AN AUTOETHNOGRAPHIC EXPLORATION INTO BIPOLAR DEPRESSION AND
SOCIAL SUPPORT AS A FACTOR OF RESILIENCE

Wonda Baugh

A Dissertation
Submitted to the Graduate College of Bowling Green
State University in partial fulfillment of
the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2015

Committee:
Sandra Faulkner, Advisor
Sheri Wells-Jensen,
Graduate Faculty Representative
Ellen Berry
Sarah Rainey
This dissertation is an autoethnographic inquiry into mental illness, social support, and voluntary kinship. I explore relationships with my voluntary kin - people who act as family without biological or legal ties - and the types of supportive relationships in which we engaged that helped me accept the diagnosis of Bipolar Disorder (BPD). Because of their communication and commitment to me, I learned to thrive while complying with mental health treatment. This document describes the process by which I went from being self-centered to other-centered; from social support receiver to social support provider; and from defining myself as an individual to understanding my role in the collective.
All that matters are relationships and health. Everything else is—there is a word in Greek its called, *skoupidia*. It means more than garbage. It means stupid. It means so much! *Skoupidia!* That’s what everything else is and I’m finding that out more, as I get older. Possessions. Even educational attainment, even business acumen means nothing. Nothing! ~ Kathy Stathis
ACKNOWLEDGMENTS

For this project to have been accomplished, I needed so much help and support along the way. First, my very large and very supportive family and friends blessed me even when I did not always know what I was saying, or where I was—they kept me in their prayers. To them and their extended faith circles, thank you. Your belief in me helps me hold myself responsible for being the best person I can be; your love reminds me to be kind to myself. Receiving and feeling unconditional love has been a great gift that I strive to pass along through this work.

To my parents, thank you for putting up with me pushing your boundaries and rising to the occasion of becoming awesome supporters, friends and confidants. Thanks to my dad for technical support and equipment, and thanks to my mom for being my biggest cheerleader and fiercest supporter. To my sister for always reminding me that a sister’s love is not predicated on agreeing on things, but really based on bad puns. To my brother-in-law and my nephews, thank you for making room in your house, including me in your life, and for always accepting me. Kathy and Andy Stathis, thank you for taking godparenting so seriously; the world would be better is everyone had an extra set of adults in their lives. Bill and Saundra James, thank you for getting me through so many rough times and teaching me that I am worthy of friendship.

Dr. Yetta Howard, thanks for inspiring me to go to college and for continuing to have the same arguments with me for over a decade. Dr. Stephanie Brzuzy, thank you for encouraging me to trust my process and for always being on my side. To Jim and Karen Van Vlerah, I appreciate all of the times I spent relaxing in your home more than you can imagine. Dr. Abby Van Vlerah, thanks for sharing your knowledge, friendship, basement, and your lake with me; I could not have done this without you on my side.
To Alison Downey, there are not enough words in our language to express how profoundly special you are to me or how blessed I am to have had you in my life all of these years. You shaped my thinking in every way possible but, most importantly, you taught me what love and compassion are and how friendship can be the most important healing action people can do for themselves and one another. I can say in all sincerity that you have saved my life on numerous occasions and, if my work touches anyone, it is as much of your legacy as it is mine.

To Vicky Kulicke, Sophia and Anthony, thank you for opening your home and hearts to me; I am glad to be included in your family. Thank you my colleagues at ASU and UC who always told me I was smart enough: Hillary Pinney, Joyce Kammoun, Mi Puchon, Kate Livingston, and Jackie Arcy. Thanks for the friendship of my BGSU colleagues: Debbie Ribera, Suzanne Berg, Lisa Wornozof-Dashcoff, Michael Hale and Tiffany Knoell. Thank you to Amy Drees for the encouragement and copyediting.

Thank you to my dissertation committee who were willing to take this journey with me: Drs. Sarah Rainey, Ellen Berry and Sheri Wells-Jenson. Finally, thank you to Dr. Sandra Faulkner who taught me that autoethnography has been my medium all along. Your guidance and knowledge has been invaluable. Thank you for believing in this project before I knew where it was going. I am glad to call you and yours my friends.

Finally, to Nick: you rescued me and have been my companion since I was an insecure re-entry student. At times you were the only reason I got out of bed, and you were always the reason I came home at night. You are the best dog in the world, and I honor you as my most constant social supporter and my chosen kin.
TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>CHAPTER I: INTRODUCTION AND LITERATURE REVIEW</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Literature Review</td>
<td>3</td>
</tr>
<tr>
<td>Bipolar Depression</td>
<td>3</td>
</tr>
<tr>
<td>Advocacy &amp; Activism</td>
<td>5</td>
</tr>
<tr>
<td>Medical Colonization &amp; Stigma</td>
<td>8</td>
</tr>
<tr>
<td>My Story</td>
<td>9</td>
</tr>
<tr>
<td>Mental Illness Memoir</td>
<td>12</td>
</tr>
<tr>
<td>Social Support</td>
<td>15</td>
</tr>
<tr>
<td>Family Systems</td>
<td>17</td>
</tr>
<tr>
<td>Voluntary Kin</td>
<td>18</td>
</tr>
<tr>
<td>Chosen Kin</td>
<td>21</td>
</tr>
<tr>
<td>LGBTQ Chosen Kin</td>
<td>23</td>
</tr>
</tbody>
</table>

| CHAPTER II: METHOD                            | 25   |
| Autoethnography                               | 25   |
| The Stories We Do and Do Not Tell             | 27   |
| Interviews                                    | 28   |
| Cast                                          | 30   |
| Kathy                                         | 30   |
| Tina Marie                                    | 32   |
| Alison                                        | 33   |
CHAPTER III: MY STORY

The First Cut Is the Deepest: Teenage Institutionalization
California Conservation Corps
Serious Depression Take Two: A Sudden Death
Sisterhood Is Powerful
Waking up Gay
Hypomanic Hospitalization: The Onset of BPD
The Beginning of the End of My Fabulous San Francisco Life
Mania

CHAPTER IV: THE SLOW ROAD TO RECOVERY

Banishment: I Wandered the Desert
Long Distance Social Support
Yetta
Alison
Julee
Kathy
Tina Marie...................................................................................................................... 178
Auntie Wonda ...................................................................................................... 187

CHAPTER V: BARRIERS TO RESILIENCE: STIGMA AND TREATMENT............. 197

Stigma ....................................................................................................................... 198
Treatment as Its Own Deterrent ............................................................................. 207
Long Term Side Effects ......................................................................................... 217

CHAPTER VI: CONCLUSION ..................................................................................... 221

The Process of the Project ...................................................................................... 221
Acceptance .............................................................................................................. 223
Identity .................................................................................................................... 225
Social Support ........................................................................................................ 227
Reclaimed Identity ................................................................................................. 231
Limitations ............................................................................................................. 233

REFERENCES .......................................................................................................... 235
CHAPTER I: INTRODUCTION AND LITERATURE REVIEW

Introduction

Before I went to college, I was diagnosed with bipolar depression after having a major psychotic event. Since that time I have been institutionalized several times and eventually I found the right combination of therapy, drugs and social support to experience long-term remission. My resilience is noteworthy; I have gone from medically induced homelessness and institutionalization to earning undergraduate, graduate and doctoral degrees. The independence and education that I have obtained put me in a position to illuminate what has made me successful in personal and academic terms. I credit my resilience to complying with medical treatment and having a very dedicated and strong support network.

The purpose of this dissertation is multi-faceted. First, it is a project that speaks back to medical colonization by reclaiming the language of mental illness from the medical industry, allowing a patient and her social supporters to speak. The medical industry has its own jargon which can be difficult and confusing for people grappling to understand what is happening to them or to their friend or family member. Often in medical charts, doctors translate what they observe into jargon, which only aids in insurance billing and diagnosis. Sometimes a patient’s words are recorded, but most likely the lasting record of a person’s illness is not under the patient’s control. It may or may not accurately record what is going on from the patient’s perspective. Thus, I use autoethnography to document and interrogate, in my own words, my experience of bipolar depression (BPD) to give a personal, jargon-free voice to abnormal psychological symptoms. In this dissertation, I also explore the relationships that have influenced my resilience and reintegration. My social supporters were given an opportunity to be
interviewed about their observations of and reactions to my severe behavioral changes and mood swings, caused by mental illness, and how my illness affected our relationships.

Second, because I feel that my success has been contingent on my having strong social support, it is important to analyze those relationships and how they have facilitated my resilience. In this project, I interviewed my social supporters and analyzed our correspondence. In my case, people who are unrelated to me by biology or by law - voluntary kin - have provided the bulk of the social support. I have maintained these relationships for long period of time, and explore how the voluntary kinship members provided social support during several periods of involuntary institutionalization, my subsequent BPD diagnosis and reintegration process. The project illuminates how my identity as a person in relationship serves as a key component to my mental health and how these relationships continue to serve as communication lifelines as well as motivation for my compliance with mental health treatment. Chosen kin can be equally or more supportive than a person’s biolegal family (biologically related or related by law) and are an underexplored resource in supporting remission from bipolar disorder. The women that offered me friendship over the years were not biologically or legally bound to me; they were chosen kinship members. In this way my chosen kin relationships contest the privileging of heteronormative family systems.

Third, this dissertation is an experimental intervention into qualitative inquiry. By using a variety of qualitative methods, I aim to give a rich and evocative presentation of difficult subject matter while considering social justice issues. Although the dissertation is an autoethnography, I infused interviews from my social supporters; correspondence between my social supporters and me; poetry and fiction. Each of these methods blends together to create an alternative illness
narrative that exposes how my chosen kin and I dealt with bipolar and how we managed the disruption that it caused in my life and my interpersonal relationships.

**Literature Review**

**Bipolar Depression.** Bipolar depression (BPD) is an affective disorder, a mental illness that affects 4.5% of the population by causing extreme mood swings (Doherty & MacGeorge, 2012). The National Institute of Mental Health states, “Bipolar disorder, also known as manic-depressive illness, is a brain disorder that causes unusual shifts in a person’s mood, energy, and ability to function” (What Is Bipolar Disorder? n.d., para. 1). BPD is episodic in nature marked by periods of hypomania or mania and depression or mania alone. It differs from “unipolar” depression, which is marked only by depression. BPD is an umbrella term for a disease with several different, more specific diagnostic codes to describe an individual’s specific symptoms. For the purpose of this project, I am less interested in a full recitation of the diagnostic manual or the observations of medical personnel about my condition, and more interested in my own perspective, my friends’ and family’s memories of my symptoms, and how my condition affected the people I related with interpersonally. However, I am going to list symptoms pertaining to my diagnosis of Bipolar I from the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000) for clarity.

Bipolar I includes episodes of mania and mixed depression and mania. Bipolar II refers to patients with episodes of depression and hypomania. This dissertation is concerned with symptoms pertaining to Bipolar I, from now on referred to as BPD. The symptoms of mania include: an elevated or irritable mood, an inflated sense of self or grandiosity, a decreased need for sleep and food, pressured speech, flight of ideas and goals, racing thoughts, distractibility, and an interest in pleasurable activities or risk-taking behavior that may have unwanted and
extremely negative consequences. The psychotic features can include hallucinations based on delusions of grandeur often manifesting around work, power, or knowledge. The psychotic features can also be paranoia about being controlled or followed. Additionally some people become catatonic or stop speaking entirely. The depressive mood is marked by loss of interest in activities and sex, persistent negative thoughts, self-harm or thoughts of self-harm, difficulty concentrating, decreased energy, and feeling irritable, hopeless, guilty or anxious (Doherty & MacGeorge, 2012).

BPD is a very dangerous disorder; people suffering with BPD are 28 times more likely to kill themselves than the average population (Tondo, Isacsson & Baldessarini, 2003). 90% of the people diagnosed with BPD have recurring bouts of depression or mania creating lifelong instability (Tondo, Isacsson & Baldessarini, 2003). Illnesses such as BPD that are on the psychotic-spectrum are some of the most disabling mental illnesses in terms of life disruptions functionally and relationally (Brent & Giuliano, 2007). Treatment including psychotherapy and combinations of drugs (mood-stabilizers, anti-psychotics and anti-depressants) can be effective in managing symptoms, but there are several barriers to getting treatment and complying with medication regimens. Medications can have severe side effects and finding the drugs that work on any given patient is a trial and error process that can be long and unpleasant. Even with treatment there remain significant negative effects, “The quality of life is markedly impaired in individuals with bipolar disorder, even in comparison to patients with chronic medical conditions or other severe, enduring psychiatric disorders” (Michalak, Yatham, Kolesar, & Lam, 2006). Most people with BPD have problems with obtaining education and finding vocations, as well as finding and maintaining financial and relationship stability (Michalak, et al., 2006). Part of the
reason why the quality of life is so impaired is because aspects of the disease make it difficult to comply with treatment.

In my twenties, I rapidly moved from a depressed person to a person incapable of communication because of a psychotic episode. Now, at forty-two, using my position as someone who has lived through psychosis induced homelessness who reintegrated back into the educational system very successfully, I am in the position to make a unique contribution to both the academy and society at large. I continue to receive and comply with treatment, allowing me to attend college. I have completed two degrees and am finishing my third. I have lived independently and have been in a healthy, long-term, committed relationship for three years. I have even been able to keep an animal companion alive for eight years. Because I identify as disabled and feminist, I have a strong commitment to sharing my feminist epistemological truth in an accessible way and I do wish this work to be useful to people who are not professional academics. I am uniquely positioned to use my experience, my education and my relationships to create a personal case study that can be useful to help counter the stigma of mental illnesses.

**Advocacy & Activism.** For me, writing and ideally publishing this manuscript is my version of activism and advocacy. There are many organizations that work to change the stigma surrounding mental illness. There are others that attempt to support family members and social supporters when they are confronting such an unfathomable problem. Others concentrate on advocating for the civil rights of people diagnosed with mental illness; they question the medical system and try to educate about treatments they consider unfair human rights violations. A few believe that people diagnosed with mental illness are not ill at all; instead they believe that they are simply part of human diversity and being judged through a lens that rewards conformity.
The National Alliance on Mental Illness (NAMI) is a nationwide, non-profit organization that serves as a clearinghouse whose mission is to educate, support, and advocate for people with mental illness. Their website and magazine offer information about medications, laws, research and how to get in touch with community support group. Their ideological bent is from a traditional medical response; that means NAMI is an organization that advocates for medical solutions including hospitalization and medication. That is not to say that they are silent on the abuses in the system, but they do not encourage people to try to help themselves without medical intervention.

I agree with the mission of NAMI; education and support groups are important tools that assist people in understanding mental illness. For many people, because it is the largest organization in the country for the advocacy of the mentally ill, NAMI serves as the initial exposure to mental health organizations. The critique of the organization is that up to seventy-five percent of its budget is funded by pharmaceutical companies (Grohol, J. (2009). NAMI is prominent in state and federal politics through lobbying. Many believe the organization is actually an arm of big pharmaceutical business under the guise of a non-profit. While I find the funding issues of this organization problematic, I tend to be more aligned with NAMI than not aligned. Through this project I also advocate traditional medical interventions, education, support groups, medications, more research, and a voice in the government for the mentally ill, their supports and the medical industry.

Some people and organizations believe that medical interventions can be worse than the symptoms that are often diagnosed as mental illness. There are several organizations that are dedicated to the “Mad Pride” movement. Modeled after gay pride and black pride, they work to change the stigma of mental illness and to foster human rights among people described as
mentally ill. Mind Freedom International advocates self-determination for people diagnosed while questioning the validity of the medical industry. They use the language of “psychiatric survivor” and position people who have been institutionalized as victims of the industry.

Some organize around the idea of “coming out” as mentally ill. They believe that if enough people come out, the stigma will lessen. The non-profit organization No Kidding, Me Too! has an advisory board full of Hollywood stars who use their celebrity and the entertainment industry to change the representations of the mentally ill and stamp out stigma. I agree with coming out as a form of combating stigma and this project is my contribution to that mission.

The Icarus Project rejects the disease model entirely and believes that people who are diagnosed with mental illness need to be understood as people who do not fit into an oppressive worldview, rather than viewed as people who are ill. They consider their Otherness (their symptoms) a gift which, when combined with creativity and collaboration, can bring positive transformation to a damaged world. I think that this is a dangerous worldview. While I agree that there can be heightened creativity during the manic phase of BPD, with the onset of BPD I experienced unemployment, homelessness, loss of relationships, institutionalization, and an inability to communicate or care for myself. Medications can work; I do not believe that people should suffer needlessly. I do not believe that creativity is more important than mental stability. I do not think that the world can be transformed through the anguish that mental illness brings to individuals and their social supporters. I believe that long term social support is predicated on a willingness to obtain medical interventions. Many people cannot get help without the support of their chosen kin and many chosen kin cannot be in relationship with unmedicated people who do not have coping skills. My work advocates both medication and social support.
The Freedom Center is a community activist and support organization that asks for alternatives to medical colonization. They advocate alternatives to the mental health industry. They consider the mental health industry rife with “fraudulent science and dangerous treatments” (Shana, 2014). The Freedom Center does not believe in compulsory medication taking and thinks that individuals should have choices that have more to do with self-advocacy. They believe that many treatments do more harm than good and are closer to human rights violations than tools that enhance people’s lives. While I understand and occasionally agree with the Freedom Center that treatment is sometimes a civil rights violation, ultimately I believe that the nature of mental illness affects patients’ ability to make informed decisions about their own care. I question ill people’s ability to reject treatment if they are in the middle of a terrible episode. Absolutely, I think that the system needs to be overhauled. It is extremely invasive; however, I benefit greatly from modern medicine and I advocate its usage.

**Medical Colonization & Stigma.** Almost all organizations, regardless of their stance on the medical industry share in common the desire to combat stigma. The stigma surrounding mental illness permeates all aspects of our culture. To be mentally ill is to be crazy; to be crazy is to be undesirable and easily discounted. Stigma and misconceptions surrounding mental illness can make people reluctant to accept the moniker that in turn makes it difficult to identify themselves as a person suffering from a mental illness. Denial is a symptom of most mental disorders, and denial creates the illusion to patients that they are well. Many people with mental illness refuse to seek help or stop taking their medications once they feel better, disbelieving in their diagnoses or questioning their treatment plans. The dual challenges of stigma and denial create a complex barrier to obtaining and complying with treatment plans. For me, the key to overcoming these obstacles is rooted in deeply satisfying interpersonal relationships with people
who invested their time and friendship in me. This specifically benefitted me when I felt out of control, isolated, unlovable or difficult - times when simple communication proved challenging.

The use of medical and academic jargon also creates an obstacle to identifying with a diagnosis. Jargon tends to create a gulf between the institutions and the people who are trying to cope with the unfathomable. I am aware that the symptoms and information above are relatively vague and do not accurately describe the way this disease can impair a life or how devastated my family and I were at its onset. Words listed on a website or pamphlet fail to convey the reality of how people with BPD are affected and how their support circles learn to cope. This work offers an example of how I experienced mental illness and how my chosen kinship circle experienced my symptoms. By using plain language and giving examples in our own words we stand in opposition to medical symptoms being solely defined by medical jargon. Ideally, this plain language can bridge the gap between medical colonization and lived experience.

My Story. This project reflects my experiences of having the symptoms of a serious mental illness and being diagnosed with bipolar depression. It chronicles my relationships with people from whom I received social support in different relationships during different times. I have been hospitalized in mental institutions during three periods in my life; each of these three periods included several different admissions. The first time at the age of fifteen I was removed from school after a teacher saw evidence that I cut myself. At age twenty-five, I experienced my first manic episode and I was hospitalized for three months. After going off my medication at twenty-seven, I experienced a period of homelessness before being admitted to a psychiatric ward.

In this work, I write my story and include the perspectives of the people who provided me social support. I believe that these relationships coupled with the encouragement I received
helped my resilience during multiple periods of major stress in my life. The project illuminates how these relationships serve as a key component to my mental health, and how these relationships continue to serve as communication lifelines as well as motivation for my compliance with mental health treatment. I specifically investigated social support provided by people who act as family members but are not legally or biologically tied to me.

Ideally, parts of this project will be the template for a book that can help people with BPD and their social support caregivers. By publishing how I experienced my symptoms and how my kinship circle experienced them, I aim to demystify the medical jargon used to explain symptoms; to show how my kinship circle communicated with me in my time of need; and ultimately to help combat the stigma surrounding mental illness in general and BPD specifically. Academically, this project will contribute to the fields of family studies, health, relational communication, disability and cultural studies.

My work has my chosen kin’s voices but I think because of how much time passed between the worst of my manic phases and the time that I recorded the interviews, some of their negative emotions are not captured my work. I interviewed them as part of my doctoral requirements, and I have been incredibly stable for well over a decade. I think that knowing that I “ended up” relatively okay may have made their recollections of my ordeal less harsh than they would have remembered if their recollections had been taken a decade ago.

I have another purpose besides explaining what it feels like to be in my body. I seek to reclaim my story from the medical system. Ignagni and Church state that, “Through storytelling, disabled people can reclaim our experiences from medical hegemony” (628). The medical system names the symptoms of mental illness using medical jargon. That jargon is used to form a diagnosis through a medical coding book, The Diagnostic and Statistical Manual of Mental
Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013). Those codes allow the doctors to bill the insurance company. Those diagnostic codes are also used for people trying to get disability benefits. Medical charts with their jargon and their numbers tend to erase the experience of the patient in favor of a professional’s vocabulary. Patients who want to comply with treatment are then asked to accept the diagnosis and use the language issued to them by the medical industry. The patient’s voice is lost. For example, “I have had an auditory hallucination” fails to capture what a truly frightening experience that can be. Because there are such a wide variety of experiences within any given diagnosis, it is important that our voices are heard as both a personal reclamation and as a political “speaking back” to the industry that is both trying to help us and seemingly marginalize us.

Using autoethnography to analyze mental illness lends agency where there is often none. Couser (2009) explains:

Long the objects of others’ classification and examination, disabled people have only recently assumed the initiative in representing themselves; in disability autobiography particularly, disabled people counter their historical objectification (or even abjection) by occupying the subject position. The representation of disability in such narratives is thus a political as well as a mimetic act—a matter of speaking for as well as about.

(p. 7, emphasis in original).

Lewiecki-Wilson, Brueggemann (2008) agree that being medically marginalized because of having a mental disability is to also be disabled rhetorically; being disabled rhetorically is to be disabled politically. So, writing becomes an action that allows mentally ill authors to claim their own identity and reclaim their medicalized subjectivities. Therefore writing becomes political resistance to medical colonization—it becomes an opportunity to write
our own lives using our own holistic epistemologies to enact agency. Through writing, there becomes a space to become more than a diagnosis, more than a collection of symptoms, and more than doctor’s jargon.

I advocate using clear language in narrative writing. Writing using plain language has the unique ability to express complex ideas without sacrificing accessibility (Faulkner, 2009). Writing to eliminate jargon and other barriers to understanding is a form of postcolonial feminist action. Removing confusing and specialized language in my writing is my action of resistance to both medicalized definitions of my own identity and a rejection of academic elitism.

Mental Illness Memoir. There are many popular mental illness memoirs on the market. While my work resembles a typical mental illness narrative in several key ways (I am a white woman writer who has been institutionalized) it diverges in several important ways. For example, Susanna Kaysen (1993) in *Girl, Interrupted* writes about her experience being institutionalized for a personality disorder. The bulk of the book is about how she identifies with the community of other institutionalized girls and women; she spends the majority of the book describing the other patients and their relationships. She includes her own patient records and they function as a way that the reader gets to know her.

Although there are many similarities, in many ways my work is in direct opposition to Kaysen’s. Our experiences inside the institutions diverged. Kaysen described an environment where she had programming, took cooking classes, and got overnight passes to visit her boyfriend. I was locked up with the indigent patients in a major urban center and the hospital was co-ed. The main difference is that my identification lay outside the institution, constructed by the relationships I maintained with my social supporters while Kaysen’s major relationships were with the other patients. In short, my life was not that of a *Girl, Interrupted*. Kaysen uses the
metaphor to mean she detoured for a while, but now is on the path she was originally intended to travel. I cannot afford to treat my illness as a mere interruption. That is partially what made me prolong getting real and lasting treatment. My recovery happened because I recognized with the help of my relationships that I was ill. I accepted life-long treatment; no amount of willpower would have made me well.

In some ways, both of our narratives are about friendship and social support. Kaysen’s is about the friendship and support she received inside the hospital. Her identification with the other in-patients eventually strengthened her will to get better. My story is about the social support I received outside the hospital, and how I accepted life-long treatment out of respect for those relationships. While my narrative includes much about my experience as a person with mental illness, this is the story of “us.” We are in relationship with each other and by including many voices, multiple personal correspondences, and various interviews of people I am in relationships with, I strive to tell the story of “us” not just the story of “me.”

Another famous mental illness narrative is *An Unquiet Mind: A Memoir of Moods and Madness* by Kay Redfield Jameson (1997). Her illness narrative is about BPD. Her position is BPD is a genetic disease and medication is the only thing that can come close to providing a livable life for its sufferers. I also agree with medication usage, although I am less certain that BPD is solely genetic. Jameson says, "Love can help, it can make the pain more tolerable, but, always, one is beholden to medication that may or may not always work and may or may not be bearable" (1997, p. 174). Social support and love have been the catalyst for me to take medication and comply with treatment. Unlike mine, Jameson’s memoir depends on her perspective alone while mine includes my social supporters’ memories. Also, Jameson’s is full of medical jargon and mine resists and complicates those terms. Additionally, her story is a
product of her wealth and privilege. While I acknowledge that my position as a graduate student is one of privilege, my illness has at times rendered me both homeless and institutionalized along with the indigent.

Two popular memoirs written by family members of people with BPD are *Daughter of the Queen of Sheba* by Jacki Lyden (1997) and *Crazy: A Father’s Search Through America’s Mental Health Madness* by Pete Earley (2007). Lyden’s memoir is not about her own BPD, but of her mother’s. Lyden gives excellent and vivid descriptions of her mother’s delusions. She recounts her difficulties getting her mother to comply with treatment and how conflicted a family member might feel when dealing with a mentally ill family member. Her memoir is about family relationships and is from the perspective of a social supporter.

Earley’s memoir traces his experiences with his mentally ill son. Early’s college-age son was diagnosed with BPD after coming home from college and breaking into a neighbor’s house to take a bath. Despite the son’s illness, he became entrenched in the legal system rather than the medical one. Frustrated with the system, Earley uses his credentials and education as a journalist to uncover the bleak world of how mentally ill people are being held in a revolving cycle of prisons, institutions, and homelessness. This book is largely devoted to investigating the institutionalized violence and inhumane treatment of the mentally ill that have been accused of a crime. Earley’s inability to change the fate of his son motivated him to expose the abysmal conditions in the prison’s mental wards. His book does an excellent job of explaining the connections between mental illness and the prison industrial complex while touching on his relationship with his son. My work is critical, but more about my interpersonal relationships and less about the historical or political implications of the mental health system.
Social Support. This work contributes to the growing body of literature about social support relationships and illness narratives but differs from memoir because of the qualitative methods I employ to illuminate my voluntary kinship relationships and social support, as well as my symptoms and treatment. Social support is loosely defined as practices that let people know that they are valued members of a community, and part of a network of care and collective responsibility (Cushman & King, 1986). Social support research discusses the benefits of being the recipient of the support and what behavior constitutes social support. Some scholars investigate support given in times of strife and some study everyday interactions and communications as social support. As Gallagher and Gerstel (1993) pointed out that extended families do not just exist, instead “Someone expends a great deal of time and energy to maintain it” (p. 598). Social support exemplifies this notion. Where being a family member might be conceived of as a noun, being a social supporter is definitely a verb.

Social support greatly benefits mentally ill people. Although some mentally ill people experiencing psychotic symptoms become alienated and disengage with their family members research shows that family interventions and social support are keys to resilience (Brent & Giuliano, 2007; Doherty & MacGeorge, 2012). Families and friends are underutilized in treatments (for the purposes of my study “family” includes voluntary kin) (Brent & Giuliano, 2007). Researchers have shown that individuals with BPD who perceive having higher levels of social support experience fewer BPD episodes (Doherty & MacGeorge, 2012) and are more resilient when symptoms recur than individuals who perceive having lower levels of social support (Cohen et al., 2011). In individuals with BPD, there is a correlation between social support and full inter-episode remission. People living with BPD who perceive having higher
levels of social support achieve full remission in between episodes more often than those who do not perceive that they have social support (Johnson et. al., 2003).

Social support comes in many forms and researchers use different terms for similar manifestations. All agree that it is behavior and communication provided with the purpose of giving general overall assistance as well as assistance in times of stress (Doherty & MacGeorge, 2012). Social support can be defined as an individual belonging to a recognized community and that the individual is loved and esteemed (Cobb, 1976). Other researchers later expanded these two categories into subcategories. Being recognized in a community includes the concepts of social integration and everyday support (Veiel, 1985). An individual being loved and esteemed includes in a more recent definition of social support, “support emphasizing emotional or psychological benefits or reassurance of self-worth that are frequently provided in the face of crisis” (Lloyd, 1995, p. 43). Kaplan et al., (1977) defined social support by how much social interactions with others satisfy a person’s social needs. Brown and Harris (1978) define social support as the presence of a confidant. Some researchers categorized types of social support into emotional support, appraisal support, informational support, and instrumental support (House 1981; Dean, Lin, & Ensel, 1981). Appraisal support includes providing affirmation and feedback. Practical assistance such as providing someone with a ride to the doctor is called instrumental support. Expressive support involves sharing of problems, and spending time with each other. Cohen and Wills (1985) pinpointed four types of support: esteem support, information support (defined as providing help in defining and coping with problematic events), social companionship and instrumental support. Social support is also defined by actions including “socio-emotional aid” such as expressions of caring and love, “instrumental aid” such as money and material goods, and “informational aid” such as advice (Johnson et al., 2003). My
research investigates this support given by voluntary kin to me since I began to experience BPD symptoms and after I achieved long term remission.

**Family Systems.** Family studies scholars study families using a social construction model. That means that they define family by the roles people enact rather than through biological or legal (biolegal) means. Families are therefore constructed through the social ties defined through relationships and functions (Floyd, Mikkelsen & Judd, 2006). This is the approach that I utilize in my research.

Theorists describe a theory called a “constitutive approach” that argues communication “defines, or constructs, the social world, including our selves and our personal relationships” (Baxter, 2004, p. 3). In the case of family communication, Braithwaite *et al.* (2010) point out that these relationships tend to be defined by what makes them alternative families, meaning they are defined by a *lack* of blood ties or a lack of legal ties. This measures all kinship relationships by traditional nuclear family standards. I researched my significant relationships by combining the role lens (the roles people play rather than how people are related) with a constitutive approach. I struggled to describe the relationships I participate in using established scholarly terms.

There are several terms used to describe family kinship relationships that are not bound by blood or by the law. Many sociologists use the word fictive kin (e.g., Chatters, Taylor, & Jayakody, 1994; Ibsen & Klobus, 1972; Muraco, 2006). Braithwaite *et al.* (2010) point out that the most frequent moniker for these relationships - “fictive kin” - is problematic because the term insinuates that the relationships are somehow fictional. I agree with the notion that the word “fictive” is problematic because it insinuates that these relationships are fictional and somehow less than “real” biolegal kinship relationships (Braithwaite *et al.*, 2010). Instead of fictive kin, they advocate using the term “voluntary kin” because “[It] implies a mutuality of selection,
rather than framing these relationships as asymmetrical structures of chooser and chosen” (Braithwaite et al., 2010, p. 390). I find the argument compelling and have also decided to utilize “voluntary” when describing the relationships I have with a non-biological or legal kinship circle who are bound by their own ongoing choice to remain involved, active participants in a person’s life in ways that are most closely described as a familial relationship.

**Voluntary Kin.** The voluntary kin featured in this project are diverse in terms of relationship status, age, gender, ethnicity, religion and class, but linked by the common thread of being in a relationship with me. Specific data comes from their different perspectives, in different voices, much like the family system and support networks they are emulating. A variety of texts and sources allow for new inroads into methodological and theoretical intervention for family communication, disability studies, interpersonal communication, American studies, and gender studies. I used autoethnography to illuminate the way that one familial circle deals with cross-generational mental illness.

Voluntary kin are more than just friends; they are people who are not biologically or legally related who take on a role generally defined as “family”. I define voluntary kin as people who are not legally or biologically related but who are bound by their own ongoing choice to remain involved in someone’s life. I combine Adams’ (1999) definition of fictive kin and the use of the term voluntary kin advocated by (Braithwaite et al., 2010). Fictive kin are active participants in a person’s life who are most closely described as being in a familial relationship (Adams, 1999). Voluntary is a term used to extend the traditional boundary of “family” to include people who do not have biological or legal affiliations (Braithwaite et al., 2010). Therefore voluntary kinship relationships are defined by what people do rather than by who they are. Describing the social support network as a function and an action is important because it
more accurately includes relational configurations and meaningful relationships with non-kin family members, such as godparents, clergy, childhood friends, roommates, and other community members.

Adams (1999) describes voluntary kinship in the United States as “circumstantial and incidental” claiming that these relationships rarely include “frequent contact, common interest, mutual aid, or strong affectional and obligatory concern” (p. 90). I disagree; in my experience, I have received much social support from my voluntary kin.

