve the best.

In 2018, I joined a local support group, hoping it would help my mental health. There, I bonded with a man much younger than me, and after a while, we started dating. Bruce was almost 14 years older than me, financially stable, highly educated yet humble. Marco was almost 9 years younger than I, did not have a college education, and was perhaps as financially insecure and emotionally unstable as I was. Although not thrilled about him being younger, I felt a sense of relief that he might have been in a better position to understand me. I found in him the emotional support I lacked from Bruce but lacked the emotional and mental stability Bruce provided. Slowly, I overcame my discomfort with our age gap, and realized he had much to teach me regardless of his lack of formal education.

As soon as I got a job in a public school, I planned for dark times, as I had grown accustomed to expecting them. Using my first three monthly paystubs to get approved to rent a 5-bedroom house in the westside, I strategically sub-rented 4 bedrooms to cover the entirety of my

monthly rent and bills and started boarding animals as a side gig while fostering for animal rescue groups. I also dumpster-dived and sold my "treasures" by doing garage sales on weekends. Thanks to Marco, I found a way back into the Ph.D. program I had started in 2013. He had been highly supportive of my journey to pursue the educational access I craved.

As I had predicted, I did not keep my public-school job for long, but I had prepared myself accordingly ahead of time and was able to make ends meet, which had been quite rare for me. My careful analysis of the what-if-this-or-that happens had paid off! I felt resourceful and capable of overcoming my past. Now, managing to have a roof paid for from sub-renters, and enough money to take care of food, my service dog Milo, car registration, insurance, and such, I was able to start teaching more classes for National Alliance on Mental Illnesses (NAMI) and Mental Health First Aid (MHFA). This was my way to successfully control the controllable! What a relief! No one knew how hard life had been for me up to then, and although I was occasionally struggling with physical issues increasingly, I had never felt so hopeful, and envisioned too soon graduate.

But life had its own plan for me, and control was not in it. On July 5<sup>th</sup>, 2020, one of my roommates died under "my" roof the night of his 29<sup>th</sup> birthday. His father came by, asking if he had been home. I did not know and told him I had assumed he was with him to celebrate July 4<sup>th</sup> and his birthday and allowed him in to go check as he seemed so very concerned. The gentleman walked upstairs, opened Jon's door, closed it, looked at me and said, "He is dead". I acted fast, called 911, rushed to his room while the father went to sit on my living room couch, gave my address, told them my 29 years old roommate was dead, and started CPR as they were dispatching a unit. I also called Marco who rushed over, but he took a while as he lived far away.

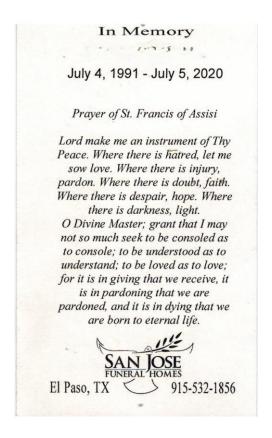


Illustration 9: In Memory

My 29-year-old roommate took his life on the night of his birthday after July 4<sup>th</sup>, and I was teaching people to read signs of suicidality through MHFA. How fit was I to be such an instructor if I could not even see signs under my own roof? How responsible was I for that death? Could I have prevented it? I was concurrently taking a NAMI Homefront course to help another roommate of mine who struggled with signs of PTSD and had recently been diagnosed with lymphoma. This course was also supposed to teach me how to read suicidality signs and how to prevent such happenings. I do not think the programs failed me in any way, but rather, held shame and grudges towards myself, as I felt responsible.

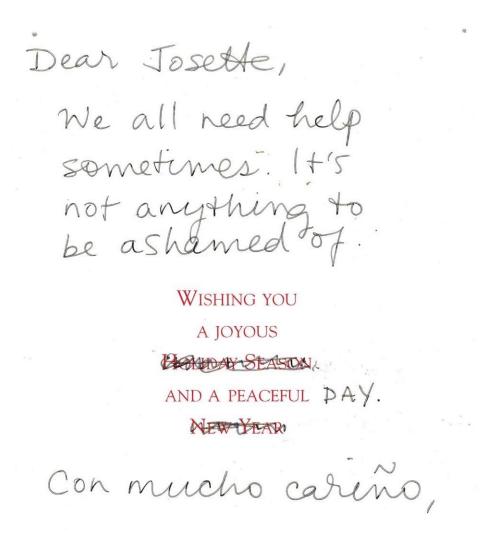


Illustration 10: Accepting Help

The police had to clear out the house and investigate and assess the reason of his death. I was lucky to have Marco and stayed at his place. Darker times were upon me as my landlord found out through the authorities that I had to contact him in regard to the death, that I was illegally subrenting, and had loads of animals, which was not allowed in the contract. My landlord was not understanding at all, and I got evicted. Thankfully, Marco shared his roof with me, the rescue took back their fosters, and the people I was boarding pets for were kind and supportive and found alternatives. Marco lived in a precarious situation, with a broken roof and very little space, but he

was always thankful and generous. I loved that about him. Being a UTEP student allowed me to move to the University dormitory with Milo and Pimpin through the Foster Homeless Adopted Resources (FHAR) and Center for Accommodations and Support Services (CASS) programs. People from the CASS center knew me enough by then to know that Pimpin, by sparrow, was much more than "just a bird" to me, and they were all determined to make her an emotional support animal so that she could also move LEGALLY to UTEP with me. What a relief! Milo and Pimpin were going to stay with me, and I had a safe roof to continue my studies! While traumas piling up, my aspirations to "make it" and advocate for others grew stronger.



Illustration 11: Milo and Pimpin

# **Incident 4**

## THE CRASH THAT CHANGED MY LIFE

As my physical health declined, I became an even bigger burden than I had been on my friends and, of course, for Marco. In March of 2021, he ended our relationship. My mental health took a turn while I had been dealing with troubling physical symptoms varying in degree and recurrence, from rectal prolapse to partial loss of eyesight, night fevers accompanied by severe spinal pain as if my spine had been on fire, and cognitive issues I can only best describe as feeling drunk (e.g., extremely slow, as if my head was pushed by a hand from side to side, extreme clumsiness), hip pain, partial loss of eyesight, very uncomfortable dyspnea... all worsening during PMS, hot shower, any type of exercise/effort. There was also discomfort on the right side of my neck, with lingering right ear pain, twitching of a toe every time I started relaxing in bed, and one side of my body going numb with a feeling of being touched by ice front head to toe, usually all at night as soon as I started relaxing leading to several trips to the ER for transient ischemic attack (TIA) symptoms.

### MRI'S

#### Report

Subcentimeter T2 hyperintense lesions within the right thyroid lobe.

### IMPRESSION:

- 1. Early degenerative disease involving the cervical spine..
- 2. No evidence of abnormal cord signal intensity or enhancement..

Finalized by 612.55 for the frequency and on 10/25/2021 10:19 AM

\*\*\*\*\* Final \*\*\*\*\*

Signed (Electronic Signature): 10/25/2021 9:59 am

Illustration 12: T2 Lesions

Overwhelmed by a panic that I might die of a strike, seizure, or heart attack and that the medical personnel I had so far encountered, treated me very poorly, I found my mental health declining to the point where I crossed the unsafe line of settling for the first person that showed interest of spending the night, to avoid being alone. How irresponsible and childish of me! While I carried shame, I do not have any regrets, I did not feel taken advantage of, as for things were a clear compromise. Nonetheless, since I tend to be extremely unfiltered... to a fault... as I mistakenly tend to assume people want the same token of honesty, I tend to provide to those I choose as family, I told Marco. To my surprise, since he had left me, he responded with anger, stating the fact that I had left him many times yet always came back. He seemed to imply (although I could be wrong) that I should have waited for him to come back to me.

A few months passed, and Marco was found in critical condition after a crash that prompted the death of two military men and severely wounded another. To this day, I do not know how much his choices were influenced by my behavior, but at that time, while still dealing with the worst of my physical symptoms, I decided I was going to get him out of this situation. While I had always been a bit of a fatalist and perhaps the most atheist person I knew, I was going to put all the cards I could on my side to succeed. I incorporated in my daily life prayers, visualization, and manifestation, went out of my way to speak to connections I had with the army, and threatened that if anything happened to him, if he successfully recovered, meaning facing prison, I was going to kill myself in a public place, making sure the world heard that this unjust system killed me through their laws.

I am not sure how much my mental health had to do with that, but I was under the impression that he had a broken spine. Later on, I found out that he had a broken collar bone (and hip, I think?), broken ribs that had pierced his lungs, and a concussion. I do not recall the details,

but I prayed, manifested, visualized, practiced quantum jumping to see him be well and free. The rest of the time was spent figuring out how to advocate for him on a legal level and how he would pay for medical care as well as basic needs. His family, of course, was there to help him, and I am so very thankful for everyone who helped him, including one of my professors who had sent me a \$400 check in 2020 when I went homeless that I had not endorsed, feeling perhaps unworthy of it. After he woke up from the hospital, I reached out to my professor asking if it was okay for me to finally use that check to then give him the money. Screenshots were exchanged so she would know Marco had received her money and was thankful.

By December of 2021, my paranoia of him facing prison as I had been given a letter of his felonies while he was still unconscious, had escalated to the point where I was making plans to bring him to South America and help him hide for the rest of his life. I shared that letter with one of my committee members, which perhaps can attest to the gravity of the situation he was in. My father had many faults, perhaps more than average. Still, he was willing to cross the ocean to help me accomplish this delusional goal because he knew that nothing could have stopped me from doing otherwise, given the circumstances. How many parents would have supported such dangerous choices to the extent of giving up the rest of their lives? I knew I was incredibly lucky.

Marco and I had an argument in December 2021. Being so cognitively, mentally, and physically unwell at the time, I am unsure of the reasons, but that month, he blocked me out of his life, perhaps for self-preservation. This is the time I died to get reborn with what I believe was Post-Traumatic Growth.

# **Incident 5**

## PAUL'S OFFER

In the spring of 2021, my focus had been medical advocacy since I was still juggling with night fevers of unknown origin that turned out to be the cytomegalovirus with high viral charge, but not yet diagnosed and therefore not treated, that worsened all other symptoms. Unable to keep up with school and meet graduate school requirements, I had no choice but to drop out yet again.

I found myself living in a garage with Milo for a bit while teaching at EPCC. I was just a part-time instructor, and my old car had many issues I struggled to afford. I was tired. I felt sick. Yet, I had spent the entire semester at UTEP practicing brain rewiring techniques, and it was starting to pay off. Something happened when I was hospitalized in Juarez for a tumor to be removed in my neck in January of 2021. Alone during a somewhat dangerous procedure as the tumor was pressing against my right carotid vein, which perhaps explained my drunken feeling and right ear pain, I felt overwhelming anger at the world. A world that had me face so many hardships, willing to compromise my health and safety for a few people who would not even grant me their presence or demonstrate concern while I faced the fear of death. I felt anger towards those I had called my friends, who obviously would never compromise their reputation to advocate on my behalf, as I would have done for them. Bitterness was always present, but now I had taken over to the extent I wished to die, hoping that might bring them some type of guilt or pain. Disgusted by my own feelings, overwhelmed by the guilt of wishing pain and judging thought I loved, I wondered if it was all Karma because I had left my aunt in France, who loved me to death yet with the same vengeful, manipulative tendencies I felt towards them.

I wanted to be a good person, but I felt like an evil one, which was the biggest battle I had to face. That night, in the hospital, I prayed to find a way forward so that I could live with myself.