Some of the support I received was from a person that Milardo (2005) describes as a generative family member. According to Milardo (2005) a generative member is an adult who is committed to guiding the younger generations to adulthood. This is done through several specific types of relational actions including mentoring, being family historians, acting as intergenerational buffers, and/or friends. Although Milardo’s (2005) study is about how uncles behave, her relational theories are applicable to my research into my voluntary kinship relationships.

As a young adult with a severe mental illness, I experienced many of my similarly aged peers enacting roles that would have otherwise been atypical for a peer to enact. For example, some of my voluntary kin act(ed) as mentors, modeling correct and appropriate behavior, and some gave me advice that could be read as paternalistic. Because of trauma, illness, and side effects from medication, I still do not have a clear memory of much of my life. Social supporters have not only helped me remember those absences, they help me remember some of my own family history. All have borne witness to my life and all acted as friends with some common interests helping me cope with life events. I utilize Milardo’s theory (2005), expanding her
relational theory to include social support given by voluntary kinship members to people with mental illness.

I make the distinction between friends and voluntary kin because not all friends have the commitment or the stamina to maintain relationships with people who are chronically mentally ill. People who are voluntary kin have shown a willingness to be supportive of me. When diagnosed with BPD at the age of twenty-five, I was lucky enough to have several people in my life who maintained relationships with me as voluntary kin. Together we learned what BPD is, how it is treated, what the symptoms are and, most importantly, how to grow together as a family. Because the symptoms of BPD are often socially disruptive and stigmatized, individuals who suffer from the illness often become temporarily or permanently estranged from biological and legal families due to years of intra-family strife and conflict, which creates the space and the need for voluntary kin. While studies show that social support matters for positive health outcomes, voluntary kinship relationships and voluntary kins’ role as caregivers (emotional and otherwise) remain underexplored in the academy and often go unrecognized in social support literature (Cohen, Ferguson, Harms, Pooley & Tomlinson, 2011; Doherty & MacGeorge, 2012).

Luckily, I have a very strong social support network that has helped me transition from psychosis-induced homelessness into becoming a full time undergraduate and eventually graduate student. I give credit to these voluntary kinship relationships that allowed me access to supportive communication when I was socially isolated and vulnerable. In my case, I define social support as behavior and communication to and from my kinship network that provided general overall assistance as well as assistance in times of specific stress (Doherty & MacGeorge, 2012). My personal experience mimics the research that shows people who perceive having higher levels of social support have fewer BPD episodes (Doherty & MacGeorge, 2012)
and are more resilient when the symptoms do recur than people who perceive low levels of social support (Cohen et al., 2011). Resilience is defined as being able to successfully adapt to adversity (Cohen et al., 2011). I am a person with BPD and my story is one of resilience deeply predicated on the social support I received by my social support network.

Voluntary kinship relationships are studied in various disciplines under various names. Some scholars utilize chosen kin (Johnson, 2000; Weston, 1997), self-ascribed kin (Galvin, 2006), urban tribes (Watters, 2003), friend-keepers (Gallagher & Gerstel, 1993; Leach & Braithwaite, 1996), othermothers (Collins, 2000), and ritual kin (Ebaugh & Curry, 2000). Chosen kin is most often used to describe LGBTQ relationships.

While the term chosen kin most closely describes my relationships, it is problematic because it creates a hierarchy between the person who is chosen and the person who does the choosing (Braithwaite et al., 2010). I do not want to use the term chosen kin because it can imply that all of the relationships in this study are predicated on non-normative sexuality or gender (Johnson, 2000; Weston, 1997).

**Chosen Kin.** Using the chosen kin lens, families are defined by how they act and interact with one another rather than who has biological or legal ties. In their study of 110 voluntary kinship relationships Braithwaite, Bach and Baxter (2010), sought to understand relationships where people “perceive and treat (one another) as extended family, yet are not related to you by blood or legal ties” (p. 392). They distinguished four main categories of voluntary kin, “substitute, supplemental, contextual, and extended families” (p. 393-396). The differences among the four categories of voluntary kin are subtle, but important. In the category of “substitute” family, voluntary kin were viewed as a stand-in for estranged or dead biological or legal family members. In the voluntary kin as “supplemental” family category, the members
were constituted as an addition to the existing biological or legal family rather than a substitution for the biological or legal family. “Contextual” voluntary kin are formed around a specific situation, stage of life, time, or space. The final type of voluntary kinship formation is called “extended” family, in this construction, members of the circle accept a person into their family who is not biologic. This configuration is not based on lack of biological or legal ties. Instead, it expands the relationship. Because of the length of my relationships, most of the relationship formations did not keep these discrete boundaries and shifted subject positions over time.

I explore the kinds of social support my voluntary kin provided me. I seek to answer several key questions: How did I experience BPD symptoms? How did my voluntary kin offer me social support? How was that social support communicated? How was social support maintained in my relationships over time and distance?

It has been fifteen years since my last major psychotic episode. Since then I have been lucky enough to maintain relative emotional and mental stability. I have been able to be successful in college and graduate school. I do not claim that this is one hundred percent my achievement. Instead, I give credit to a solid, long-term support network of women who have continued to be in my life despite my symptoms. Researchers (Brent & Giuliano, 2007; Doherty & MacGeorge, 2012) have recognized social support as an important factor in peoples’ resilience when it comes to their mental health. What makes my situation an interesting case study besides the severity of the symptoms and my unusually high academic achievement is the fact that so many of the people who have been supportive of me are not biological or legal family members. They are mostly voluntary kin; some became chosen kin because of my sexual orientation.
LGBTQ Chosen Kin. A small body of research exists about LGBTQ chosen kin circles. Oswald (2002) focuses on resilience within gay and lesbian family circles by exploring “intentionality and redefinition” (p. 375-379). Many gay and lesbian people are rejected by their biological or legal families or are afraid to come out about their sexual orientation to them. Because gay marriage is still illegal federally and in many states, queer people search for communicative behaviors to explain their relationships. Intentionality is defined as the things people do that bolster and validate their relationships. Redefinition is defined as the action of creating communicative processes to make sense of these kinship networks. When close relationships are not easily defined, the communicative process becomes more complex. Explaining and justifying the relationships becomes a difficult process when words fail us. In the gay community many have intentional family systems and the words to (re)define our relationships are still lacking. These notions of intentionality and redefinition are useful in explaining my relationships.

For some people, these voluntary kin relationships supplement or replace strained family of origin relationships. Ana Muraco (2006) did a compelling study of cross-gendered, different sexual orientation friends and found that lesbians and straight men have tight intentional lifelong bonds that serve some of the functions of nuclear families (Muraco, 2006). These roles are influenced by gender role stereotypes; for example, lesbians provide nurturing emotional support and straight men are more likely to provide financial support (Muraco, 2006). In my life, there are people who have been voluntary kin, providing social support and making me feel much closer to them than to my biolegal family. There have been people who have played roles that are traditionally held by biological and legal family members: kinkeeping is one.

Another important aspect of social support is the role of kinkeeping. Kinkeeping references a series of actions and communications that maintain the family. Braithwaite et al.
(2010) identified five marks of a kinkeeper: providing information, facilitating rituals, providing assistance, maintaining family relationships, and continuing a previous kinkeeper's work. These duties are pertinent to my work. I now embrace my role as an aunt and my role as a mentor for children of people I consider family. It is part of my contribution to generative culture.

Generative culture, simply put, is the action of creating and nurturing the next generation. When providing social support for people with BPD, there are several things that social supporters do. These include emotional support, everyday support, and illness-management (Doherty & MacGeorge, 2012). Emotional needs are met by conversations in general as well as specific communications that help boost esteem. For example, some social supporters might check in on the telephone and help their kin to feel less isolated or they might send greeting cards regularly to remind a person that they are loved. Social support includes material tangible support such as food or clothing as well as encouraging someone to engage in social activities or exercise. Illness management support includes giving advice and information about their illness, helping a person to make doctor appointments, or reminding them to take medicine or use coping mechanisms.

The voluntary kin featured in this project are diverse in terms of relationship status, age, gender, ethnicity, religion and class, linked by the common thread of being in a relationship with me. Specific data comes from their different perspectives, in different voices, much like the family system and support networks they are emulating. A variety of texts and sources allow for new inroads into methodological and theoretical intervention for family communication, disability studies, interpersonal communication, American studies, and gender studies. I used autoethnography to illuminate the way that one familial circle deals with cross-generational mental illness.
CHAPTER II: METHOD

Autoethnography

Carolyn Ellis (1999) helped develop the field of autoethnography to legitimatize the practice of research that does not seek objectivity, but instead highlights researchers’ own selves. Researchers are emotional; they are vulnerable and they have bodies. Autoethnography is about creating evocative stories and mimicking reality. Autoethnographers document their intimate experiences to help understand the meaning of life itself. Ideally, it encourages compassion and empathy and teaches us to cope. According to Ellis, readers co-construct the narrative. Ellis’ ultimate goal is to expand social science ethnography to include the autobiographical, the emotional, and the artistic under the name of autoethnography. Denzin (2008) states, “Interpretive biography, or autoethnography, re-tells and re-performs these [personal history] life experiences” (117). It is in this re-telling and re-performing that I can also analyze familial life events. The process of writing and pulling what data I am going to use is itself part of the analysis process.

Autoethnography allowed me to illuminate the way that my familial kinship circle continues to deal with cross-generational mental illness and relational patterns because:

1. it offers a research method friendly to researchers and readers;
2. it enhances cultural understanding of self and others; and
3. it has a potential to transform self and others to motivate them to work toward cross-cultural coalition building (Chang, 2008, p. 52).

The genres of qualitative data I used include: interviews, personal writing, blogs, letters, poems, fiction, postcards, and emails to analyze the types of social support that voluntary kin provided and what they experienced as loved ones witnessing mental illness symptoms, including
psychosis. I also used several forms of my own writing including blogs and autobiographical fiction to (re)construct a trauma narrative, and letters that document my resilience.

I examined the communicative strategies employed over the span of a decade tracing my journey of BPD with the women in my life who have served as my social support network. It culminates in an examination of my kinkeeping role in the lives of the next generation of mentally ill people in my voluntary kinship circle.

This project examines mental illness and resilience from multiple perspectives and many ways to triangulate. This project uses qualitative methodology to address key components of relationships that aided a BPD patient to comply with treatment and, in turn, become resilient and reintegrated into society. This work not only gives voice the marginalized and oppressed subject of “mental patient” through fiction, poetry, and first person narrative, it accounts for under-examined voluntary kinship and aunting relationships.

I use what Markham (2005) has called a fragmented narrative, “[An] Individual sense-making processes, dyadic and group relationships, and that which we call ‘knowledge’ are increasingly composed of nonlinear sound bites, transient connections, truncated texts, hyperlinked cognitive processing, multimediated understandings of what is real and meaningful, and so forth” (p. 3). Autoethnographers intend to give marginalized groups voice (Chang, 2008). Similarly, I intend to give voice to my experience as a marginalized subject through the use of autoethnography, in general, and a fragmented narrative, in particular. Incorporating several forms of qualitative data allows for triangulation and greater diversity of resources. Additionally, each method has specific strengths that will appeal to specific readers. For example, poetry alone will not appeal to everyone, nor will reading a mother’s blog posting. Similarly, each person who
is part of the kinship circle has a different role in my life and has different ways of providing social support.

Researchers theorized that because readers help co-construct the author/subject’s story, sometimes narratives fail to convince the reader of its authenticity (Ellis, Adams & Bochner, 2010). This can be particularly true if the reader has a similar but varying experience or if the narrative does not fit into the reader’s own experience with the subject matter. My purpose for this project was not to claim to be speaking for anyone but my own life and my own story. There are certain aspects of my life that do not fit in with the dominant narrative of drug use, sexual awakening, mental health symptoms or treatment. The stories nonetheless represent my truth as I remember it.

**The Stories We Do and Do Not Tell.** There are stories people tell and there are stories that we do not tell. There are memories that are accurate and there are memories that change a bit with every retelling. There are things we remember and things we forget. Goodall (2006) states:

> We are shaped by our memories and circumstances, and each and every morning we awake to carry ourselves and who we are into the world and see what happens. We make all of it up as we go along (p. 348).

What Goodall describes is specifically important for my work for several reasons. The interviews and analysis was done sometimes more than a decade after the events took place. Each of the social supporters have a memory that is slightly skewed by understanding that my story did not actually end in despair. There are facts that I cannot hold in my brain; for example I cannot remember who called the police on me even though Alison has repeatedly admitted it to me. Goodall (2006) reminds us that people’s stories are “a version of the truth, not the whole
truth, or maybe even the main truth” (p. 155). The foundation of our stories is not based on journalistic “truth”; instead it is based on our own individual relationships and circumstances.

Telling my story and allowing a space for my social supporters to tell their stories is a political action as discussed in the literature review. Speaking back to medical colonization is an important reason why I picked this project. For this project, writing my narrative involves trauma and hardships. According to Zingaro (2009), sometimes when a story is too different or too threatening to a reader or listener’s own experience, the author alone no longer seems credible. Instead, readers believe their own experiences, an expert’s opinion, or the dominant narrative as more accurate: “A story without recognizable landmarks, or some measure of a familiar narrative trajectory, marks the teller as lying, or possibly exaggerating—as a deranged, or at least, confused” (Zingaro (2009), p. 11). There are parts of the way I have told my narrative that will undoubtedly leave the reader questioning my truthiness or even feeling unsatisfied with my personal identity. For example, I do not identify with the terms “addict”, “survivor”, or “victim” in this manuscript and briefly identify my reasons in the text. To help put in “recognizable landmarks” and to make my story less jarring and unreadable, I have added dates and tried to create a relatively chronological sequence.

Interviews

For this project I interviewed several people in my voluntary kinship circle who witnessed at least one manic episode. These people continued to maintain a relationship with me by employing specific communicative devices. Each of these interviews was approximately one hour long. They took place in various extremely casual locations out of necessity; the locations reflect the lives of the women interviewed and most do not have private space to have these kinds of personal conversations. The only private place to interview Tina Marie was in her
bedroom, and the only piece of furniture was her king sized bed. Alison did not have any private place to talk either, so I interviewed her in a parked car. Julee’s house was not private so we borrowed someone else’s kitchen table. Kathy had me sit in her living room by a roaring fire, while I interviewed Yetta in a hotel room. Per my Human Subjects Review Board application, this work, because of its autoethnographic nature, is not considered research based on Federal guidelines. To contend with ethical issues, I gave each person I interviewed the opportunity to use a pseudonym; however, all declined. They consented to having their real names used with the understanding that this project would be published and made available to the public.

They answered questions about relationship maintenance, communication strategies, and social support action. They talked at length about their faith, and their roles as voluntary kin to me, and other people they know who are struggling with mental illness. They also spoke about the BPD symptoms I exhibited that they witnessed. They spoke about how those symptoms forced them to renegotiate their expectations of me and their expectations of our relationship because of the multiple disruptions and disclosures of my self. I asked the following questions:

1. How do you define family?
2. What do you do to maintain a relationship with me?
3. What are some of the things that we talk about on the phone?
4. What do we e-mail about?
5. Are there challenges of maintaining our relationship because of my sexual orientation/gender expression?
6. How did my coming out as queer change your expectations of me?
7. How did my diagnosis (or the onset) of BPD change your expectations of me?
8. Did the diagnosis (or the onset) of BPD challenge our relationship?
9. Are there specific strategies you use to help me or someone else in your life deal with mental health?

Beyond these specific questions, all of the participants spoke freely about their experiences with me while I was experiencing symptoms as well their experiences interacting with the mental health system.

**Cast**

**Kathy.** My relationship with Kathy began when she married my godfather. My godfather had been my father’s friend since they were in grade school in Oakland, California. They spent much of their youth and their teenage years integrated into each other’s first generation immigrant families. My godfather, Andy, was not only my father’s best man, he was also involved in my grandparents’ lives, my great-aunt’s life, and my uncle’s life. Even as an adult, my godfather lived with my great-aunt and still counts her as a major influence. So, while they were best friends, my father and godfather respected each other as family. By the time I was born, Andy had been an extended family member for about two decades. When I was born, Andy had no children of his own and my parents asked him to be my godfather as an honor to fuse him to my life as a family member.

The godparent-godchild relationship is a long-standing tradition in many communities and probably one of the oldest recorded forms of fictive-kinship. Because I was baptized a Roman Catholic and my godfather is Greek Orthodox, my mother asked her sister be the godmother so that the Church could sanction a special dispensation for Andy to be my godfather. For my agnostic father, this served as a tribute to their brotherhood, much like being his best man; however, for my mother and my godfather this was a religious commitment. Andy does not believe that he was asked to serve as my godparent by my parents, instead he believes God called
him to be my protector, my guardian, and my spiritual guide. When Andy married Kathy, she took on the role as a godmother and became part of my family.

My godfather married Kathy when I was in grade school. She has acted as a mentor and advisor ever since. Growing up she always encouraged my cultural development. We went to plays, ethnic restaurants, and museums. We spent long hours talking about my dreams and desires. Kathy was the only woman I knew who had been to college or had a white color job. I realized while sitting in front of a fire gazing up at their book-lined walls, Kathy and Andy modeled a life that was unknown in my family of origin. Kathy was someone I always trusted, as much as I trusted anyone. The relationship she built with me became very important when my home life became unmanageable.

When I was sixteen, I ran away from home. Kathy found me and took me to her house to live with them. This caused an irreparable rift in Kathy and Andy’s relationship with my parents. While my parents did not get the legal system involved to extract me from their home, my parents never spoke to them again. For the time I lived with them, Andy and Kathy acted as substitute parents because I was estranged from my own biological parents. I have since reconciled with my parents and continue to have Andy and Kathy in my life. Although Andy is my godfather, my relationship with his wife, Kathy, is in many ways closer. It is she who does the bulk of maintaining our relationship through phone calls, e-mails, and letters. In addition to the interview, I analyzed years of e-mail correspondence that survived.
Tina Marie. Tina Marie is my biological kin, my only sister. I strategically include her in this project for very specific reasons. First, although we are blood related, we have had a difficult relationship resulting in long periods of estrangement. Our parents are not people who deal with interpersonal conflict well; when faced with conflict, they completely abandon friends and families over perceived betrayals and hurts. Our family default conflict resolution model is abandonment. Our differences are often ideological. My sister believes that marriage is for one man and one woman; I am gay. My sister is against abortion; I think a lack of access to abortion stems from, and leads to, poverty and oppression. She is a Republican and I think the Democrats are too moderate. Tina Marie and I deciding to work through, and sometimes around, our problems while remaining in relation to each other represents an active choice to be each other’s kin that is not inherently imperative in our own family system.

Another reason why I include her perspective is because while she does actively choose to be in my kinship circle, she has a life-long history of feeling as if being responsible for me was not a choice. For her being responsible for me at a young age represents my parents’ shirking their duties. This creates a more complex conflict than my truly non-biological kinship members face. Our perceptions and memories are not always in alignment.

Beyond me, other members of her social circle have BPD and depend on her for social support. She offers something unique to this project in terms of divergent opinions about how to lend social support. She is much more protective of her boundaries than anyone else I interviewed and much of her caretaking style is about understanding, knowing, and respecting her boundaries. Her language is firm in comparison to the other interviewees and her opinions seem place more responsibility on the mentally ill person to know how to behave correctly.
Alison. My long-term relationship with Alison is both that of contextual and substitute family. We lived together for years with her toddler, sharing an intimate but non-sexual relationship. Our relationship was closer than my relationship with Tina Marie and other family members both in terms of emotions and geography. During my first manic episode, in the absence of legal documents, the hospital and credit card companies refused to allow Alison to act as my next of kin. At a time when I had not spoken to my sister in over a year—and I had a strained relationship with my parents who lived out of state—the hospital refused to allow the woman I lived with for years to help my treatment team. Alison knew my day-to-day life struggles. She shared my life and my bills. Alison could write my narrative; she observed more, and knew me better. But, because our unconventional relationship was unrecognizable by social-legal construction, she could not act on my behalf in my time of need. But she tried her best to coordinate my care and visited me often in the institution.

Our relationship remains strong. Although we generally only see each other once or twice a year, we continue to consistently speak on the phone several hours a week. She remembers more about my periods of instability than I do because my memory is hazy. We now have a long history of social support and emotional bonds that I believe will last our lifetimes. We have already been close for more than half our lives respectively. Unlike most of the social supporting relationships I feature in this project, our communication is specifically oral and not written. As a busy, single mother who works in an office, written correspondence is not her preferred method of communication. Our conversations are often fit in when she is commuting or moments stolen away from her biolegal family.
Julee. I met Julee and we became fast friends only a few months prior to my first psychotic event. Despite the fact we only knew each other for a brief period, she remained my friend and acted as a family member at a time when I was estranged from Tina Marie and had a tenuous relationship with my parents. She, along with Alison, attempted to navigate the medical and justice system without a model to follow and without any legal rights. Julee performed many difficult tasks on my behalf including speaking to my biological kin, including my sister and parents. She took the time to visit me in the hospital and took me out on an overnight pass. I believe she helped make the decision to call the police for help when I needed treatment yet seemed unable to care for myself. Although this crisis happened early in our relationship, Julee has remained one of my closest friends.

Yetta. Originally our contextual kinship was based on our mutual queer identity. While my other voluntary family members have always accepted me, they are all straight. However, Yetta and I shared queer culture and subjectivity. We lived in San Francisco at the same time and were part of the same queer culture. We have spent important holidays together that are generally considered “family holidays,” such as Christmas and Thanksgiving. She visited me in the hospital when my biological and legal family did not. She has been one of my most loyal friends through the mental illness. Additionally, because she went to graduate school, received her PhD and is now employed as an assistant professor, she has been a mentor for me in the world of academia. When I moved from San Francisco to rural Arizona, Yetta sent me a postcard every week for several years. Dozens of these postcards survive today, and I use them in this project to show how Yetta’s written communication helped me cope with the severe isolation and mental illness that accompanied my relocation. They represented the only real connection that I had to my previous life in the city.
**Written Correspondence**

I have copies of written correspondence from several of my social supporters from 2000 to 2013. These include postcards, letters, e-mails, and cards. I coded them for recurring themes. Beyond coding for recurring themes, I searched for the types of communication that researchers determined people between the ages of 18-30 with BPD found supportive (Doherty & MacGeorge, 2012). In particular, I searched for instances of emotional support, everyday support, and illness-management. In addition, I used letters I wrote to young people who faced similar mental health issues in their adolescences. I have taken creative license to modify them for this project to conceal their identities by addressing the letters from my older self (Auntie Wonda) to my younger self (Wonda). These letters communicate my identity as an adult who has been resilient and show social support I provided, as well as the kind of social support that I think might have been useful to receive as a young woman.

**Blog**

I looked at a blog written by an extended family member whose teenager is grappling with mental illness. The blog shows her efforts to socially support her child and the comments on her blog represent the ways in which her community socially supports her and her family. This particular blog was written as both a way for her to vent her feelings, and share and record information. She is negotiating the mental health system while coming to terms with her own ever-changing and shifting relationship with her spirituality, her child, her family, the school system, and the mental health system. It provides invaluable first person, intimate knowledge that can be used by other families who face similar confusing, painful, frustrating, and helpless feelings when their loved-one is diagnosed with a mental illness or struggling without a diagnosis. The blog serves as a vital, up-to-date, instant database for qualitative research. Robert
Runte (2012) discusses the advantages to analyzing blogs, “Because blog entries are not produced within the research context, the commentary may be considerably more forthright and revealing than when directly solicited” (p. 317). It also provides insight into some of the emotions that my family might have been experiencing when I was very symptomatic. Like the letters I wrote in support of a few of the young people I interact with, I take creative license to act as if my sister wrote the entries about me. This is clearly impossible because blogs did not exist and she was not that active in my care, but her words speak the truth of her time caring for someone incapacitated by mental illness.

**Poetry**

I utilize my own poetry to (re)construct the symptoms of mental illness. This will allow the reader to better understand what a person with BPD is feeling and thinking. Specifically, I will use poetry to voice my teen self. Using poetry to give the teenager voice is important for several reasons. “Poetry allows us to articulate matters of concern in such a way that they become physical, tangible, and immediate” (Parini, 2008, p. 25). Experiencing mental illness and the confusion surrounding sexual orientation is a visceral experience, physical as well as mental. In addition, “By using clear language, (poetry) has the unique ability to express complex ideas without sacrificing accessibility” (Faulkner, 2009, p. 63). Accessibility is one of my guiding principles with this work, and my typical storytelling is an inadequate method to mimic chaotic and vulnerable states. Poetry has the potential to pull the reader into that space; it invites the reader to identify with the author. Effective poetry has the potential to show, rather than tell. It is very difficult for someone who has never had a psychotic episode to understand that the person experiencing it literally cannot tell the difference between the reality everyone else is experiencing and the reality he or she is experiencing. Family members specifically might have a
hard time being compassionate towards their ill loved one. It is exceedingly difficult to distinguish behavior choices from mental illness. Poetry has the potential to offer these family members and loved ones a much needed glimpse into the word of the mentally ill. Faulkner (2009) explains, “A good poem is one that can describe things that can’t exist, such as an imaginary knife in someone’s hand” (p. 65). This is exactly why poetry is a useful methodology for describing mental illness, in general, and psychotic states, in particular. Also, poetry has the potential to help give my teenage self-agency a space to not only express and explain the symptoms, but also an art form that is particularly suited to resisting hegemonic forces. As a mental patient, specifically as an underage institutionalized mental patient, I can be viewed as a colonized subject. As a hospitalized person, caught in a complex web, I had to negotiate being powerless. Having been committed can become a powerful yoke that has a long-term affect/effect on a person’s life. Poetry works as a way for a marginalized person to speak back to that colonialism. I will be using my own poems inspired by my own childhood. Some of them are over twenty years old, while others have been created with this project in mind. The most recent poems were written in a teenage voice informed by my own experiences and those of my nieces and nephews as they struggle with mental illness and the mental health industry.

**Trauma Writing/Autobiographical Fiction**

During the height of an extreme BPD manic phase, I wrote a long piece of autobiographical fiction titled, *Going Crazy Faster than the Speed of Sound* (Baugh, 2000). This book is not an autobiography or memoir as much as it is a creative reimagining with instances of truth. This is an unedited manuscript I wrote during a few weeks about being manic and queer. It is a primary source document composed after I moved from San Francisco to rural Arizona. This serves as a window into my experiences in my queer San Francisco community in the late 1990s.
Additionally, this is a piece of illness writing because it was written not only about being manic, but it is also a primary source document of a manic episode itself. The justifications for including this in my dissertation are similar to that of poetry. This gives voice to a younger self, demonstrating how time as functioned in my recovery.

This text is a piece of critical political action—a manifestation of the fact I believe the personal is political (Miller, 1991). My illness disrupted my life plot and threatened my sense of identity. Couser (2009) states that illness has the potential to make an ill person struggle to reconcile the diagnosis and their (new) impairments with their conception of self. Illness requires new identity formation.

Illness writing helped me accept this new identity while untangling the differences between disability and impairment. My mind has an impairment, but my disability is socially constructed. The writing helped me problematize my identity. Frank (1995) states that illness can create a disruption in life that causes a loss of sense of self, destination and purpose; people can lose not only the map to where they are going but also they can lose sight of their destination. BPD made me lose both the “destination and map” that once guided my life (Frank, 1995). Not only did my illness writing help me care for myself, it helped me to rewrite and talk back to my past. Thus, including my fiction writing in this dissertation serves multiple purposes.

**Data Analysis**

I used an audio recording to record the interviews and transcribed them word-for-word. Because I know each of the women I interviewed intimately, transcribing the interviews personally, rather than hiring a professional transcriber, allowed me to gain a more in-depth understanding of my social supporter’s experiences and perspective. After typing each of the interviews, I member checked (Lincoln & Guba, 1985) by sending an electronic copy of the
transcript back to each person to make sure that I recorded their sentiments correctly. Then I coded the data, line by line. For each interview I used a number of codes in the process of coding. I was not looking for specific themes at this initial stage; I was simply coding all of the pertinent text by using short words or phrases that described what I understood being conveyed. I excluded very little at this phase, regularly coding one sentence with many different codes. For example, I wrote this letter to a teenager who at the time was in a lockdown mental facility. In keeping with the creative reimagining I have addressed it to my sick self from my aunting self:

Wonda,

Yeah, I use my friends and family as a net. Because I never want to go back to the hospital again. I would rather look needy and weak than be tough and try to do it myself and fail. I really hate the hospital, I really, really hate there and I am enough like you, really hardheaded. I am the kind of guy who hits walls and yell fuck you to the people who are trying to help me. Sometimes you just have to breathe and try to go with the program. Just wanted you to know I miss you and can’t wait to visit!

Auntie Wonda.

This short paragraph is actually very dense in meaning. I use myself as an example to try to encourage the patient to comply with treatment, use self-care by breathing, and learn to rely on social support. I also identify with the patient, empathize with the situation, send hope that we will see each other, and let her know that I am thinking of her. This paragraph is fairly typical in its density.

I entered this data into a database that assisted me in the process of axial coding where I found larger, higher-level codes that became overarching themes that existed across the different data sources. The reoccurring themes of the interviews that emerged were: reporting symptoms;
feeling scared, helpless, worried, grief, and a sense of loss; using advice giving and listening skills; retelling stories from before the symptoms emerged; and just keeping in-touch.

These themes created the basis of my analysis. I coded the data for specific evidence of social support including: emotional support, everyday support, and illness-management support. For example, when the participants discussed how they communicated their listening skills, or how they did not judge or correct me, I considered that “emotional support.” Similarly, “everyday support” for me included just having small talk about mutual friends or updates on day-to-day activities. These conversations connected me to mundane aspects of my social supporters’ lives and these types of conversations did not focus on my illness. The data that I coded “illness management” included when my social supporters gave me advice about how to navigate the medical system, information about specific medications, or shared coping skills.
CHAPTER III: MY STORY

Bipolar disorder is a mental illness marked by periods of depression and mania. When depressed the symptoms include: extreme sadness, loss of interest in normal activity, crying, instability, anxiety, hopelessness, guilt, weight gain or loss, substance abuse and suicidal thoughts or ideation (Torpy, Cassio, & Glass, 2009). Bipolar disorder generally presents itself in teens and young adults between the ages of 15-19 (Wellman, 2007). Because this time in a person’s life is often marked by moodiness that is considered culturally normal, it is often extremely difficult to diagnose. While some people are first affected as children or as older adults, the vast majority of people with bipolar experience the onset of symptoms before the age of 30 (Wellman, 2007).

This chapter focuses on three different episodes of BPD that required police intervention and hospitalization which I experienced between the ages of 15 and 27. The first time I was hospitalized, I did not get diagnosed with anything and did not take any medications. The institutionalization acted as a temporary break from my life at school and home, and I perceived it as a punishment rather than as medical treatment or therapy. The experience left me resistant to and skeptical about mental health care. The second episode occurred when at twenty-five, following a series of traumatic incidents, I experienced such profound psychosis my friends, fearing for my safety, contacted the police to have me institutionalized. I stayed there for many months and received both medication and a diagnosis of BPD. The final episode discussed in this chapter chronicles another psychotic episode that rendered me homeless in San Francisco. From homelessness, I bounced in and out of two separate institutions. Eventually I went to recover in Arizona at my parent’s rural campground. This chapter serves as the background for my
autoethnography exposing my experiences as a patient/object in the medical system as well as introducing the social support relationships that will be discussed in later chapters.

**The First Cut Is the Deepest: Teenage Institutionalization**

People suffering from depression feel guilty or anxious, have difficulty concentrating, have decreased energy, and experience feelings of irritability and hopelessness. I lived with depression for the majority of my fifteen years, experiencing many of the aforementioned symptoms. I had little interest in most aspects of my life. Failing school and the constant fights with my family, in retrospect, signified depression. I had few friends, and the ones I did have tended to be based on drug or alcohol use. Irritability, and persistent negative thoughts about myself and everyone else around me followed me everywhere. Miserable, I believed life, humans and society irredeemable. I lost myself in a negative and pessimistic spiral for at least four years before I progressed to self-harm at age fifteen.

I cut my arms a few times in a few week - scratching really. Pressing a razor blade into my flesh allowed me to feel something. Anything. I just wanted to make sure I was alive and not totally numb. I managed for the most part never quite doing anything to alert the authorities but the cutting landed me in the hospital at the age of fifteen. I received no diagnosis and no medication; only endless days locked up with other people who also seemed dangerous to society or dangerous to themselves. I was not sick; at least I did not think I was. The problem was the whole system of doctors and police and parents and the schools. I felt misunderstood and silenced. My parents did not think children were people whose feelings and opinions mattered and the educational system was interested in conformity.