I visualized myself as successful in every way and let it fill me with healing joy and sufficient selflove to wake up anew. I did that because I realized that, coincidence or not, whatever I had manifested for Marco had happened. This felt magical. This was my power, I just had to choose myself now. After that night in the hospital paid for by my friend Rose, I woke up practicing every brain rewiring technique I encountered along the way. I incorporate breathing and meditative practices, earthing, and grounding techniques. I started using my Facebook to post positive things that I wanted to believe in or that made me smile. To fight off intrusive negative thoughts, I went back to my Facebook wall, scrolling through it to expose myself to those same messages. I listened only to empowering stories, practiced morning affirmations, visualization paired up with matching feelings, gratefulness exercises, and art therapy, and encouraged myself to write happy and purposeful poetry. I prayed for the many wounds I had to heal, as I knew to my core, my bitterness, negativity, manipulative, and vengeful feelings were but misunderstood and unhealed traumas. I learned how to be gentle with myself, uncritical of my errors, and nonjudgemental of the hate I carried towards my mother. I learned how to love myself as I would have wanted to have loved a child of mine. Seeing the best in myself and my potential. Healing my pain through unconditional love. I became my own best friend, and I then knew that, since I would not have given up on my child's diagnosis, treatment, or aspirations of any kind, I was going to make it all happen.

In the summer of 2021, while living in that garage, Paul, an older French man whom I had known since I was 17 years old, who had provided me with many recommendation letters, lent me money (that I always paid back promptly even though he always had told me to keep it), offered to pay for the rest of my PhD program or even for a new PhD if I found a way to get back to school. I was then more than ready to accept all types of help, especially from him as he was one of my emergency contacts, and a father figure to me, with the means. I attempted to get back to the school

where I had left off, but that was not possible due to administrative graduate school requirements. I had up to 9 years to graduate, and I had reached the deadline. I did not give up. There had to be a way. I felt a sense of strength and purpose, nurturing the idea of fighting for the aspirations of the children I did not have and doing so for myself. Mental health had been part of my education as I had been teaching many programs for NAMI and EHN and had been trained in different sectors every time there was a free training I could attend.

I had told Bruce for many years that I was fascinated by the brain, had taken some free courses, and wished I could have studied health sciences formally. I wondered if that calling could perhaps be achieved now that it felt more purposeful than ever. I reached out to several people at UTEP and did my research. If I successfully transferred departments over the summer, I would be given two more years to graduate! That was my loophole! Bruce, as usual, did not believe I could reach such aspiration. He told me "You might be able to be transferred to liberal arts, but not health sciences with any formal science education". By then, the negative intrusive thoughts of inadequacy were easy to redirect. No! I WANTED health sciences! I NEEDED to learn more about health to advocate for myself! And I had a story to tell that would influence policy and education and social work and public health! I saw value in the research I envisioned, and therefore, so would they!

"An autoethnographic research in Health Sciences?! Even if you get into an Interdisciplinary Health Sciences Ph.D. Program, they will not approve of that!", he said. Time was of the essence. I prepared accordingly in a coffee shop or at work since the garage did not have internet. I was given the chance to have someone pay for the remaining time of my academic journey, and I would not waste that opportunity. It felt as if the universe was fully supporting my

endeavors. I did not need anyone but myself to believe in me. I would be my best therapist, social worker, medical private investigator, professor, best friend, mother, and friend.

After confirming that I had made it into the program, Paul contacted me because his wife was hospitalized for a stroke. Nancy is very dear to me. She has been a fervent advocate for animals throughout her life. She has two daughters older than me who live out of town. Nancy and Paul had been considering giving me their house with their many cats after their passing. They know I love animals and would have taken good care of them all had I had the means. Their two daughters are well off financially and too busy to care for all their cats. This was a great honor. We discussed this as an option if my health concerns settled enough to be responsible for their cats' wellbeing.

As I headed over to Paul's house, I assumed he needed me there to give me more details about Nancy's state and to have me care for his cats while he joined her at the hospital. Paul had other intentions and put the moves on me by inappropriately touching me and attempting to kiss me. He is an old man and was a father figure to me. I would have never suspected such intentions from him. Well, when he offered to pay for my education, intrusive thoughts of his potential intentions did actually creep in for a minute, but I redirected them quickly, with the guilt of even considering such a thing of someone whom I had absolutely no reason to suspect of such intentions. Thanks to post-traumatic growth, I now knew that my intrusive thoughts were able to be redirected gently, as they were due to past trauma, which made me assume the worst of everyone. I also learned how to redirect my guilt of dealing with such intrusive thoughts and embrace empathy instead.

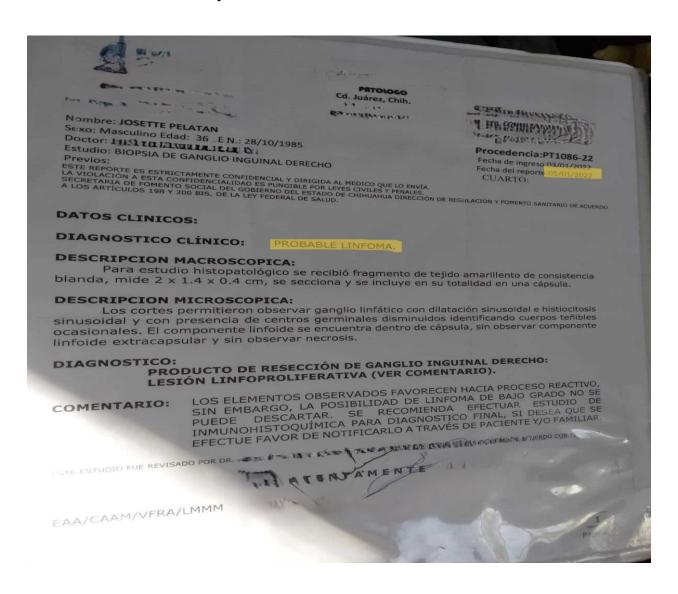
I pushed Paul away promptly, in shock. As I rushed out, feeling confused, heartbroken, and disgusted, I decided to give myself 48 hours to be angry, saddened, disgusted, confused, but never discouraged. I told myself, as I would have told my hypothetical daughter, that it was not her fault

and that, somehow, everything was going to work out and be okay. I went to the mountain to scream and to cry. I encouraged myself to let it out as I had no time to waste and a great purpose ahead. I refused to let myself fail. This was just a tiny roadblock compared to the ones I had overcome in my past. My priority was not to get dropped out of school for lack of timely payment, on my first semester in the program. I had a week to figure it out. I applied for a payment plan and reached out to Mike who paid for my first two installments right away. I applied for student loans. As soon as I got approved and the money was dispersed, I paid Mike back and paid for the rest of my semester. Looking back, I am still amazed at the ability I had found... or perhaps built from post-traumatic growth, to bounce back. This was the new me I had envisioned becoming. It had not been the first-time men had tried to buy their way through my financial vulnerabilities, but this was the moment I knew they would never have their way. I had often been concerned about how much more I could take before giving in to the idea of prostitution. Offers were there, and so was my financial need. It was a bad combination of my emotional, mental, and physical exhaustion, really. I think the reason I have never crossed that line is potentially due to my discomfort with sex, even in long and serious romantic relationships, paired up with my rebellious feminist stand of not wanting to be bought. The double-edged sword of sex had been a blessing in disguise all along.

Looking back, I see myself having moved promptly from anger into pity. I no longer desire to understand what went on in his mind. I feel sad and ashamed for him and proud of myself for how I dealt with it all. One of his daughters reached out to me a few months after the incident, wondering why I no longer visited her mother, who was back home and missing me. I explained something had happened with her father, and I was no longer comfortable seeing him alone. She replied she understood without inquiring further, which puzzled me and gave me the impression

she might have assumed correctly. She organized 3-way calls through WhatsApp. I eventually found friends to very occasionally go visit Nancy (no more than 5 times since the incident) who pointed out that she loved her cats most as they did not abandon her, implying that I had abandoned her. I chose to let it be.

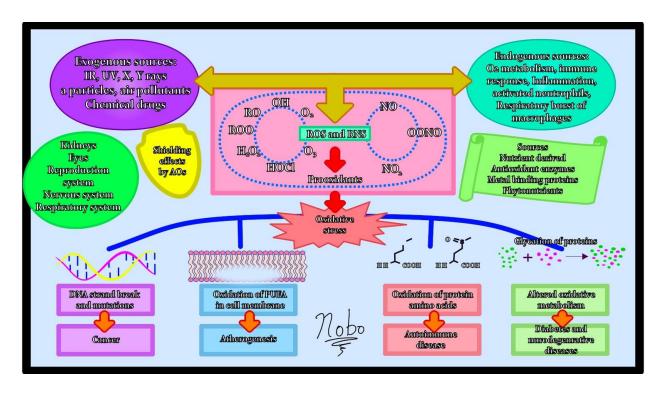
# **4.2.3 Medical Journey**



*Illustration 13*: Probable Lymphoma

Mapping my medical journey has been an intricate part of advocating for my treatment. After a car crash involving my latest serious relationship in July of 2021, my complex-PTSD was blamed for all of my physical symptoms. While fighting for him as much as I could, I dealt with the most severe physical symptoms I had ever experienced, triggered by my second COVID-19 vaccine.

After several hospitalizations due to TIA symptoms, night fevers with agonizing spinal pain at night, and a long list of other complaints that soon labeled me as hypochondriac, I knew my best bet was to take that fight over the border. One tumor was removed from my neck; night fever was finally explained by a very high charge of active cytomegalovirus and treated accordingly. I continued my advocacy toward what I knew much more than simple, very severe, complex-PTSD.



*Illustration 14:* Sadaf Kalam, Mir Zahoor Gul, Rupal Singh and Sravani Ankati. 2015. Implications in Etiology of Chronic Diseases and Their Amelioration through Nutraceuticals.

While my mental health was certainly serious and worsening, I knew it did not cause night fevers, loss of eyesight when exposed to heat, exercising, or during menstruation. The obvious experiences triggered by temperature changes were part of the Uthtoff's syndrome that narrowed down my diagnosis to a demyelinating disease. I knew since 2015 that I was positive for antinuclear antibody (ANA), meaning there was indeed an autoimmune disease, but lupus did not cause demyelination.

Uhthoff's syndrome is a well-known sign depicted as a temporary deterioration of neurological function lasting less than 24 hours that can occur in multiple sclerosis (MS) patients due to an increase in core body temperature (Pearce, 2010). It is unclear why some patients experience the Uthtoff syndrome more than others, and I wonder if this could also prompt the correlation of new studies with sensory processing sensitivity (SPS as a personal disposition to being sensitive to subtle stimuli and being easily over-aroused by external stimuli. It has recently been proposed as a human neurobiological trait found to be significantly higher in 10–20% of the population. I feel that this case could insight new research that encourages the interconnectedness to many medical concerns often studied in isolation. I was experiencing the Uthtoff syndrome daily, as I was living with a high charge of cytomegalovirus reactivation, left undiagnosed for almost two years. To this day, I believe that since I was not tested for it in the United States was not simple negligence, nor the plain assumption that I was exaggerating, but rather the fact that the treatment for it is very expensive. I had not yet been accepted into the medical discount program for student loan forbearance. The drug Valganciclovir cost me \$400 in Mexico, but soon after starting the treatment, my night fevers lessened to fully disappear. With it, the Uthtoff's syndrome worsened the experience of my demyelinating disease.