Before I learned to cut myself, I learned to cut all my classes at school. Both helped me temporarily cope with the time I was forced to interact with people I could not understand. My
peers at school seemed to be from a different world—a world where football games and school dances mattered. I found them insufferable, the teachers, too. Students who parroted the teacher’s ideas back were rewarded. I felt stifled; when I tried to voice a thought or further a discussion the teachers were unduly angry with me. I stood up for myself and my morals only to be punished. For example, I did not believe we should waste an animal’s life in a science lab when a student had no interest in pursuing the biological sciences. I refused to dissect my frog sophomore year. The teacher, disinterested in my dilemma, gave me an alternative assignment of a 20-page paper, unequal punishment for my ethics. This assignment offended me so deeply, I never turned it in, and failed the course. My classmates were uneasy with my convictions and open rebellion. A flashing neon sign over my head blinking “weird” inspired the swift anger and judgment of students and teachers alike. This certainly did not help me blend in. Bullied by today’s standards, by 1980s standards I just needed to learn to toughen up or ignore it. My perception may have already been skewed by my mental illness, because my own internalized mind-chatter made school a hostile and unsafe environment for me. Lunch highlighted my isolation. I generally sat next to a Japanese exchange student who could not make conversation, or I took my lunch sitting crouched down in between parked cars in the lot. My name might have been Outcast. Eventually I just stopped going to school.

Remarkably, no one seemed to notice me slip away; I simply stopped going to school. My unsuspecting parents dropped me off, but I simply did not show up to classes. Hiding in the library during my classes became an easy escape away from everyone. My parents held me to high standards and my rigid schedule left me little free time; cutting class was my way of carving out some breathing room for myself. Monday through Friday I got dropped off at the public high
Every day after school, I walked to the shop and worked until six o’clock or until we completed work. I worked to help put food on my family’s table. My duties equaled an adult’s: I helped customers. I stocked shelves. I placed orders with the wholesalers and did all the office work associated with running a small retail business that supplied commercial accounts by delivering supplies. Walking through the backdoor signified my transformation from a high school kid to a productive member of a family unit, actively supporting my family.

Paradoxically, the responsibilities of an adult did not earn me the rights of an adult. I received no allowance, and I received no pay. My mother picked out my clothes and enforced a strict dress code that made me a target at my public high school. Rules dictating my social life included never riding in a car with anyone, no dating, and never being alone with boys. Monday through Friday we left the home around six in the morning only to return at seven or eight at night. Saturdays we only worked nine hours and Sundays our establishment closed. Sunday brought mandatory church and often family functions. My lack of social life and the responsibility of working to support my family suffocated my teenage self. My family was not always that way; the constant work only started when I turned eleven.

My parents lived and grew up in the 1960s in Oakland, California, adjacent to Berkeley and San Francisco. At a time of great social and cultural upheaval, they retained relatively conservative values, with the exception of being anti-racists. Both of my parents were born with physical impairments. My mom has cerebral palsy and my father severe low vision. Neither of my parents ever allowed their disability statuses or impairments to define them or become part of their identities.
I think my mother explained her “walking funny” only a handful of times before I made it to school; her legs were different lengths and that is how God made her. End of discussion. Mom was the first person born in a hospital in our family and I am certain that most of my family blamed my mother’s disability on my grandmother for acting so uppity. My mother had no special medical care or even a proper diagnosis until after her fortieth birthday. One of seven (living) children, talking about her “walking funny” seemed frivolous compared to putting food on the table.

My father’s extremely low vision and severe color blindness is a rare genetic anomaly that is passed down through the maternal line, only affecting male children. My father’s grandfather had it, my father and uncle have it, and my nephews have it. Those are all the males on that side of the family that I know about. My father’s vision problem was seldom discussed. My dad never drove. Occasionally he hoisted my small body into the attic to do some electrical work that required seeing the difference between red and green.

In their childhoods, other children treated them unkindly. Boys purposefully tripped my father and my mother’s siblings convinced her to navigate obstacle courses. They managed to make some long-term friends and found ways to utilize their other talents. My father’s mathematical talents helped him launch a career in computers in the 1960s. My mother’s leadership qualities and talent with office work allowed her to be a valued employee, and later business owner. My parents do not identify as disabled and have never received government benefits, although at times that might have been a wise financial decision.

Their refusal to identify as disabled has been both a blessing and a curse. My parents’ disabilities entitle them to government benefits that they have always refused; in many ways this is part of the reason I worked as a child. It has been a blessing because their lived experiences
provided me with two strong role models who never let one facet of their beings dictate how they saw themselves or limit what they could do. My parents were avid campers and hikers in their youth and still enjoy the outdoors even though my mother uses an electric wheelchair. My parents held jobs their whole adult lives and have owned their own businesses, where they work together side-by-side, for thirty years. Their partnership has lasted over fifty years and they still enjoy each other’s company. Their example taught me that I am allowed to invent myself.

Identity is an existential state (Deleuze, G. (1995). When we become something new, we must have been something else before. For me, to become someone labeled mentally ill or disabled, I must have identified as abled bodied before. Here lies part of my problem with identification. Both of my parents have physical disabilities, so I grew up understanding that I did not share in their trials. Paradoxically, because they did not become disabled, but were born disabled, their identity does not reflect their “Otherness”. Instead they view their physical Otherness as proof of human diversity rather than a marginalizing identity. Their refusal to identify as disabled or, in their words, “handicapped” certainly does not stop the rest of the world from identifying them as such. Therefore they are confronted regularly with a misidentification. There is a slippage when a stranger treats my mother as if she cannot drive a car or should be considered a hero for going about her day. My parents do not live in a binary world where the able bodied people are in opposition to them; the majority of their own families are able-bodied and that is where their support lies.

In each other my parents found complementary partners and dated for five years before marrying in 1967 in the Summer of Love. They maintained traditional gender roles with my mother staying home with my sister and me, and my father working sometimes very late nights in the computer industry in the Silicon Valley. My father worked in an office using his brain, one
of the only men on either side of my family who did not work outside in construction. Few people understood computers at the time or what he did for a living.

I grew up around a very large extended family; my mom was one of seven children. We regularly spent loud weekends at parties and potlucks surrounded by generations of family. Being a large, Catholic family mostly geographically close, we always had something to celebrate: a birthday, an anniversary, a religious sacrament, or a graduation. My dozens of cousins and I almost all had at least one similarly aged cousin as a built in best friend.

At ten, my maternal grandfather died leaving a third of his lath and plastering company to my father. The other two-thirds went to my mother’s brothers who spent their entire lives working in the family business. One of my uncles and my father were friends since high school; he introduced to my dad to my mom. For a time, the business venture went well, and I got to hang out with my two best friend cousins late into the night while our parents plotted our collective future. At first, my father ran the business side of the company, dealing with clients, making bids, and handling payroll. In the early 1980s, construction jobs started to dry up and my father left the office and went to work on the crew onsite. The economy got worse and the business started to fail. My uncles asked my father to leave because they had twelve kids between them and no other skills; there was not enough work to support everyone. Betrayed, my parents did the unthinkable: they never spoke to my uncles again. In one second, I lost sixteen of my closest relatives and I learned an impossible lesson for a child to actualize: love is totally transitory and conditional.

By the time the construction business broke up, my father could not go back to the computer industry. We moved too far away for him to ride his bike to work and by then people obtained degrees in computer science and he could not compete. With no way to support the
family, my parents bought a dying office supply store. This change meant several things to my sister and me. We could not speak to our cousins, the people who comprised our emotional and social lives up until that time. We also became estranged from our aunts and uncles, four adults who served as important adult role models up until that time. My sister and I also began working for a living at that time in our family store. In many ways our carefree childhoods surrounded by family and laughter morphed into our having real grow-up responsibilities and a lack of leisure time.

A few years into running the store, I became isolated and depressed. After years of Catholic school, I attended the local public school. I could not fit in academically or socially. I felt constricted by my life where I did not have any free time or agency. Coupled with my parent’s abnormally strict rules and high standards, the constant monitoring of my thoughts and behaviors made me feel completely trapped. Teenagers generally experiment with new adult roles, but I had all of the responsibility of an adult and none of the freedom. As I got older, my parents’ grip got tighter. As their grip got tighter, I cut more classes. Mostly I just stayed alone.

Occasionally, out by the parking lot I found other kids to smoke and drink with, but I had a hard time maintaining relationships. The friendships never felt reciprocal; I always liked them a little more and no one ever initiated interactions with me. No one ever asked me to hang out outside of school. No one called me on the phone. I never felt accepted or authentic. I rarely felt comfortable around other people, but I did not want to be alone either. I found my solace in books. I sat alone for long hours in the stacks, hiding from the librarian with my nose stuffed in a book just hoping and wishing I would soon disappear.

By disappear, I do not mean die, exactly; I mean I wanted to escape. I soon found out that self-injury provided small bursts of relief. The first time I cut myself accidentally. When
scraping paint off the window at work and the razor blade slipped out of my hand. An electric current of pain pulsed up my arm followed by a rush of adrenaline. White-hot pain snapped me out of a dark place and helped me feel grounded. At fifteen, I thought I invented something so wonderful, but so taboo, that I could not tell anyone.

Just as I accidentally discovered cutting, I accidentally exposed my secret. I had only done it a handful of times before I got caught. I decided to brave my English Composition class. I could not stand the teacher who favored the popular kids. I mustered up the courage to show up to the class, even though I sat next to one of the mean, popular girls. I chose to, as my mom says “turn-over-a-new leaf.” I decided to start over. I arrived late because forcing myself to walk into a class I avoided for weeks proved difficult. I tried to blend, to act tough and casual, but the other student’s faces contorted and their whispering sounded like screams, “Oh my God, someone sits there?” Tammy, the cheerleader I sat next to, lisped snake-like, “Sssssshhhheeeeee sssssssshhhhhowed up!” The stares disturbed my bravado. I forgot about the red scabs all over my arms. I took off my long sleeved jacket and the whole class seemed to go silent as the teacher prodded, “What happened to you? Are you okay? Did you hurt yourself?” I turned on my heels and left. I do not know why I thought that would get me out of trouble. Clearly, the teacher called the office because the truant officer found me huddled in the women’s bathroom like a hurt animal. I recreate a lost journal entry below, similar in content to the one I wrote when I was fifteen:

One day I am going to be pushed a little too far by some jerk at school and that will be the day that I put someone in the hospital. Not the mental kind, the other kind. Some poor unsuspecting teenager will end up really hurt because I will see red and inflict serious damage. I will pass along the hurt like I’ve been hurt. Never mind, I will find a way to
survive. Cutting feels like letting air out of an overinflated tire. I cut to let out tiny bits of rage out into the universe. Somehow that seems better than letting it fester any longer. How can I explain this when they keep acting as if I am trying to kill myself? How can I explain this when they call it “self-mutilation”? No one can understand that I am actually protecting the world. What will I tell them? Absolutely nothing, because them knowing what I know doesn’t undo anything. I will wait them out and one day I will get out of this town and reinvent myself.

The high school administration called the police. Students filled the parking lot and the quad, the outdoor area where different cliques congregated. Two policemen, one on each side, flanked me. Both of these men matched my idea of what cops should look like so well that what they actually looked like morphed; all I can think of is “average.” One officer held my right elbow pushing me lightly to the parked squad car. My wrists ached where cold metal bit into the thin skin; the over eager policeman clicked the handcuffs one notch too tight. With wrists shackled in front of me, the deep scratch that traversed the whole length of my arm was visible to the lookers-on. It was as if someone had yelled, “FIGHT!”; the whole lunch period dropped their books to get a better look. The spectacle and gossip I generated that day—of being hauled away in a flashing police car while hundreds of kids stared—was the opposite of disappearing. My cheeks burned red with humiliation. I sobbed all the way to the local hospital.

At the emergency room, the doctor determined that, although I was physically fine, I needed further evaluation. At this time in 1987, cutting and other forms of self-harm were not part of the public consciousness.

*I did not try to kill myself! How insulting they don’t think I am smart enough to commit suicide correctly. A multitude of ways to off myself drawn in black stick figures on white*
paper flash before my eyes. Stick figure Wonda is hanging! She’s shooting herself! Now she strapped steak all over her body and is jumping in a tank full of alligators! I begin to giggle but stop abruptly, sure my every action is being recorded. No one believes anything I have to say but cutting is the opposite of suicide; it helps me feel like I belong in my body (recreated journal entry written in 2001).

Self-harm researchers have pinpointed 1996 as the date when it entered America’s popular culture (Adler & Adler, 2011). My experience mimics their research: my cutting was self-invented. My self-harm was coded as suicidal behavior rather than coping behavior and it was determined I needed to be on a psychiatric hold. Because of a coincidentally timed nursing strike, I was transferred to a lock down psychiatric facility in Oakland, California. At the time there were no laws separating the adults and the children. When I arrived, someone wearing all white ushered me through multiple sets of double doors, manually locking them behind me. It felt like being lowered into a mineshaft, falling deeper and deeper into the core of the Earth, although I know I am in compound designed in the shape of the wagon wheel with the most crazy, people like me, in the center.

I am tired and more than a little confused when a female staff member grips the back of my arm and guides me down a long corridor that ends in thick door with a tiny window. She unlocks it, gently pushes me through before locking it behind me. We walk further and further down an ugly white hallway lined in closed doors with small windows in them. The chemical smell of bleach burns the inside of my nose. They confiscated my few belongings. They took my shoes replacing them with slipper socks. Afraid I will hurt myself with the wire from my spiral notebook, they take it away. The thought of someone reading my innermost thoughts makes my stomach sour and do flip-flops. I don’t know
why the caged bird sings, but I do know why the fuck it screams. When I open my mouth nothing comes out. The blood on my white tee shirt dried into an abstract patterned textile each drop starting where the other left off individual but also somehow integrated into the whole. I think it’s beautiful but know that no one will let me paint in my own blood. Why don’t more people don’t paint in blood? Everyone here looks hollow, washed out, green and waxy—some sit still like statues. Others shuffle, rock or mumble (memory 2013).

Their bizarre and erratic behavior frightened me—rocking, pacing, they smoked cigarettes and begged each other for more cigarettes to smoke. The Plexiglas smoking room was technically a television room where a seventeen inch set was bolted to the wall. Through the smoky haze, I noticed most people wore loose-fitting clothes or hospital gowns. Everyone looked somewhat crazy. They seemed to stare too long with paralyzed faces and stiff movements.

You are scaring the other patients!” A second later I realized she was speaking to me. She sat behind what looked like bulletproof glass wearing starched white scrubs with her hair severely pulled back.

She repeated herself pointing at my shirt. “You are scaring the other patients!” Looking down for the first time I noticed the rust colored blood-smeared down the front of the white v-neck undershirt I stole out of my dad’s drawer. The other patients made no indication they were scared. They ignored me, preferring the private movies playing in their heads lost in their shuffles and mumbles. They showed no fear, only a kind of desperation and fragility that was somehow both pathetic and awful. It made me turn away (Author’s memory, 2013).
I wonder now if I, too, stank of pathetic desperation? At fifteen, terrified, forced into a lock-down, in-patient facility mixed in with adults, my desperation must have had its own affect - a sickly sweet, all-encompassing, putrid fog. Probably that was what the nurse was sensing, an indescribable quality that makes neediness not merely unattractive but revolting. Maybe it was simple deviance, but in some people it inspires the most brutal kinds of violence: neglect, poverty, and mistreatment of unspeakable kinds.

_I sat there wide eyed until the nurse came out and handed me a hospital gown asking me if I were sexually active. I lied and said, "No," as she walked me to get pelvic exam anyway. What my vagina had to do with my cutting myself, I am not sure. I was alone in what felt like a basement with a man pushing duck-lips up inside of me while I cried._

_Other girls my age were planning to go to prom while I was in the inner circle of hell._

_The pelvic exam lit the way for the next intruder (Author’s memory, 2013)._  

The rooms were typical of industrial settings. We sleep in twin beds, two or three same sex people to a room. Same sex patients are all housed in segregated hallways; opposite sex patients are not supposed to even walk down the wrong corridor. We were each assigned a slim closet to keep our few possessions. The rooms made it very difficult to hurt yourself or someone else. There were no sharp edges and the rooms were designed so that minimal staff could easily control and watch multiple rooms at the same time. They had one flaw. If you stepped inside the room and wedged the closet door behind the doorknob of the room’s door—it created a small section of privacy. The closet and room doors had to be angled perfectly to secure a small space.

_The stench of Drakar Noir still makes me want to barf. An adult patient followed me to my room and maneuvered me behind that tiny space. It isn’t scary at first, his interest in me. It’s even kind of fun being reckless. But he didn’t stop. I don’t want them_
to “treat” me any longer than I have to so I convince myself that nothing happened—I put it in the trash can of my mind marked “delete.” For years on-end this works, but the smell still makes me nauseous. My mind doesn’t allow me to focus on his appearance; he is a vague twenty-nothing white guy with a blur for a face. His smell, that god-awful cologne still sours my stomach.

In the made-for-television version of my life, I kick him off and run into the matronly arms of a night staff member who promises that I am safe. She decides then and there that she vows to adopt me. Let’s just go with that…the details are unimportant. Just understand that the second time since I got there something unwanted pushed inside me. I tried to convince myself that it is no different than the speculum. I did not cry out, I did not tell anyone that I only had sex twice before. I did not report the patient. All of the convictions I once had of being brave enough to stand up in the face of injustice vanished. I just needed to forget. I just clicked those invisible ruby slippers again and this time I retreated into myself and I mustered up a plan to get out. I decided to repent, cooperate and comply. I wiped the desperation off of my demeanor and gave them all what they wanted; I played the role of recovery. (Author’s memory, 2013).

The treatment was highly invasive, beyond the pelvic exam. I could not wear my own clothes or shoes. Sometimes my bed was pushed into the hallway at night because of a suicide watch. There, I half-slept under the glaring fluorescent lights while watched at all times. To use the bathroom, I had to find a female staff member to unlock the door and be present while I eliminated. I took my meals on the ward, again, under the watchful eyes of staff. I ate everything with a plastic spork, and then someone charted about how much I ate. In hindsight, I understand these precautions; however, at the time it did nothing to instill trust or foster a therapeutic
relationship. In fact the opposite was true. The more the staff tried to control me, the more they tried to just keep me quiet, the more our relationship became adversarial. My only healthy outlet: journaling. But I could not even write my truth down on paper because they confiscated my notebook out of fear that I would poke myself with the metal on the spiral. The so-called therapeutic environment did little but make me intensely angry.

The only treatment in this facility consists of someone taking my vital signs and writing down how much I eat. There is a “grooming group” where I am forced to paint my fingernails with old gummy nail polish. There are kidney bean shaped plastic hospital bowls filled with used makeup and dirty hairbrushes. Somehow getting lice and pink eye is supposed to make me conform to my gender and cure my depression. Apparently wearing makeup is the mark of healing and progress. It is really just sad. The make-up reminds me that I am in the pit of hell, left to groom myself with items found in a dumpster.

Maybe, if the people who worked there had been given a living wage to begin with, I would not have been placed in a facility that could not keep me safe. Maybe later my goal could have been my own mental health rather than staying out of the hospital. Maybe I could have believed that help existed for a girl like me. Maybe I could have learned to manage my symptoms, learned yoga, and embraced art therapy. Maybe I could have gone to college. Maybe, but instead the people who were charged with my care were not particularly invested in me, nor were they particularly kind.

Bad experiences of treatment became later barriers to treatment. For example, my early hospitalization became an obstacle for me to ask for help later because the so-called help seemed worse for me than the problem itself. The conditions in the first institution I was placed in were dismal at best. The actual interaction with my doctor was infrequent, brief, and frustrating.
A doctor, a dead ringer for Woody Allen peers at my file and barely even looks up before saying, “Do you wear all black, listen to heavy metal music and play Dungeon’s and Dragons?” How can this be real? I shit you not, my doctor literally just asked me that and I don’t even have my journal to process! Clearly, what is wrong with me is that I have listened to too much rock and roll? Can’t be that I have no freedom? It can’t be that my parents are giant controlling assholes? No, it’s the heavy metal. Every time anyone asks me if I’m sexually active I lie. Nope, I’m a virgin. If I am being treated for my taste in music than I am really not going to open up my mouth about my sexuality. I think they will put electrodes on my nipples and flash photos of naked women at me. L-E-S-B-I-A-N. I push the image, the word, the very notion far away. I pretend to sleep with a lot of boys, but people can see through me. Rumors fly at school. My locker got vandalized with the word “Dyke” and someone claimed to have seen me kissing a girl from the rival high school near the music building. I never even met her or went to the music building! There is no way I’m confiding in this guy who thinks that a role-playing game is making me suicidal. (Author’s memory, 2013).

I start thinking I’ve been taken to some kind of concentration camp. I write my number on my arm so that they can identify me when they come across my emaciated body.

At some point, when the nursing strike was over, I moved to a nicer, less restrictive hospital. There I was offered group therapy, meditation group, art therapy, and a staff that actually interacted with me rather than making sure I was not dead. I related to my roommate, a girl my age who had a breakdown after finding out her dad was gay. I met a crack addict for the first time—a beautiful, intelligent woman who waxed poetically about the amazing high that ruined her life. I met a bewildered young mother who, in severe postpartum depression, drank...
bleach while alone with her newborn. Desperate and sad, some in the throes of addiction, these patients functioned enough to work on their problems and benefit from treatment. They did not scare me.

My aunt and uncle lived close to the institution. When I became stable enough to be taken out of the hospital for a few hours, my parents took me to visit them for dinner. On the way my mother informed me that my relatives had no idea I had been under treatment in the psychiatric ward and warned me against mentioning it. I understood that my parents felt deeply ashamed of me. The notion bad parenting created my mental illness confused them and robbed them of chance to receive social support from their friends and relatives at a time when they needed support the most. Fear of judgment isolated them as parents, facing the chronic and potentially fatal illness of a child. In silencing me, my parents taught me they believed in certain tropes surrounding mental illness. They reinforced that psychiatric illnesses are somehow fake, the problem of poor parenting, a ploy for attention, or poor behavior. At that time my parents thought I exhibited bad behavior rather than symptoms of a chronic and potentially fatal illness.

I actually liked the second hospital more than I liked my home, but after thirty days my insurance ran out so I signed a contract with my parents promising to attend school in exchange for being able to spend the night away from home twice a month. After that initial period of hospitalizations, I had little follow-up care, only one session of “family therapy.” Immediately after that session, my mom proclaimed we would not be going back ever. She did not want to pay for me to be self-indulgent or for her parenting to be scrutinized. My parents did not really believe in psychiatry or psychology instead they thought my behavioral problem that could be fixed through “tough love.” My parents attended exactly one “tough love” meeting - one was enough. All these years later, my mom said that they believed in the common sense ideas, but the
other parents at the meeting who shared about their families were “just nuts.” For my parents tough love parenting philosophies appealed to the school of hard knocks that served them well.

Tough love was a concept which originated in the twelve step programs of Alcoholics Anonymous and Al-Anon. It was employed as a response to alcoholic’s drinking and later adopted as a method for parents to effectively deal with teenager’s behavioral problems (Newton, 1985). The basis for the philosophy is that parents have the right and the responsibility to control teenagers by working with authorities such as school officials, the justice system, and mental health institutions. In this popular parenting style, parents are encouraged to set firm limits and consequences for children’s behavior. Techniques include behavioral contracts, bottom lines that cannot be crossed, and parents literally closing their doors in the faces of teens who misbehave. The basic tenets of tough love include notions that culture is responsible for family problems.

Since James Dean’s time we have increasingly focused on teenager’s feelings, especially their “sad” feelings and their “bad” feelings, which has led us to psychiatry’s most pervasive contribution to modern culture, the victim. We have absorbed through our collective cultural skin psychological notions about the normality of Oedipal conflict, that it is expected and acceptable for children to want to destroy at least one parent. (York & York, 1985, p. 30)

For the creators of tough love, the problem with teenagers stems from newfangled ideas that children misbehave because their parents have not controlled the children enough and the children erroneously believe that they are partners in relationship with their parents instead of understanding that they are not on equal footing with their parents. Tough love proponents also believe that, “The essence of family life is cooperation, not togetherness” (York & York, 1985,
p. 110). In practice tough love is supposed to be worked on and worked out through support
groups for parents helping other parents. However, in my family’s case, tough love was the
sound bite off the television that my parents adopted with no real outside input. They attended
one tough love meeting, but they did not believe that the other parents could be supportive of our
family. My parents did not think of that early period of institutionalization as a place for me to
heal from an illness; they thought of it as a place that would “scare me straight.”

*Scared Straight!* is the title of the popular 1978 documentary where New Jersey
delinquent youth are brought into a prison and confronted by prisoners and the reality of prison
life; the experience is meant to convince the teenagers to turn away from crime. The dominant
ideology behind the documentary is that crime exists because of individual bad choices, not any
other extenuating circumstances (Cavender, 1981). My parents are a product of their times and a
combination of “tough love” and notions of being able to “scare straight” teenagers set the stage
for my earliest institutionalization. Lost in words and sound bites on the nightly news and
silenced by shame and stigma, they believed if I was confronted with the horrible consequence of
institutionalization that I could and would stop misbehaving.

My parents, both born during WWII of parents who struggled financially, thought
psychology and psychiatry indulgent, expensive, ineffective, and stigmatizing. Mom always told
me that poor people were crazy and rich people were eccentric. Not only a funny quip, this
revealed a deeper truth. Firmly rooted in the working class, they never met anyone who had the
luxury to pay someone to talk to about their feelings. Rich people and women’s libbers got
analyzed. My parents proved that they loved us by feeding and clothing us, not through words or
touch. They were not the type of people who examined their emotions and they had an overall
distrust of psychiatry, psychology, and group therapy. Beyond therapy being a “racket” my
parents were hostile to the notion that there may have been something wrong with the family system or their parenting which may have caused my acting out. So, they were critical of being critiqued by the system they did not fully believe in. At the time, their choice to allow my institutionalization to continue past the required seventy-two hours was motivated by the idea that living in that awful environment could scare me straight. Their enactment of *Tough Love* and *Scared Straight!* was predicated on their class identity and the stigma associated with being the parent of an out-of-control teen. They thought mental illness was deviant behavior—not a medical problem—that could be corrected if the teenager was made miserable and desperate enough that they were willing to submit to appropriate cultural standards of behavior as dictated by their parents.

My parents forced me to return to the same school where I got hauled off into the back of a police car over a month before. The hospitalization did not make me any better; all it did was reassure me that my rights could be taken away at any time. I did not stay home long before I ran away or was kicked out again. At sixteen, my living circumstances became so unbearable that I left home and had no intention of ever returning. My godfather’s wife found me and asked me to get in her car. Ultimately, I moved in with them for several months. My parents threatened legal action to try to stop them from harboring a runaway, but did not get the justice system involved. Kathy and Andy’s intervention ended the friendship they had with my parents, but their concern for me trumped their allegiance to my parents. Kathy relates:

I feel bad that we crossed them because they are the parents and so I understand where they were coming from when then denied us the permission of having you stay with us but I’ll tell you I never ever…I can still see it right now. You were behind Nob Hill in a garbage bin. I will never forget the picture. I was in the car looking for you and I saw you
and I got you. I was very angry with your parents for allowing that. Allowed. Yeah. They made a choice to let you learn your lesson. Well kids don’t learn their lessons. If you don’t have the tools, how are you going to learn a lesson? But between your ego and your dad’s ego, I mean two battlefields there is no ground zero. There is no place to go with that (Kathy, personal communication, 2014).

With Kathy and Andy I enjoyed the most normal part of my adolescence. In the absence of my parents, Kathy provided social support. In this case that meant long fireside chats where she listened more than she talked. It also meant that she paid for my food, clothing and shelter. She and my godfather set rules of behavior that I largely followed. I got a job at a fast food place and then at a local answering service. Much like before, I walked to work after school, only this time I got paid and got to keep my paycheck. I lived in the same place my school was, so on the rare occasion I got invited to go somewhere, I was allow to go as long as I got home by my curfew. Kathy trusted me to go out with friends, have a paying job, and even do some extra-curricular activities. This newfound normality did not last long because the school informed me that I would be held back a year because of all the classes I missed. I returned to school, but it was too late to graduate with my class. I had failed way too many classes. I decided to go to continuation school to get my diploma but my godfather disagreed. At that point, I begged my parents to let me go to the continuation school and they did on the condition I return home. The school allowed me to work at my own pace so, instead of graduating a year late through traditional means, I graduated six months early at sixteen.

I stayed home until seventeen; I left a few days after my June graduation ceremony and party provided me enough cash to buy a beat up Ford Maverick a year older than me. I stopped speaking to my parents again. I slept in my car at night and showered at friend’s houses when
their parents were at work. About a week or two into my transient life, I met my older cousin and her husband for dinner. Aghast at my sleeping arrangements, they invited me to stay with their family. They had a three-month-old child. I helped care for the baby and got a job as a cashier at a large hardware store. Although I conceptualized my lack of freedom as the reason I acted out, in retrospect I had autonomy in that living situation but also behaved recklessly and self-destructively. I drank and did a variety of drugs in unsafe combinations. Although I performed well at work, my attendance became a problem so eventually I got fired, but not before befriend ing the worst influences available at my job.

One of the older women at the hardware store introduced me to the joys of methamphetamine. After being fired from the hardware store because of calling in sick too often, I found a job as a maid for individual’s homes. The meth enhanced my job performance; I became meticulous and I was paid every day to reinvest in more drugs. For three or four months, I lived an unhealthy cycle: I worked to get money to get drugs to do good work. I barely slept and at night I drove around, did drugs and wasted my time socializing with the dregs of society. Luckily, I only took meth for a short time before arriving at a crossroads.

A month before my eighteenth birthday, my rock-bottom moment happened. I arrived at a drug dealer’s house to buy my daily supply of meth and he offered me a much larger quantity of the drug if I performed a sex act on him. Tempted, I considered it. I took meth for three months straight and three months of use was enough for me to seriously consider prostitution for a small quantity of free drugs. For once in my young life, I managed to make a good choice. Maybe I had watched enough after-school specials in my life, but somehow I knew if I crossed the line into exchanging sex for drugs the slope would be so slippery that I would never recover. In a rare moment of clarity, I knew I did not want to be a whore and I did not want to give this
drug this kind of power over my life. Perhaps it is because the proposition came only three
months into my serious drug use instead of three years, but I stopped using that day. Many
women with BPD are not lucky enough to stop serious drug use before it becomes a factor in
their becoming violent criminals. Researchers have proven:

The high rates of violent arresting charges among these women are consistent with
previous studies that indicate that women with major psychiatric disorders are
significantly more likely to commit violent offences than women without major
psychiatric disorders and that substance use increases the odds of women committing a
violent crime (McDermott, Quanbeck, & Frye, 2007, p. 539).

Luckily I knew I needed to change and I got out before I ended up compromising my morals,
dead, or incarcerated. I stopped doing meth and avoided a life of selling myself or robbing other
people for drugs. I will never be sure why I had the ability to walk away when so many other
people cannot. It might have been because even at my most desperate, I knew that people who
used drugs with me did not care for me. I knew that they would rob me or take advantage of me
if it meant they could somehow profit. I did not ever confuse those people for people who were
my family.

I also remember thinking how disappointed Kathy would be in me after she had invested
in me and even severed the relationship with my parents to care for me. The people who loved
me would never approve of my destroying myself and they would not want to be in relationship
with me if they knew I was a drug whore. Part of the reason I quit meth was because I did not
want to lose my voluntary kin or social supporters. This same reasoning would later inspire me
to comply with treatment for my mental illness.
My social supporters inadvertently helped me because I did not want to disappoint, or worse, lose them. That particularly lecherous drug dealer also set off some kind of internal alarm and I had a vision of my future as a drug addicted prostitute; it made me ashamed. Something shifted for me in that instant and I am grateful it did. This is not to say that I never craved speed again. For several years I could taste the chemical nasal drip siding down my throat. The drip tasted paradoxically like the rush of invincibility and utter destruction. That physical sensation, the residue of the drug use itself was both delicious and horrifying. For me, it was almost impossible to resist.

I managed to resist largely by changing my environment. Right after I turned eighteen, when I was quitting methamphetamine, I joined the California Conservation Corps to get out of the Bay Area and to start fresh. This would be the first of many moves, but the only one that had to do with stopping a potential life of drug addiction. It was not easy, starting a new life, but for me, it worked. I used methamphetamine only a few more times in my life, but I never came that close to compromising my body and soul to a drug again. The new place where no one knew of my drug-using past made it easier for me to reinvent myself as a responsible person who did not regularly use hard drugs.

**California Conservation Corps**

At eighteen all I wanted was to be free—free of my reputation, free of my past, free of my neighborhood, and free of people who thought I could be bought with drugs. I craved the freedom to finally make it on my own. Grades, finances, and self-esteem prevented college. Pacifism would not allow my joining the military. Instead, I joined the California Conservation Corps (CCC). The public service youth organization with the tag line, “Hard Work, Low Pay and Miserable Conditions” did not disappoint. The state run program with dozens of bases employed
and housed people between 18-24 and contracted their (mostly) manual labor to help with any public, and occasionally private, agency that needed temporary, cheap help. The CCC provided minimum wage, three meals a day, and a place to live. It also gave me a change of scenery and a way to change my life. It supplied plenty of rules and structure, lots of hard manual labor, and an opportunity to work in the sunshine.