This phenomenon was first described by Uhthoff who observed the appearance of reversible optic symptoms induced by an increase in body temperature, "marked deterioration of visual acuity during physical exercise and exhausting," and is most observed in MS but may occur in other optic neuropathies or disorders of afferent pathways. The most widely accepted mechanism is the temperature-sensitive conduction blockade of partially demyelinated axons in the demyelinated plaques, and several other factors, including exercise, fever, hot showers, and even hot meals and smoking cigarettes have been reported in the literature as triggers for the Uthtoff syndrome. My sensitivity to it was so acute that the most shocking relationship I found was during my premenstrual cycles. I knew that exercise was supposed to help with mental health and physical health, but the physical therapy sessions I was undertaking proved to be wrong in generalizing this statement. Here was the key to moving... fighting... towards a diagnosis. During every session of light exercise, my cognitive state declined, my clumsiness increased, my drunken feeling worsened, and my eyesight on one side would no longer let me see colors as if I was wearing a veil in front of it. One of the most disabling symptoms I had was dyspnea, which worsened drastically when taking walks and trying to do any type of exercise. My father had had 8 heart surgeries, including 5 bypasses, and I was worried about having heart problems myself. Yet, no matter how hard I tried to advocate for myself in the doctor's office, all was attributed to my mental health. I became so desperate to get the help I needed that I attempted to hide any sign of depression and anxiety. Unfortunately, it had also become obvious that my mental health records seemed to transfer over from hospitals to most if not all, medical practitioners.

Knowing that my mental health was certainly also a big issue, I was determined to work on that as I would have wanted my hypothetical child to. It had appeared that I was treatment resistant, as the drugs had no effect on me. But I knew there was hope in the combination of

lifestyle changes. Moving away from inflammatory foods and towards more fresh and organic produce, I started reading extensively on different alternative medicine, herbs, and seeds benefits while trying to narrow my search in diagnosis. Reframing my mindset with hope, faith, and a big sense of purpose, I investigated treatments for severe and chronic diseases. Incorporating earthing, grounding, breathing, and meditative techniques and exposing myself to empowering success stories, I reminded myself that this fight was not just about me but that I needed to start for and by myself.

Acute neurological worsening with recovery within 24 hours is a marker of Uthtoff syndrome in MS, and its causes are still unclear. Because it is due to impairment in demyelinated fibers transit caused by heating, peripheral nerve conduction in demyelinated nerves may have similar damage during heating. Since strength evaluation is practiced in the acute phase of MS, researchers should consider fever as a possible trigger of temporary strength deterioration also in peripheral demyelinated syndromes. Cortisol is intimately correlated to immune system function and is higher during the day, so these higher levels suppress immune activity to a large degree. When cortisol levels go down at night, the immune system is more active in fighting illness or infection. This is why fevers spike at night. I experienced severe spinal burning pain at night, which was tolerable during the day. My neck lymph nodes, especially on the right side, were swollen most of the time. Although I did notice that my stress level also increased the severity of my signs and symptoms, I knew this was much more than my mental health alone. Temperature overnight evaluation is crucial to confirm the presence of an active virus. Accumulating evidence indicates that Cytomegalovirus (CMV) contributes to MS disease via interplay of different mechanisms such as molecular mimicry, bystander activation, and epitope spreading. The activation and expansion of a specific T cell subset, CD4+CD28null T cells, via CMV infection

could also contribute to MS pathology. Given the opportunity to be taken seriously, my case could have been used for research while granting me access to an accurate diagnosis, followed by treatment. But would it be in the interest of our capitalist system to be aware that I, a person with massive medical and academic debts, without family or means, and extremely unlikely to ever pay it off? Not to mention the fact that the three known demyelinating diseases are labeled incurable and cost around \$100,000 yearly per patient, that concurrently collect disability. This is a question left for readers to ponder about. While most people would assume my mind simply lives with paranoia, due to the nature and number of experiences with the medical system, I choose to call it purposeful intuition.

Depression was quite severe, but recalling the disabling symptoms I was experiencing, worsened every night from night fevers, felt that it was justified. Furthermore, the lack of answers and support, including the very poor treatment I received from several medical practitioners while I was begging for help explaining this was nowhere near simple severe mental health would, I believe, have driven most healthy people to experience depression themselves.

For sociodemographic variables and existing depression, individuals with MS exhibit notably elevated scores across all Childhood Trauma Questionnaire (CTQ) categories except for physical abuse and neglect when compared to the general population. According to research, the adjusted odds ratios for various forms of childhood trauma were notably higher in the MS than in the control group. While childhood trauma does not seem to correlate with the extent of ongoing MS-related impairment, MS patients with a background of physical and/or sexual abuse experienced considerably higher rates of relapse compared to those without early-life adversity. I knew these findings fit my profile, but having hypochondria discarded in this side of the border was too long of a process for me to tackle amid a severe episode worsened by the high-viral charge

of cytomegalovirus. I had to choose my battles widely, and the financial terrain for it was most certainly an unavoidable stressor.

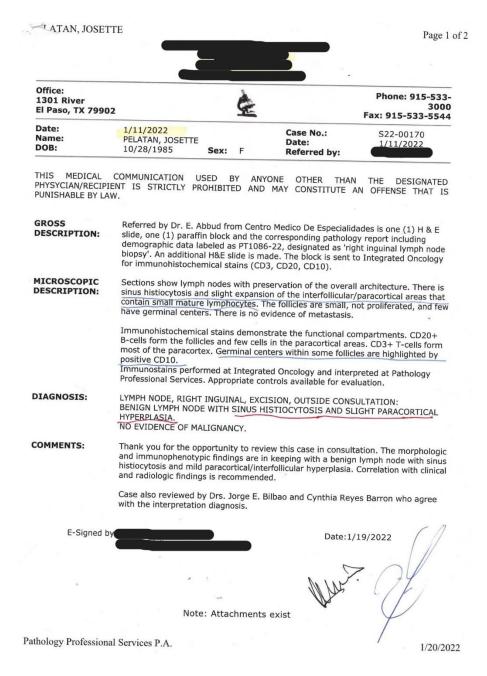


Illustration 15: Biopsies from Mexico analyzed In the United States

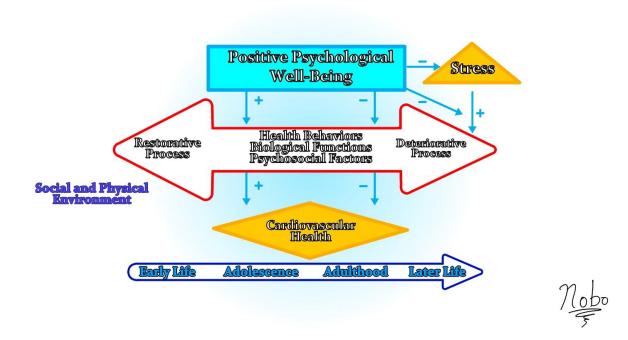
My in-debt research made it harder for me to gain credibility to get the hypochondria discarded. Still, it indicated a potential connection between childhood trauma and MS as observed

in a cross-sectional analysis. To elucidate the relationship between early-life stress and MS risk among genetically predisposed individuals, larger prospective longitudinal studies are warranted. Another study I read in the Journal of Neurology Neurosurgery & Psychiatry suggested that childhood trauma could be associated with an increased susceptibility to multiple sclerosis (MS) later in life, particularly among women. While dealing with severe cognitive issues (feeling drunk), I still kept track of my research on demyelinating diseases and potential causes. I started looking at alternative medicine guidelines, treatments, and practices. Although I knew all that I was experiencing was certainly not JUST severe mental health, I also had no doubt that if I was going to survive this episode and all the challenges I had to face concurrently, I had to try it all and have faith that it would work.

Keeping track of my signs and symptoms was a tedious task. Rewiring my brain was even harder. Since I had lived with worsening depression throughout my life and was perhaps the most negative person I knew, I chose the following approach, undoubtedly due to Post-Traumatic Growth. There were a few qualities I liked about myself. The main one was how fiercely I was ready to fight for the few very close friends I had, and for romantic partners. Impulsively and relentlessly willing to compromise my own safety and future to protect this handful of people, I knew nothing, nor no one could keep me from successfully advocating for them. I now had to be ready to fight for myself like I had been fighting for one of these few people. In order to succeed, I needed to reframe my negative and self-sabotaging insecure mindset, which I had carried within for over 35 years. No one was willing to believe in me. This was a great opportunity to start believing in myself. The ego, which had played its purpose, was no longer needed. Being believed and supported was for the ego, and the ego had to die. Trusting my instincts and remembering how powerful I could be when fighting for those I loved meant dropping all expectations of others, for

there was no room to mingle with the disappointment of people not being as I wanted them to be. I had become too much for the world. This was perfect. It left me no other way but to become my own savior, and I was determined not to fail.

While I still had plenty of occasional intrusive thoughts of not being believed, not reaching some type of diagnosis, not recovering, failing at graduating, and making ends meet, I learned to reframe all my thoughts and feelings. Inspiring podcasts, alternative medicine methods books and documentaries, churches and temples, faiths of all kinds, I was now receptive to it all like a brandnew antenna had been given to me through PTG. I was going to unlearn how I viewed the world and relearn how to feel about it and myself.



*Illustration 16*: Kubzansky, L.D. 18 September 2018. Positive Psychological Well-Being and Cardiovascular Disease: JACC Health Promotion Series.

After reading studies on post-stroke patients, things made sense! During the first six months after their stroke, their ability to relearn basic things like motor skills was surprisingly

drastically uphill. No PTG studies have been done extensively enough to assert such a thing, but speaking from experience, I feel this ability to unlearn and relearn fast after PTG might follow the same pattern as one of post-stroke patients. A switch I had needed happened while I felt physical, emotional, and mental agony altogether, and I never woke up the same. A miraculous drive to do and be better had been instilled in me overnight, and whatever the reason had been, much more complex than can be explained in a dissertation, rock-bottom had become a thirst for survival through mental and physical healing, and thirst for justice that meant advocating relentlessly to obtain a diagnosis and treatment, and a purpose so much greater than just myself that interdisciplinary research provided me with the perfect platform to do so. I was ready to heal at all costs and fight for the one I was now ready to love fiercely. The cliché of "the best apology is changed behavior" had become my legacy as an apology to all those I have loved and hurt along the way, me included, as I was no longer less important than anyone else.

I had been passionate about social justice, but now was the time to put it aside, temporarily, as I had become my primary focus, and one that needed a village to "make it". My use of social media was now new ground for therapy for my dark days. Every positive message I wanted to believe in, I posted them on my social media and bedroom wall, to go back to and read it, when feeling down or unwell. I shut out all negativity and only welcomed the hopeful and joyful. From meditation and breathing practices, to Reiki, acupuncture, grounding, the Clinician Administered PTSD Scale (CAPS), Campus Advocacy, Resources and Education (CARE), Eye Movement Desensitization and Reprocessing Therapy (EMDR), Emotion-Focused Therapy (EFT), talk therapy, to Family Constellation Therapy (FTC) in Juarez, I was going to give it my all. Affirmations and gratefulness practices became part of this New-Me. My research on brain rewiring became second nature. I was not competing with anyone, and was ready to gain the

knowledge I lacked, by myself and for myself, to one day help others better heal and advocate for themselves. How many people have had the chance to rewrite their story, so deeply drowning in physical and emotional agony, from seeing death as the only possible answer, to waking up with emotional strength and determination like no other?! This is my story, my purpose, and a blessing that simply cannot be dived in enough in a simple write-up. Therefore, I envision many others who will give a voice to those who have been silenced by a discourse claiming they do not know enough and do not belong.

The available research indicates that early-life trauma has the potential to modify immune responses and could elevate the likelihood of developing autoimmune disorders. I had been ANA positive, perhaps my whole life, but formally diagnosed through a very expensive blood test in 2019. Instances of maltreatment, disregard, and unstable familial environments have been linked to an escalated probability of encountering both psychological and physiological challenges later in life. However, the question remains unanswered as to whether such experiences might also amplify the susceptibility to multiple sclerosis (MS).