When new recruits joined the CCC they were sent to the Academy in San Luis Obispo, their version of boot camp. The experience tore civilians down and created new corps members who followed the chain of command and would be capable of working in dangerous situations. It weeded out people who were too willful to follow directions or argued with authority. As a corps member trainee, my direct supervisors were also corps members who had seniority and had been promoted. They acted as pseudo-drill instructors and, unfortunately, some allowed the power to go to their heads. During my time as a trainee, I was both hazed and sexually harassed. One crew leader forced me to clean a completely clogged toilet in the men’s latrine without the appropriate tools. Another forced me to stand in formation while he yelled in my face that I “just needed to get fucked.” For each woman in the CCC, there were about a hundred men. Training pushed the limits of what I could tolerate both physically and emotionally. Proving that a woman could handle the job demanded that I worked harder than I ever worked before. I pressured myself as an individual and as a feminist. I did not want to go back to where I surrounded myself with people who used drugs and a place where everyone pegged me as weird. I felt proud of my work and compelled by my feminism to prove I could do as well as any man. Quitting the CCC also would have made me homeless; the CCC provided me with room and board and a paycheck of a little less than four hundred dollars a month. I could not afford to leave impulsively.
After two weeks at the Academy, we were sent out to our permanent bases all over the state. Mine was in southern California in San Pedro. We lived on an abandoned military base; the two hundred men lived in two giant dorms and we three women were housed in the drafty old WWII infirmary. “Miserable” does not begin to cover the conditions we lived under, in terms of sexual harassment, sexual discrimination, and housing. I persevered for both personal reasons and because I thought my being a woman in that environment gave me a space to enact my feminism. I thrived. I learned discipline and I cared about my job. I cleaned an oil spill, picked up trash on the freeway, trimmed and planted trees, and cut and maintained trails in a park. I also distributed pamphlets warning residents in Compton that they were going to be sprayed with chemicals to kill a specific fly that could destroy agriculture.

A few months after I joined, the Academy hosted the CCC’s version of team building exercise called the Main Event. The Main Event, a corps-wide, two-day annual game and cookout, had events including a tug-of-war, a fire-hose drag, and other feats of strength. At the end of the weekend, one base achieved bragging rights and a trophy as the best center. My center arrived the night before the first day of the games and that is where I met Ronny. He had long hair, almost to his waist. He dyed it black, but the first eight inches or so displayed his natural color, the most beautiful red-auburn, thick mane I ever saw. I cannot be objective about this portion of my life but, looking back, I cannot be certain which I was more drawn to - his amazing hair or the fact he had a car.

Being in the CCC without a car meant that we could only get places by walking, often walking miles just to go get beer or cigarettes. To me, the Main Event provided the opportunity to party. The Academy was located about seven miles from town and I did not want to stay on the military base with the same guys I worked with every day. Used to being the only woman
around, I boldly walked up to Ronny and asked him if he wanted to go get beer and, of course, he said that he did. His 1978 Monte Carlo with a plush bench seat, wires hanging from the stereo, and cassette tapes all over the floor felt like a Bentley to me. The men I worked with displayed various degrees of hostility to the women. Ronny surprised me with his gentlemanly manners; he even opened the car door for me. Many of the men thought us incapable of the hard manual labor required of the job and many simply wanted to sleep with us. After months of men only trying to get in my pants or berate me, it was refreshing that Ronny was interested in what I had to say. Apparently all I ever needed was to be really listened to, because I jumped in his lap and kissed him. As cliché as it sounds, everything I needed to know was in that kiss.

I left the Main Event smitten with Ronny. I had the goal of getting promoted. To be promoted, I would need to go to officer training back at the Academy. Ronny permanently lived at the Academy and if I could get sent to the officer training, I would be with him for a month. It only took me a few months to get sent for the special training. During the days I took leadership classes and I hung out nights and weekends with Ronny and his friends who were stationed at the Academy. By day I went to officer’s training school, it was more academic and less physical than the other CCC training. At nights and on weekends, we spent our time drinking and smoking pot on the beach. Even though I killed my brain cells nightly, I got the highest overall score in my class which carried with it option of picking a new center. The Academy became my new home. Although my relationship with Ronny motivated me, more women worked there and female companionship appealed to me.

My relationship with Ronny moved quickly; in a few short weeks I knew I loved him. Somewhere in between the drinking, the pot smoking, and the sex we told each other everything about ourselves. I never felt accepted or loved before from a boyfriend. I found his past
dangerous and anti-establishment, but the man I knew was responsible and loyal. But most importantly he listened to me, really listened. My undiagnosed mood swings were in bloom, but he never judged me for it. I remember on more than one occasion keeping him up all night rapidly cycling through a myriad of emotions. One minute I would rant about international politics, the next cry about my dead grandfather, then suddenly I would try to seduce him. He treated me with care; he listened to me as if I was the most interesting person he ever met. He never pressured me, never scolded me, and never pushed. Every single time we kissed, I swooned.

Beyond his insanely intoxicating kisses, he was generous, kind and fair. He defended the underdog and never took advantage of his power. He tutored math, was a gifted musician and athlete. He was well liked and a strong leader. Unfortunately, he never really overcame his own troubled childhood. Adopted into a farm family in North Dakota after his birthmother broke both his legs, Ronny never established a sense of self-worth. He believed his family only adopted him to use him as a free farmhand and, although his parents cared for him, their brand of parenting also included harsh corporal punishment. Seeing his parent’s refusal to pay for college because he wanted to major in music as more proof that he did not belong in that family, Ronny rebelled by joining the Army.

During his short-lived military career he went AWOL twice. The first time, he was caught and made to rejoin his unit. The second time, Ronny traveled as a skeet-ball operator for almost a year before an angry, jilted ex-girlfriend turned him in to the authorities. He somehow charmed the military into giving him an honorable discharge instead of jail.

After the military, he moved to Hollywood, landing a job bagging groceries by day and envying musicians by night. Somewhere along the way he fell into hanging out with the tough
crowd filled with prostitutes and junkies. He regularly drank too much and injected methamphetamine. Like so many people, joining the CCC worked as a kind of drug rehabilitation. The Corps relocated him out of Hollywood and gave him a new environment where he did not have to interact with his hard drug using associates from the streets of Hollywood. He claimed that the CCC saved his life. By the time I met him, he regulated his drinking by only drank beer and, although he smoked pot almost nightly, he seemed pretty responsible. His bad boy past made him more attractive to me.

The residue of his birthmother’s abuse coupled with a true allergy to alcohol eventually destroyed him, but not before damaging our relationship. For months I happily drank with Ronny and our other friends until I thought maybe it was taking up too much of our time and money—before every payday we barely scraped together coins for beer and cigarettes. So I slowed down on the drinking and urged Ronny to do the same. One night when drunk, Ronny accidentally hit me in the face while he tried to get his car keys out of my hand. I realized for the first time how domestic violence could live in the same place as love. He only hit me that one time, and I knew even then that his actions were unintentional. I also knew in an instant I had to leave him the same way I knew I did not want to be a drug addicted prostitute. In that moment I simply knew that if I allowed myself to get sucked under by his drinking that it would cause irreparable damage to my own life.

Although I loved him, I broke up with him the next day, telling him I would consider getting back together with him if he could maintain sobriety. Despite my reckless behavior, impulsivity and all around self-destructiveness, I refused to give up my hard-earned independence to live a life as a wife of a man I loved dearly but who would not challenge himself to sober living. My adolescence and early twenties were peppered with depression and
my inability to tolerate authority figures. I simply could not tolerate anyone or anything controlling me. I instinctively understood that living with an untreated addict would be giving up control of my life in favor of a roller coaster of drunken outbursts and instability. I worked too hard to be free of my past to willingly submit to fusing my life with an out of control person.

When I ran away as a teenager, chosen kinship members gave me shelter, advice, and love. They allowed me live with them rather than struggle as a homeless youth. I used alcohol, drugs, and sex to self-medicate and luckily avoided addiction, prostitution, or incarceration. Ironically, when I finally took steps to try to treat myself, I turned to the CCC, a heavily structured environment. This is the same kind of structure that mental institutions try to provide. Breakfast is always served at the same time, everyday follows a tight schedule; there are rules for everything, and there are people to enforce the rules. The CCC also provided me with fresh air, direct sunshine and a sense of pride in my work. I responded very well to the clear-cut rules and I believed the mission. Although it did not cure me of my mental illness, the lifestyle provided me with my first sense of pride and independence. I met and fell in love with a man, who I now recognize as having awful untreated mental illness coupled with drug and alcohol addiction. In my youth, I thought that a combination of love and will power could heal him. But, I did not have the emotional or mental tools to help Ronny since I could barely help myself; I did what in many ways my parents taught me to do when I had interpersonal conflict—I just ran away. I never cut him off entirely though and, because we tried with our limited emotional and mental resources to work on our relationship, there was always a space in my heart for him.

**Serious Depression Take Two: A Sudden Death**

Between the ages of nineteen and twenty-five I grew tremendously. During this period of my life, caring for myself became more important than open rebellion. My focus shifted from
myself largely because my perception changed from feeling like an outsider to feeling like a community member. I quit the CCC and dated other people, all the while waiting for Ronny to kick his addictions and marry me. I knew that would happen in my core; I waited for him to mature. Maybe I was young enough to believe in romance or maybe I craved security. I will never find out. I also knew that if he did not kick his demons, our life together would be miserable. I thought he would outgrow the party lifestyle and go to college. I made the mistake many young women make, falling in love with potential not reality.

I left the structured environment of the CCC and applied the work ethic I learned there to washing dishes in a nursing home. For the first time outside the CCC, I understood my job as important—if I did not do my job correctly, old people would suffer. I showed up and did my best. I got Ronny a job working there, too. We worked well together but spent too much time flirting. This represented a change in my mentality towards work. I also fostered a fairly healthy relationship with Ronny while waiting for him to deal with his addiction.

For the next several years, Ronny stopped drinking off and on and I would return to his life and his bed. Ultimately he failed to stay sober long enough to quell my fears of poverty and violence. I envisioned us living in a trailer park with five hungry kids while he managed a Pizza Hut, staying long nights drinking from the keg while those kids trapped me in a twelve by seventy foot box. My being scared of poverty (or mediocrity) soured our once-in-a-lifetime love; I refused to commit. However, I never cut ties with him. My attraction overwhelmed my fears enough to bring me back to him time and time again. But underneath the attraction and chemistry, my fear of his alcoholism won out.

Our time living in the same city was over when I found a mysterious lump in my neck. My parents paid for my insurance, and to get treatment I needed to be seen at their facilities
about 300 miles away. Because I needed so many appointments, I simply could not afford to take
the time off work and pay for my apartment with my $4.25 an hour job. I moved back to my
parent’s house to an uneasy time of HIV tests, MRIs and biopsies. The doctors never figured out
why my lymph nodes swelled, but they ruled out all major diseases. Still in love with Ronny, for
years, I continued to drive back and forth the three hundred miles to be with him. Although I saw
other people, my heart waited for his potential to catch up with his reality. Unfortunately, that
day would never come.

I thought psychiatric hospitalizations were behind me; it had been seven years since my
last one. Nursing a hangover from my twenty-third birthday party the night before, I picked up
the phone and heard Toni’s voice. Toni worked with Ronny and me in the nursing home. From
300 miles away with one crack in her voice I knew. I knew. Ronny. All I said was, “Is he alive?”
hoping against hope he was in the county jail. She said, “No. A car hit him and he died.” The
heavy telephone receiver hit the floor sheer moments before vomit spewed out my nose. It felt
like I had run full speed into a closed glass door, lying on the floor gasping for air. My knees
buckled.

On the night of my twenty-third birthday, when he was twenty-nine with an uncashed
paycheck and twelve pack of beer, Ronny attempted to run across the freeway and got killed.
Later, his friends told me he ran across the freeway as a shortcut because he broke his
eyeglasses. Some poor, unsuspecting old man driving a pickup truck struck and killed a man who
darted out of nowhere. The news of this tragic event devastated me. Depression descended on
me, enveloped me, strangled me, and incapacitated me. I breathed sorrow in and it infected me
like a quick growing cancer. I was born on November 23, Ronny died on my twenty-third
birthday on November 23. I received the following letter a few days after he died. Even with
what can be arguably read as a suicide note, I could not process the unbelievable cruelty of him killing himself on my birthday. Something inside could not let the full impact touch my consciousness. I lived in denial for years and believed it an accident.

_November 1994_

_Won-_ 

_Just so you know, you were right. I am a loser. I got my second DUI and I was holding. I’m getting kicked out of the class (DUI). I think my life is out of control. Hopefully by summer I can bail this state. There’s nothing left for me around here but memories of maybes. Anyway I honestly do hope you’re doing better than I am. Just so you know how I feel about you will never change. You should already know that by now. I wish you many happy birthdays and a fruitful life._

_With Love Forever,_

_Ronny_

_PS- Enclosed is a poem I can’t seem to finish. Finish it for me. Who knows maybe after I die all this shit I write will become famous. NOT!_

The poem enclosed was:

_I see you through shaded eyes_  
_They say it ain’t right_  
_I just can’t seem to cry_  
_Even when I’m alone at night_  
_I reach out in front of me_  
_To grasp at what I see_  
_Yet I never seem to get a hold_
An illusion is all that you must be
Unable to define
Understanding seems beyond my means
Inside I feel confined
It’s always better in my dreams

His last words felt like a cut on the inside of my cheek that I could not stop poking with my tongue. It’s always better in my dreams. By Christmas, almost a month later, grief almost immobilized me. I rarely got out of bed. I almost never ate. I lost all ability to care for even my basic needs. I could not muster the energy or desire to even bother to dress or shower.

Tina Marie hosted Christmas dinner with her in-laws. She invited me, thinking that being around people might be good for me. I showed up late, wearing a set of red flannel pajamas. I experienced my grief physically, and I needed the soft flannel on my skin. I simply sank into Tina Marie’s couch staring off in space, unable to hold polite conversation or care about proprieties. I could not even eat properly; trying to choke down food that would have normally tasted great required great concentration and effort. When I ate I could not keep food in my stomach. Food hit the knot of sadness-induced bile and I vomited—surely the other guests heard.

As days turned into weeks, I did not get better. I barely went to work and I never went grocery shopping. My family first grew frustrated and thought that I just craved attention and was being melodramatic. Tina Marie did not understand that depression made taking care of myself impossible, but she cared for me the best she could. She grocery shopped and left two full bags of groceries on my doorstep. Everything in the bags could be easily heated up or ready to eat. I experienced chronic depression. It would be an understatement to call me unmotivated. I rarely left my bed. I stopped answering the phone. I did not pay my rent or even open my mail.
In between sobbing and vomiting, I simply waited to die. I did not try to kill myself because I did not believe that there would be any relief in my own death. Sleep would not come, so I started drinking enough alcohol to pass out every night. My social support network reached out to me, but often I did not respond. Julee sometimes came by to visit me, she understood grief having survived the death of her baby. During the grips of depression, Tina Marie supported me by helping me feed myself and included a card expressing that she loved me.

My thoughts were on a loop. I stayed in this grief stricken state for months. The following poem, written during my initial grief, words on the page shaped like a zero articulate my thoughts from the time. The zero represents the hole in my heart, an emptiness that paradoxically was both nothing and took up space.

Regret-
Sadness- Anger-
Repeat- Regret-
Sadness- Anger-
Repeat. Regret-
Sadness- Anger-
Repeat. Regret
Sadness Anger.

The time period above represents much emotional and mental growth on my part. In a few short years I moved from being dependent on my social supporters for material help to learning how to survive off very little money. I learned to value myself enough not to marry an addict, even though I loved him. I placed value on my health enough to move back into my
parent’s home and leave behind the life I loved. On my twenty-third birthday—with the devastating news of Ronny’s death—I suddenly, abruptly, and painfully became an adult, baptized in grief. I turned again to social support to help me cope with the most devastating event I ever experienced.

**Sisterhood is Powerful**

Friendship and social support helped me survive the loss of love. Alison, wise beyond her years, helped me process the unfathomable death of my lover. My roommate and chosen kinship member, she provided me with both female friendship and intellectual stimulation. She introduced me to feminist theory at a time when I worked in a highly sexualized space and helped me mostly by listening to me. She helped me feel less alone in the world. Sometimes, my coping skills manifested in self-destructive behavior or perhaps early undiagnosed rapid cycling BPD. This section illuminates that crucial time period in my life and tells how social support changed the bleak trajectory of my life into the building blocks of long-term friendship.

When Ronny died, I lived in a house with a woman who was and is a true friend. Alison and I knew each other for years, but by my twenty-third birthday she became my closest friend and confidant, someone I trusted implicitly. I grew up feeling isolated and alone in the world with few girls as my friends. Alison was different than any of the girls I knew; she never tried to compete with me. She remains one of the most naturally intellectually brilliant people I have ever met. Her strong sense of spirituality inspired in her a gift for friendship and an inclination to nurture. A born feminist who embodied sisterhood, she taught me much about how to be a friend. I can say with absolute certainty that if she had not been my friend and roommate at the time that I faced the tragedy of Ronny’s death I would have killed myself.
But somehow, even though we were so young, she seemed to intuitively know how to be of service to me in my time of need. Alison reflects on our friendship in an interview responding to my question about why we became such good friends in the two years before Ronny’s death:

*Initially, we had all the ingredients that make friendships. We had a similar backgrounds growing up. We were raised fairly religiously, we had both been involved in service based organizations, we both had relatively large and involved geographically close families that were relatively dysfunctional without being off-the-charts abusive. As teenagers we had both been put in mental institutions that our parents treated as punitive rather than therapeutic* (Alison, personal communication, 2014).

Alison articulates our chosen kinship relationship as being based on mutual experiences, similar background, interests and a lack of functioning healthy relationships with our families of origin. Our relationship was at first contextual. According to Braithwaite, Bach and Baxter (2010), these relationships are “contextual” voluntary kinship; they are formed around a specific situation, stage of life, time or space. In our case, we were both in our early twenties, fairly independent financially and emotionally from our birth families, shared the history of teenage institutionalization and went to high school in the same town. We also had common spirituality and morality, although our politics were not totally aligned.

As time went on, we began to view each other as “substitute” family. When we began to share our stories with each other and realized we both had painful relationships with our only sisters we began to accept each other as chosen family.

*Later, our friendship developed because we put in the time talking and hanging out and time to understand each other. I already went through an awful custody battle for my daughter while living with you. I could have used a little support as a young single*
mother, but instead, what people tried take my kid away and erase me. I felt judged at every turn, and you were there for all of that! We had been through other pretty heavy stuff at that time. We both had very tense relationships with our sisters. It was like we became the sisters that we should have had; we picked each other. It just clicked (Alison, personal communication, 2014).

As substitute voluntary kin we acted as stand-ins in many ways for estranged or dead biological or legal family members. Because relationships are constantly evolving, sometimes there were over the following years long periods where one or both of us would not speak to our sisters. In those times we acted as substitute sisters to each other (Braithwaite, Bach & Baxter, 2010).

There were other times when we did maintain positive relationships with our sisters. During those times we also continued our relationship with each other, so the relationship was not substituting for our relationship with our own sisters, but acted as an additional sister. Social support literature classifies these types of voluntary kin relationships as “supplemental” family (Braithwaite, Bach & Baxter, 2010). That is we constituted as an addition to the existing biological or legal family rather than a substitution for the biological or legal family.

The vast majority of the support we provided for each other was non-material. Our relationship was almost entirely based on supportive communication. I rented a small house from my boss. Alison and her three year-old moved from her parent’s house in with me. While I say our relationship was not based on an exchange of money or goods, we certainly shared food, cigarettes, and alcohol. Alison became embattled in a child custody dispute largely because her child’s father did not want to pay child support. He decided to marry another woman he was having a child with while dating Alison. Beyond breaking her heart, he violated their financial
agreement. He was to put himself through college without the burden of child support and then he would help Alison financially while she worked on her career. Instead of finishing his engineering program, he dropped out and started a second family. When he was served with child support documents, he countersued for custody. His choice to leave college a year before getting his degree set Alison and their daughter up for a life of financial instability.

I listened to Alison and enjoyed playing with her daughter. We formed in many ways our own family. Most holidays the child would spend with her grandparents or her father and Alison and I would have our own rituals. We generally spent the time alone in the house just hanging out and letting each other feel whatever feeling came up. Although we cried, we also always found a way to laugh at ourselves and give each other decent advice. Before Alison, I never had a female friend that I trusted implicitly. I never felt as if someone was on my side entirely. I never one hundred percent trusted another woman before. When we were not laughing and crying, Alison taught me about feminism. Prior to the hours spent talking on our couch, I had been relatively brainwashed by the political right; I thought that feminism was a dirty word for angry women. Under Alison’s tutelage, I understood that while I did not I identify with the “f-word” I certainly believed and enacted feminist principles. Our friendship was and is in many ways a feminist political action—a relationship based on mutual, corporative communication for the benefit of all parties. Our living arrangement enacted a feminist ethic of care:

Sensitivity to the needs of others and the assumptions of responsibility for taking care lead women to attend to voices other than their own and to include in their judgment other points of view. Women’s moral weakness, manifest in an apparent diffusion and confusion of judgment, is thus inseparable from women’s moral strength, an overriding concern with relationships and responsibilities (Gilligan, 1982, pp. 16-17).
Alison used to say frequently: “At the end of the day everyone wants to come home to someone who is on their side.” After a lifetime of not feeling unconditional love, with Alison I was finally home, and she loved me warts and all. She continues to prove that every day.

In the months following Ronny’s death, Alison drove me around for hours, afraid to leave me alone. Contained in her car she could be assured I was alive and eating although my spirit, my personality, and my essence were completely obscured by grief. The withdrawal symptoms from Ronny, and the idea of Ronny, landed in the pit of my stomach forcing vomit. I felt my grief so corporally that Alison still remembers pulling over her car frequently for me to vomit. I had the advantage of being in massage therapy school so I understood that the mind, body, and spirit were intricately connected so, while the constant purging was unsightly, I was not concerned for my physical health. I knew that sadness created my fragile physical state. Beyond vomiting, I could not stay warm enough. The generally mild California winters did not ever leave me so cold. I vividly remember cranking up the heater, taking all of the blankets in the house and piling them on to try to stop the ever-present goose bumps and shivers. But Alison could not spend all of her time babysitting me. She had a young daughter, several jobs, and a full social life. I found some other, less positive ways to pass my time.

In the months after Ronny’s death, when Alison was not there, I found other ways to cope mostly unhealthy ones. Sex made me feel better, however temporarily. I am and always have been unapologetically sexual. I live by my own ethical code largely hinging on honesty. I do not tell lies, I do not cheat, and I do not allow people to believe I am capable of becoming someone I am not. I have never felt guilty about my sexuality or living freely. I enjoy giving and receiving pleasure. In high school I combated the sexual double standard by expressing myself with whomever I wanted whenever I wanted. I did not have steady boyfriends for longer than a few
months and did not reserve sex for monogamy. Although, I never identified as strictly heterosexual, my relationships were with men and while in the CCC I was popular primarily because I was female.

Before the term “friends with benefits” became popular, I participated in a mutually beneficial sexual relationship almost every Friday night for years with one particular man named Dave. He was a coworker of mine in the CCC. We cared for each other, but our dating relationship was the equivalent of a dead-end, entry-level job—there was simply no room for advancement. The CCC operated many bases located all over the state. After a few years at our base, Dave transferred to a base five hundred miles away. He wanted to take advantage of working outside in a different geography. When he moved, staying in touch was difficult. We did not have access to the kinds of instant communication we take for granted today. Telephone calls were hit and miss because we relied on group payphones located on our bases. The phone could ring for hours without anyone picking up. Even then the person who answered had to be kind enough to find the recipient of the phone call. The office phones did not handle personal calls. We rarely connected. We did write letters, but life on a CCC base with no car was not conducive to having both an envelope and a stamp. Although we never had a falling out, eventually, we lost touch.

After Ronny’s death, I tracked Dave down through an old phone number of his mother’s. Even though Dave and Ronny did not particularly like each other, it comforted me in my period of mourning to have someone around who had known him. Unemployed, Dave spent days at a time at my house. We loved each other, but mostly we entertained and distracted one another. In periods of depression or other life altering circumstances, “sex can become a source of support, comfort, pleasure, affirmation of endangered identity, intimacy, a medium for connecting with
significant others, and a way of feeling ‘normal’” (Berdychevsky, Kleiber, Nimrod, & Gibson, 2013, p.50). Dave fulfilled all of the needs aforementioned. When Ronny was alive, he helped construct my identity as a sexually desirable person; in his absence Dave affirmed that he sexually desired me. While I gave and received pleasure in those moments, I risked pregnancy and disease. I behaved recklessly, “. . .sex can serve as a coping strategy with depressive symptoms, on the one hand, but may also be related to physical and mental risk taking that can aggravate depressive symptoms, on the other hand” (Berdychevsky, Kleiber, Nimrod & Gibson, 2013, p.51). Prior to this time, I diligently used birth control. Depressed, I cared about nothing, including birth control. Maybe subconsciously I thought getting pregnant might snap me out of the pit of sadness. Thankfully, that did not happen.

Dave and I shared intense sexual chemistry. We also shared a history, enjoyed the same music, made each other laugh, and both loved the outdoors. We got drunk and stoned emerging from a sex stupor only for pizza and hang out with Alison, who never did drugs. None of this behavior was entirely unusual for me, but it took on a new fervor. Since high school I drank alcohol frequently in large quantities predominantly on the weekends. I preferred smoking marijuana and would consume it daily if possible. Now I recognize this as self-medicating behavior that I employed to try to mitigate my mental illness. At the time, I thought I liked to “party.” After Ronny’s death I accelerated the drinking, and drank nightly not only to numb myself from emotional pain, but also to put myself to sleep. I attended massage school and worked in the financial aid office as a student worker. For twelve hours a day, five days a week, I lived at massage school. The minute I walked through the threshold of my home, I started drinking and smoking pot until I passed out. I somehow functioned at school and work, concealing my nighttime ritual. Despite all the circumstances, I finished massage school and
eked out a living doing professional massage.

Although I am reluctant still to define myself as an addict or an alcoholic, I definitely met the *DSM-5* definitions for Cannabis Use Disorder (CUD) and Alcohol Use Disorder (AUD). Specifically, three of these symptoms were present with my marijuana use. First, I spent much of my time trying to obtain my drug. I often spent time with people I did not care for if I could get my drugs from them. Also, I craved smoking marijuana. I wanted to be high all of the time. I frequently drove my car when I had been smoking, putting others and myself in “physically hazardous” situations (American Psychiatric Association, 2013). I justified that it was generally only a few miles, but it was not a responsible or safe thing to do.

The criteria for alcohol use disorder are similar. I scored high on that assessment tool, but for different reasons than my cannabis usage. With alcohol I used large quantities, frequently, and rapidly built a high tolerance. It was not unusual at that time for me to drink seven days a week at least five drinks a day. Although I functioned at work, at home I drank to get drunk and pass out. I often blacked out entire hours on any given day (American Psychiatric Association, 2013). Prior to the death I regularly drank, but after Ronny’s death I drank for different reasons. Primarily, I drank to forget and numb my feelings. Also I drank to put myself to sleep at night; my insomnia plagued me.

Regardless of my lack of self-definition as an addict or alcoholic, I readily admit that the sheer quantities that I used were likely problematic to my already fragile psychological state. Although my rates of consumption accelerated in my period of grief, I had used since I was a child. I would soon find my drug and alcohol history was typical of someone struggling with BPD. Lifetime rates of drug abuse or dependence for patients with bipolar disorder ranged from 14%–65% compared with rates of 6%–12% in the general population (Levin & Hennessy, 2004).
Similarly, nearly 60% of sample of patients hospitalized for manic or mixed episodes of bipolar disorder had a lifetime substance use disorder (Levin & Hennessy, 2004). I did not know I had bipolar yet, but I became acquainted with the behavior of one of its sufferers at my job.

Ironically, my boss at the store front massage place had BPD. Almost every day I came in to find he had rearranged the store, or created new forms or procedures. This instability did not affect my job because I mostly worked on clients and did the laundry. However, more often than not when I arrived the receptionist, Stacy, would almost be in tears. She could not keep up with his frantic vision. His mania manifested itself in irritability and Stacy did not deserve his verbal abuse. I developed a friendship with her and often drove her home because she lived in my neighborhood. I soon met her live-in boyfriend and we began hanging out and smoking pot quite frequently—almost daily. I enjoyed cooking for them and Stacy taught me about how to sculpt with clay. I did not like to be alone with my thoughts. Stacy lived close by and always had marijuana. I cannot remember the circumstances exactly, but one day I went to their apartment and I met Stacy’s friend Julee. We literally met in a pot-smoking circle. She said I reminded her of her friend and, coincidentally, I knew him. We laughed hard because it seemed odd we could both know the same guy. Julee had returned to our area after living out of state for a few years. She and Stacy were old friends and we all fell into a quick habit of smoking pot, cooking, and doing crafts. It felt like fate. My friendship with Julee developed unusually quickly and intensely over a period of days. I trusted her implicitly. I spent many nights at her house partying and crashing at her house because it was unsafe to drive home. We both worked the bare minimum and spent many hours talking about everything including deeply personal psychological wounds. I did not work many hours and she sold advertisements out of her car, so she had no set schedule.

Between the two places I worked doing massage I only worked about ten to fifteen hours,
barely eking out a living. I had difficulty mustering up the energy to get to work, but once I got there it rewarded me both emotionally and financially. I knew my job helped people to feel better, and generally my clients thanked me. My job gave me a sense of purpose and I mostly felt doing massage therapy connected me to the clients and the universal healing force. However, at its worst, it made me angry because sometimes men at the store front massage place thought that they could pay me for sexual favors. On those days, I became suspicious of all of the men that walked in the door and it made me mad that I needed to be licensed and fingerprinted to work in the city, but men could solicit me with no fear of prosecution. On those days, I went Julee, who also had her massage certificate, and complained.

Waking up Gay

I finished massage therapy school and found a few part time jobs that I pieced together into a living. Because of the blurred lines between professional massage therapists and sex workers, the massage school taught us to be diligent about not dating clients and I never anticipated crossing that line before I met Anne. After a car accident, she ended up on my massage table at the chiropractor’s office. The fender bender left her tiny frame with the usual neck and back pain. She wore her short, dark hair cropped on the sides with curls on the top. When I met her she held eye contact while shaking my hand warmly, letting her hand linger just a bit too long. At first she did not have much to say, but soon she chattered away during her hour long massages. When I did not understand her flirtation, Anne flat out asked about my sexual orientation. The question startled me. I still saw Dave at that time and I certainly enjoyed sex with him, but I knew we had no future. The only man who ever took me seriously died; most men treated me like a booty call. My sexual relationships with women up until that time were drunken encounters that we pretended never happened and chalked up to intoxication. I never
really thought I could have a girlfriend. I knew lesbians in the CCC, but their relationships were so dramatic that I did not want part of that.

To my surprise, I answered truthfully, “I’ve mostly been in relationships with men but I’ve slept with women before. I’ve never had the opportunity to take a woman seriously.” In retrospect, the truer answer would have been that although my true sexual orientation was bisexual, I did not identify it as a lifestyle choice at that time. What I mean is that I thought of being with women as a sexual choice, not as part of my larger identity. I enjoyed the heteronormative privilege having men around afforded me. I did not feel strong enough about any particular woman to fall in love or to come out at that time.

Anne changed that. Maybe I grew tired of mourning Ronny, or maybe being with a woman felt like I still honored his memory since I did not replace him with another man. Anne helped lift my spirits even though seeing a client broke my own ethical code and I normally would never be someone’s mistress. We mostly enjoyed an exciting flirtation. Anne loved to surprise me. I would wake up to a card stuck under a windshield wiper on my windshield or she would call me at work from the parking lot. She had a cell phone, so she would talk to me on her long commute.

In retrospect, she had almost none of the character traits I wanted in a person. She knew how to make me feel special even though she was not particularly smart, political, spiritual or faithful. She paid attention to me, listened to me, and valued my opinion. She urged me to stop seeing Dave, and I did. She could not be with a bisexual; so very quickly I embraced my gay identity. It never occurred to me to ask her to break up with her girlfriend. I think I liked being second-string—less pressure. One day I woke up with the words, “I am a lesbian” on my lips. I have never looked back.
My friends did not care about my expressed sexual orientation and even seemed unsurprised. I never would have maintained a friendship with homophobes. Apparently, they never thought of me as particularly straight. Alison likes to say, “You were always curly.” Coming out meant, for me, telling my parents and “adult” social supporters. I told my parents over the phone that I was dating a woman because it was about having an honest relationship with them. By then I talked on the phone with my parents about once a week on Sundays. We never spoke about anything important or too interesting. The conversations mostly retold the mundane bits of our lives and avoided confrontation. Our relationship had been so tenuous at that time that none of us wanted to rock the boat. I became agitated after the superficial conversations ended. I wanted an authentic relationship with my parents, one where I could tell them how I spent my time and how I felt about social issues. It became more and more difficult for me to not blurt out that I was dating a woman.

I spent time talking with my therapist about how to break the news to my parents. My therapist believed my feminist worldview and rhetoric allowed me to escape my own issues. I did not know what she meant.

I only started seeing my therapist, Sharon when Anne told me I was the unhappiest person she had ever met. It took me a long time to realize that she had really shallow relationships. I thought about meeting someone new at the lesbian bar. I knew Sharon thought being promiscuous was self-destructive and I shouldn’t meet women at the bar. She never said it, I could just tell by the screwed up face she made. I told her that it was heterosexist of her to think I had the same options that straight women do. She said that there were plenty of social groups for my community and even a group that meets in the
building we were in. I told her I’d think about it, but why would I want to meet a crazy person? She did not smile (Baugh, 2000, p. 21).