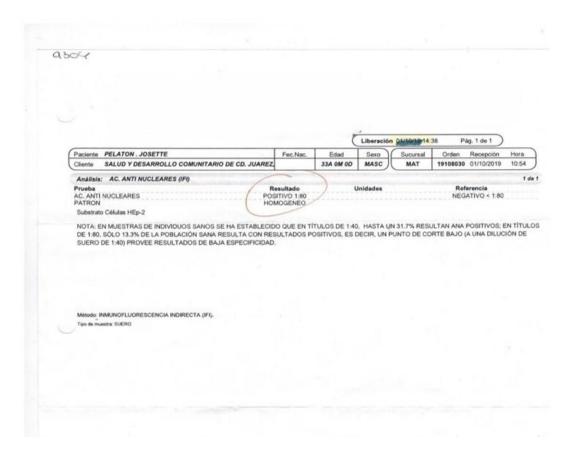
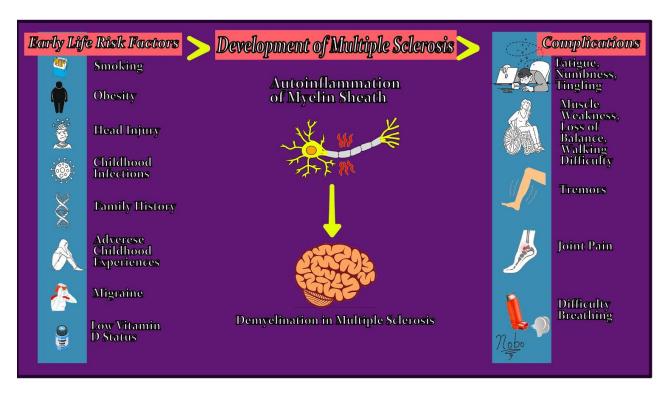


Illustration 17: ANA Diagnosis

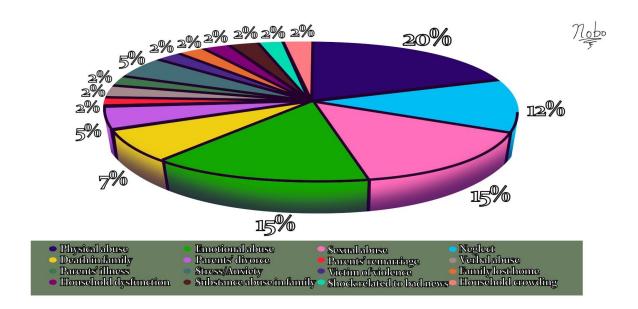
The most notable correlation I found with MS was with instances of sexual abuse, which showed a 65% increase in risk, followed by emotional abuse with a 40% elevation in risk, and physical abuse with a 31% rise in risk. Furthermore, the risk escalated notably when individuals were exposed to two categories of abuse, showing a 66% increase in risk. This risk further rose to 93% for those exposed to all three categories of abuse, suggesting a progressive relationship, as indicated by the researchers. It has been suggested that there could be viable biological rationales behind the observed correlations. They propose that childhood abuse has the potential to disrupt signaling pathways in the brain and glands, specifically the hypothalamic-pituitary-adrenal axis, thereby triggering a state of inflammation.

Gaining a deeper understanding of the risk elements and the timing of exposure to these risks could pave the way for preventive measures and offer additional insights into the mechanisms

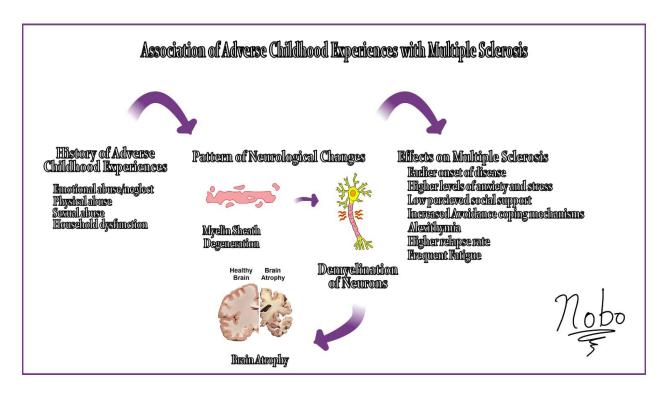
underlying the disease. While my diagnosis went from probable lymphoma to probable lymphoma, spinal MS, to probable MOGAD, I now have access to treatment in Mexico. The treatment I envision could be a cure, and I believe it will be. No longer afraid of what the future holds nor of what others may think, I now trust the universe that everything will play out in divine timing as I keep my eyes on a greater purpose.



*Illustration 18:* Syeda Tayyaba Rehana, Zayeema Khan, Syed Hasan Shuja, and Afia Salman. May 2023. Risk factors of MS development, pathogenesis, and complications of illness.



*Illustration 19*: Rehan, S. T., Khan, Z., Shuja, S. H., Salman, A., Hussain, H. U., Abbasi, M. S., & Surani, S. (2023). Association of adverse childhood experiences with adulthood multiple sclerosis: A systematic review of observational studies. *Brain and Behavior*, *13*(6), e3024.



*Illustration 20*: Rehan, S. T., Khan, Z., Shuja, S. H., Salman, A., Hussain, H. U., Abbasi, M. S., ... & Surani, S. (2023). Association of adverse childhood experiences with adulthood multiple sclerosis: A systematic review of observational studies. *Brain and Behavior*, *13*(6), e3024.

In MOGAD, inflammatory attacks within the central nervous system (CNS) can trigger acute pain through the release of pronociceptive factors such as brain-derived neurotrophic factor (BDNF), cytokines, and chemokines, including interleukin (IL)-1ß, IL-6, IL-17, and tumor necrosis factor (TNF). This cytokine release contributes to heightened glutamatergic signaling, which serves as the primary pronociceptive neurotransmitter within the spinal dorsal horn. This could be explained by the fact that my worst episode was prompted by high stress, the activation of the cytomegalovirus, and that it caused the tumor in my neck, which was removed in January 2022.



Illustration 21: Cytomegalovirus

This surplus of glutamate, combined with neuroinflammation and sensory neuron dysregulation, can lead to sustained elevated levels of brain-derived neurotrophic factor (BDNF) and glutamate, impacting susceptible inhibitory neurons like alpha-amino-3-hydroxy-5-methyl-4-isoxazolepropionic acid (AMPA) and gamma-aminobutyric acid (GABA) neurons, respectively.

This imbalance between excitatory and inhibitory signals can contribute to the development of chronic pain. Moreover, astrocytes release the endocannabinoid 2-arachidonoylglycerol (2-AG), which enhances GABAergic inhibition. The reduction of 2-AG due to astrocyte loss in NMOSD is likely to contribute to nociceptive pain and hyperalgesia. Investigations indicate that subcortical structures play a significant role in cognitive, emotional, and pain modulation processes in individuals with AQP4-Ab-positive NMOSD. While the study of MOGAD is in its infancy, as it was confused with MS until 2007, it is likely to share these findings.

In MOGAD, inflammation primarily leads to demyelination due to the binding of MOG-Abs to myelin-forming oligodendrocytes, resulting in the loss of the microtubule cytoskeleton (Asseyer et al., 2020). Normally, nerve growth factor (NGF) exhibits a strong affinity for MOG and is involved in the nociceptive system by binding to tropomyosin receptor kinase A (TrkA), which is expressed on unmyelinated nociceptive axons in the spinal cord, regulating synaptic strength and plasticity of sensory neurons. Consequently, the destruction of MOG by antibodies in MOGAD may lead to increased NGF levels in the central nervous system (CNS), causing abnormal sprouting of unmyelinated nociceptive fibers in the posterolateral tract of the spinal cord and resulting in nociceptive pain.

The brainstem plays a pivotal role in the pathophysiology of headaches. Lesions in the brainstem are observed in around one-third of individuals with MOGAD and may contribute to an

increased susceptibility to conditions like migraines and trigeminal neuralgia. In MOG-Ab-related optic neuritis (ON), MOG is abundantly expressed by oligodendrocytes that myelinate the optic nerve, making it a prime target in this condition. ON-associated pain tends to be notably intense in MOGAD and can manifest as a headache resembling migraines. In such instances, the substantial edema may cause irritation of the meningeal nerve sheath encircling the optic nerve, housing nociceptive fibers of trigeminal origin. The trigeminal nerve supplies sensory innervation to the ocular and periocular regions, and its recurrent branches innervate the intracranial dura, venous sinuses, and cerebral vessels, potentially triggering headaches.

Pain may manifest during acute episodes, serving as a marker of ongoing damage, or it may evolve into a chronic condition as the disease progresses. Common pain syndromes observed in MOGAD encompass optic neuritis (ON)-related pain, headaches, neuropathic pain, and musculoskeletal discomfort, which includes spasticity, painful tonic spasms, and back pain. In the following sections, we delve into these symptoms within the framework of MOGAD, noting any distinctions between the two disorders when data permits. Pain associated with optic neuritis in MOGAD cases appears to be notably intense, occasionally accompanied by migraine-like headaches occurring before the onset of visual impairment.

Women exhibit a higher susceptibility to autoimmune diseases compared to men, with a female-to-male ratio varying between 1.1:1 and 3:1 in MOGAD, depending on geographic location. However, research has not revealed any sex-based differences in the prevalence or intensity of pain associated with these conditions. Several studies have demonstrated an association between depression and fatigue in both NMOSD (66–83% AQP4-Ab positive) and MOGAD. Depression and pain are recognized to interact, although it remains uncertain whether

depression exacerbates pain, arises in response to pain, or manifests through both pathways (Kronzer, V. L., Bridges, S. L., Jr, & Davis, J. M., 2020)

The International Association for the Study of Pain (IASP) depicts pain as an "unpleasant sensory experience linked with actual or potential tissue damage or depicted in terms of such damage".



Illustration 22: MOGAD Negative but out-of-range

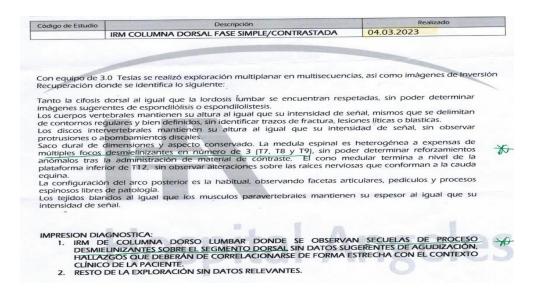


Illustration 23: First lesions findings

Undergoing a traumatic experience is already distressing. However, when your trauma is dismissed by others, it can exacerbate the harm. Equipped with appropriate resources and therapy, I regained inner resilience and established limits and boundaries with unsupportive individuals.

As per the Substance Abuse and Mental Health Services Administration (SAMHSA), trauma stems from various events or circumstances that are perceived as physically or emotionally harmful or life-threatening. Its repercussions can profoundly impact an individual's functioning across physical, mental, emotional, and spiritual realms. SAMHSA further acknowledges trauma as a nearly ubiquitous experience among individuals grappling with mental health issues and substance use disorders.

While certain traumas may be shared among individuals, it is crucial to recognize that the experience of trauma varies significantly from one person to another. Trauma encompasses any event or situation that has had adverse repercussions on an individual's life. Traumatic events encompass a wide range of experiences, including being involved in or witnessing sexual assault,

car accidents, combat situations, or natural disasters. Additionally, childhood experiences such as neglect, abuse, or growing up in a turbulent household can also be traumatic.

According to the U.S. Department of Veterans Affairs (VA), approximately 60% of men and 50% of women encounter at least one traumatic event in their lifetimes. While some individuals may recover within a relatively short period, others may continue to experience lasting effects that persist throughout their lives.

As per the National Institute of Mental Health (NIMH), individuals may exhibit a variety of responses following a traumatic event, with many recovering from initial symptoms as time progresses. However, those who do not experience immediate recovery may go on to endure persistent symptoms, possibly leading to a diagnosis of post-traumatic stress disorder (PTSD).

The enduring impacts of trauma are extensive, and each person's journey through it can be distinctly unique. It's crucial to recognize that no two traumatic experiences will unfold in identical ways, even if the situations appear similar. Over time, individuals may grapple with various effects, such as depression, substance abuse, and anxiety, emerging months or even years after the traumatic incident.

Everyone's trauma is inherently personal and distinct. It represents a profoundly intimate ordeal that may evoke feelings of vulnerability and fear. When others dismiss or discredit one's narrative of trauma, it can exacerbate feelings of fear and isolation. Experiencing a sense of being overlooked and dismissed can lead individuals to resort to substances or engage in unhealthy behaviors as coping mechanisms. It can also instigate doubts about one's own perceptions and understanding of reality. Therefore, it is crucial to establish a structured strategy to facilitate the establishment of a sturdy framework for healing.

Family members who lack sensitivity may urge you to "move on" from your trauma or label you as weak and overly emotional due to their inability to comprehend it. Despite their well-intentioned efforts, such comments can exacerbate the distress of someone who is already vulnerable. Additionally, it is not uncommon for family members to deny the existence of trauma, particularly if it transpired within the confines of the home.

Instances like child abuse often evoke denial, particularly within familial settings. The Centers for Disease Control and Prevention (CDC) report that 91% of child sexual abuse cases are perpetrated by individuals known and trusted by the child or their family members. Such traumatic experiences can result in significant ruptures within family dynamics.

Certain individuals might prioritize maintaining a façade, choosing to ignore the reality of the situation. Alternatively, some may struggle to grasp the concept of a trusted figure causing harm to a child. Regardless of the rationale behind such reactions, they do not justify the lack of acknowledgment or support. It is imperative that you receive the utmost compassion and support in navigating your trauma.

Initiating the healing process for trauma involves establishing healthy boundaries, particularly with individuals who invalidate your experiences. Expressing how their words and behaviors impact you can be empowering. Additionally, informing them that you are prioritizing your healing journey and may not be available for support or assistance can reinforce the importance of self-care.

Discussing your trauma with individuals who don't believe you can exacerbate your emotional distress. In such situations, it's beneficial to reserve these discussions for individuals who provide support and understanding. Some trauma recovery programs offer a safe and

nurturing environment conducive to healing. I had to go the alternative route to be believed and shown empathy.

## Witness Testimony: Acupuncturist

When (date of time frame) did you meet Josette, and under what circumstances? How did she seem? What did you observe? What signs and symptoms did she describe?

- Ms. Pelatan had her first appointment with me on September 12, 2020.
- <u>Complaints:</u> Partial blindness, anxiety, chest pressure, depression, PTSD, Shortness of breath, loss of balance, tremors, cognitive difficulty (earthquake feeling), needle piercing sensation on her skull, left facial area numbness, migraine headache, fatigue and burning sensation on her whole spine at night, episodes of seizures, mood swings that started 7 years ago. Patient also reported a medical history of allergies, mononucleosis, asthma, breast lumps, heart disease, auto-immune disorder, emotional imbalance, and shingles along with multiple significant traumas. Although she sleeps 8 hours a night, the sleep quality is affected by nightmares and restlessness. The bowel movement is relatively regular but difficult to pass and there is a presence of hemorrhoids.
- <u>Appearance:</u> The first time I met Ms. Pelatan, she was agitated because the whole left side of her body was numb, had some tremors and had difficulty answering the examination questions. In my experience, the patient was experiencing an inflammatory flare up.
- <u>Diagnosis:</u> According to signs and symptoms, the Chinese medicine pattern is one of heart blood and spleen qi deficiency.
- Treatment: Acupuncture and food recommendations
- <u>Follow up: I gave acupuncture treatments to Mrs. Pelatan 29 times between September 12, 2020, and October 24, 2023. The patient reported symptoms decreased after the majority of treatments; on a few occasions, the burning pain on spine didn't abate.</u>

## JOSETTE CHRISTINE MARIE PELATAN

### Indicaciones medicas

- Dieta normal Premedicacion:
- 2. Difenhidramina 20 mg IV DU
- 3. Hidrocortisona 150 mg IV DU
- Paracetamol 1 gr IV DU 30 minutos después
- Rituximab 500 mg en 500 cc de SF al 0.9% para 4 horas, Iniciar a 30 cc/hr e internediendo paulatinamente hasta dosis fina a 4 hra (125cc/hr)
- 6. Vigilar Rash cutaneo, en caso de aparecer bajar velocidad de infusion y avisar
- 7. SV cada 30 mins durante aplicación

## Illustration 24: First Rituximab treatment

Josette now has access to treatment in Mexico (500ml Rituximab infusions every 3 to 6 months), and her diagnosis is now narrowed in the US to MOGAD and MS and/or other potential demyelinating disease (As of 01/10/24). Were there any points throughout the time you have known Josette, that the medical concerns she claimed to have and/or have had, might have been due to hypochondria, and/or simply due to severe Complex-PTSD, and/or that she was just seeking attention.

Under the scope of my practice, it is my responsibility to only evaluate the signs, symptoms, and medical issues and history reported by the patients. It is however my experience that patients who experience conditions like severe pain, loss of motor or sensory abilities, chronic insomnia, or heightened emotions (anger, anxiety, depression, sadness, fear, etc.) present in my clinic in a state of distress. Given her positive response to treatments, I suspect Mrs. Pelatan suffers from physical issues exacerbated by past emotional traumas.

In 2014, she started complaining of swollen lymph nodes (neck), fatigue, and feeling generally unwell. This escalated in length and severity with added symptoms. If there was any point at which you stopped questioning the validity of her medical concerns being beyond mental health, what prompted your stand?

I started seeing Ms. Pelatan on September 12, 2020. As I mentioned in my answer to Question 2, I only evaluate the signs, symptoms and medical issues and history reported by the patient in front of me. I never questioned Ms. Pelatan's reports on each visit. Part of the acupuncture treatment is to help regulate the central nervous system which typically diminishes the pain response. The fact that there were some residual physical symptoms left after an acupuncture treatment suggested that there was a deeper inflammation response existing.

Josette finds purpose in believing she will obtain a stem cell transplant and recover fully against all odds. She also believes she will overcome all her financial struggles through an intensive social justice involvement to expose the medical system and win personal medical malpractice cases. Knowing all that you know, how realistic is this? Why or why not?

I believe any system is built to accomplish a specific valuable purpose. Over time, changes occur, and improvements may be necessary to help the system evolve. I think if injustices occurred within a system, it is important to help that system improve by presenting solid facts and measurable data to the right channel or institution. Although a tedious task, it is the most realistic way to contribute to the bigger change.

A significant majority, approximately two-thirds (62%), of adults residing in the United States have encountered a minimum of one ACE (Merrick et al., 2018). Advocates advocating for necessary policy measures to prevent and alleviate the repercussions of this exposure strategically highlight various forms of scientific evidence. These encompass evidence pertaining to bodily health (Hughes et al., 2017; Sonu et al., 2019), social health (Afifi et al., 2008; Lee et al., 2020; Dube et al., 2003), disparities in health among racial and ethnic assemblies (LaBrenz et al., 2020), the economic burden of ACEs on society and public systems (Fang et al., 2012), and physiological impacts and epigenetic alterations (refer to Supplementary Appendix 2 for additional evidence) (McLaughlin et al., 2013; Lang et al., 2019).

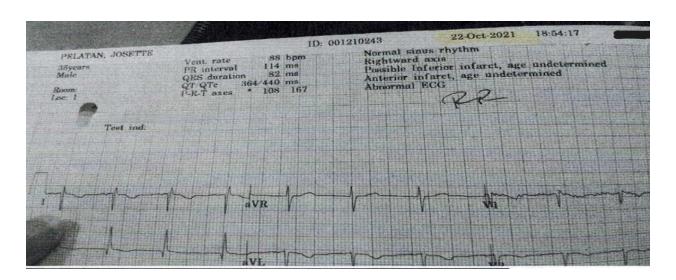
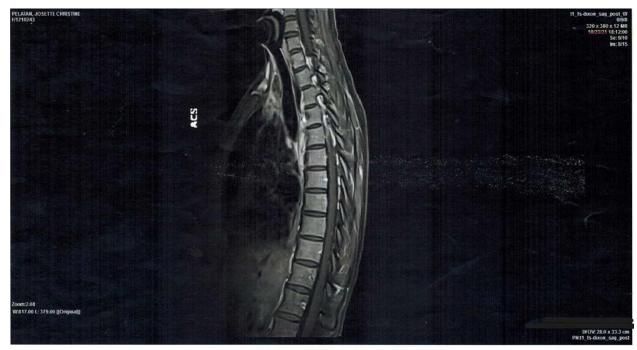


Illustration 25: Infarct



**Acute Coronary Syndrome** 

Illustration 26: Acute Coronary Syndrome

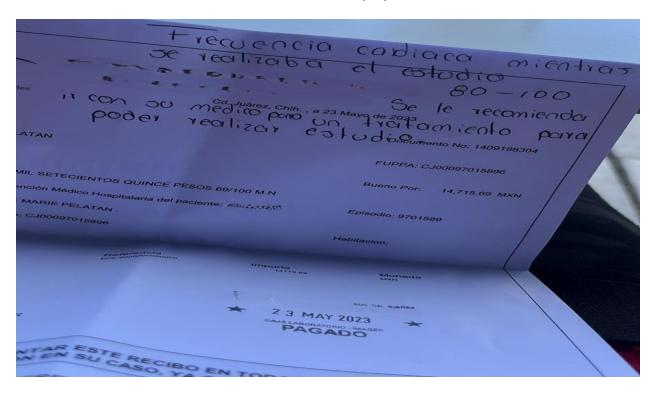


Illustration 27: Cardiac Frequency

## 4.2.4 Hypochondria

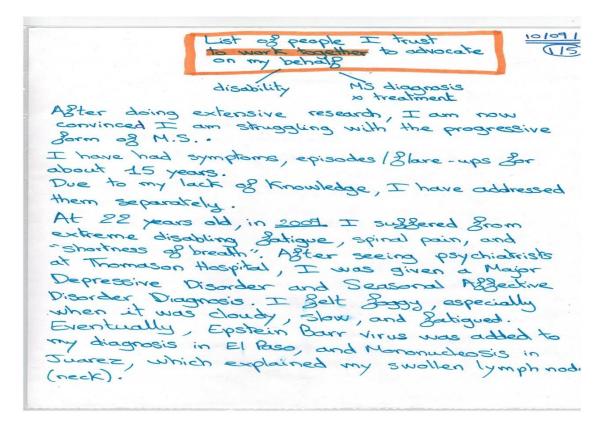


Illustration 28: Cry for Help (1/4)

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For years on end these symptoms came back lasting anywhere from a few hours, to eventually weeks a months, and increasing in severity a recurrence.

The fatigue, forgoines, were accompanied by a so-called seizure disorder suspected to be due to ongoing stressors and traumas.

At 26, my hip started hurting ... again sometime lasting few hours with period of remission, and sometimes weeks on end. In 2018, the pain became so bad that I saw a doctor who injected me with a steroid. He said it was most likely Bursitis. (Dr. 12 illi: 12)

In 2018, I was no longer able to function and developped excautialing spinal as hip pain, especially at right accompanied by chest pain a severe shortness of breath.