The time arrived for me to come out as a lesbian to my parents in a way they could not dismiss. Holding secrets hurt me. I believed they could handle it, and that they already knew. I called my only sibling and told her my plans about telling my father. She informed me that she did not talk to our parents about her sex life and she did not understand why I always wanted to shock people. I think the lesbian thing sickened her, both because of the sex and because it did not fit into her version of what our Norman Rockwell family should look like.

My therapist thought coming out served me, but warned the outcome might be painful and reminded me that I could not control it. I worked with her for about six months before I mustered up the courage to tell my parents. During that time Alison and I spent many nights sitting around processing how to tell my elders. We also managed to find laughter in the serious situation.

Alison and I planned how to tell my mother about my sexual orientation, “Mom, I’ve decided I want to convert to Judaism, I am a lesbian and I want to work as a sexual surrogate.” That was a favorite. I also loved when we sang, “Mom, I’m a bull-dagger, bull-dagger, bull-dagger, bull-dagger, bull-dagger!” in the melody of some wild western dude-ranch melody. (Baugh, 2000, p.15).

We made up elaborate scenarios that almost always ended in me telling a roomful of relations to “Please pass the butter to the lesbian!” We always laughed as a coping mechanism and during this time I really appreciated her wit more than ever.

I told my dad first because he did not subscribe to the same Roman Catholic doctrine that I thought would make my mother’s acceptance problematic. I convinced myself that he already knew. I felt like I displayed all the classic signs. I worked on cars. I did not buy into feminine
standards of beauty. I lived with another woman. I never talked about men. Maybe my folks just thought one day I would grow out of being a tomboy. I guess I did not ever use the word lesbian to my dad. I said, “I’ve been dating women and I don’t think I’ll date men ever again. It’s not because I hate men or anything, it’s because I’ve been denying how much I love women.” He asked no questions. He expressed no outrage. He simply said, “I’ve got to go now” before hanging up on me. He did not call me back and I did not call him for several months.

My mother could not mask her feelings. Her Catholic upbringing and her rigid sense of right and wrong made accepting my sexual orientation problematic. Clearly, she loved me and thought that she “should” but she also believed I was making a dangerous spiritual choice by living a homosexual lifestyle. She blamed her own parenting and thought other people would judge her. She only knew of one gay person, but his story scandalized her. This man married a woman that my mother knew and they started a family. Fifteen years later, he came out, leaving his wife emotionally and financially devastated. We lived near San Francisco in the 1970s. We saw the flamboyance in the streets that was indicative of the time and place. I clearly remember her saying that two men holding hands was disgusting; I also remember in my four-year old matter of fact voice telling her that it was okay if they were in love.

The only other point of reference that my mother had was from the local news about the assassination of Harvey Milk. Elected to the San Francisco City-County board, he was one of the first American openly gay elected officials. Dan White, a disgruntled former city official believed that Mayor Moscone and liberals like Milk were destroying the city. He tried to get Moscone to reappoint him to a job from which he had resigned. When the Mayor refused, he shot him three times, twice in the chest and once in the head. He proceeded to walk to Milk’s office and shot him.
White’s defense became famous as the “Twinkie” defense. A jury convicted him of manslaughter instead of murder because he binged on unhealthy sugary foods. In 1979, although I was seven and a half, my mother could lift my small frame up and sit me on the kitchen counter. The news of White’s six-year sentence upset her greatly. She firmly let me know that religious views against homosexuality never excuse murder. I distinctly remember her looking me in the eye saying, “Just because you disagree with someone doesn’t mean you can hurt him!” I received the message gay people’s behavior could not be condoned, but certainly my family would never be moved to hate crimes or even open public protest of anyone’s lifestyle.

Not believing you should murder someone for their sexual orientation and accepting your daughter’s deviancy are two separate things. My mother did not speak to me for three months. Not a word. I assumed that she cut me out of her life the way I saw her cut other people out of her life. There were limited resources about gay and lesbian children at the time and my parents would never attend a Parents and Friends of Lesbians and Gays (PFLAG) meeting. I did not have the Internet, so I mailed my mother the only book I could find, an anthology of short first person stories written from mothers of lesbians. I read the book first and thought it was a good start. The following letter is a letter that I wrote to a young relative upon his rejecting me because I am gay—in many ways it is the letter I wish I had been able to write all those years ago to my mother:

Thanksgiving, 2010

You act like never want to have a relationship with me because you hate all gay people.

You said that it doesn’t matter to you that I am your relative or that I help you anytime you need anything. Your opinion is that all gay people need to be shunned, so you are going to start with me. That hurt me in the moment, but I would like to know that I already forgive
you. In case anything should happen to me before we repair our relationship you need to know that I love you and I am not mad at you. However, when you say you are mad at me for being gay—I don’t really understand what you are mad at…. the part where I trusted you enough to tell you the truth or the part where you know something that makes you uncomfortable. It is not your place to judge me, just as I have gone out of my way to not judge you. Understand that I am still the same person who has gone out of my way for you, who loves you and will continue to accept you unconditionally. However, I do not condone bigotry, hatred or ignorance against me or anyone else. You have a long way toward healing and that you are worth my time and patience. I understand you might not want to see me the rest of this trip—but you cannot avoid me your whole life and when you are ready to treat me with the respect I deserve, and the respect I try to show you—I will still be here, and I will not hold this bad day against you. If you decide that you really do never, ever, ever want to have a relationship with me—I will be very sad—but you do not have the power to banish me from this family. I have a full life with friends and other family who love me and support me—I will miss you, but I think that in the long run you will be punishing yourself. Again, I hope you change your mind and find some compassion along your path.

Wonda (1996)

Even though the rest of my mom’s family also attended Church, coming out to my mom’s youngest sister went smoothly. “Of course you are gay! I talked to my kids about it a few years ago. I’m not blind!” my aunt responded. She is six years younger than my mom and has a more diverse peer group. She wanted me to be happy. Eventually, ironically, it was the Church that helped me reconcile with my mother. Years later she told me that in the aftermath of my coming
out she spoke to her parish priest and he told her that her job was to love me, not to judge me. I am lucky that my mother had the right priest at the right time. Not all Christians can move to tolerance and acceptance as easily.

Telling my godfather terrified me, but I mustered up the courage. Andy has no children of his own and when he agreed to be my godfather, he took the job very seriously. My mother got a special dispensation from the Roman Catholic Church to allow Andy, a member of the Greek Orthodox Church, to stand up for me. He had been my father’s closest friend since they were in fifth grade and my parents considered the title of godfather to be a position honoring his relationship to our family. Andy’s perception of the position varied because of his own culture and religion. He believes that God chose him to care for me. Over the years he and his wife have proven over and over that they take this job seriously.

As a teenager, after I left the hospital, I ran away from home. I do not remember the exact circumstances, but it culminated in my living with Andy and his wife, Kathy, for several months of my junior year. My father wanted them to kick me out and Andy refused, knowing that I would become victim of the streets before ever going home. Because of what my dad perceived as his best-friend undermining his parental authority, my parents never spoke to my godfather or his wife ever again—dissolving a friendship that spanned almost thirty-five years. I eventually returned to live with my parents until I graduated high school before leaving again at seventeen.

By the time I came out to Andy and Kathy at twenty-three, seven years passed since I lived with them. Andy continued to support me emotionally and help me out financially with small expenses. He has always been a stabilizing force in my life, steadfastly showering me with affection and never forgetting to tell me that he loves me. His political beliefs and religious views are the most rigid and conservative of anyone I choose to keep in my life. When I was in
my early twenties, he still held out hope that my liberal politics were a product of youth and that I would eventually settle down with a nice, white man and vote for a Republican. When I told him I was gay, I am reminded of two phrases that sum up the four hour long “conversation” which felt like a military debriefing. At some point he blamed my parents. Maybe Andy thought Dad played too rough with me or allowed me to play in the dirt too much, or maybe he thought Mom was unfeminine or cold; he did not elaborate. I chalked that up to their bitter friendship breakup. The other thing he proclaimed I remember verbatim, “I was preordained by God to get you off of this unholy path.” He believed that his Supreme Deity created his life so he could rise to the occasion of stopping me from expressing or acting on my sexual orientation. I left his house in tears and did not return for a long time. His disapproval strained my relationship with Kathy. I knew that they loved me, but I did not want to hear their opinions about my newly formed identity.

Although all of these relationships have since been mended and they have all come around to accepting my sexual orientation, at the time, I experienced their reactions as personal rejection. While I had Julee and Alison to turn to at that time, being rejected by the people I could generally turn to in times of need contributed to my mental illness getting so out of control.

**Hypomanic Hospitalization: The Onset of BPD**

Many of my issues surrounded my identity. I grappled with my sexual orientation and my feminist awakening. Other stressors piled on during that time period. A female friend of mine from the CCC had been drugged and brutally ganged raped in Minneapolis. The men remained unprosecuted largely because of my friend’s stigmatized identity. At the time of the incident, she bartended at a nightclub, wearing short skirts and corsets to increase her tips. She was waiting for a bus in the cold at three o’clock in the morning. A car-full of men asked her if she wanted a
ride. She knew one of the men so she felt safe. She met him when she worked at an adult
bookstore; I believe he also worked there. In the car they decided to go to one of their homes to
continue the party; this happened frequently in her profession and social circle. There, someone
spiked her drink with the date rape drug called Rohypnol. She woke up to the flashing of a
camera. The men not only raped her, but posed her in pornographic photos against her will. A
sexual assault nurse took a rape kit and she made a statement to the police. It was December 24,
and according to this woman the police did not investigate the apartment until December 26,
giving the men the time to clean up the crime. In rape cases women often have to have
unimpeachable characters. She did not. She regularly used drugs and alcohol. She wore
provocative clothes that night, had dread locks, and facial pricings. Her jobs were not jobs “nice
girls” took; she tended bar and had worked in the sex store. She lived in the city with no support
network and the men were locals with influential families. By the time they finished
assassinating her character, the men would not have needed a defense.

Almost every close female friend of mine at one point or another had experienced sexual
discrimination, sexual harassment, or a sexual assault. I spent hours of my time talking about
social justice and feminist issues with Alison by that point. Between being solicited at work by a
few of my clients and my friend’s rape, the notion that the personal is political became extremely
apparent to me and relevant in my life. She asked me to come stay with her while she fought for
her rights, and a perfect storm of rejection, grief, and outrage made me ready to wage a feminist
crusade.

All at once I understood that I had been buying into to illusion that men and women had
equal opportunities in our society. I felt duped because I believed that we lived in a meritocracy.
It wounded me deeply that my gender organized my life and my worldview shifted; it was
painful. In many ways I began identifying as both a woman and a feminist for the first time. That is not to say that prior to that moment I identified as male because I did not. I thought I was a human. That initial understanding of power and privilege blew my mind. Finding out that the whole rest of the world saw me as second class literally made me crazy. I ranted about my newfound perspective to anyone who would listen.

I am invisible class of women and a subclass of lesbian! I have a big butt, a big mouth and a big brain! I felt constantly attacked by images of starving white heterosexual women on magazines, on billboards, and on television! I keep butting up against all of the same issues women grappled with twenty years ago. We came a long way, but now there is a backlash. Her rape was a political action perpetrated by men who decided to slap not just any woman to the ground, but an independent woman! We came a long way, but the revolution was in hibernation and violence comes in many forms! Rape is only one type of violence, but being a woman in our society exposed us to more subtle forms of violence on a daily basis. Women’s voices are silenced in part because they can’t afford to speak! But all the women I know are too busy trying to pay their rent and simply survive to get out and rage with me against the machine. They all have something to lose; I don’t. Having nothing to lose did make me free, truly dangerous, dangerous but free.

(Baugh, 2000, p. 112)

Many individual injustices and hurts combined to rock my foundation. My feminist awakening coupled with my friend’s rape and the subsequent institutional (re)victimization of her made me lose faith in the justice system and the government. The stress led to my first manic episode. My disclosure about my sexual orientation created strife in my relationships with my elders. I thought that they were conservative yet compassionate, but their response seemed puritanical and
overly mean. I was still mourning Ronny and using destructive means to grieve. His death made me feel like no one would ever love me.

In many ways, my first manic episode was typical. At the time of my first hypomaniac episode, I was twenty-five; “[For most] Illness began in the late teens or early 20s more frequently than in any other age group with a median age of onset in that early or mid-20s” (Court & Nelson, 1996, p. 15-16). Beyond being born with genetic predisposition, the two years before my first hypomaniac episode were stressful. I suffered the death of an intimate partner and a close relative. I became estranged from many family members. I started a new career. I struggled with poverty. I came out as both a feminist and a lesbian and used excessive amounts of drugs and alcohol. Between the stress, the genetics, my age, and the drugs—the onset of my illness was fairly typical. My inability to work through my grief alone could have been traumatic enough to trigger bipolar.

Ambelas (1979) published a study confirming what clinicians long suspected: the correlation between stressful life events and first manic admissions to mental institutions is strong, specifically with younger patients. Sleep would not come, although I was exhausted. I never had slept well and always was a night owl. When Ronny died, my mind could not quiet; the constant mind chatter kept me awake with my thoughts spinning very quickly. Grief studies indicate that most common somatic symptom after the stress of losing a loved one is insomnia. Research on sleep-deprivation studies posits sleep reduction as a final common pathway to mania (Ambelas, 1979). In my case, hypomania preceded the mania. Hypomania is a lesser form of mania; “hypo” means lower and the symptoms are the same as for mania but they are less intense. I did not understand what was happening to me but, because I felt good for the first time since Ronny died, I wanted to hold onto the feeling.
Thump. Thump. Thump.

Thumpthump. Thump. Thump.
thumpthumpthumpThumpThumpTHUMPTHUMPTHUMP!

My heart is racing and when I open my I can see for the very first time. Colors are beautiful, intense and rich. The sky is so beautifully blue that tears are running down my face. The purple pansies smile up at me with tiny cheerful faces. Overnight a rainbow painted the world. Every sense is heightened. The lush grass tickles my bare feet and warm sunshine nourishes my soul. All is as it should be in the world. I skip around the yard like a puppy. I am ALIVE and I fully understand the unique circumstances that happened in order to give me life. I must honor them. I open my mouth and explain my newfound euphoria, although my friends look terrified. I feel amazing. I am a perfect manifestation of God’s love and I am not afraid. I am inside of the warmest feeling, I understand that I belong. I belong to the warm, light, Godhead and my Earthly life is just an illusion. I am filled with living perfection. I weep like I have only wept because a perfect piece of music or art. I am moved to my core. Free and perfect and freeFreefree and brilliant and freeFreefree and creative and freeFreefree and spiritual and freeFreefree and everything is beauty and FREE! The light banishes oppression, degradation, inequality and poverty from their regular perches in the recesses of my mind. I am h-i-g-h for hours just being. Better than sex, better than drugs, better than being in bed, better than love, better than the ocean, better than going fast on a bike, better then wining, and better then ice cream. Better, better, best!!! I breathe and absorb and understand the entire universe. I have discovered the answers that unlocked the door that bound my once tortured mind to this Earthly existence. I AM! (Baugh, 2000, p.102)
According to *DSM-IV-TR* (APA, 2000), the diagnostic manual for psychiatric illnesses used at the time of the onset of my disease, the criteria for hypomanic episode are as follows:

A. A distinct period of persistently elevated expansive or irritable mood lasting at least four days that is clearly different from the usual non-depressed.

B. During the mood disturbance three of the following symptoms have persisted and have been present to a significant degree:

1) Inflated self-esteem and grandiosity

2) Decreased need for sleep

3) More talkative than usual or pressure to keep talking

4) Flight of ideas or subjective experience that thoughts are racing

5) Distractibility

6) Increase in goal directed activity or psycho motor agitation

7) Excessive involvement in pleasurable activities that have a high potential for painful consequences

C. The episode is associated with an unequivocal change in functioning that is uncharacteristic of the person when not symptomatic.

D. The disturbance in mood and changing functioning are observable by others.

E. The episode is not severe enough to cause marked impairment in social occupational functioning board to necessitate hospitalization there are no psychotic features.

F. The symptoms are not due to the direct physiological effects of a substance our general medication. (p. 332)

Hypomanic behavior generally comes before manic behavior or episodes and includes enhanced and increased productivity, decreased need for sleep or food and feelings of euphoria.
Hypomanic people generally resist treatment because the symptoms of hypomania feel good. I still remember that feeling. Although I experienced this stage as euphoria, the people around me became alarmed and worried for my safety. I relived the experience of interacting with my social support network by creating a composite figure named “Jane” to represent all of the people with whom I interacted with at the time of my first hypomania:

*God is real and if only I can only tune in a little more and get in touch with my psychic potential Jane can build me a wagon and we will travel like true gypsies with me reading palms and her hocking me even though we are all victims in the war against women I know we will rise up in the new millennium I am so happy happy happy to be happy again! I started and finished this great art project it in just five hours the well of energy builds in my core I keep dance dance dancing to the Grateful Dead all around my house spinning and swirling sucking back in time in the parking lot of a show with so many kindred spirits hearing ganja ganja ganja goo balls! The community opened its tie-dyed arms enveloping me I am not on the outside looking in or on the inside looking out I belong. I am one… I feel so warm so accepted I’m light and life and a bit of perfection. I run around dancing with tears running down my face, I am freedom. Finally. FREE. PerfectfreebrilliantcreativespiritualPURE! I am better then sex, better then drugs, better than being in bed, better then love, better than the ocean, better than going fast on a bike, better than wining at gambling, better then ice cream, better than anything HIGH. I am a living breathing manifestation of God in tune with the entire universe. I have discovered the answers to everything and unlocked the door that bound my mind. Enlightened. But, I made the mistake of calling her and she will show up. I will be gone. My faith, my love, and my grandiosity. Gone. She will think I’m sick, but I am not! I am a prophet! I’m...*
finally well! She will try to help me. I don’t want her fucking help! I don’t need any help!

I hate her. Why did I call her? I am surely going to the nut house again (Baugh, 2000, p.123).

Part of the problem of trying to rewrite a hypomanic or manic phase is that my memory is not clear. I cannot be certain of the sequence of events. No one I knew had a cell phone at this time, so I communicated by pay phones or not at all. The sense of urgency created instability and a sense of fight or flight. I spent hours talking nonstop to one social supporter and when she got tired or had something else to do I would get in my car and drive up to 15 miles to somebody else’s house where I would talk nonstop to them. My incessant talking during this hypomanic stage was different than my normal talkativeness. During this time my speech was pressure and it seemed as if I was speaking very quickly without being able to control the words that came out my mouth. The words did not always make sense in a sentence. I spoke in parables. For example what I was thinking was, “I should go see my parents.” What I said was, “I need to cross the desert to see my father” confusing my friends who thought I was speaking in garbled Biblical language. The words were all English but the syntax of the sentences was abnormal, bizarre, and often gibberish. Although I initially trusted my friends, along with the pressured speech came this overwhelming desire and need to run away.

Relationships are hard to maintain under the best of circumstances, but they are extra challenging when one of the relational partners is suffering symptoms of an undiagnosed mood disorder. The onset of manic symptoms changed the nature of my relationships as well as the expectations my social supporters for my future. The people who interacted with me frequently and intimately became concerned with my immediate safety. They witnessed a rapid and radical shift in my behavior and quickly understood that I could no longer be responsible for meeting
even my own basic needs. My friends and family who interacted with me less frequently took a long-term rather than a short-term view of my future.

For me the initial onset of mania happened seemingly overnight. For some the mania moves from a “high” and turns into full-blown psychotic breaks with reality. These episodes can be very frightening to the people around the afflicted and render the person with BPD unrecognizable and unable to communicate. My friends and family were somewhat used to my dealing with depression since it had been my constant companion for as long as anyone could remember. The mania was different. It altered my personality and behavior in a way that was dramatic and rapid.

Faced with a person who is rendered incompetent, unreliable, and often combative, family members and clinicians must make the unpleasant phone call to the police to have the person institutionalized on a temporary, involuntary police hold. This difficult decision strains relationships because often the ill people do not believe they are ill and feel betrayed by their friends and family. Scholars have yet to address the complexities of voluntary kinship relationships when the relationship involves the caretaking of a member suffering from BPD.

Two of my voluntary kin were on the front lines of this rapid shift in my moods. Alison, my best friend, roommate, and confidant, and Julee, a woman I had only known for a few months but had become my fast friend. I spent almost all of my waking hours with the two of these women. Although slightly older than me, they were both in their twenties and did not have any experience with this particular type of mental health problem.

The days and weeks after the onset of mania changed the nature of my relationships because my friends turned into protective caretakers and I was so incapacitated that I could not really participate in a relationship. The relationship I had with Alison, which was once mutually
supportive, became one-sided and emotionally difficult for her to handle. It also changed the expectations my social supporters had of me and for my future. The people who interacted with me frequently and intimately became concerned with my immediate safety. They witnessed a rapid and radical shift in my behavior and quickly understood that I could no longer be responsible for meeting even my own basic needs.

At some point my older cousin convinced me to go home with her so that she could care for me. I spoke to my counselor over the phone and when she suggested that I seek further help I fired her on the spot. I am not sure whether it was my cousin or my counselor who called the police but the police officers came to my cousin’s house. They quickly determined I needed to go to the hospital. I did not go willingly, instead I physically struggled. I kicked, screamed, and made all the neighbors come out and stare at the police who half pulled and half carried me to their car. One of the men was African-American and the entire way to the hospital I taunted and badgered him:

How can you work for the man? Do you think they respect you? You drank the white man’s Kool-aid and you make a living locking up your own people? Do you think it’s an accident that one forth of all black men will be in the prison system? Race traitor! Race traitor! (Author’s memory, 2015).

When I got to the emergency room, I refused to move. I made them carry me. They handcuffed me to a wheelchair and I might have still been screaming because someone shot me up with something. The experience of being inpatient is captured by the following poem written for a poetry class:

Isolated in a parade
of bee sting blood draws,
Invisible yet surveyed
by thugs dressed in white
with name badges and dead eyes,
word salad shoots out of my mouth
like an auctioneer of mismatched words
Faster and faster
my voice is a malfunctioning machine gun
slaughtering innocents accidentally. (Baugh, 2013, p. 277-8)

The sequence of events is unclear, but at some point I ended up back in “my” county inside a lockdown psychiatric ward. The involuntary hold lasted seventy-two hours. At the end of that time, there is a short perfunctory hearing where the patient can ask to be released. A judge shows up and some other court officials to protect patients from being held unnecessarily. I went before this court and was promptly held for another fourteen days. Every fourteen days I went before the judge to plead for release; it never came. Convinced the court and the hospital were in cahoots to make me a political prisoner, one of the times I faced the court I begged to defect to Cuba. Somewhere in the recesses of my mind I remember Olympic athletes asking for asylum from their unjust governments. The situation of being held against my will for unpopular speech acts seem similar enough that I was surprised that my request for passage to the Cuban consulate was denied and what I felt was incarceration was extended. The time sequencing of these events remains unclear due to stress and potentially being overmedicated.

Again, the sequences are all off and my recollection is fuzzy, but I remember that one of the drugs they treated me with was Navane, and I experienced the side effect of super blurry vision and very shaky hands. They added Cogentin to help stop the shaking, but I have no idea
how long I was incapacitated. I know when my friend William came to visit me I could not communicate at all or even hold my head up. Instead of talking, I drooled and slurred. Time compressed and expanded, and I lost all track of time. People came and went and I remember trying to play cards with a deck that had missing cards—what a perfect metaphor! Once I got well enough to move, I tried to run away. I darted out into an enclosed courtyard, my escape easily foiled.

My diagnosis was Bipolar Depression I (BPD). I experienced a host of symptoms including severe debilitating depression and intense periods of psychosis. BPD is a very dangerous disorder: people who with BPD have mood swings that are intense and extreme, fluctuating between depression and mania (Doherty & MacGeorge, 2012). People suffering with BPD are 28 times more likely to kill themselves than the average population (Tondo, Isacsson & Baldessarini, 2003), and 90% of the people have recurring bouts of depression or mania that create lifelong instability. The long-term consequences of mania can be dire. Many people lose their jobs, their fortunes, their reputations, their housing, and their self-esteem. Hallucinations combined with paranoia and delusions of grandeur compel people into risky behavior such as gambling or unsafe sex. The symptoms I experienced during the onset of my disease are codified in the DSM-IV-TR (APA, 2010) the diagnostic manual for psychiatric illnesses used at the time of the onset of my disease. Because of the nature of psychosis, I am unsure what happened and what I deluded myself to believe. Court and Nelson (1996) agree that the psychotic episodes often frighten the individual experiencing them and some people can understand that they are experiencing an altered state without being about to stop the sensations. Court and Nelson (1996) explain,
Also, their sense of reality is just diminished or absent, and they may not know what they did during that period of time. A psychotic individual believes, perceives, or senses something that is real, in part or in whole, only to that person (p. 60).

I am in the minority of people with BPD who experience psychotic episodes. Each time I had these experiences it was more painful and destructive than the last one. For me, when I am about to shift into a psychotic state, I lose my appetite and my need for sleep entirely. This means that I can stay up for upwards of four days without sleeping at all. Some of my thoughts and beliefs have no basis in reality; for example, I thought my friend’s brother was working in the Secret Service. I also thought that I could read clues and signs. I drove around looking for them to lead me to a mystical path. The clues could be a color, shape, or phrase. I thought that I could put together some important puzzle and I was qualified to do so. I thought that I could unlock some holy mystery. I just needed to submit to God’s will and pay closer attention. God tested me and put me on a scavenger hunt. I heard some voices, but mostly they just called my name from behind my head.

I would not stay in one place and soon my friends became so concerned for my safety they called the police. I vividly remember sitting in Stacy’s apartment with two police officers trying to assess my mental health and my ability to take care of myself. I refused to trust the man who wore his sunglasses inside. Not only a clear sign of disrespect, I knew from the pit of my being that he had sinister intentions. I counted the points of the stars on their badges to ascertain if they really did take their vows to protect and serve me seriously. This time when the police came, I went, more or less cooperatively. At the same time that I felt utterly betrayed by my friends who turned me in, but I also knew that they loved me.
I returned back to the institution that had released me; I stayed for a total of three months. The place largely operated as a giant, communal holding cell. There was a level system where patients could earn privileges if they earned enough points. I earned points by awatching *Let’s Make a Deal*, and participating in group activities such as watching movies or attending Alcoholics Anonymous meetings. At the time smoking was allowed in the institution. The smoking area was outside and we had access to it at various times. In the smoking section there were pockets of privacy where the staff could not see from inside the building. At the time I was there, the institution was getting ready to eliminate all smoking and caffeine. The reason for this limitation was that these substances are stimulants and stimulants were not conducive to treatment. The patients were very upset about the potential of losing their only freedoms. Beyond smoking outside, patients used the area to break the rules against touching; sexual relationships took place out in the open. Occasionally, someone managed to smuggle in drugs and they shared them with their favorite people. I somehow managed to get high inside the mental institution.

The restraints they used were mostly chemical. I have no proof, but I think the standard procedure was to overmedicate us and slowly bring us back. There are no blood tests or other types of physical tests for most mental illnesses. Doctors must rely on patient history and observed behavior to come up with a diagnosis. While prescription medications work for many, for most of us it is a trial and error endeavor that comes with very severe side effects. When I was institutionalized over the span of a few months, they tried at least six different medications on me in numerous combinations. I remember this time of my life as a very long, very fuzzy nightmare. My senses did not all work at the same time. One medication made my vision blurry, my hands shake, and my facial muscles stiff. They gave me another pill to counteract those
effects. I could not really communicate and I have been told that even during visiting hours I
could not hold my own head up.

When the worst of the side effects wore off, I still experienced psychotic thoughts. I
called specific sequences of numbers and said code words to the people who answered the
phone. I called Alison’s parents collect hundreds of times sometimes saying that my name was
number three. I started hearing things like never before. When I was not busy calling Alison or
other people I already knew, I used to pay phones to place collect calls to strangers. The numbers
I dialed were not random—I used what I thought were complex algorithms and codes I had
unscrambled both on paper and in my head to figure out how to reach sympathetic strangers that
could help champion my cause. My human rights were being violated under the guise of
medical treatment and my first amendment rights trampled on because the speech I used was
obnoxious. My identity as an American citizen and my belief in the metanarrative of American
freedom and justice was destroyed.

I not only called but felt called by gibberish whispers coming from beneath the floors or
from behind my head. I would sit in my room staring into the bathroom and I could hear the
whispering. I knew there was nothing there, but I could not stop the sound. I thought the
institution was hell, not metaphorically, but literally hell. I became certain that if I spoke to a
Catholic priest he could get me out, or at least get the sounds from the back of my head to stop. I
started thinking of Job from the Bible and that maybe this was a spiritual test. I took many, many
showers. I do not remember any staff talking to me; I do not think anyone could communicate
with me. I remember uneventful days stuck inside the building and lost inside my head.

My friends visited me and brought me treats. I remember soda, candy, and fresh fruit, but
I cannot recall any of the conversations. It took me several months to become more lucid. Alison
told me that the county mental hospital had a finite amount of days it could treat me before transferring me to a long-term facility. She would not be able to visit me often if it happened. She pleaded with me to use my best manners and all of my strength to go along with the program. Somehow, I heard her. I never got better, but I faked it well enough to get discharged; I cannot remember who picked me up or where I initially went, but at some point I showed up at Julee’s house.

While my illness affected my perception of time and how it passed, outside the institution, outside my mind, time moved on without me. Everything changed. Already in the process of moving when I got sick, Alison and her child moved back in with her parents. My friends stuffed everything I owned into my compact car. Stacy got engaged and married. Her teenage stepson moved in permanently. Julee and Alison became close friends. My friend from Minneapolis took my rent money and refused to speak to me entirely.

I invaded Julee’s house, emptying the contents of my car onto every flat surface. A neat freak by nature, I exhausted Julee’s hospitality. She was emotionally exhausted already in anticipation of receiving her out-of-town father into her home for a visit. Her small home could not handle everything I owned, my mood swings, and a visit from her father all at once. Although my biological sister lived less than two miles away, we barely spoke. Julee called my friend Bill and made arrangements for me to stay with him.

My friend Bill lived in San Francisco with his soon-to-be wife, Saundra. They lived in a terrible neighborhood filled with prostitutes and heroin addicts. The building felt safe enough, but the streets in the Tenderloin section could be described as “gritty.” Julee played phone tag with Bill and Saundra and finally decided to drop me off at their house with a backpack of necessities while keeping my car parked at her home. I was lucid enough to stay on the block and
wait for my friends to get home. I crouched in the doorway watching the working girls in their incredibly high platform shoes dart in local shops yelling “Five-oh!” every time the police officer drove close. Mostly the streetwalkers ignored me but one kind woman bought me a pizza slice and a bottle of water. Bill and Saundra eventually came home and took me into the tiny studio apartment and showed me to my makeshift “room.” It was half of a closet they cleared out, just wide enough that I could lay down inside and close the door behind me. Tomblike, it made me feel secure rather than claustrophobic.

I do not know how long I stayed with them, maybe a week or so but, eventually, my parents came to get me. My urban family did not have the means to take care of me. My parents rented a trailer to tow my car behind their large pick-up truck. I believe I slept for twelve hours, the most I had slept in months. There is no way my parents could have been prepared for what I looked like or how I behaved. I wore my once long curly hair in a crew cut. I had lost a considerable amount of weight, my eyes were sunken. I looked vulnerable and frail, two adjectives never used to describe me in the past. They had not seen me for about a year and never saw me in the throes of mania. I could not manage my own medication; I intended to take it but I could not tell day from night and clocks confused me. I do not remember much about the ride except my mother wanting me to be quiet about my lesbianism and my craziness to the people in the town.

The town in Arizona managed to be awful and exactly what I needed at the same time. The town spanned two miles and housed two gas stations, a tiny grocery, two bars, three restaurants, a handful of hotels, and at least ten churches. Built on Route 66, the town died after the freeway bypassed it. It now exists as a small roadside attraction; tourists sometimes stop on their way to the Grand Canyon or if they have an affinity for Route 66 nostalgia. My parents
owned a campground catering to people going to the Grand Canyon and senior citizens traversing the country in expensive RVs. My parents owned one of the few businesses in a town smaller than most grade schools. Anyone new is noticed, and I was a woman with a shaved head; there was no privacy let alone anonymity. If I got lost wandering around, I would have literally been picked up and brought back to them. My parents confiscated my car keys. They were the only people I knew they did not live at least twelve hours away. Fifteen miles away from the next, even smaller town, forty-five miles from the next real grocery store, and hundreds of miles from the closest airport, I had nowhere to run.

With my mother regulating my medication I slowly began to feel normal again. Each of my days still flowed into each other. I lost weeks in the rural slow pace and the never changing landscape. I wrote to Alison and we sometimes spoke on the phone; her situation was oddly similar. She temporarily moved in with her aunt and uncle who were victims of a terrible car accident. She helped care for them and their young daughter for month, leaving the care of her child to her mother at home. We had the misery of unfamiliar environments in common. Using my parent’s land as an institution worked. My moods stabilized and I felt normal again.