My x-rays, blood tests, and wrine tests were perfect, as usual. My heart a lunger were said
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Illustration 29: Cry for Help (2/4)

Nowadays I struggle with basic Burchioming The HS hug makes me diszy. The Baginess & Balique do not allow me to keep up with school, not keep a job.

I consider myself to be very hard working, and I swear than I am not exaggerating any 8 this. In Bact, it is quite likely that I am Braetting many important details to help my case.

I cannot keep a job. I cannot keep a roof.

The PhD program & the FHAR program (\* Fater & Homeless & Adopted Resources) at with a are running out of options to keep me in the program and in the dormitories, as I do not have any compelling medical evidence to help my case.

I am willing to disclose every lany information about every lany aspects of my life.

Illustration 30: Cry for Help (3/4)

Though I have gone homeless twice since 2018 and that some documents were certainly last in transition, I have Kept plenty. Including proof I was Seen by a specialist ALSO in 2018 for Amaurosis Sugax.

Please Sind attached a list of people that can attest I am hardworking, trustworthy, have known me for a while and can confirm the organcy of my state.

*Illustration 30*: Cry for help (4/4)

Because my best friend still believes to this day that I live with hypochondria, I felt compelled to conduct a brief section on it. Being concerned about health to varying degrees (Freeston et al. 1994) is to be expected when experiencing partial vision loss and cognitive issues. Specific medical conditions such as Multiple Sclerosis (MS) are alleged to be especially anxietyproducing, generating substantial unease and anxiety about health. When asked whether they thought they worried more about their health than most people, 62% of participants with MS agreed (Taillefer et al. 2003). Anxiety about health as an independent concept from generalized anxiety, nonetheless, has not been researched steadily within this populace. My present study asks for a better understanding of health anxiety amid people with MS and/or MOGAD. MS is an erratic, gradual neurological disorder caused by demyelination of the nerve fibers of the central nervous system. Aside from physical (e.g., spasticity, pain) and neuropsychological symptoms (e.g., cognitive dysfunction), people with MS and MOGAD also experience various psychological symptoms. The occurrence of Major Depressive Disorder is approximately 50% for people with MS, but point-prevalence approximations range from 14 to 57% (see Mohr and Cox, 2001; Pakenham, 1999). Contrasted with the literature on depression, generalized anxiety prevalence in people with MS is scarce. Prevalence rates for anxiety have been found to range from 19 to 34% (Mohr and Cox, 2001). In one study (Feinstein et al., 1999), anxiety was found to be more prevalent than depression (15.8% anxiety only compared to 4.6% depression only). In another study, higher state and trait anxiety has been associated with moderate physical disability in participants with MS (Stenager et al., 1994). Very little research has been conducted on MOGAD or seronegative MOGAD as these were recently still assumed to be a form of MS, and an even harder one to diagnose as lesions come and go.

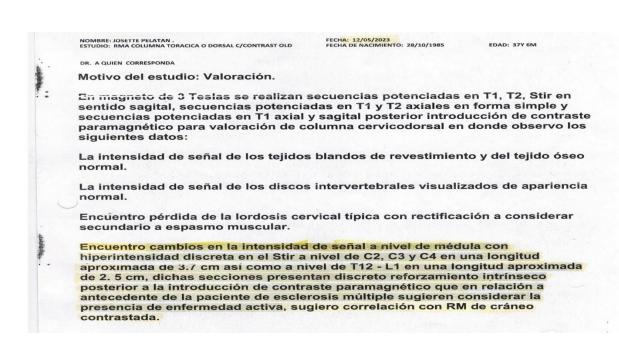


Illustration 31: Hyperintensity

MRI Spine Thoracic w/o Contrast – Order ID: 2723395189  Requested Start 01/10/24 10:39:00 MST Date/Time: Priority: ASAP Priority: Routine Reason For Exam – DCP: Other (please specify) Reason For Exam: demyelinating disease of unknown reason, currentl beeing tested for Mogac MS ICD-10-CM: G37.9 – Demyelinating disease of central riervolus system, unspecified CPT Code: 72146	_		ma ) ( 1/1/20)	
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43.12			sease of central nervous s	ystem, unspecified

Illustration 32: First hope in the United States

#### THE NEED FOR CCSVI Testing AND Treatment Hope

CCSVI stands for chronic cerebral-spinal venous insufficiency which means impaired blood flow from the brain back to the heart. In most cases, such problematic blood flow results from blockages in the one or both of the internal jugular veins which carry most of the blood from the brain when one is lying down. Such blockages have a variety of causes including internal structures such as webs, the occurrence of malformed valves, and external pressure on the veins from bone, muscle or an artery.

#### CCSVI AND MS

CCSVI was found to occur in most persons with MS by numerous researchers and practitioners over the last 6 years. Unfortunately, because CCSVI relief can potentially eliminate the need for MS drugs, MS researchers who are generously funded by drug companies have mounted a disinformation campaign about CCSVI and, by using inadequate and highly questionable research methods, some have claimed CCSVI does not exist.

Overall, the available data leaves no reasonable doubt that CCSVI exists and that it is highly associated with MS. Furthermore, the occurrence of CCSVI fits well with the MS disease process in that it causes the veins in the brain to become leaky and to allow the easy passage of the immune system into the brain. This in turn greatly increases central nervous system inflammation which is the undisputed hallmark of MS.

#### TESTING FOR AND TREATING CCSVI

Anyone with MS, especially those in the early phase, should be tested to see if they have CCSVI. There is about a 90-95% chance that they do. Such testing must be done by a facility which has a solid track record of being able to recognize CCSVI. Once the presence of CCSVI has been determined, it is important to have the vein blockages opened up if possible. In most cases CCSVI can be treated with angioplasty of one or both of the jugular veins and, in rare cases, one or more of other veins which drain the brain.

### BENEFITS

By restoring proper blood flow from the brain, the veins of the brain can then strengthen their walls and greatly reduce by testiming proper blood how from the brain, the veries of the brain can then strengthen their wails and greatly red the leakiness that allows problematic immune cells to enter the brain. This in turn reduces inflammation and allows healing in the brain and the lessening of symptoms. Of course, CCSVI treatment in conjunction with the nutritional strategies which also reduce inflammation and strengthen the veins can be very effective for promoting well being and the resolution of such symptoms as brain fog, fatigue and bladder problems. Many people have reported major improvement following CCSVI treatment and practitioners report about one third of their clients enjoy substantial benefits with another third having miner benefits. benefits with another third having minor benefit.

Tens of thousands of CCSVI treatments have been done in clinics in numerous countries and serious side effects have been extremely rare. Overall CCSVI has a far better safety record than the current MS drugs and is considered a very

#### REOCCURRENCE OF CCSVI

In many cases (estimated to be at least 50%) the blockages in the jugular veins reoccur and the problems associated with CCSVI return. Currently there is no reliable way to prevent this from happening or to reverse the repeat blockages outside of having angioplasty again.

Anecdotally it has been found that vigourous exercise, which substantially increases blood flow to and from the brain,

## FINDING A CCSVI CLINIC

To find a reliable clinic for CCSVI testing and treatment, it is necessary to go online and to get advice from persons who have had it done. MS neurologists who are compromised by their close association with drug companies will not provide reliable information regarding CCSVI.

The two best sites for CCSVI information are:

Facebook CCSVI in MS-(https://www.facebook.com/pages/CCSVI-in-Multiple-Sclerosis/110796282297)

& Dayton Interventional Radiology (http://daytonir.com/)
MS Hope has plans to compile and maintain an up-to-date list of reliable clinics and their contact information

*Illustration 33*: Correlating the path & looking for, finding, & creating Hope

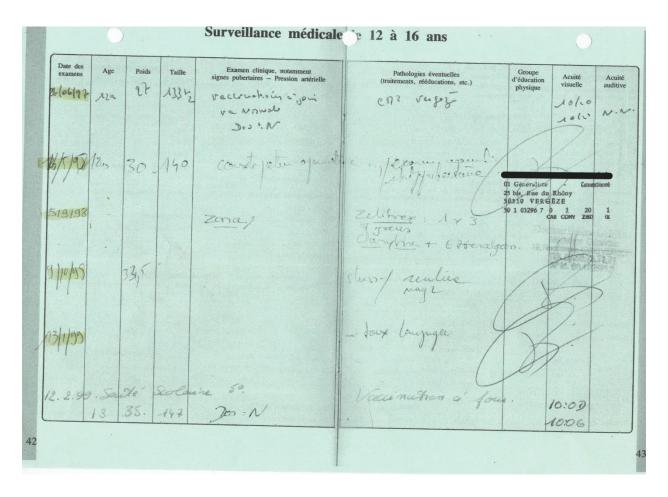
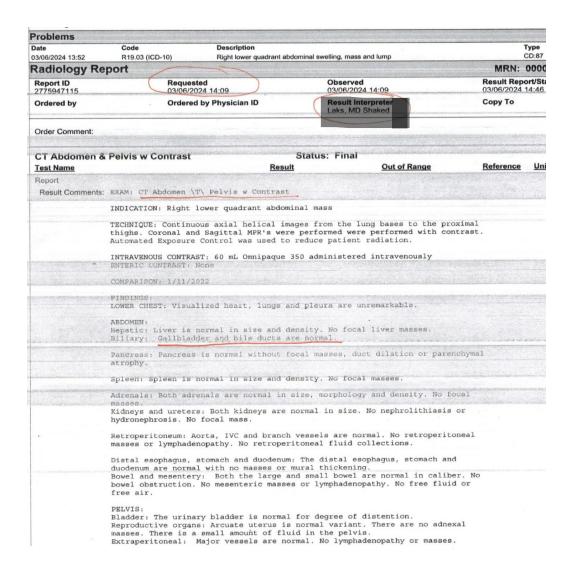


Illustration 34: Chicken Pox, Measles & Shingles

Maladies	Date	Observations Complications	Signature et cachet du médecin
Varicelle	23/12/88	01 - Gé 25 lais, rue d 30310 30 1 00122	
Coqueluche			
Oreillons			* 3
Rougeole	2/93		
Rubéole			7307
Scarlatine			
Diphtérie			
Typhoïde			

Illustration 35: Chicken Pox, Measles right after getting vaccinated



*Illustration 36:* The Funny Thing is "Gallbladder"

If the pharmaceutical industry had not fully protected all hospitals and medical practitioners in the State of Texas, the above report could have been accepted as my 7<sup>th</sup> medical malpractice case within three years, by medical malpractice lawyers. My gallbladder described here as "normal" had previously been removed in Mexico and should have therefore been listed as "missing".

# 5. Chapter V: Implications and Conclusion

# **5.1 Implications of Findings**

Here, I delineate the implications of this autoethnography for clinical, personal, and academic practice, research, and policy.

## **5.2 Clinical Implications**

The primary clinical implication drawn from this study underscores the imperative of recognizing and enhancing patients' involvement in the care of individuals grappling with chronic undiagnosed conditions. Advocacy plays a crucial role in offering support to navigating chronic undiagnosed illnesses. While existing research extensively covers nursing and interventions for various chronic conditions, it notably lacks emphasis on those tailored for individuals with undiagnosed illnesses. Given that many patients with chronic undiagnosed conditions frequent outpatient settings, where they predominantly interact with physicians and auxiliary technical personnel, the inclusion of self-care education and drastic brain rewiring techniques is vital. Addressing care coordination underscores patient-centered care coordination as a fundamental professional standard and competency across nursing practice (Camicia et al., 2013).