In three months, I thought I was well enough to rejoin my life. My friend Bill wanted me to be his best man in his wedding to Saundra. She sweetly flew into Las Vegas and drove back with me. Everyone must have been concerned that I might get lost if left to do the twelve-hour drive by myself. And so I slowly started living my life again. I took my medication and took a stupid temporary job answering phones. I did not drink much, but soon began smoking marijuana again. I thought of my mental illness as a broken leg that healed. I did not really accept my diagnosis. I could not understand that my options in life diminished. I had no idea how to care for myself or that I deserved to treat myself kindly. After Bill and Saundra’s wedding, I rented a
room in the same town that Alison lived in. I hung out with her, but spent far too much time
smoking marijuana with some acquaintances. I waited for my great life to start. In the suburbs
the gay community did not exist. I decided to move to San Francisco. I answered an
advertisement in the back of a free, San Francisco gay paper to work in exchange for rent in the
basement of a house in Ocean Beach. The next chapter of my life began.

The Beginning of the End of My Fabulous San Francisco Life

When I moved to San Francisco, I lived for free in the basement studio on the bottom of a
lesbian couple’s home. In exchange for one half of a studio apartment I shared with a lesbian my
age named Lisa, I worked twenty hours a week doing odd jobs, largely housework and manual
labor. In theory, this was a win/win situation where the landlords temporarily provided a home
for young lesbians and they received help running their multiple businesses. It quickly became
indentured servitude when they went on vacation and we had to make up the hours when they
were gone.

They learned about my retail experience and offered me a job in their vintage
establishment. No two items were alike in the store. In retrospect, I understand them to have
been hoarders who opened a shop pricing everything so high it could not succeed. The
expectations and rules constantly shifted and the work environment depended on my boss’
moods. After almost a year, I quit their shop to work for a corporate retailer recruiting their other
employee, Mike, to go with me. After working for a small business too reminiscent of working
for my parents and for the man who owned the massage place, a large public corporation
appealed to me. They paid well and the codified rules and structure suited my needs. A month
after I left the retail job, I freed myself from the indentured servitude by leaving with no notice
and forfeiting my five hundred dollar deposit. I moved to the heart of the city but not before establishing a social life full of people I met through Lisa and at the store.

One day Lisa brought me to a bar meet her friend. Yetta just arrived in San Francisco but already looked the part with a bleached blonde crew cut and a nose ring that made her look like a tiny bull. I loved her style and she impressed me by holding intelligent conversation in a crowded and loud bar. I instantly liked her and felt a connection. We had similar taste in music and, we soon found out, women. Only later did we discover that we both thought we were dating Lisa. For a brief time the three of us enjoyed each other’s company, but by the time I moved out and left Lisa behind, she and Yetta had a falling out and did not speak. I remained friends with both of them, but eventually Yetta and I began spending several days a week together, often bar hopping in the Castro together.

From my new house, I could easily walk to the Castro, the famous gay neighborhood filled with bars and dance clubs. In the 1990s, San Francisco experienced a rental housing shortage, so I felt lucky to live in such a prime location, even though I shared the place with two other people. Although three of us officially rented the place, we regularly had at least one other lover or friend crashing because of the housing problem. A Victorian shotgun house, it had only one bathroom, a laundry room and a kitchen to share as common space. In the few years that followed, our house regularly filled with friends and family visiting, doing their laundry, and partying. The house became the pre-party destination; people met and drank there before going dancing at the clubs almost nightly.

I hit the clubs every night after work. I danced and drank for hours sometimes stumbling home and sometimes going home with strangers, but always making it to work the next day. I enjoyed my social life and, although perhaps I should have noticed the series of bad choices I
made, I did not. I lived a fabulous, urban gay life. Since I succeeded in my social life and my career, I thought that proved my mental health must be stable. I rapidly moved up the ranks from salesperson to co-manager to manager of a retail-clothing store specializing in children’s clothing. Because of the diversity of San Francisco, my relatively butch gender presentation did not bother the customers or the regional manager. I almost never left the city and the only straight people I knew were people I had known for years.

To prepare for the back-to-school season the company held a regional meeting at a secluded hotel where they spent three days and nights brainwashing managers to sell the new line. I do not know if I was manic, but I drank heavily and resented that this company was trying to act like their sales meeting was a vacation. I did not even get my own room. Three of us came from the San Francisco stores, two gay men and I. When I arrived that first day, it surprised me that the vast majority of the managers from the region that spanned eight states looked the same. They looked like adult Barbie dolls.

As the managers trickled into the hotel the night before the big meeting began, the other two San Francisco managers, who happened to be gay men, invited me to the bar for drinks. I brought an icebreaker book about love and relationships and we began asking and answering questions with each other. A few of the Barbie doll managers joined us. Someone asked me a question about my lover; I answered the question seriously using the feminine pronoun. By then the director of human resources sat at our table. I answered my question and the two Barbie dolls, maybe drunk or maybe just ignorant, both exclaimed, “Eww!” Barbie number one reached over put her hand palm down over Barbie number two’s mouth and leaned in while fake making out. The novelty of girl-kissing apparently inspired hilarious public antics. The director of human
resources got up and left the room without saying a word. I lived in San Francisco where the gay population is so large that no one would behave that way regardless of how they felt.

This behavior, seemingly condoned by the official representative of the company, silenced me for the rest of the conference and I am almost never silent. I called my dad to complain about what I thought obviously egregious behavior at a work function. He betrayed his true feelings about my sexual orientation by saying, “You brought this on yourself.” With his exclamation our relationship got more distant. It became apparent that he could not understand that being gay organized my world in a way that made non-disclosure problematic.

After the harassment at the sales meeting, it became increasingly more difficult to remain working for a company that did not seem to be interested in treating me with the respect that I deserved. I would have dismissed the two women as ignorant suburbanites, but when the human resources representative walked away rather than standing up for me, I lost my motivation to be a decent team player. My regional manager already jumped ship and went to work for another national brand preparing to open its first store in California right around the corner from my current job. I called her at home to complain about my experience and she recruited me to work for the new company. The store promised to usher in the brand on the west coast.

As part of a management team supervising the flagship store opening, I worked twelve to fourteen hour days for a little over a month, effectively destroying my social life. My lover left me to date another woman who practiced monogamy. I threw myself into my work and somewhere along the line I prioritized my job over my mental-health. But stigma played a major role in my non-compliance as I related to Alison in our interview:

I stopped taking my medicine because it was inconvenient to try to get the time off during my job to make my appointment and they gave me too much shit over trying to go to the
doctor. It became an issue of sigma and lack of self-acceptance, plus the inability of being able to say to my twenty-five year old boss, boss, “I’m deserving and capable of doing this job but I need this time off and you legally have to give it to me.” It’s sort of a maturity issue at forty I can say, “I don’t need to tell you what’s wrong with me, I’m going to the doctor.” At twenty something…not so much.

I thought I had a career with the company and I wanted a promotion. I simply stopped following up with my inconveniently located doctor and allowed my prescriptions to run out. I did not consciously decide to go off my medication as much as it felt unsafe to try to take time off work to make my appointments. I like to say that capitalism made me sick.

I excelled at the job and had great friends. I worked hard and played hard. Almost every night I went with friends and co-workers dancing and drinking in gay bars. I stumbled the few blocks home in a blackout then I did the same thing again the next day. Beyond drinking and smoking marijuana, I joined a few activist groups and participated in advocating for gay rights. I never felt fully rested because of my job; I never had two days off in a row. I managed to maintain this fast pace for about a year before a series of unfortunate events triggered another manic episode.

At the same time I accepted a promotion at work, the store manager transferred to another location and his boss, the regional manager quit. With the two supervisor spots immediately above me vacated, the next person above me in the chain of command worked in the corporate office in charge of the entire company’s retail branch. Calling him for guidance did not seem appropriate, so I floundered a bit on my new job. Beyond job stress, other factors contributing to my breakdown included getting my wisdom teeth pulled and the location of my apartment. The pain kept me up but it did not occur to me to call the doctor for pain medication. Over five
hundred thousand people attended the gay pride parade and my centrally located apartment made solid sleep impossible that same weekend.

**Mania**

Symptoms of mania include anorexia, rapid heartbeat, paranoia, hypersexuality, religiosity and delusions of grandeur. Manic episodes can include very elevated mood, angry, fast and pressured speech, racing thoughts, distractibility, gambling, sexual promiscuity, substance abuse, reckless spending, poor judgment, grandiose mood, and decreased need for food or sleep (Torpy, Cassio, & Glass, 2009; Wellman, 2007). Severe manic phases can include psychotic components including hallucinations, delusions and loss of touch with reality (Wellman, 2007).

_W-O-N-D-A!_ I snap my head around and wonder how a man knows my name. No one on the busy street looks like they talked. I can’t recognize the masculine voice. I only know a few men and it can’t be any of them. Dad lives hundreds of miles away; none of the men I work with are on the street _W-O-N-D-A!_ I freak out inside my body. Tiny beads of sweat cover my whole body and hairs rise over my goosepimply flesh. Now I am hot. My stomach sours and I vomit in the gutter. City folks ignore me and keep walking. In a flash of terrible clarity I understand. I am crazy—really crazy—I logically know I imagine the voice. I am certifiably-bat-shit-get-a-straight-jacket crazy. I instinctually want to hide like a scared animal; I really dread the nut house. It took me almost ten years to recover from the last time I was there; I am not sure I can survive it again (June 1999).

The next eight days blur together, but I know a few things happened. At one point at the pride celebration I climbed on the roof of a building and danced topless on a billboard. I responded to the store alarm on two occasions in the middle of the night before the police did. I bought strange
mismatched items that meant something magical to me. I started smoking cigarettes after having quit for years. I tried to talk about undermining the Internet and how we should redistribute wealth. I paid a doctor five hundred dollars in cash to come to my house and give me a note allowing me thirty days off to recover in my own home. I wrote and emailed a two-page diatribe about the labor conditions at my work and sent it to corporate executives who called me at my home. I set the table for dead people; this frightened my roommates enough they called the police on me and eventually got a restraining order against me effectively kicking me out of my own home. I wandered the streets of San Francisco following signs only I understood and at some point visual hallucinations accompanied the auditory ones.

_The man who bullies me is perched on top of a fire hydrant on a seat he had made specifically to form around the giant nut of the plug. There he sits, propping up a professionally printed sign occasionally yelling. The sign is completely covered in text, some of the letters in a different color spelling out “NO SEX.” A San Franciscan institution, he sits on the fireplug five days a week yelling about the dangers of “unlawful sex.” The only kind of sex that is okay according to him is, “sex between a virgin man and a virgin woman.” Every weekday that I worked near the Powell Street and Market Street cable car turn around this man yelled at me at least once—every single day. “Same sex not okay! Same sex not okay! Lawful sex is between a virgin man and a virgin woman.” For years I ignored him, only slightly embarrassed by him when he yelled at me when I was walking with the CEO of my company—a family man from the Midwest. Sometimes my friend Yetta screamed back at him, but I didn’t believe that did anything. Now, I know my journey is to get the devil out of him. God doesn’t want this hatemonger to use those words in his name; I must save my city from the devil dressed as_
a preacher. I rub one of the knots on my belt, and I finger the beads on the rosary ring and head towards him. I look at his dark black skin and his fedora expecting to see what I’ve always seen, an old man. But, this time when I look into his eyes and I know that he recognizes me for whom I really am. The corners of his mouth turn up and he inhales me in. I loose my breath and I see three dark black hellhounds leap out at me through his eyes. He must be tapped into the dark force through the fire hydrant. The smug knowing smile sends shivers down my spine. He is too strong. I push back through the crowd of tourists knowing he can’t follow me. I must find a natural source of energy to replenish; I have to find a pinwheel; I will blow it and it will breathe the winds of life and energy back into me so I can try to face my adversary again. God is allowing the adversary to test me like he tested Job . . . my crops have failed, my livestock is gone, the devil incarnate is fucking with me…and much like Job it is hard for me to understand why God gives life to those who long for death.

I find myself at a crossroads literally and figuratively looking for pinwheels. If I go west I will surely die with a needle in my arm or by the hands of an angry John. If I go east I will submit to His will and I will be with Him by hook or by crook. I choose being a servant of the Almighty over dancing with the devil into a long life of hedonistic pleasure and fuzzy false consciousness. I submit to the will of God. I am thinking clearly for the first time in my life when I speak with all of my senses . . . “I can’t do this anymore. Tell me what to do! I am your servant” (Author’s memory, 2014)
Figure 1. Photo of the preacher who sits near the Cable Car turn-around and shouts at pedestrians. He is sitting on top of a fire hydrant, dressed in a suit, tie and fedora holding a large sign. Artwork titled: No Unlawful Sex (Hawk, 2004)

I make my way back to the home I am banished from and beg my roommate to let me in so I can call my mother. She refuses. When I ask her to go in my room to get me my address book, she says that she cannot. I only think I can recreate what she saw. I looked as homeless as her lack of compassion rendered me.

My lips are so painfully chapped they are cracked and bleeding. The tops of my ears and cheeks are sun burnt pink and peeling. I smell my own rancid body odor made worse from walking several miles every day and going a month without showering. Black and purple bruises of varying sizes are dispersed all over my body, I only recall where one came from—the one on my face. I ran from the hell hounds, but I swerved and ran
full-tilt-boogie down into a parking meter with such force that I fell backwards and hit the back of my skull. As I lay on the ground I flew up out of my body and looked at myself half expecting to see the two-year-old version of myself. The girl who didn’t see well enough to stop when running towards a sliding glass door. The sensation of recognizing myself on my back regardless of space and time made me giggle in delight. Only now can I begin to understand what that looked like to other people. A hundred and sixty pound woman wearing a rope as a belt with a giant raised bruise on her face flat on her back—laughing instead of crying. I’ve always been told I have an infectious laugh, but under these circumstances I am surprised no one called the police.

I hold my baggy pants up with a piece of rope that I found on the side of the road instead of a belt...the rope reminds me of the rope on a monk’s robe. I need the makeshift belt because I have not been eating much on my journey. I have no money. I knot the rope to remind me of the unofficial orders I’ve taken. I am all religions; “I Am who Am” (Exodus 3:14, New International Version). I pray ceaselessly by trying to ignore all desire. One knot on the rope represents my vow of poverty—all I need is my prayer book and begging bowl. I left all my things on the stairs of the apartment—everything except the clothes on my back and my jewelry. The jewelry also is symbolic. It helps me remember who I am and meditate on my purpose. I have a ring that Wanda the street artist made me, it is a triangle crystal held together by wrapped wire; it is for physical healing. I have a ring from Mission Dolores; it is a rosary ring with beads and a crucifix. I know Jesus is my homeboy. I also have a plastic coffee mug tied on one of my ropes. This belt and these amulets give me safe passage and also help me decode the signs. I depend on the kindness of strangers. Migrant women working at the fruit stands press
free oranges in my hands. Can they tell I am God? I see myself in the window glass of a shop and see a purple halo surrounding my head. Can they see it? Or do they see my frailty or the innocence despite my experience? I believe in love. My journey will be long and arduous but I am not afraid. I have been chosen for this mission. I am trying to stay off the government’s radar. I do not believe in the binary code. The zeros are suspect, it is written. “Let him not trust in emptiness, deceiving himself; for emptiness will be his recompense” (Job 15:31, Revised Standard).

There can be no zero because God fills all. I wish I could call my mom but there are zeros the phone number I can remember. Her other number is in my address book locked inside of my apartment. My roommates changed the locks and won’t give me her number. My tortured crying and begging didn’t sway them. The door slammed in my face. I understand now that this is part of my destiny. It is some kind of game or test; can my faith be broken? I am the new Job. This is how Jesus felt when Judas gave him up. These roommates I once trusted locked me out and left me to literally starve to death on the streets. But Allah has my back. One day my mother will understand that I am the only one who can do this faith-based-scavenger-hunt quest. I try to comfort her with the special pinwheel energy in my mind that has heightened my senses (Author’s memory, April 2013). Eventually, after riding public buses all night, walking miles every day, barely eating or drinking I wandered back to my home. I undoubtedly smelled like sweat and urine. I am sure I looked even worse with the dirty, baggy pants and sun chapped face. I wandered the streets for weeks by this time without eating a real meal. I lost at least thirty pounds. When I came back to my apartment my roommates called the police. I sat patiently on the curb waiting to be hauled off
again. I experienced the single most beautiful experience of my life. Maybe the severe
dehydration influenced the sensations in my body, or the wonderful complete sensation could
have been a hallucination.

I float above myself and see

Them coming. Well intentioned.

Coming to gather me off the street

To let me be

I am above looking down

Close to my source wanting to die

But death is not

Death is not pain

Death is lovely and warm and I

Understand everything

And I am one with everyone

And everything

And I can see their light source

Because it is the same as mine

We are all one

Interconnectedness

My ego is dead, I am spirit

But my body is pulling me back

Pulling me back onto the curb

Where the police are waiting
Waiting for me
To submit this time
I sacrifice my chance for peace
Because it is not my time
And I am now grounded
And the illusion of separateness slowly fills
In the space where I understood we
Are one.

I am here for a reason. I don’t know what it is yet (Baugh, 2012).

I felt completely utterly spiritually connected to everyone and everything. I believed I operated as a Rosetta stone capable of decoding and translating any information to anyone. I peeled back the false layer that separated me from other humans and the universe itself and I desired the ability to stay in that state forever. The now familiar click of handcuffs pulled me back into my body and out of my spiritually enlightened state. A day or two before I had drained my bank account, wandered into a tattoo shop and got the Sacred Heart of Jesus over my root chakra. The unhealed tattoo on my back created a source of contention when the police mandated me to the psychiatric ward of San Francisco General.

I think the government held me in the institution in San Francisco somewhere between seventy-two hours and fourteen days on two separate occasions. The nurse handed me yellow lotion that smelled like chemicals in one of those tiny paper condiment holders that are generally filled with catsup. But I was not there for French fries. The wise police officers from my beloved city of San Francisco thought that I was a danger to society or a danger to myself and put me in the psych ward for observation. Humiliated when they took me from my apartment in handcuffs
I screamed, “A plague on both your houses!” The time for Shakespearian irony is not when you are in handcuffs. When I arrived at the hospital, they made me sign a patient’s bill of rights. One of my so-called rights was to have access to my own belongings.

My friend, Yetta, visited me in the nut house and brought me the all-organic natural salve we used on fresh tattoos for proper healing. The staff signed it into some secret place and refused to give it back to me. No matter how hard I begged, no matter how often I complained, cajoled or badgered the people who lived behind the desk and controlled everything—no one would actually give me access to my own belongings. No one would give me the tattoo salve. I applied the salve to make sure the tattoo healed correctly. Instead, she gave me the paper catsup cup filled with the cheap yellow lotion. The awful lotion burned my flesh as I rubbed it into my still unhealed sacred heart tattoo. This poem written in the summer of 2013 revisits that time:

Yesterday cleaning out my linen closet, I found
The Shroud of Angelica…
It is a sheet with the image of my sacred heart tattoo
burnt onto the bleached fabric stamped "Angelica"
The wound seeped the color of my faith leaving behind the fleshy reminder of my degradation, my absolute humiliation and my painful but inevitable submission.
The ink stains smudged yellow and red
Because an overworked nurse refused to give me my tattoo salve
Instead she pushed some chemical based lotion with a tongue depressor
Into a Dixie cup
It burned my flesh
Then transferred the image of the sacred heart of Jesus
Onto the white crisp sheet

Leaving the shroud of Angelica

As proof of my divinity and proof of my incarceration (Baugh, 2013).

To survive in any institution the key is compliance. I continued to make mistake after mistake because I thought the staff would follow the small handbook of patient’s rights that they forced me to sign. It stated I had the “right” to my belongings, but the overworked staff treated the list of “rights” as suggestions rather than mandates. Getting my signature on patient’s rights booklet documented that they fulfilled their legal obligation, but what I treated as a contract the staff treated as mere suggestions. Already mentally impaired, this inconsistency between the rules supposedly protecting me and the reality of living in an understaffed institution run by underpaid workers confused me to the point of loudly protesting the fact I was not allowed my belongings. After incessantly asking for my access to my stuff, I was surrounded by three staff members and pushed into a tiny room. I fought the whole way, but three people trained to control the uncontrollable won. Soon I could not move at all. One of the staff members wrenched my wrist behind me and they eased me on a bed designed to fetter unruly patients. Patients in four point restraints (4PR) are put on a bed, “which is bolted to the floor, and both of his/her ankles and wrists are secured in leather restraints. Two additional leather straps are [then] placed over the patient’s legs and chest” (Schreiner, Crofton, & Sevin, 2004, p.451). While these restraint systems are common in the United States and Canada, in “some European countries the use of 4PRs is almost unheard of” (Herrera, 2006, p. 2). Many critics and human rights activists seek end to the use of 4PRs entirely (Herrera, 2006). In those restraints I felt like a butterfly pined to a board. Somewhere between my upper thigh and buttock I felt a needle sting injecting me with
some kind of anti-psychotic medication. After the staff members left, I lay in my own urine
utterly humiliated and defeated.

Unrelenting and stiff

I am fettered

by locks from tiny diaries

holding down pubescent secrets.

Spread eagle, tethered

unrelenting and stiff.

Wrist[s] out, humiliated

Like with the period

Stain on my six-grade skirt.

This restraint is a corset

truncating my freedom

It is a pit bull’s jaw

Unrelenting and stiff. (Baugh, 2013, p. 279)

Because of the nature of the county lines in the San Francisco bay area, I have been held in three
different counties’ mental institutions or emergency rooms. The timeline is not clear in my mind,
but I know I have been restrained or put into seclusion many times in one particular facility in
Alameda County. The reasons did not conform to the standards of why restraints should be used;
they are supposed to be used as a last resort if a patient is going to hurt himself or someone else.
They are not to be used as a matter of convenience for the staff. My memories are fuzzy and I
purposely blocked much of the unpleasantness from my brain. Many medical ethicists agree that
4PRs should not be used, primarily because involuntary treatment threatens the “the integrity of
the patient,’’ and 4PRs are “among the worst [treatment]” (Johansson & Lundman, 2002, p. 646).

To me, the restraints felt like a violation. The sequence of events is unclear. It comes back in flashes, dreams, and an amalgamation of images, sounds and affect:

Here, cold.

Goose pimples and nipples

Erect, clothes stolen.

Here, kidnapped

Stashed in shackles.

Removed from my kin.

Here, barred.

Forced to disrobe with privates exposed.

Here, blocked

Nostrils congested with urine covered in bleach

Here, violated

With needle

Stung into submission

Here. (Baugh, 2013 p. 278)

During the manic episode when I lived in San Francisco, my illness was peppered by homelessness and great mobility. I moved in and out of institutions, transient hotels, and the street on foot and by public transportation. The only reason I am not still homeless is because I could remember where my uncle lived and he took care of me when I went there. Most mental
patients do not share in my luck. Over the last thirty years, mental patients have been released into the streets without follow-up care. “Lacking medication and resources of any kind, these homeless people roam about aimlessly” (Falk, 41).

Penniless, I am unsure how I got on the train to the East Bay, but I did. I walked the five miles to my aunt and uncle’s house, somehow remembering the name of their street and using the bright yellow 1956 Ford truck he left parked outside his house as a visual guidepost. I showed up unable to communicate clear thoughts. Unannounced, hungry and haggard, I was brought in and fed. I answered their kindness with my psychosis. My aunt and uncle left me in their house while they went to a funeral. While there, I wrote tiny pieces of paper with my name on them and hid them all over the house. I marked my territory by writing my name and birthday in their family Bible, something I deeply and profoundly regret. The sane me would never violate a sacred text but in the moment, deep into my delusions, I thought that it provided me protections from the dark visions I began to have.

I saw the mountains on fire. I saw planes crashing into buildings. I saw white horses running toward me. I always enjoyed flying, and my uncle decided to put me on a plane to Vegas to get me to my parents. With the visions of the planes crashing into buildings, I refused to get on a plane without being able to protect myself with my own weapons. My parents and uncle coordinated their schedules to get me to Arizona so I could return to my parents. The visions of fiery crashing planes persisted as I kept telling my uncle that I could read signs. He gave me a Walkman with a Charlie Pride tape and I listened while pacing around the backyard. Unmedicated, I could not come down. I took entire boxes of Benadryl to try to put myself to sleep. I did not want to worry my friends and family and I wanted to be safe off the streets with access to plumbing. I stayed with my uncle until the court date for my restraining order.
My uncle took me to the courthouse in San Francisco. The judge confirmed that my roommates did not have the legal authority to change the locks regardless of their restraining order. The victory was intangible. Their lack of compassion and the overall stigma surrounding mental illness forced me to live on the streets. At one point during my ordeal, I tried to walk into the police station to report the illegal eviction, but they quickly dismissed me as the lunatic I had become. Even in my psychotic state, I defended my integrity. I needed to have the official record show, while I might not be innocent, I did nothing to deserve being kicked out of my own house with the clothes on my back. My disease rendered me incompetent, but the lack of resources, education, and compassion from my young roommates, the justice system and medical industry created a dangerous and much worse situation. Having settled the court record, my uncle put me on a bus to Las Vegas. It was August 6, 1999. I had been wandering around the city—riding busses and walking, in and out of hospitals and sketchy alleys with heroin addicts and whores—for somewhere between six and seven weeks.

Stress racked my body emotionally, physically, spiritually, and mentally. Living outside for even a few weeks changed my appearance. I lost forty pounds and the skin on my face sunk in. Sunburns on my skin left deep open wounds on my face. Painful blisters on my feet oozed through inadequate footwear. I stopped getting a period for six months. Emotionally, I clung on to my faith that my social supporters cared about me enough to help me. Subconsciously I knew that my friends and family loved me, but I felt incredibility guilty for adding stress to their lives. Mentally, I grasped for the ability to tell the difference between my false reality and the reality everyone else seemed to participate in.

As I got on the Greyhound bus headed to Las Vegas where my parents would meet me, I still hallucinated. I remember sharing my oranges with a group of Mexican travelers who spoke
no English. In my psychotic state I translated their Spanish into my English even though I do not and never have had that skill set. I enjoyed vibrant conversations and warned them of the fiery planes and horses. I learned of their family in Mexicali and I missed them when they exited the bus. I sat near the back of the bus for the duration of the long road trip. I could not sleep because I knew we were going to be hijacked at any moment. I wore my steel toe boots to protect myself and wore sunglasses over my regular prescription ones so that no one could read my thoughts. Somehow I made it to Vegas in one piece without the intervention of law enforcement.

My parents picked me up without any real understanding of my disease, my mental state, or what I had been through. While my physical state visibly shocked them, nothing could have prepared them for seeing the evidence of my starvation and exposure to the elements. My clothes hung on my small frame and my own mother had a hard time recognizing my weathered and sunburned face. My ranting and mumblings confused them because they thought the treatment I received while hospitalized should have helped me enough to hold a conversation. Most of all, that day I arrived in Las Vegas disheveled, babbling, and in an agitated psychotic state, my parents faced an abrupt shock. Because I was utterly incapacitated, my parents had to adjust their expectations of me.
CHAPTER IV: THE SLOW ROAD TO RECOVERY

I did not have very many options when I left California. My roommates effectively evicted me for having an illness: they got a restraining order and changed the locks. My friends all had busy lives and could not manage taking care of someone as sick as I was. My aunt and uncle who helped me get to my parents were elderly and could not take on the extra responsibility. Kathy and Andy did not offer. If I had stayed in San Francisco, I would have been stuck on a never-ending cycle of being homeless, in police custody, institutionalized, and released into transient hotels. That assumed I would not have been murdered on the streets, raped, forced into prostitution, or lured into serious drug use. The prospects of a homeless woman under thirty who cannot take care of herself are not good. So, I banished myself to the desert, again. This time I knew that I had a serious mental illness and knew that I would be living there indefinitely. My life, my self-confidence, my career, my home—my illness shattered everything. In this chapter, I explore the ways that the rural location and slow-paced lifestyle worked to my advantage in finding myself and finding the will to recover.

Banishment: I Wandered the Desert

My parents owned and lived on a campground located between Las Vegas and the Grand Canyon on Route 66 in the middle of nowhere Arizona. I recovered there for a few months after my original bipolar diagnosis a few years before. Using the small town that boasted a population of four hundred and twenty people proved invaluable but also lonely. My block in San Francisco housed more people than the surrounding 20 miles in rural Arizona. The isolated location coupled with the fact I had no transportation made the campground ideal for my recovery. This is not to imply that I enjoyed living there or that my parents and I had no conflicts.
My relationship with my parents had been a difficult one for many years. They read the early symptoms of my mental illness as rebelliousness and instead of treatment I received punishment. This time my parents could tell that I was not acting defiant; they recognized that I was sick. It took some time for them to understand that I needed supervision, guidance, and help with small tasks. For example, my mom found out that for the first few months I could not be responsible for taking my medication on my own. At first when she realized that I was not taking my pills, she became angry and assumed that I was not taking my pills on purpose. When she confronted me, I admitted that I could not keep track of time. She softened and took over managing my pills.

My parents did not believe I should stay inside all day alone while they worked. They did not allow me to sleep or watch television all day. Instead, they woke me up and forced me to paint picnic tables outside in the sunshine. In the first year I lived on the campground I painted about eighty picnic tables, a fence surrounding the perimeter of their property, the swimming pool and the pool deck. I cleaned countless toilets, and planted dozens of plants. My parents only had their own work ethic and common sense guiding their makeshift mental hospital but recent scholarship gives credence to their ideas. Researchers studied self-care that high functioning BPD patients do to help stay well and they identified exercise as a key component (Murray et al., 2011). Exercise in nature called “green exercise” is specifically good for the mentally ill; that population received the most improvement in self-esteem (Barton & Pretty, 2010). Although I hated it and do not remember that time fondly, the endless outdoor manual labor gave me something meditative to do. It helped me do something besides lament the awful sequence of events that brought me to Arizona living with my parents at twenty-eight. Also the tasks required of me left something tangible behind and helping my parents gave me a certain amount of pride.
at a time when I felt defeated. The isolated location that benefited me also forced me into dealing with a smaller pool of psychiatric professionals.

The closest psychiatrist who could see me was almost two hours away and specialized in pediatrics. It was important that I see someone who could monitor my medication, but the man, used to dealing with children, asked my parents come into my appointment. He asked me questions I did not feel comfortable about answering in front of my parents, questions about my sex life. I became so angry I bolted outside after screaming, “Fuck you!” He talked in a low sing-song voice, had a ponytail, and wore socks with his Birkenstocks. I hated him but I needed someone to prescribe my medication and with my history no family practitioner would help. After seeing me for a few sessions he referred me to a colleague he described as “feminist” and the treatment got much better.

But the recovery did not go smoothly. I cried nearly every day for the first six months I lived in the desert. The flat desolate landscape depressed me. I hated how cold the stupid trailer we lived in was and that my parents lived with the previous owner’s super ugly sofa in their living room. I could not believe that my parents kept the television on almost all of the time. The noise irritated me. I wanted to jump in front of the train, but it always moved too slowly. The depression following mania for me is all encompassing. I cannot find joy or beauty or even compassion. I lived in Arizona on 9/11 and my mother rushed into my room to tell me of the terrible news she saw unfolding on the television. I barely looked up from my bed. I could not believe anyone cared that a few thousand people might have died. In monotone I replied,

People die everyday. No one cares about them. Is it because it’s concentrated in one location? Because it happened in the United States? Because they were people with jobs?
Horrible things happen everyday all over the world. Americans are responsible for much suffering, seems like just rewards.

My mother had been as patient as she could with me up until then. I will never forget the look on her face when she told me that I was a monster.

Overnight rural Arizona looked like a permanent Memorial Day float. Without exaggeration, nine out of ten people began wearing American flags on their person or on their cars. The motel next door advertised that their business was “American Owned” and the local diner started selling “Freedom Fries.” There I lived, stuck in a jingoistic nightmare where even my normally intelligent father lost his head when I argued instantly for peace over retribution. In small town Arizona, I stood totally alone in my convictions and I soon became afraid to voice them because of the sheer volume of guns, ignorance, and alcohol. The town only had a few businesses and my family frequented one restaurant almost daily. The woman who owned the place had a son who was a year younger than me and she told him to take me out. Sean became my friend and took me to spoken word poetry a few times a month. I do not consider him voluntary kin and we have not sustained a close relationship, but I include his published description of me to help contextualize the time I spent in the desert.