One of the areas earmarked for healthcare system reform involves devising an evidence-based framework for care coordination and transition management, particularly for chronically ill patients in outpatient settings (Haas & Swan, 2014). Leveraging the expertise of advanced practices in care coordination could offer an effective care delivery model for individuals grappling with chronic undiagnosed illnesses. It is imperative for any profession to explore avenues for identifying and providing care to struggling individuals to obtain a diagnosis, whether in inpatient or outpatient settings. While initiatives like the Undiagnosed Diseases Network (Spillman et al.,

2017; Undiagnosed Diseases Network, 2019) are commendable for their efforts to diagnose patients with undiagnosed illnesses, their reach is limited, and their primary focus on diagnosis and treatment may not adequately address the needs of a broader population living with undiagnosed illnesses.

The emphasis on the diagnostic "quest" overlooks the psychosocial challenges associated with living with an undiagnosed illness, such as managing or adapting to an unknown condition in everyday life. As someone who navigated life with an undiagnosed illness for years, I would have greatly appreciated the opportunity to connect with others facing similar experiences. Establishing support groups for individuals with undiagnosed illnesses is essential to help them cope with feelings of isolation and the complexities of living with a concealed identity.

Another significant clinical practice implication arising from this study is the imperative for patient-centered care and holistic strategies in addressing individuals with chronic undiagnosed illnesses. Patient-centered care, endorsed by the medical and public health fields (Institute of Medicine, 2001), underscores the importance of considering a patient's desires, values, and concerns, positioning them at the forefront of care and treatment decisions. This approach contrasts with disease-centered models and seeks to actively engage patients in their care plans and goals. It encompasses not only an objective evaluation of the patient's condition but also an exploration of their subjective experience of illness (Liberati et al., 2015). This study underscores the necessity of integrating the patient's subjective experience of illness into both patient-centered and holistic care approaches.

The findings have significant implications for mental health, social justice advocacy, and medical education. Caring for individuals with chronic undiagnosed illnesses should be integrated into education across all levels, including pre-licensure, advanced practice, master's level, and

doctoral programs, without leaving out those most vulnerable, lacking a support system and financial stability.

It is imperative that medical curricula incorporate teachings on the experiential aspects of illness alongside the biophysical aspects. Patient narratives regarding illness are invaluable tools for conveying the patient's firsthand experience to medical and nursing students, fostering empathy among future healthcare professionals. Wear (2000), a prominent figure in medical education, criticizes the reliance on traditional scientific methodologies, emphasizing the importance of understanding the human experience of health and illness alongside functional knowledge. She advocates for an approach that allows students to engage in meaning-making within their learning process, enabling a deeper comprehension of the complexities inherent in health and disease.

Robert Nussbaum (2017) stands out as a key physician-researcher who played a pivotal role in identifying alpha-synuclein as the inaugural Parkinson's disease gene in 1997. Less common hereditary variations of Parkinson's disease represent a minority within the spectrum of the condition. Insights gained from studying genetic variants of Parkinson's have not only enhanced our understanding of specific forms but have also yielded novel therapeutic approaches, thereby illustrating how research into uncommon manifestations can enrich our comprehension of more prevalent presentations. Nussbaum (2017) harkens back to William Harvey's assertion in 1657, emphasizing that nature often reveals its hidden intricacies most conspicuously in atypical cases, which, when meticulously investigated, can significantly advance medical knowledge and practice.

Therefore, it is essential for interdisciplinary health sciences and medical social justice education to adopt a cautious approach when relying solely on disease archetypes as a teaching method. Balancing instruction on archetypes with lessons on the atypical manifestation of

symptoms is imperative, supplemented by the inclusion of case studies involving patients with undiagnosed illnesses (although such resources are currently lacking). While archetypes and standardized symptom patterns have proven valuable in nursing and medical education by facilitating the association of symptom profiles with specific ailments (Welk, 2002), it is equally crucial to acknowledge the existence of atypical disease presentations, which may be more prevalent among individuals with chronic undiagnosed conditions. Consequently, textbooks should be updated to reflect the latest medical research findings. Newer research on atypical Parkinson's syndromes, often overlooked in medical education (Levin et al., 2016; Marras & Lang, 2017), highlights the limitations of relying solely on traditional archetypes. These archetypes, once ingrained, may hinder the recognition of alternative signs that could potentially indicate a diagnosis, reflecting outdated knowledge. Moreover, they may fail to encompass symptoms that are not readily observable.

Hermanns' ethnography (2013) delved into the personal experiences of individuals with Parkinson's disease (PD), revealing a crucial dichotomy between visible and invisible symptoms of the illness, both of which carry their own stigma. The study identified invisible symptoms as a source of stigmatization, leading to shifts in self-perception, a sense of identity alteration due to PD, and a feeling of disability, all of which contribute to heightened self-seclusion. Additionally, invisible symptoms were associated with feelings of uncertainty and fear stemming from the unknown aspects of the condition. The study highlighted the stigma faced by individuals with invisible disabilities, as they may appear capable of performing tasks that they struggle with due to their condition (Hermanns, 2013). This misconception can lead to them being wrongly perceived as noncompliant. Neurological disorders, in particular, present difficulties as many symptoms are

not readily apparent. For instance, multiple sclerosis manifests symptoms like numbness, blurred vision, weakness, and paresthesia, which may go unnoticed by others.

Similarly, Parkinson's disease patients grapple with non-motor symptoms such as autonomic nervous system issues, cognitive impairments, and fatigue, which are often invisible to outsiders. Consequently, there is a pressing need for intervention strategies to support individuals living with chronic undiagnosed illnesses. Individuals grappling with chronic undiagnosed illnesses may necessitate extended interactions with healthcare providers, wherein inquiries should encompass not just physical but also mental health aspects, such as feelings of social isolation. Typically, interventions are triggered by a formal diagnosis. However, in my experience, symptom management was paramount, yet medical consultations primarily revolved around pinpointing the illness, often discarded for severe mental health conditions. Whether or not this discarding and/or redirecting of diagnoses were accurate, no basic help was provided aside from medicine. The likelihood of recovering from severe and very disabling mental health conditions while facing a lack of support and housing insecurity is quite low. The provision of housing, running water, and healthy alimentation, with the support of incorporating new healthy routines, are all indispensable to recovery, for both mental and physical health. Groups such as the Food and Housing Equity Council at UTEP are a nesting ground in endeavoring a future with hope for those that lack basic needs.

Interventions aimed at alleviating symptoms like bladder and gastrointestinal complications, autonomic nervous system dysfunctions, and fatigue could have significantly enhanced my quality of life despite the absence of a diagnosis. Interventions for individuals facing chronic undiagnosed illnesses should extend to addressing their psychosocial and cultural encounters with illness.

## **5.3 Research Implications**

This autoethnography serves as a springboard for a forthcoming interdisciplinary research agenda, not only targeting patients with chronic undiagnosed illnesses, but also public health and social justice policies to aid and protect the most vulnerable players of this capitalist game. Addressing issues of potentially intentional medical malpractice by funding groups willing to practice judiciary social justice terrain might contribute to a fairer redesigning of the pharmaceutical siege one may be trapped in. Further investigation, employing both quantitative and qualitative methodologies, is imperative to guide effective care provision for this demographic. Exploration into chronic undiagnosed illnesses aligns with several focal areas outlined in the National Institute of Nursing Research's (NINR, 2016) existing strategic blueprint.

Promoting wellness involves grasping the impact of physical, behavioral, cultural, and environmental factors on health status and crafting interventions customized to specific cultures to prevent illness and foster well-being, and assisting individuals grappling with chronic health issues entails empowering them to comprehend and take charge of their conditions, engaging them as proactive participants in their health management, cannot be separated from socio-economic issues.

This autoethnography of an individual that has lived with both, mental health concerns and with chronic undiagnosed illness, no justice would be done to this research by living out the paranoia held from a system that has mistreated me, likely due to my socio-economic standing. A significant takeaway from this autoethnography is the scarcity of social justice and medical research on addressing patients with undiagnosed illnesses. There is a clear call for research studies employing both quantitative and qualitative methodologies. The epidemiology of chronic undiagnosed illness can be explored using quantitative methods such as surveillance data analysis,

population trend assessments, and community-level data analysis to evaluate factors like morbidity, mortality, and disease impact associated with undiagnosed illness (Gordis, 2014).

Quantitative surveys offer a valuable tool for pinpointing barriers to care among patients grappling with a chronic undiagnosed illness and gauging the quality of life using established quantitative instruments. Additionally, quantitative intervention studies hold promise for pinpointing nursing interventions and gauging their efficacy in managing individuals with chronic undiagnosed illnesses. The necessity for further qualitative research into patients with chronic undiagnosed illnesses is underscored, allowing for a deeper analysis of their illness experience. In this study, autoethnography has showcased its efficacy in uncovering cultural influences and contextual relevance to illness experience. Ethnographic research, which entails conducting interviews with individuals living with chronic undiagnosed illness, could be leveraged to expand our understanding of navigating life with such conditions.

It is imperative to conduct studies that document how cultural life and identity are affected by chronic undiagnosed illness. Additionally, various qualitative methodologies such as grounded theory and phenomenology offer promising avenues for exploring the lived experience of individuals grappling with chronic undiagnosed illness. Exploring individual experiences through case studies focusing on chronic undiagnosed illness is crucial for gaining insight into the diverse ways people navigate their health challenges. Using focus groups in nursing research presents an opportunity to delve deeper into the collective experiences of patients grappling with undiagnosed conditions. Additionally, investigating self-management strategies for undiagnosed illness warrants attention, employing quantitative and qualitative methodologies to understand the efficacy and impact of holistic or complementary self-care practices. As articulated by the NINR

(2016), nursing science endeavors to transcend conventional disease-centric approaches, aiming instead to comprehend the nuanced experiences of individuals and families living with illness.

Through such understanding, personalized interventions can be developed to optimize health and well-being across various life stages, populations, and healthcare settings. Tailoring care to individual needs requires a qualitative exploration of the patient's unique journey, emphasizing their subjective experience. Furthermore, future investigations should adopt a health equity perspective to discern the impact of health disparities on the landscape of chronic undiagnosed illness. It is essential to recognize that communities of color and those with lower socioeconomic status encounter heightened barriers to accessing healthcare services and diagnostic procedures, exacerbating the complexities of obtaining a diagnosis in cases of chronic undiagnosed illness (LaViest & Isaac, 2013).

# Context Critical to Studying Illness

One significant implication drawn from my autoethnography is the recognition of the importance of analyzing the patient's social context in understanding their illness experience. Throughout this study, delving into the realms of family, social, and professional environments revealed that my illness was not solely characterized by physical symptoms. Instead, my perception and encounter were profoundly influenced by the cultural norms, values, and assumptions prevalent within these diverse settings.

Moreover, this research underscores the dual perspective of a financially vulnerable woman grappling with an undiagnosed chronic illness. Karen O'Reilly, a sociologist and ethnographer, introduces the concept of practice stories, emphasizing the need to illuminate the intricacies of individuals' lives, comprehend cultural nuances, and challenge stereotypes and generalizations (Patton, 2015, p. 131). Amid the prevailing focus on patient-centered care, the necessity of

pinpointing suitable research methodologies capable of encapsulating the intricate social dynamics of healthcare encounters becomes increasingly apparent.

Present investigations into patient-centered care often fall short in comprehensively capturing the array of practices, relationships, and viewpoints constituting the patient's journey within healthcare settings (Liberati et al., 2015). To bridge this gap, Liberati et al. advocate for the adoption of ethnography and reflexivity as research methodologies aimed at translating the implicit knowledge embedded within everyday practice into actionable insights. Additionally, the authors propose that insights gleaned from the direct encounters of healthcare providers and patients within care environments can enrich the understanding of patient-centered care (Liberati et al., 2015). Such experiential knowledge often takes a backseat in biomedical science.