Sean had been in the Navy before and, after losing friends in 9/11, reenlisted. I begged him not to, but soon the time came for our final poetry reading. Sean writes about this time:

I was out at my mom’s house one weekend and ran into this dislocated and this oriented girl that looked to be going through some shell shock from her transplant from San Francisco she seemed a bit lost and depressed that’s totally understandable reaction for having just moved to a very small town… I placed her under my wing and took it upon myself to introduce her to the dark side of Prescott nightlife which included our Thursday
night jaunts to poetry readings. All she needed was a finger to point her in the right
direction and she was off on her own. When Won read her poetry people set up and
listened. After the first time she read there, she owned the place. 9/11 happened, I went to
the local recruiter and signed back up. At our last weekly trip together to the poetry
reading, Won wrote this poem for me. After she was done there wasn’t a dry eye in the
house:

I say that he is joining the Navy
For that he’s moving away
Or that I’m helping them pack
I avoid saying that he’s going to war
And then I’m scared
I avoid saying
That my heart is breaking
A thousand times all over again
I avoid screaming
I cannot take one more
Of my friends dying
I avoid screaming at God
How come you can’t
Just leave me alone for a while
I try to put on my happy face
But I fail
I am proud of him I love him
He is no longer my sensitive ponytail man
He has been shorn into a beautiful
Monk ready to sacrifice
Ready to jump to help the helpless
I admire him, but I don’t want him to go
I avoid telling him that my heart is breaking
A thousand times all over again
I am learning to pray ceaselessly to that deity
I’m not sure I even really believe in

Insomnia tormented me again; I memorized every crack and mark on the ceiling of my parent’s spare bedroom. Because of my recent history of hospitalization, the doctors feared prescribing me anything to help me sleep because of my high suicide risk. Getting the right combination of drugs to stabilize my mood and control my psychosis proved difficult. It took several weeks before the doctor could tell if any one medication worked. In the first several months I lived on the campground, I took at least twelve different medications in numerous combinations. Some of the drugs made my hands shake, others blurred my vision, some gave me blinding headaches, and others gave me terrible gastrointestinal problems. We finally found an effective but imperfect drug cocktail. The side effects included severe weight gain and a rise in blood sugar. They seemed permissible at the time under the circumstances. I remember constantly saying to myself that I preferred fat to crazy.

The practical and therapeutic advantages of living on the campground almost outweighed the emotional pain of my social isolation. The only people I talked to were my parents, their
friends, and their customers. My parent’s gracious friends treated me with respect, but I did not identify with them. Almost forty-five years older than me, they had conservative backgrounds as retired military officers and wives.

If being out-of-control and misunderstood is scary and taps into a universal fear that leads to stigma—the reality that sometimes there is no help available is truly terrifying. Fully understanding that we have no control over mental illness is a terrifying prospect. Witnessing people and families at the mercy of a disease that makes perfectly nice people into potential homicidal or suicidal maniacs is so entirely frightening and awkward that normally caring supportive people are uncomfortable with or do not know how to provide social support.

For example, if I moved back into my parents’ house with a cancer diagnosis, my mother’s church friends would have set up a schedule to make and deliver meals to lessen my mother’s caretaking burden. They would have made themselves available to listen to my mother’s grief and maybe even have volunteered to sit with me so my mother could take a small break. The stigma surrounding mental illness influenced my parents’ decision not to share the reality of my disease. This effectively cut them off from potential social support that could have been offered by the community. They denied my condition because of their perception that mental illness is fundamentally different than physical illnesses or disabilities.

Friends and family members, parents in particular, are not exempt from the fallout of stigma. Families can be ashamed of the behavior of their loved one and often feel complicit in the illness based on psychological theories that blame psychological problems on poor parenting or dysfunctional family systems. Even within the mental health field, old stereotypes about dysfunctional families causing disease often frustrate obtaining health care and medication. While talking out and working on my familial problems is potentially a road to mental health, no
amount of interpersonal communication skill will change my brain chemistry. There have been times when medical practitioners have wanted me to use behavioral changes and coping skills for a problem that was ultimately solved with medication. For my parents, having a mentally ill daughter has wrapped into the overarching theme of stigma, because at times they have been treated as if their relationships and parenting are the problem rather than simply another mitigating factor in their child’s care. That stigma alienated them in their community in Arizona.

The people I spoke to in Arizona, I spoke to because we shared a geographical location, not because we shared things in common. I cried almost every night out of loneliness. I missed my city where people understood me and I missed interacting with friends. I lost many friends in San Francisco; people refused to talk to me after my manic episode. Maybe I misjudged the nature of our relationships at the time, or the psychotic transformation frightened them too much to ever forgive me. I did not lose all of my friends. Some of my friendships were actually strengthened. The quality of my relationships and the fact people stuck by me in my time of need is a major part of why I have been able to continue treatment. I credit my social supporters with my resilience.

**Long Distance Social Support**

For me, social support proved to be a key component in my learning to combat the stigma of mental illness, in finding motivation to comply with treatment, and in bolstering my self-esteem. Knowing that other people cared for me and about me allowed me in some small way to care about myself. Because I lived through Ronny’s suicide and the devastating ramifications of his passing, I understood fully that my own suicide would similarly devastate the people who loved me. Although I thought many, many times that killing myself was a justifiable option, I could not pass along the misery that I felt to the people who expressed love for me.
People demonstrate social support in a myriad of ways. Most of the social support I received was emotional and conveyed through written and verbal communication. This section analyzes the types of communicative processes that my social supporters enacted to demonstrate their ethic of care. Maintaining my relationships did not prove easy; beyond my impaired mental state, many other obstacles existed. I moved across state lines into my parents’ small home; we did not have privacy. The landline phone rang both at their home and in the office of their business. Anything I said on the phone could potentially be heard throughout the house. My social supporters all had full lives with jobs, school, relationships and children. They had to carve out time to exert the effort to communicate with me. None of us had enough money to visit very often.

In this section I purposefully conflate the terms social supporter and chosen kin. Each of these people had no biological or legal obligation to stay in my life or to help me through such a life-altering and difficult to understand experience. We were deeply connected through years of love, friendship and an ethic of care. Each of these women consented to be interviewed about our relationship, about what it was like to be in relationship with someone struggling with a mental impairment, and how we managed to maintain connection over the last fifteen years.

At the time I moved to Arizona, we did not have cell phones and, although we began using e-mail, video calls were not yet available to residential customers. We relied on snail mail, telephone calls, and e-mail correspondence. This section explores individual forms of social support communication enacted by specific social supporters and uses recent interviews with those people to illuminate their experience of interacting with me when I experienced a radical decline in social functioning.
Yetta. There is no word that adequately defines the relationship we share, so I use a series of words researchers use to describe our friendship. We consider each other voluntary kin; we actively choose to be social supporters for each other. Our relationship is “contextual” (Braithwaite, Bach & Baxter, 2010). At first, our friendship relied on our queer identities and the fact we lived in San Francisco. We lived far from our biological families in terms of miles but also in terms of culture. We participated in social activities that could only have happened in that time and place. Because Yetta and I are the only queer members of our immediate families, we found in each other what our biological families could not offer us. We shared both sexual orientation and butch gender expression. Embodying female masculinity, even in liberal San Francisco had hardships; together we found acceptance and a community. So, our relationship was contextual. We looked to each other for support for our queerness.

Although we each maintained relationships with our families of origin, we turned to each other for support and comfort. We quickly became chosen family, initially because of our similar sexual orientation and gender expression and later because of shared common interests. We became supplemental family; we met “emotional needs unmet by the blood/ legal family as a whole” (Oswald, 2002, p. 400). Beyond being queer people from totally straight families, we were geographically bound together because our biological families did not live in the city (my sister lived about forty miles away, but we were estranged and I had no car). Yetta had an emotionally close relationship with her family but they lived across the country in Florida. I experienced a tumultuous relationship with my parents and they lived in Arizona. We became family to each other during a unique time and place. We enacted rituals by spending important holidays together that are generally considered “family holidays,” such as Christmas and Thanksgiving. We shared interests and belonged to the same subculture of the queer community.
Our voluntary kinship worked in several ways; we demonstrated our love in several ways. We helped each other through housing problems unique to that time and place. At that particular time, during the dot.com era of San Francisco, housing became scarce. Newly wealthy people bought properties, and legally displaced renters who were protected by rent control by moving a family member in before raising the rent. Many of my friends lost their housing, including Yetta. For a short term she lived in my room with me while she obtained a new apartment. I cared for her in other tangible ways; I convinced her to get medical treatment. When she needed an operation, I also helped her realize the best option was living with her mother, who is a nurse, for a month. Similarly, she visited me in the hospital when my biological and legal family did not:

You were talking about becoming a nun. The way you were talking about it was like that was what you genuinely wanted, but there was this strange disconnect because it was the shell of the Wonda I knew. I brought you tattoo ointment so you could care for your tattoo. I think I brought you something else—something religious. You were not a religious person. That’s why there was this really fascinating but terrifying confrontation between this person who was Wonda who was speaking without any irony or acting about the fact you wanted to being nun…You seemed very sincere in your intention to move in this religious direction and I thought “great” but it was not great because this was a shell of the person I knew (Yetta, personal communication, 2014).

Despite her always-busy schedule, she took the bus to the hospital and visited me more than once. She came back, despite the fact I did not resemble the person she knew. She trusted in our relationship and cared about me enough to face the fact that she felt uncomfortable and terrified
by the person my symptoms made me. Another observation she remembers about my manic episode:

I almost did not recognize you when I saw you in the hospital. It was extremely scary. It was the confrontation that I knew very well, that I was very intimate with in a familial friendship context the confrontation of that and someone who seemed like a mere shell of themselves. You were a shell (Yetta, personal communication, 2014).

The timeline is unclear to me, but I moved in and out of San Francisco General psychiatric ward several times. A few people came to visit me in the hospital and, during the times I wandered the streets, I ran into other people I knew. During that confusing, blurry time, I managed to make some phone calls, sometimes from the hospital and sometimes at pay phones in the city. Yetta remembers one such call:

This is where it started to become real in terms of your condition. There was a conspiracy theory tone and delusions perhaps about the freemasons. You were talking about people giving you certain hand signals (Yetta, personal communication, 2014).

I knew many people in San Francisco; many people with whom I tried to communicate during my illness. Many people were scared of me, thought I might be violent, and abandoned our friendship. Yetta described being scared as well, but the major difference was that she was scared for me not of me. She thought me defenseless and vulnerable in my mental state:

I also sort of felt that that was the effect of the illness and this was someone who was very ill in a way I am glad there is some treatment, but I wasn’t thrilled with you being there. I thought that was not the right place for you to get the help you needed, but I didn’t know where that was. It was not that place [San Francisco General], it was not that
place…I was not sure they weren’t being violent with you. That freaked me out quite a bit. (Yetta, personal communication, 2014).

During the time we lived in San Francisco we saw each other several times a week. When I moved from San Francisco to rural Arizona, Yetta sent me a postcard almost every week for several years, re-enacting our friendship. When I asked her about why she maintained our relationship in that way she replied:

When you were hospitalized and then you moved from San Francisco—I’m kind of an analog and an old school person and I believe that there is something really intimate about personal correspondence. Even though this was a time when people were e-mailing and things like that, I felt like I could maintain a connection with you by sending postcards and writing letters. You were always excellent at writing letters back. So, that was something that—when I wrote other people letters they didn’t always write me back—you always wrote me back. So, when I started sending you postcards it was something that I thought was a good way of maintaining a connection with you because I couldn’t physically be there, so if I could be there in this small way—like in terms of a postcard—that I would send on a weekly basis sometimes…whenever I would see a postcard that might brighten your day for a minute, that was something that was a very specific way of maintaining a friendship with you, someone I considered to be at that point someone who was my family (Yetta, personal communication, 2014).

Yetta’s articulation of our relationship as family is an example of “redefinition” (Oswald, 2002). Redefinition is the action of creating communicative processes to make sense of these kinship networks and is very normal in the LGBTQ community. This redefinition has been so historically important in the gay community that the question “Are you family?” is a signal
phrase that used to be used among gay people to ask if someone was also gay. If the person did not understand the question, the inquirer understood a negative answer without risking rejection or violence. Yetta became family and, although she was not my only gay friend, she became my closest gay friend. She articulates that she thought of me as family and implicit in her definition of family is an ongoing commitment to be in my life and to take action to be a social supporter.

Yetta sent postcards after I moved because she wanted to maintain a relationship with me. The action of picking, writing, and mailing postcards to me replaced in some small way the in-person relationship we used to have. She remembers even though I continued to suffer intense symptoms I sent correspondence back to her. In the years to come I thought of the postcards as an altruistic action, but Yetta wanted me to understand it was not charity:

In terms of the postcards I genuinely missed you… I missed having you around. We palled around and we were together all the time. I felt like a huge loss for me too. It was a way I could in a small way still have you in my life. It was important for me to maintain that in the best way I could (Yetta, personal communication, 2014).

The pictures on postcards themselves show years of Yetta’s travels and mostly trips to art museums. She interacted with me at the height of my psychosis and witnessed my bizarre behavior, but she was unsure what “normal” emotions looked like for me. Prior to my breakdown, she knew intellectually of my diagnosis, but she truly did not understand the symptoms of BPD until she witnessed it.

To be honest, I knew that you were bipolar, but I can’t say that I knew exactly what it was, or what it encompassed or what the effects of it were. What I do remember when you were in the hospital, that is when it kind of hit me that this was a disease, condition that was something very, very serious. I don’t know if I was just ignorant of the
symptoms or if I just didn’t understand the magnitude of the disease or if I was just too young to have met enough people who were identified as bipolar…it hit you in a very significant way or when its effects were made clear in a really kind of visible way. I thought this is my friend Wonda; this is someone I care about very much and why is this happening? Even though I knew why, I still had to educate myself in even an abstract way about the sort of “realness” of the effects (Yetta, personal communication, 2014).

At twenty-three, Yetta had no idea the drastic changes a bipolar episode could make on my physical appearance or my personality. Her prior knowledge of my bipolar did not prepare her to interact with me when I articulated strange desires or when I became convinced of conspiracy theories. Because she knew me to be a functioning member of society with a job where I supervised dozens of people, and as someone she identified with as being similar; it was not only difficult to understand the changes I experienced but difficult to even process that her friend changed so dramatically and quickly.

The postcards Yetta sent me that have survived the last fourteen years or so and are valuable to me as a historical record of our friendship and of social support. They are interesting on many levels. First, they are postcards sent to my parents’ post office box. My parents and postal workers could read their content and see their images. They are not exactly private. They display a unique form of loyalty and discipline from a young person living a very busy urban life including starting graduate school. They reflect many forms of social support communication. Yetta repeatedly writes about cultural events, romantic relationships, graduate school, mutual interests, and friends. She encourages my writing and poetry, and makes different plans to visit me. Surprisingly, she does not mention my mental health or attempt to advise me about my illness at all. These postcards read like small diary entries into a day in her life. They provided
me a much needed anchor to the life I once lived and provided me a sense of normality when my world felt turned upside down.

July 27, 2001 Hey Won,

Well, we went to the Lex last night for a bit and I hadn’t really been there in ages. I’ve been asking people randomly about San Diego and still don’t look forward to it, but do look forward to being about to live alone. I wish Judith was at a cooler city! Oh well. Nothing’s set in stone and UCSD is good and it would only be for five or six years. The thing is, I defiantly have to look into buying a used car. You’re going to have to give me some pointers! I’ve never bought a car, nor have I ever really had one that was my own (I drove my mom’s in high school and various rentals since then).

(heart) Yetta

[ps] oh: I ran into Angelique on MUNI she’s moving to the East Bay!

This seemingly mundane postcard is full of references that are important to the two of us. “The Lex” is an abbreviation for The Lexington, a lesbian bar that we frequented. Judith is Judith Halberstam who worked in San Diego at the time and is a leading scholar in female masculinity. Yetta planned on moving to San Diego to go to graduate school to work with Halberstam (Halbertam moved on the USC and Yetta joined her there). I worked with Angelique and we were close friends. Despite my mental state, Yetta still trusted I could advise her about buying a car. In this short paragraph, she kept me abreast of her educational goals, reassured me that I was still useful as a friend and mentioned a mutual friend that kept me connected to the life I once had.

Here is a typical example from an atypical time:

Sept 13, 2001 Well Wonda,
It’s been quite a strange couple of days. I’m still trying to wrap my head around it all. Heard back from my friends in NYC and they’re all okay. I’m still trying to actualize what the fuck it would have been like. Anyway, I have some other unrelated things that I wanted to tell you. But funny how everything seems trivial in comparison. First thing is, the Loudmouths broke up! Very, very upsetting since I missed the last times they played bcs of all the schoolwork from last year. Also Deanna and I went to this poetry reading along with Carol Queen your ‘ex-fuck’ did some wonderful pieces. 

(heart) Yetta

On this tiny piece of paper she crams in her feelings about 9/11, news about a local band we enjoyed seeing together, and news of my ex-flame’s poetry reading. Many of the postcards she sent follow a similar format. She writes in very small block letters to make to most of the space. Most of the postcards also include dime-sized stickers marketed to children. The combination of the stickers and the postcards, which are mostly avant-garde art works, always made me happy. This one is an example of a postcard where she references finishing her master’s thesis. She also writes of her travels and mentioned the artwork on the flip side of the postcard:

May 16, 2002 Hey Won,

Yes, I’m done! Finally, I’m trying to actualize it. Sorry for not sending a card in awhile but you’ve gotten emails from me. Went to the aquarium thinking there were jellyfish but it was the wrong aquarium—figures. Anyway, there was this cool “skulls” exhibit but it was annoying bcs it was field trip day for a bunch of schools so there were annoying kids everywhere. Well, I miss you. 

(heart) Yetta
The postcards I quote represent but three of hundreds she sent, mostly similar in content. Regardless of what the actual text or images conveyed, I appreciated the action of her taking the time to pick, write, and send me the correspondence. I knew even then that in every scrap of paper, every blot of ink, she was telling me that she loved me and that she did not forget me. Her postcards created a physical and visual record that I had someone caring for me. They became very important to me, a lifeline to the world I once knew. When some got destroyed through my father’s negligence, I became very upset. I am unsure Yetta could understand at the time.

I expressed my emotions to her:

> You were very frustrated, I wouldn’t call this an episode linked to bi-polar, but I don’t know… You broke down a little bit. You cried you were very upset. There was a hole in the ceiling and some of the postcards I had sent you that you hung up got damaged. You said, ‘Oh my God! These are the worst fucking landlords that I ever had! My parents!’ It turned into you really being upset and frustrated because you were dealing with a living space that was literally crumbling before your eyes. I don’t know if that was bipolar.

(Yetta, personal communication, 2014)

Not only have some of the postcards Yetta sent me survived, she kept letters that I sent her. I rarely sent postcards. I tended to send long letters mailed in envelopes; I did not send them weekly, but often they were very long—eight to ten pages. Sometimes I handwrote them and sometimes I typed them when I watched the store inside the campground. The following letter shows me struggling with my diagnosis and trying finding the courage to attempt to claim my own agency by writing back to medical hegemony:

> 2000.
Yetta,

I’ve been thinking about writing about my life not so much for publication but for my own sanity. Let me rephrase that. I’ve been writing a lot about my insanity and I’ve been thinking about trying to find a way to organize it. How can I organize a radical thought process my mind doesn’t all the way comprehend? Did that even really just happen to me? Maybe took too much acid as a teenager trying to cope. I seriously used it a lot. We used to go to the Grateful Dead concerts and buy it in the parking lot. It opened doors into vast colors and connected my molecules with all the energy that is ever been never will be. Once I dove into the black one world of Ansel Adams and I seriously really climbed Half Dome. The suck thing is that I used to say I wanted to feel that way all the time. Being manic is almost the same only it won’t stop. I panic and freak too many people out. Sometimes I think if I could get through it without giving away all my possessions or becoming evicted or institutionalized I could create great art. I also don’t understand why we know so many other crazy people walking around pretending to be okay and they don’t fall the way I have. I guess it’s because everybody else’s crazy doesn’t disrupt other people’s hold on reality. I guess I’m just brave, stupid, and honest and no one likes the wool pulled off.

Love,

Won

After I lived at the campground for a few months, I decided to go to work at a diner at the end of our property. I liked the woman who owned the place. I basically worked for cigarette money. I made less than two dollars an hour plus tips. Unfortunately, there were never enough customers for me to make any real money in tips. The restaurant never became profitable, instead it was
like an expensive money losing hobby. I never waited tables before, but had always done
customer service. I wrote to Yetta about my job:

(undated circa 2000)

Yetta,

Maybe it’s confidence, maybe entitlement, or maybe they’re just plain rude. They
are one step away from being my Johns, they want a piece of me, they want to think I like
them, they want to be cared for with special attention. They even get jealous when I have
to wait on other people! Sometimes they leave a huge tip like 40% and others I like it is
$.70…We the women of the service industry are in fact on the job! We are above all
actresses who grin and bear it, waiting for the coins to roll on in. I never remember their
names; I simply don’t care. Maybe these guys are playing out a male fantasy—swooping
in as a hero who saves me from my pathetic life of waiting tables in a nowhere town. I’m
friendly enough and good serving food, isn’t that enough? The local guys buy four dollar
breakfast and drink twenty dollars worth of coffee, they are okay when they are alone,
but in groups they become feral.

I bent to pick it up a dropped plate from behind a male voice asked when my next
table dance was going to be. When I turned around they became cowards, no one willing
to admit the harassment. I’m doing this for cigarettes…it’s clearly time to quit.

Won

This letter is about me trying to overcome the culture shock of living in a relatively
hostile environment for women, let alone a gay woman. I did not get along well in that town
because I had almost nothing in common with anyone. At the time I was an ethical vegetarian,
and the town newspaper published photos of children posing with carcasses they killed. I never
wanted children and the inevitable response, “You never know!” always followed. I am certain that they assumed my lesbianism, but the same short hair that marked me one in San Francisco marked me as a hard-working woman. So, to cope with my banishment, I wrote to Yetta and often talked to her on the phone. I quit the waitress job—well really I just never showed up again one day—and took the time to write some autobiographical life writing. Writing the letters to Yetta helped me come to the conclusion that (re)writing my experiences was a valid endeavor as a means to self-healing. I never stopped writing to Yetta, and still occasionally draft a long e-mail to her, but over the years the letters became more mundane and less frantic.

I reflected back to her all these years later in our interview:

Your postcards weather you knew it or now were a real lifeline for me at a time when I very much needed it. And people who are in the position that you were in when you were so young are often like, ‘That person’s crazy. I don’t know what to do. I can’t do anything.’ So they do nothing. And people get isolated. The simple action of working to stay in my life, helped give me hope that I could re-enter society again. (Author response to Yetta, personal communication, 2014)

After several years in the desert, my friend Yetta, among other things, inspired me to go to college. I did not have any idea how to get there from where I stood: I had a below “C” average from a continuation high school. I did not take the required courses like science, upper division math, or a foreign language. I obtained decent grades from community college but, because of my BPD, I withdrew from as many courses as I got “A”s in. I applied to only one school and, despite my poor high school record, I gained admittance as a non-traditional student. Because I survived off of Social Security, I also got a great financial aid package. When I moved to Tempe, Arizona to attend Arizona State University, the postcards from Yetta trickled slowly to a stop.
She saw me through the worst of times and knew that college life held new and exciting things for me. We certainly remained friends, but she sensed that I no longer needed weekly postcards.

**Alison.** My relationship with Alison never faltered. She saw me through the first psychotic breakdown and continues to support me. When I moved to San Francisco she stayed in the suburbs and I did not spend very much time with her. She did not witness me going off my medication. She did not witness the risks I took with my mental health in terms of drinking and smoking pot. Alison could not have imagined all of the nights that went by without my sleeping and how much stress I put myself under by taking a job with such intense demands. Our contact mostly consisted of telephone calls and maybe getting together every few weeks. We lived relatively close together, but we rarely saw each other. I did not have a car and never had two days off in a row. She worked full time and had responsibilities as a single mother. We stayed in touch fairly often, but she did not predict my second major breakdown.

The first BPD manic episode happened while we lived together. Alison knew me better than anyone else, and spent more time with me than anyone else. She experienced my severe mood swings. She recounted the onset of my BPD:

The onset. It was just. I didn’t know what to expect. It was so extreme, so sudden, just like really scary. I remember very, very, very clearly going to the pay phone by our house and called my mom. I was just like looking for any kind of adult answer I was just like, I don’t know what is going to happen to Wonda. I don’t know how this gets better. I don’t know how this fixes. I don’t know what to do with this at this point. I had, you know, I had called your shrink, I had invaded your privacy into your Day Planner trying to find somebody who could help, I made all kinds of phone calls, I called everybody I could
think of and nobody had any good answers. You were getting worse and worse and worse
(Alison, personal communication, 2014).

During the time Alison and I lived together, my family and I were relatively estranged. My
parents already lived in Arizona and my sister and I did not speak. Despite her youth, Alison
tried to take care of me but, because we were not considered relatives, she could not take care of
business for me or even speak to my doctors. She wanted her mother to help, but her mother had
no good answers. She felt helpless as my condition accelerated.

She describes my deterioration as being very fast, like within a month. Depression
quickly changed. I became overtly rude in a way that was not characteristic of my “real”
personality. She recalls a situation where my behavior seemed specifically abnormal. We lived a
few miles from my Aunt Debbie and her family. I did not have a close relationship with them at
this time, but her husband, my Uncle Don had always been a favorite. He had recently died, very
young, of work related lung cancer leaving behind two young children and a wife who had been
a stay at home mother. I gave my aunt my condolences and when I came home to talk to Alison
about it, she said I was rude. When I asked her what “rude” looked like she replied:

Like specifically after you went to see your aunt Debbie and I was trying to ask you some
questions about like how were they doing with Don’s death and everything and you kept
giving me these weird answers. Like, “She’s fine. What’s really important here is I need
to work on getting to Minneapolis.” That’s not normal, that’s not how Wonda acts. That’s
not, not Wonda. [If you were not sick] You would have been involved with her and your
cousins. You would be involved with comforting them and talking about them and
dealing with their situation. The illness created its own wind, almost (Alison, personal
communication, 2014).
At the time that I visited my aunt, I could not think about her situation. I could only think that I needed to be in Minnesota to help comfort my friend who had been a victim of rape. I felt like my destiny was to avenge her. My thoughts raced about the fact she had been sexually assaulted and the fact I had nothing to lose by fighting the powers that conspired to keep her from getting justice. I became so concentrated on getting to help my wounded friend that I lost track of how to be Alison’s friend. I asked her if she felt like illness affected our friendship:

I don’t know. That’s so hard to say. In the end, I don’t think so, you know—over time there was other times when—when a person doesn’t react to you normally anymore are you still friends? (laughs) Do you know what I’m saying?…Before that I had liked worried about you for different things like, you should tell me when you aren’t going to come home at night. (laughs) We are roommates. If you don’t tell me that you are leaving and your tire explodes, I don’t call anyone to look for you cause you didn’t say you were going to be gone! That kind of stuff. It was sort of the same, there was still a certain amount of caretaking or connection or whatever you want to say, but there were definitely points there where I was like “Ok if Wonda’s still friends with me!” (laughs) (Alison, personal communication, 2014).

Alison articulates that prior to my illness we had a close family-type of relationship where we looked after each other and for each other. Our roommate situation was not just about sharing a house; we shared our lives. She already enacted an ethic of care as my roommate. When I was symptomatic and not doing well, she did not feel like we were in a reciprocal relationship and although she continued to care for me she questioned if I had the capacity for friendship. She talks more about how difficult it became trying to care for me as a non-biologically or legally
family member and how overwhelming it became to try to manage that alone along with her own life:

I definitely started thinking like how do I know when this is more than I can handle? On one level I knew it was more than I can handle but…there is only so much time I can take off of work or there is only so much time I cannot be at home with my kid or you know what I mean? I’m very tenacious. I just kept calling people, trying to find somebody who could do something or would know something or tell me something that made so kind of sense. But, I was alone, and it’s not okay to be the only person standing there. That can be a full time job (Alison, personal communication, 2014).

She discussed her frustration with the tendency for people to give up on caring for the mentally ill. She knows that I lost friends and relationships because of my illness and is critical of the advice she has gotten to walk away from sick people.

People are quick to be like “this is more than I can deal with” and to run away from the situation. They would never do that to a person who had a cancer! “Fuck you and your cancer!” People are so quick to think it’s more than I can handle! You need a professional! Something that is frustrating to me is when I am trying to ask for help and I make phone calls—the support people are always there with an excuse for why its okay for you to give up and stop trying. What I like to call “Why is your tough love all tough and no love?” (Alison, personal communication, 2014).

Alison’s twenty-seven year old tenacity did not get her satisfactory results. No agency helped, no doctor helped, nothing happened while she dialed number after number because the only way to get help in that situation is to wait until the circumstances are dire. I asked her to share her
experience of the mental health system; I asked her what she would want a family member of a mentally ill person to know.

I wish they would have been straightforward and said, “Things are not good enough.” I wish that they would have been straightforward and said…Treatment, support, medication…everything. The mental health system is woefully inaccurate, underfunded, guesswork. I had a hard time trying to find someone to help you; I partially blame on us not being ‘relatives,’ but really, we use the justice system for all of our crisis (Alison, personal communication, 2014).

When I experienced that first manic episode when Alison and I lived together, she called the police on me because none of the avenues for help panned out, and because our relationship status remained unrecognized. Alison had no legal right to coordinate my treatment with the hospital because we never legalized our relationship. Also, she also no real rights to visit me or consult with my doctors despite the fact we lived together for years and she had the most information about me. The system did not recognize my chosen kin. Instead they recognized my biological sister, a woman who I did not speak to regularly and saw even less frequently, as my next-of-kin. Because we never created legal means for Alison to speak for me, she could not act on my behalf in other important ways. Because I became hospitalized for three months, I could not pay my credit card bills. Armed with my statements and my social security number, Alison attempted to activate the disability insurance on the card. I paid for an insurance policy religiously with my monthly statement that was supposed to cover the payments if I became disabled. The credit card company refused to even speak to Alison or send the forms to get someone to fill out. Unpaid medical bills stacked up because I had no one to help negotiate the medical and financial institutions—not one that these institutions would recognize as valid.
When I moved to Arizona that first time I owed thousands of dollars to ambulance companies, doctors, hospitals, and the bills I previously incurred. By the time I could handle making phone calls to these businesses myself, I missed the date to file a disability claim and the health insurance refused to pay such a delinquent claim. My story is not that unique. All these years later, my credit is still ruined. Occasionally I still get creditors calling me about a bill I cannot remember from a time I would much rather forget. Sickness and disability is a luxury that most people cannot afford.

When I moved to Arizona I could not worry about unpaid bills. I just relished the fact I no longer had to live in an institution. Compared to being in a lock down county facility, I enjoyed the simple life with my parents. Our relationship improved mostly because I showed up so fragile. Because of my BPD diagnosis my parents accepted parts of me that they previously struggled to accept, such as my lesbianism and my gender presentation. Losing a child on the streets of a major city and having her friends call for help humbled them. Having a child who teetered on the brink of insanity and who was at times unrecognizable put the gay thing in perspective. The diagnosis itself allowed my parents to conceptualize my behavior as illness driven rather than as rebelliousness or irresponsibility. There was something else unique about living on the campground. Alison articulates that in many ways I had the best of both worlds:

It was very helpful that your parents let you stay on the KOA... We don’t allow people time to convalesce. There are two parts with really severe mental illness—the emergency and the long term. Occasionally, taking care of the emergency takes care of the long-term problem. I think there are a lot of modern techniques that can help you feel better about things and some old fashioned techniques like, “you can have some time.” On the
campground you did not have pressure squeezing down about how you were going to pay your rent or buy your food. That has value (Alison, personal communication, 2014). Although my parents met my material needs, Alison still met my emotional ones. Alison and I maintained our friendship through sometimes hours long phone conversations. We continue that ritual today and there has not been a week that has gone by when we were both in the country that we have not spoken or at least e-mailed in the past decade. I really credit my relationship with Alison, the social support she lends me, for giving me the inspiration to work on complying with medical treatment. In our interview, I expressed this to her:

I would say that you have been better than all my therapists and social workers combined, perhaps because you listen. You call me on my shit—you listen to me up until a point but then you say, “No, Won. That’s not it” You challenge me. I think that might be your personality (Author responding to Alison, personal communication, 2014).

After my last manic episode, I became very cognizant of the fact that my friends did not have to stick through me by my illness. I lost enough relationships and I valued the people in my life enough to try my very hardest not to put them in a position where they needed to call the police on me, receive a garbled phone call from me, or visit me in an institution. I consciously decided to be accountable because I had love in my life. Their social support inspires me to comply with treatment. Those relationships are the motivation for my resilience. Alison was not the only person who talked to me on the phone often; our friend Julee did as well.

Beyond talking on the phone the three of us communicated over the Internet via blogs. Our blogs that we actively participated in for about five years, were set so that only people we invited into our websites could read them. They served as a quick way to tell each other what was happening in our lives, a place where we could express silly thoughts as well as major
stressors. The vast majority of Alison’s entries surround her frustration with her job and the
difficulties she faced as a single mother. Very little reference is made to my illness, but this one
entry explains Alison’s thoughts surrounding depression:

I was driving home listening to a talk show interview with Peter Kramer who just
published another book, this one called *Against Depression*. He points out that people, in
general, tend to think of depression as a personality trait rather than disease. He
chronicles the devastating physical and sociological repercussions of prolonged untreated
depression, including damage to nerve cells, brain function, the heart, and blood vessels.
He attempts to de-romanticize the image of a dark and brooding “artist” or “thinker” like
Picasso or Hamlet. Then the woman conducting the interview tells the author she
wonders what humanity would have lost if anti-depressants had been available to
guy who never felt comfortable or secure that spent years and years in the care of doctors
and wandering the countryside beset with religious mania who was a constant source of
worry and responsibility to his brother, a guy who famously mutilated himself and
ultimately died a slow and painful suicide never having witnessed so much as a moment’s
success in his life. That’s what humanity would have “lost” you ignorant overwrought
literati from Hell! (Alison, personal communication, 2014)

She also writes about suicide:

It is not noble to suffer. It does not make you “better”. It is not romantic. Suicide is not
for people who have given up all hope or lost all faith, you must have faith that death will
relieve your suffering to put yourself through that. A truly hopeless person wouldn’t
bother. Don’t believe me? Look up the research on people who kill themselves in the
beginning stages of treatment for depression, right when they start to feel a little better…It’s the absolute height of self-centered ignorance to talk about how depressed people who kill themselves are “selfish” because of what they put “the survivors” through. Let’s really run the numbers on that, shall we? This person you profess to care about is supposed to live out all the possible days of their entire life suffering so you don’t have to go through a grieving process? Not that I am pro-suicide, I am not, I probably would have been 50 years ago, but today I think there actually are “win-win” plans to escape suffering. This is just the unbelievably wrong argument that inevitably comes up when people start talking depression and suicide (Alison, personal communication, 2014).