Leeman and Sandelowski (2012) underscore the necessity of incorporating evidence pertaining to experiences and methodologies of healthcare providers in authentic clinical settings. They highlight the prevalent trend wherein research literature systematically overlooks practice-based evidence or insights derived from perceptions, practices, clinical observations, or professional experiences.

## Autoethnographic Research on Illness Experience

The methodology employed in this autoethnography draws from the analytic framework outlined by Anderson (2006). It emphasizes the significance of analytic reflexivity and theoretical examination of the autoethnographic data. According to Anderson, an analytic autoethnography necessitates an ongoing dialogue across various data sources to enhance the qualitative robustness of the research. Consistency and corroboration among different data sources are vital aspects of this approach. Wall (2016) raises concerns regarding the analytical rigor of certain

autoethnographies, advocating for thorough analysis that encompasses observation, participation, and utilization of multiple data sources.

In alignment with Anderson's framework, this study integrates material and visual data sources to conduct an analytic autoethnography. This autoethnography adhered to the criteria outlined for analytic autoethnography (Anderson, 2006) as well as Wall's (2016) guidelines. Initially, I harbored concerns that failing to emphasize the emotive aspect of my illness experience might hinder a comprehensive understanding of the personal dimension. However, employing the analytic autoethnographic method revealed that adopting a systematic approach not only encapsulated the emotional essence of the experience but also facilitated a nuanced depiction and narrative of the encounter with undiagnosed illness, encompassing its social and professional contexts. Without the analytical framework, the study would have been confined to a rudimentary narrative analysis focusing solely on symptoms, neglecting the broader experience of my undiagnosed illness.

The analytic approach facilitated an exploration of the social and cultural facets of illness, as perceived through my journey, and questioned throughout this writing process. These findings have significant implications for researchers contemplating which autoethnographic approach to employ in their studies. The analytic method aligned well with established qualitative research standards, employing narrative and thematic analysis to generate findings that were consistent across various data sources and timelines. This suggests that other researchers could confidently utilize analytic and critical autoethnography to explore diverse research topics, as the approach maintains scientific rigor while also acknowledging and exploring the emotive dimensions of the illness experience.

My adoption of an analytic approach to autoethnography embodies a person-centered ethos in ethnographic research. Robert LeVine, an anthropologist renowned for his contributions to psychological anthropology, advocated for a similar approach termed person-centered ethnography (Gaines, 2015). This perspective posits that when a discipline imposes its abstract conception of culture onto individuals, it risks overlooking nuanced and meaningful cultural experiences of individuals (Hollan, 2001). Employing a person-centered approach involves initiating from the individual and prompting them to contemplate their own cultural background.

Robert Levy, an anthropologist and psychiatrist, introduced the concept of "person-centered ethnography" to delineate an ethnographic method focused on how individuals interpret their experiences, encompassing aspects such as self-perception, morality, physical health, emotional states, and familial dynamics within broader sociocultural frameworks (Levy & Hollan, 1998). By commencing with my own encounter with illness and subsequently exploring its cultural underpinnings, I have embraced a person-centered ethnographic stance. The examination of undiagnosed illness, as elucidated in this autoethnography, benefits from an inductive approach that commences with individual experiences before delving into broader cultural contexts. The holistic examination of illness experiences requires patient-centered approaches (Liberati et al., 2015), incorporating LeVine and Levy's method (1998).

A potential avenue for future research could entail a meta-analysis of multiple autoethnographies pertaining to individuals navigating chronic illness amidst societal incomprehension, stigma, and financial insecurity. Research is required to delve into the personal experiences of people with illness and how the dual role of being both diagnosed with mental health conditions impacts the journey to obtain a physical diagnosis, and what this means for advocacy practices. Grappling with undiagnosed illnesses can exacerbate psychosocial stress,

particularly stemming from the uncertainty surrounding their diagnosis. Furthermore, the norms prevalent within the mental health professions also exert an influence on the experience of those living with chronic undiagnosed illness.

## **5.4 Policy Implications**

Interdisciplinary Health Sciences Ph.D. Program can play a pivotal role in advocating for individuals grappling with a chronic undiagnosed illness, not only by championing broader social policies geared towards assisting such individuals but also by advocating at various levels of care, including individual, family, community, and population levels. Propelling policies that cater to the needs of those with chronic undiagnosed illness resonates with the endeavor to try to connect all medical research by giving voice to patients and providing them with medical exams that might not be affordable outside of the research context, which underscores the profession's commitment to advocating for societal issues in healthcare.

This statement underscores the imperative to expand social justice and healthcare knowledge, rooted in the understanding that healthcare encompasses the cultural perspectives, values, and beliefs of the individuals receiving care. Advocacy can help shed light on a patient demographic that remains largely overlooked in the research literature, thereby addressing the unmet needs within this population. Research and analysis in policymaking are essential to assess whether the absence of a diagnosis presents obstacles for individuals grappling with chronic undiagnosed illness in accessing federal and state disability benefits and legal protections. It is imperative to identify policy reforms pertinent to individuals enduring chronic undiagnosed illnesses. Future policy analysis should engage disability rights organizations alongside the health sciences and social work profession in addressing this issue.

Public health policy analysts should forge partnerships with other entities to promote a policy agenda that caters to the needs of those living with a chronic undiagnosed illness. Additionally, advocacy education for the allocation of public and private funds to research initiatives focused on individuals with chronic undiagnosed illness at local, national, and international levels. In federal advocacy for healthcare research priorities, medical personnel should incorporate patients grappling with chronic undiagnosed illness as a demographic warranting attention. On an individual scale, health care research advocacy is imperative for individuals enduring chronic undiagnosed illness. This could manifest through direct care interactions with patients or involvement in support groups, where everyone plays a pivotal role in facilitating care. In instances of care coordination, case management, and patient navigation, medical practitioners can deliver comprehensive, patient-centered care to those with chronic undiagnosed illness by prioritizing the patient's overall illness experience.

## **5.5 Educational Implications**

Pondering upon my long journey and reflecting on my identity as a student and an instructor, I feel that education is what has saved me. Because of the knowledge I acquired along the way, I was able to research my rights, access the data I need to better advocate for my needs, and find empowerment in a greater purpose.

Thanks to post-traumatic growth, I now see that my past roadblocks were all steppingstones to reach much higher ground than I could have ever envisioned otherwise. I feel that most people know what they need in order to move forward in life but that the right support is often lacking or hard to access. What I needed the most was to change my mindset and habits to overcome chronic

mental health concerns. I now feel confident to have done so. The journey was, however, incredibly difficult, and I, unlike many others, had the luxury of being an instructor.

I knew that I needed to incorporate affirmation, gratefulness, and breathing exercises, surround myself with positive encouraging, and inspiring messages. Unfortunately, like most people living with depression, willpower and energy were scarce, and hope often felt absent. Stuck in a loop, yet recalling the power I had found in wanting to fight for myself as I would have done for a child of mine, I began teaching from home. I did so to continue to make a living without having to worry about getting around. This was also a way to force me to clean up and get up on a daily basis. The classes I offered were mostly language classes, and whether private or small group classes, I began incorporating daily readings in the target language strategically grounded in empowering stories.

My students were aware that my classes would start with 5 minutes of breathing exercises, followed by 5 minutes of meditation, 5 minutes of affirmations, and 5 minutes of gratefulness practices, all encouraging the target language whenever possible. The reading of an inspiring story followed, then the discussion of it, and the encouragement of an inspiring story of their lives or a visualization of their success, narrated in the present tense as if they had already attained it. The wrapping up of each class was a written practice that revolved around writing about positive quotes and stories they had read or heard, and then by listening to a TED talk or vesting commercial.

I had been told years ago that I could not have more than one therapist at a time, supposedly because it could cause a worsening of mental health issues. I knew I needed several hours a week, and therefore, I sought different therapies by avoiding mentioning this fact to my therapists. Soon, I had found a therapist who made me listen to the loving messages of my parents while imagining myself safe and loved as a fetus, another to simply vent over my worries, one to practice cognitive behavioral therapy. As if the universe was conspiring in my favor, an EMDR therapist pro-bono

through one of my committee members. When I could afford it, I attended meditation groups, acupuncture, and reiki sessions. I even joined a Constellation in Juarez.

I feel that all these tools I was incorporating were absolutely needed and crucial in making it this far. Thanks to all the help I received and kept on seeking, I was able to keep advocating for my case. Although far from being where I envision myself to be, I finally have access to medical discounts through financial assistance provided to individuals in need. The type of financial assistance depends on one's income, the number of people in the household and where one lives. Interestingly enough, after I struggled to access this program, the hospital forwarded my medical delinquents fees to a collection's agency, preventing me from qualifying for Credit Cards.

Effective August 1, 2007, the Healthcare Options (Indigent Health Care) Program in the United States, a free social worker, and a free psychiatrist, and most importantly, now hold the credibility of a demyelinating disease with hope of a diagnosis closer than ever in the United States. The purpose of education might be different for us all, but I hope that we all agree that health, both mental and physical, is at the core of our achievement and productivity. With this basic understanding, I feel that educational policies must be crafted around the betterment of our health and the benefit of us all, leaving aside competitions, and envisioning growth. If academia and education at all ages incorporated breathing techniques, empowering messages that represented all our struggling students, and even meditation, I have little to no doubt that we would provide our children with easier access to their untapped potential toward a world facing lessening mental and physical health challenges, better able to focus and more driven.

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## **IRB** Waiver



FWA No: 00001224 El Paso, Texas 79968-0587

P: 915-747-6590 E: irb.orsp@utep.edu

Date:

July 21, 2023

To:

From:

Josette Pelatan

University of Texas at El Paso IRB

Study Title:

[2083176-1] FIGHTING FOR A HEALTH DIAGNOSIS: AN

AUTOETHNOGRAPHIC RESEARCH INTO THE ROLE OF ACCESS AND

LIMITATIONS OF RESILIENCE IN THE FACE OF POVERTY

IRB Reference #:

College of Health Sciences

Submission Type: Action:

New Project NOT RESEARCH

Review Type:

Administrative Review

Approval Date:

July 21, 2023

**Expiration Date:** 

Thank you for your submission of New Project materials for this research study. The University of Texas at El Paso IRB has determined this project does not meet the definition of human subject research under the purview of the IRB according to federal regulations.

We will put a copy of this correspondence on file in our office.

If you have any questions, please contact the IRB Office at <a href="mailto:irb.orsp@utep.edu">irb.orsp@utep.edu</a> or at (915) 747-6590. Please include your study title and reference number in all correspondence with this office.

Sincerely,

Lorraine Torres, Ed.D, MT(ASCP)

IRB Chair

AL WAS

Vita

Josette Pelatan is a graduate of The University of Texas at El Paso, holding a bachelor's

degree in Linguistics, a master's degree in education with a focus on literacy education, social

justice, and social context of education. She holds teaching certifications and has been teaching

for the past 20 years, from elementary school to College/University courses, in both private and

public institutions.

Her passion for mental health and social justice has led her to gain experience as an

advocate in several sectors, and she endeavors to conduct mixed-methods research to contribute

to the understanding of the link between neuroimmunology diseases, mental health, and cures

through stem cell transplant treatments. She also aspires to create therapeutic plans to nurture

brain-rewiring frameworks and aid her students and the public at large in improving their

physical health concurrently with their mental health.

Furthermore, she aspires to partake in Public Health educational reforms and innovative

mental health treatment approaches, and to expand her horizons in unconventional ways to push

for interdisciplinary approaches required by modern problems.

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