I included two entries of her blog to serve as examples of the kinds of conversations Alison and I have participated in over the last fifteen years. She often repeats these sentiments because in her heart she understands about mental illness. In these discussions Alison talks in general terms rarely bringing up me as a case study. Both of us suffered from depression at various times, and the blog served as a sort of collective group therapy. Since the time of our mass journaling has past, we are more likely to have small weekly group chat sessions or rely on short social media statuses. Alison and I also include our friend Julee in these chat sessions and periodic updates about our lives and thoughts.
Julee. When I lived with Alison and worked as a massage therapist I became fast friends with Julee. Our relationship started as bonding over our mutual love of partying and became a much deeper friendship very quickly. I spent countless nights at her house where we drank, laughed, smoked, and cried for hours. We talked about everything: our hopes, our dreams, our rather dysfunctional families, our depression and our grief. Julee survived the SIDS death of her infant daughter. I admired her strength and grace; she managed to be overwhelmingly positive and loved fiercely. We hung out at her house because she had two dogs to care for and I often spent the night because I did not drive under the influence. Sometimes I slept on the couch and sometimes in her bed with the dogs. Our relationship is and was sisterly, not sexual.

The man she dated became jealous of our relationship and with Julee out of the room started grilling me about my intentions towards his girlfriend. Julee recounts:

I can’t remember what he said, but it was something negative about being gay. But I was like, “You can’t say that!” I was like, “That’s not cool; you can’t talk that way about my friend. You can’t hurt her feelings like that. I think I made him leave. I think I told him to get the fuck out.” Yah, that was the last time we were dating. I broke up with him at that exact time…At that point it was becoming more and more clear to me what kind of creep he was. I think you are the person who named it. I have this mama bear protection and I am not going to put up with that, it’s just not going to happen (Julee, personal communication, 2014).

Only two or three months into our friendship my manic symptoms appeared. I do not remember, but my anti-establishment rant crossed a normal social boundary that I would have otherwise maintained. She clearly remembers my uncharacteristically bizarre and erratic behavior. Julee recounts:
I was like, “You might want to tone that down a half a notch.” I didn’t think you would want to disrespect someone like that or hurt somebody. Normal Wonda wouldn’t do that [I] started noticing things like this—“this doesn’t seem quite right.” Especially when you were disinclined to really listen to me. That was when I was like, “this feels unsafe.” Not like I was in danger, but like you were not in the right place and you weren’t coming down from that place. Kind of manic. But I didn’t have that word for it. (Julee, personal communication, 2014).

Both Julee and Alison recall overwhelming uncertainty about how to handle the very rapid onset of mania. They could not name it; they had no experience with it. However, they felt concerned for my safety. Julee articulates, “There is fun crazy fun loving—then there is crazy psychotic/unsafe…our main concern was your safety” (Julee, personal communication, 2014). Luckily these women remain in my life, but they both remember struggling with the challenging nature of being friends with someone who had changed so dramatically and rapidly:

It did initially [changed our friendship] when the condition was really part of your new personage, your personality, your Wondosity. The medication made you way different. I remember feeling that feeling of grieving that person who had been my friend. That person was not there anymore and so it changed our relationship initially. I would say and maybe forever. You can’t rewind or unobserve that (Julee, personal communication, 2014).

Although we only knew each other for a few months, Julee and I spent several hours together every day achieving real intimacy in a very short amount of time. She interacted with me on a daily basis and noticed the erratic shift in my behavior. She questioned my ability to care for
myself. Julee also grieved the friend she once knew. She was unsure that I would ever be the person she knew, a person capable of being in a relationship with her.

There was definitely a grieving like, “My friend is way different now than she was a month or a few weeks ago.”…I would call Ali, “this is going on, is this normal?” Just to make sure things weren’t going to be dangerous for you. That was our main concern was your safety (Julee, personal communication, 2014).

Years later, when I lived in San Francisco, she continued to worry about my safety. I spent more time with her than I did with Alison because she worked in the city and did not have to rush home to take care of a child. We met several times a month and went to bars and parties. I remember that as carefree, fun times where I coped very well. She remembers that time as tenuous and tumultuous:

But you got used to being on certain medications, and the doctors would change them for one reason or another. You felt healthy and went off your medication and had another bout that was really, really bad…I was very worried for you (Julee, personal communication, 2014).

During those instable times, my illness driven behavior modified our friendship. Although Julee had no part in actually taking care of me and gave no tangible aid during episodic periods, she still had an emotional commitment:

I guess the illness would change the relationship in that I would feel more like a caretaker than a friend. Even though I wasn’t responsible. When your friend is in the hospital sick, you are in a different place than “Hey! Lets go get a cup of coffee and hang out” It became a different friendship. I still liked being your friend (Julee, personal communication, 2014).
I told Julee that the illness made me lose friends. Together we reminisced about our long friendship and I asked her why she stood by me during the first episode even though we only knew each other for such a short time:

Cause I liked you! (laugh) I don’t know. We had a quick friendship, we were very tight very quickly and I have a lot of loyalty towards people I feel are important to me. I don’t walk away very easily. There has to be something really traumatic for me to walk away from a friend. What you went through and it was difficult for me to watch. I still saw that friendship as important to me even though it was a short-term friendship at the time. I felt a little bit responsible because I was with you so much when you were transitioning from depressed to psychotic…I thought that you were important to me and that I wouldn’t walk away from you in a time of need or any other reason. So, I stayed. (Julee, personal communication, 2014).

Julee values loyalty and friendship. She understands humans come with their own challenges including inconvenient and difficult ones. Although having mental health challenges would disqualify me from being in relationships some people, it did not disqualify me from her friendship. Our friendship is reciprocal and over the years I have had an opportunity to help her when she needed help.

Several years ago, when talking on the phone with her I became very concerned with her level of depression. She normally keeps a very clean house and is a feng shui expert. She indicated that the laundry piled up. Over the phone I could tell she was despondent and left to care for a small child while her husband worked. For reasons I am not privy to, her husband did not seem to really understand the severity of the situation. I became concerned for her safety and
the safety of their child. I hopped a plane and flew there to be with her. Julee articulates both
disappointment that her husband did not care for her and gratefulness that I did:

You flew out here to be with me when I was in my worst and he decided to spend the
time in San Francisco. The worst I’ve ever-ever-ever been he would not come back to the
east bay. It was forty-five minutes away. It seemed like you were being supportive. I
mean who would fucking do that, drop everything and get on a plane? First of all. Who
would do that? People don’t typically…I was more than sad…I was suicidal. I was on the
wrong medication (Julee, personal communication, 2014).

I only stayed a few days with Julee that trip, but in some small way I provided her with the kind
of help she provided me years before. Because she had seen me at my worst, she did not need to
minimize or hide her feelings. Going through a series of mental health problems where I was the
impaired person allowed her the leeway to be vulnerable and speak her truth knowing I of all
people could see her, empathize with her pain and not judge her for being depressed. We gained
strength as individuals and as a chosen kinship circle.

Ultimately our dealing with my BPD and her depression strengthened our friendship.
Dealing with my illness also created a bond between Julee and Alison who originally met
through me and became close while they both tried to care for me. While their friendship began
because they were frightened for my safety; they subsequently found we all had much in
common. The three of us grew up within twenty miles of each other in families with one (full)
sibling; Julee and Alison each had a sibling within six months of me. Our closest familial
relationship had been with our grandfathers who were all deceased. We actively tried to deal
with our personal psychological issues through self-help books, crafting, writing, and long
discussions. Raised Christian, we each embraced wide interfaith worldviews and considered
ourselves spiritual not religious. We practiced ethical vegetarianism; we all attempted to enact holistic living integrating our minds, bodies and spirits. Beyond that, Alison and Julee shared motherhood and being artists. They have an individual friendship, and because they live close together they continue to see each other more than I see either one, but when I am in town the three of us get together as if no time has passed. I know that all these years later, regardless of our individual stresses or circumstances, something about our youth and my mental breakdowns cemented us together in a forever family bond.

Very recently, in a group chat over the Internet, the following excerpt demonstrates an example of the type of social support we enact for each other and with each other:

*Julee:* I don't know if you remember me talking about my friend XXXX. I'm pretty sure he's on a manic tear right now and I'm scared for him.

*Wonda:* Oh no!

*Alison:* Did he go out of state recently?

*Julee:* Yeah. He's broke and homeless and acting like a hurt little boy. I'm IMing [instant messaging] with him right now.

*Alison:* I'm sorry. Is there anybody to call?

*Wonda:* Family? Closer friends in the area?

*Julee:* He's pissed everyone off. They all know and he's mad that they want him to go to the hospital.

*Wonda:* I was not thrilled when the police were called on me but it was in my best interest.

*Julee:* Yeah but we were with you.
Alison: I feel terrible because I barely know whom to call here! Out of state is a mystery to me.

Julee: Plus he won't tell anyone where he is.

Wonda: I'm sorry. This sucks.

Julee: He just told me he's in XXX at McDonalds. He asked me to send him money.

Alison: How long has he been homeless? Is there a church or shelter he knows? Maybe they have someone who can help. But....if he’s manic, he probably needs meds first to get help.

Julee: I'm thinking that if I can figure out where he is I can call the police.

Wonda: Sending him cash will just make it easier for him to stay lost…I am so sorry you are facing this.

Alison: Yeah, I agree with everything you both just said

Julee: I'm thinking of sending him $5 for a burger. Not enough to do anything.

Alison: Sad, sorry, call the police.

Julee: I will if I can figure out where he is.

Wonda: I hate that sick people can starve and freeze and are disregarded because they are annoying. And that the only option feels like betrayal all around.

Julee: My heart is kinda wrenched right now.

Wonda: I know. Ali would say a pissed off friend is better than a dead one.

Julee: His family doesn't want to send him money. They want to force him to seek help but it's still snowing there!

Wonda: Let the police try to find him. Tell him you can't send cash without a location.
Julee: He's going to call me in a little bit. I'm trying to get him to give me the address for where he is.

Wonda: I am so sorry Julee.

Julee: Thanks, Won.

Wonda: I am doubly sorry I ever put you through this. It sucks.

Julee: I have known this guy longer than any other friend. I'm glad I went through this before with you. It makes me a better friend now.

Wonda: I'm home by the way if you want to talk instead of text. I'm always here Julee.

Julee: Thank you so much. I just needed to support myself. By reaching out.

Wonda: We love you (Author, Alison & Julee, personal communication, 12 March 2014).

This brief text conversation highlights several things. Even though all three members of the group have been through being social supporters of the mentally ill or have been mentally ill themselves and are educated middle-aged women, dealing with a mentally ill friend does not pose easy answers. There are several typical factors going on. Julee is trying to help a member of her kinship circle who is out of state, homeless, and estranged. He is in eminent danger because of the weather among other things. He claims to have no money and no ability to care for himself. Julee is concerned with his primary needs of food, clothing, and shelter. Her friend is starving and very cold. She is simultaneously concerned that mania may put him in further danger by forcing him into risk taking behaviors that will have long-term consequences. He can easily give his jacket away or step into traffic. Julee intellectually understands that she needs to act in his best interest, that is calling the police on him so that they can get him the help he needs, but it never feels good to call the police on a friend and there is a real danger that he will never forgive her. I also mention in this dialogue how having the police called by loved ones feels like
betrayal. I know that my friends felt conflicted about it at the time, yet it took me over fifteen years to first time to express that their actions felt to me as betrayal at the time.

There is something about the affect and stigma of mental illness that is quite different than a physical illness or injury. It has to be about how we as a society really think about mental illness. There is a myth that is internalized that if someone tries hard enough she can somehow control it. There is an implicit blame for the condition. Because there are such intense emotions involved, it is hard to tell where a person begins and the illness stops. Even after all of these years, I found myself naturally apologizing for my own manic behavior and putting Julee in the situation to call the police on me. Clearly, if I had any other medical condition I would be not apologizing for the fact my friends had to call 911.

**Kathy.** Kathy is another person with whom I have a chosen kinship relationship. It is a much different type of relationship then the ones I enjoy with Yetta, Alison, and Julee. First, the three aforementioned friends are part of my peer group; we were all born within five years of each other. Kathy is older than my mother and inhabits a role that has been about guiding and mentoring me rather than being a similarly aged friend. Kathy came into my life when she began dating my godfather, Andy. Initially, I resented the fact she caught his eye because suddenly he gave her the attention that was once mine alone.

They got married in a small, childfree ceremony with my parents as their witnesses when I was around nine or ten. From then on, she became part of my family. My initial resentment turned into pure unadulterated love and admiration. Kathy went college and held a job. The only other adult women I knew lived traditional lives where they stayed home and raised children. She also had been divorced before marrying Andy; I had never met a divorced woman. She reeked of sophistication and worldliness in my young opinion. She played the piano beautifully,
she smoked long skinny cigarettes, she had a tall thin frame, and she knew things. She knew about culture, food, poetry and spoke more than one language. She loved big and had the single most infectious laugh that ever graced the earth. When our family visited, she pulled out art supplies, sat on the floor in a cross-legged yoga pose, and taught my sister and I how to draw. When I spoke she listened. She did not hush me or rush me or ignore my questions. She displayed genuine interest in what I had to say. One of Kathy’s many positive traits is a God-given gift with children. Now in her mid-seventies, she continues to teach piano and actively mentor many local children.

Kathy has always been a generative member of my kinship circle; she is an adult who has been actively concerned with guiding me adulthood by serving as a mentor, family historian, intergenerational buffer, and a friend (Milardo 2005). Although I am middle-aged now, she still acts in this capacity. Originally, she became part of our family when she married my father’s best friend, and my godfather, Andy. In that capacity she was a type of Bohemian aunt figure, the one person who lived outside the confines of stereotypical wife and mother. She supplemented my family; she became an extra adult whom I could bring my problems. If I saw them without my parents, I mostly visited with Kathy and Andy together in their living room. Andy obsessively poked at the fire while having long philosophical conversations. We would sit on the plush carpet before a fire with the adults smoking cigarettes. Together they challenged my mind and always assured me that they loved me. Occasionally, Kathy would take me somewhere by myself. Small gestures of sitting and drinking tea with her made me feel grown-up, important and valued.

After my parent’s business broke up, our relationship became more important to me, as my pool of non-parental adults drastically shrank. Andy and Kathy lived in the town where my
parents operated their business and I went to high school. Their proximity to my high school became important when they allowed me to live with them my junior year after I had a major falling out with my parents that left me dumpster diving. Kathy saw I was in crisis when she invited me into her car and her home. Although she did not understand the specifics of mental illness or of my particular problems, she did now that left to my own devices at that moment I would have squatted in an abandoned building before groveling to go back home. She and my godfather intervened on my behalf and my parents made another decision that profoundly affected our extended and supplemental families: after decades of friendship they never spoke to Kathy and Andy again.

At that point my relationship with Kathy and Andy became a substitute family. “Some voluntary kin, called substitute family, replace biological or legal family because of death or estrangement” (Braithwaite et al., 2010, p. 398). Many people have biological family but for some reason there is an estrangement, meaning that there is little or no contact between the family members. This tends to be considered as a deficiency in the traditional family. While I always had a difficult relationship with my biological family, I now understand that some of my interpersonal difficulties stemmed from my mood disorder, while others stemmed from my parent’s unwillingness to effectively handle conflict with their family systems.

I have always stayed in contact with Kathy and Andy describing their position in my life as “godparents,” but it has always been an active role. The guidance they have provided has always been the kind of guidance one would expect from parental figures. As supplemental and sometimes substitute chosen kin, they supported me emotionally and occasionally helped me with expenses. Once I remember they bought a filling for my tooth. They have always
remembered my birthday and Christmas, giving me generous checks. When I decided to go back to college, they bought me a laptop.

Even though I only lived with my godparents for a few months as a teenager, I have always known their kindness saved my life. I simply would not have survived without them giving me shelter and love. I would have either ended up dead on the streets or dead by my own hand. It is difficult for anyone to understand depression when they themselves do not suffer from it, and Kathy is not a depressed person. She wakes every day excited and happy to be alive. For her, interacting with a child as morose as I was must have been more than a little challenging. She speaks of that time:

When you came to live with us, Andy and I, we both felt you had a really bright future because you had a good intellect, but we were afraid of and suspected that you didn’t have the discipline and that you needed the discipline. Not that we tried to discipline, we tried to set some ground rules, but you are not disciplinable (Kathy, personal communication, 2014).

Her description of my not being “disciplinable” and my lack of discipline is her way of discussing my unreliability, my being frantic and my erratic behavior. All of these things are symptoms of the BPD that we did not know I had.

I have always maintained a relationship with Kathy and Andy and, although we have divergent religious political views, I have never questioned their love for me. When I came out as gay, it was difficult for all of us. Andy is a right wing, retired Army officer whose religious convictions prohibit homosexuality. In his heart he believes that God literally pre-ordained him to look out of my religious character. That is an oath he took, and he is a man of his word. He did not react well to my sexual orientation, but he never turned his back on me. Because of the
sacred ceremony of my baptism when he promised his deity to keep me from Satan’s grasp, he will not ever reject me entirely. Kathy talks about the last boyfriend I dated and her reaction to my lesbianism:

I liked him but I questioned your relationship with him, I didn’t see you as being wholly completely comfortable. Not 100% into it. I don’t know how I figured that out, I just sensed it. And so, when you started talking about your homosexuality then I feared you would be susceptible to as so many people are not just homosexual or whatever everybody heterosexuals too. When you are out there looking for a mate there are going to be disappointments there is going to be reversals. And because it was the gay community and because I had an attitude that in the gay community there is a lot of instability so I was fearful of that. But when you brought your last girlfriend over I was fine (Kathy, personal communication, 2014).

Kathy’s religiosity is less punitive than her husband’s, and she feared the kinds of people she perceived as being part of the gay community rather than the state of my eternal soul. For Kathy, the relationships she has with me is an extension of her faith in God has a role in her relationships:

My relationship with everybody not anyone in particular, but everybody reflects my deep belief that God exists but He does not plan. I don’t believe that God plans anything, but I believe that God loves everything. I believe that God made everything. I see that proof in nature, and in human nature too. My relationships are based on this belief that we are all here because of some spiritual God/force/I-don’t-know what it is. It doesn’t matter, I know that It is. So, since I know that it is and there is so much diversity in this world that is like a joy to see it all and to try to understand it all and I believe that religion is not
always good it can hamper so many things and is harmful because people are egotistical, or so embedded in their culture or their social mores that they believe that theirs is the right way. There is no right way. There is just being human, being kind, and being humble to a point. There is another word-curious. So, that’s all that has been given to me by this force that created me. (Kathy, personal communication, 2014)

Her objection to my being part of the gay community was less about a religious prohibition, and more about her thinking the gay community could not provide the structure she thought I needed.

Like my parents, Andy’s awareness of my BPD seemed to reduce his rather outspoken anti-gay rhetoric, at least to my face. Kathy and Andy visited me in the hospital after the first psychotic episode and must have been terribly shocked to see me, someone they both defined as having a “good intellect,” rendered completely incapable of any coherent communication. Kathy remembers a phone call during that time period:

There was a phone call many years ago when you were not under medication. I seriously thought that my relationship to you may have been destructive not helpful because of that phone call. That was before you had help. And I didn’t understand you. We had a conversation, you and I, for a good two hours where I was trying to talk with you with your life and your dreams and you were okay while we were talking and then Andy got on the phone with me and that is when everything went bad. I couldn’t understand. When I was talking to you, I was trying to get through to you and talk to you about how you felt about things and how I felt about you and how I was scared and what I saw and what I didn’t see but I wasn’t aggressive. I wasn’t judgmental but Andy came on the phone and he says it like it is, and you couldn’t take it. You called him a Judas, because you thought
he was betraying you. So, that was the only time that I wasn’t sure about how I was going to continue with you (Kathy, personal communication, 2014).

In all the years we had been interacting this was the only instance where Kathy doubted my ability to benefit from communicating with her but other than that one instance she describes us as having a mutually respectful and healthy relationship. But after visiting me in the hospital and having conversations that were difficult to understand, she had fears about my future:

I envisioned you having a lifetime of wild, uncontrollable mental illness emotional upheaval. This was a very short period of time, but I did see this. I felt it. I felt helpless and not knowing what to do next. It was like out of my hands whereas I have always felt like I had some kind of communication with you, some kind of tie; during that period I didn’t feel that. It was out of my hands (Kathy, personal communication, 2014).

Beyond feeling helpless, my diagnosis included her changing her expectations of my future. Kathy said, “I lowered them [my expectations]; I couldn’t expect of you what I expected of you when you were young. You had such a good intellect and you were going to go far in education” (Kathy, personal communication, 2014) At this point during our interview, she started to cry, something that I never saw her do in her entire life. I grabbed her hand and she found her voice, and continued:

I’m not disappointed. The opposite is true. It just took a while. I hoped where you are now is where you would have been in your twenties. So, there was a lag…I’ve always thought your intellect should lead you, not your emotions-me personally. I thought that would happen-and it has…it just took long. I knew you were highly intellectual and now you are living that potential. You are blossoming with it. So now I raised the bar (Kathy, personal communication, 2014).
When I moved to Tempe, Arizona to attend Arizona State University at the age of thirty-two, Kathy started corresponding with me regularly. As a woman who re-entered university life as an adult, she had pertinent advice to offer me. Kathy, a University of California at Berkeley alumna, was the only woman I knew who finished college. Going back to school proved to be a difficult transition and being a first generation re-entry student, I found Kathy’s words of encouragement and advice invaluable. The emails from the past ten years largely reassure me that sticking with my education is important and the various insecurities, fatigue, and frustrations I express are normal in the process.

Family communication research on the relationships between aunts and their nieces is a useful lens to use when discussing my relationship with Kathy. She acts as generative kin to me. Being generative kin simply put means that there is a concern for the future generations (Korte, 1999). Kathy offers mentorship, acts as family historian, and as a friend. Mentors act as guides who model, teach and advise. Historians help make meaning of family tradition; she retells the stories of my family to me. As I get older and more stable, Kathy acts more as a friend and fellow traveler. We have common interests and we both have the ability to help people cope with difficult life events.

Beyond mentoring advice about negotiating academia, Kathy’s letters and emails to me include family updates. They chronicle ten years of normal lifetime events for an extended circle of people including marriages, births, illnesses, and deaths. She writes of her children, grandchildren, her piano students, and other godchildren (who I have not seen in decades). The notes speak about caring for her mother, elderly chosen kin, and my godfather. Similarly, my emails to her keep her abreast of the mundane aspects of my family’s lives. I write about my
parent’s health, the struggles my friends are working through, as well as small talk about people I know through college.

The notes also record entertainment and leisure activities. Kathy tells of vacations and cultural events they attended. I write about my dreams to travel and even sent a few e-mails from when I had the opportunity to travel outside of the country. Many of the letters negotiate my travels back to the San Francisco area and discuss the logistics of my visits. The letters all convey our love for each other.

Regardless of the actual text of them or the literal messages they convey—they serve as a way for us to stay in contact even though we talk on the phone infrequently and see each other about once a year. Kathy purposefully and deliberately keeps the lines of communication open as a form of social support. Her method is not overt. When she speaks to me and my moods seem off she employs specific communicative devices, “My strategy is to never correct. That is one. Don’t correct. Another is reflecting, reflect back what you’ve heard. Keep an open ear” (Kathy, personal communication, 2014). Demonstrating empathy is extremely helpful in cases of mental illness, yet it is also very difficult. Wiseman’s (1996) work analyses empathy and breaks empathy down into the aspects that must be present to convey empathy. First, empathy can only occur if the caregiver can see the world as others see it. This is especially difficult when the loved one is experiencing psychotic behavior. The second defining characteristic of empathy is understanding another’s current feelings. Understanding a depressed person’s feeling of hopelessness is not always an easy task. Being nonjudgmental is another key component. Again, this can be proven to be difficult when there is distorted thinking. Finally, communicating understanding is also imperative.
Kathy does not ask about my health or my mental health often; she never mentions complying with treatment. Instead she provides what she has always provided: steady unconditional love and support. She trusts in me and in the relationship she spent decades cultivating. She has purposefully created an environment where I feel safe reaching out to her for help if I need it. Without her support as a teenager, I am uncertain that I could have managed. Her faith in me has helped inspire me to make difficult choices that have ultimately served me. I never want to disappoint her; I never want to lose her love and guidance. Sometimes, when I have to get my blood drawn or when I have to swallow one more pill, I think of Kathy and I muster up the ability to comply with treatment. Because Kathy supports me and has high expectations of me, I am motivated to try my best.

**Tina Marie.** All of the previous relationships I have discussed thus far have been with non-legal and non-biological chosen kin members. This relationship varies, because we are blood related. It is the most complicated of the relationships and the most enduring. This relationship is with my older sister, Tina Marie. At times our previous relationship was peppered with long periods of estrangement and long periods that we did not speak. This has sometimes been because of petty disagreements or very different worldviews, and sometimes because we just live different lifestyles in different locations.

I include her in this project even though she is not technically chosen kin because the relationship that we currently construct is one based on small active choices that help maintain the relationship despite our mutual frustrations. Our relationship serves as a departure from the way my parents have historically dealt with conflicts. We chose to endure instead of abandoning each other. While this can be said of all relationships, in our family of origin our parents regularly cut ties with people they have been in long-term relationships with rather than
compromising. Tina Marie and I, in our choice to stay in relation with each other, take steps to foster positive relationships rather than walk completely away.

So, I stretch the definition of chosen kin to include her interview in my project. Beyond being a biological voice, her testimony is important. The way she interacts with mental illness and relationships is a divergent voice that has not yet been heard in this narrative. This is important because often Tina Marie’s opinions and advice are different than the advice I receive from the people I chose to be in my circle. That is, Tina Marie’s voice is more likely to differ from my own and I believe that diversity is a positive thing. During my major illnesses Tina Marie was not as emotionally close to me or geographically close to me than my other social supporters, so her perspective is different.

Tina Marie and I grew up in a relatively traditional home where our dad worked and our mom stayed home. All of our young summers, we roller-skated, played with friends on our block, and explored California by camping. We generally socialized on weekends and holidays with scores of cousins; in many ways we constructed our identities through our interactions with our relatives and family. On my mother’s side alone we had: six sets of aunts and uncles, three sets of great-aunts and great-uncles, grandparents and twenty-two first cousins. The relationships inside our tribe included other kinds of special relationships: some aunts are also godmothers, some people share birthdays or astrological signs, some people were born within a year of each other or shared common interests. We attended Catholic church every week. My father’s agnosticism never seemed to pose a problem for anyone since my mom raised the children in the faith.

In first grade mom enrolled us in a Catholic school about thirty minutes away. Most of the children we went to school with went to church at the parish that housed the elementary
school. We had our first taste of being outsiders. My sister and I never experienced going to
school with children of our neighborhood. So when our peers sent time outside school forging
relationships, my sister spent our time outside maintaining relationship with our cousins.

Because the school was private and most of the other kids could walk there, we did not
have access to a school bus. Our mother formed a carpool with the other family who lived
outside walking distance and we commuted to school that way for the most part. At some point,
and I am unsure when, we started taking the public bus.

*My mom pressed two nickels and two dimes into my hand and reminded me not to
lose them. I put the coins in the front pocket of my uniform shirt that the thick straps of
my plaid jumper concealed. The small round metal circles pressed into my flat chest; she
told me these tokens would bring me home. Mom assured me that I just needed to follow
Tina Marie’s lead onto the bus—we had done this before. We sat at the stop with goose
bumps rising on our bare legs between the top our socks and the hem of our uniform
jumpers; we couldn’t wait until fifth grade we were old enough to wear skirts instead of
the little girl clothes. We played patty-cake. Say, say, oh playmate, come out and play
with me! The silver house key that dangled on a shoestring slapped against my sister’s
chest as we clapped our hands. The airbrakes wooshed to a stop and the driver cranked
the accordion doors open. Tina Marie seemed unafraid as she gathered her book bag and
charged up the huge grooved rubber steps. Her fare clanged into the glass reservoir and
the faceless driver handed her a scrap of paper, “Transfer!” he called. I followed the
ritual and lurched into a run and spun myself into a seat near the back. Tina Marie
already an avid reader, dove into her reading material. I looked at the transfer and made
out some of the words but could not figure out all of them. Not being able to read the big
words frustrated me; I focused my eyes on the advertisements and tried to make out
words and match them to the pictures. The bus was hot and crowded with people of all
sizes and races standing in the aisle. The swaying of bus made the letters I tried to
decipher jump up and down and lull me to sleep—I never slept well at night and often
found myself sleeping in class.

When I awoke alone in an empty parked bus, I thought I was in a dream. The bus
parked in yard full of other busses and through the window I made out a small hut with a
person sitting in it. I choked back my panic and my tears and justified talking to a
stranger, “I forgot to get off the bus,” I said in a small voice. He led me to an office with
a woman who sat me down and gave me a paper cup of water. Someone recognized my
uniform and thought to call the school’s number and someone there contacted my
mother. Mom picked me up rambling the entire way about how she could not believe my
sister forgot me on the bus (Author’s memory, 2014).

When this story is told in our family it is told in three different ways. My mother tells it as a
story of my sister neglecting her duty as a sibling. My sister tells it as a story of my parents
shirking their responsibilities and putting too much responsibility on her eight-year-old self. I tell
it as clear proof that my sister always hated me. My assertion that Tina Marie hated me and
specifically tried to lose me along with the fact I had a serious sleep disorder already
foreshadows the mental health issues I would deal with later. Tina Marie believes I already
struggled and when I asked her to describe being the sibling of the acutely mentally ill child she
replied:

You are left to your own devices. You raise yourself. All the air in the room is being
sucked up. I learned how to cook things by the time I was 8 years old, you know? You
were crazy at 4, they called it being a pain-in-the-ass. Not following directions, never
doing what you were told. Being dramatic about everything all the time. I don’t know
which part is you and which part was our parents; I don’t know how to separate it out.
But, when all of the attention goes to the one squawking the loudest, there is no such
thing as equality. I don’t care what anybody says, there isn’t. It’s not equal, it’s never
equal. Because to a large extent, I raised myself for whatever reasons (Tina Marie,
personal communication, 2014).

At the time of my manic episode after Ronny died, my sister and I had a very strained
relationship. We had much in common, we have similar talents; we both enjoy writing and I
became a massage therapist a few months after she did. But our common interests and similar
senses of humor could not bridge the long time resentments and personality conflicts. Our
parents taught us through example that when you disagree with a person you should stop talking
to them, and that is what we did for much of our twenties. Tina Maria felt because my parents
did not have enough emotional resources to provide for both of us and were somewhat ill-
equipped to deal with the day-to-day realities of parenting, she had to pick up the slack and help
raise me as well as herself. The burden of performing caretaking duties returned when we were
adults and my mental illness (re)surfaced.

When you were in Wondaworld (laugh) it was like it’s not a relationship. It’s a caretaking
relationship/position. It’s finding the best care. Trying to take care, trying to make the
best decisions for your best welfare. It’s not an equal relationship where there is give and
take. It was all one directional. So, that is very difficult. It’s difficult because it’s all about
them and its incredibility taxing. It’s just difficult to convince any kind of health benefits,
to help the person to take care of themselves…Well, yeah. There is a level of
responsibility…if you were not stable it puts a different obligation and duty on me to make sure that you get the help that you need. To an extent, I’m not your caregiver, but there is a duty to help people who need the help (Tina Marie, personal communication, 2014).

Tina Marie’s recollection of trying to handle my health care is a version slightly different than Alison’s. Alison felt alone in making the phone calls and trying to work on my behalf, and did not know Tina Marie also tried to negotiate the system. Clearly, my sister had access to the doctors and the hospitals and could advocate for me because of her biological ties in a way Alison could not. Tina Marie also contacted my parents. But Tina Marie and Alison did not coordinate efforts to make any required phone calls or meet up with social workers. Tina Marie and I were estranged, and Alison and I were very close. My sister had the same phone number for years and it was one of the few I memorized; I called her frequently both times I experienced mania. Tina Marie writes:

She called the house phone tonight, the only number she can remember. I picture her singsonging when she dials and she actually sounded not too bad. She asked how I was doing and how the family was doing. She said that she’s feeling pretty good and I asked if she had a theory as to why she’s starting to feel better. She became evasive and quiet. Then my cell phone rang and it was the therapist calling to say Won had not been taking her meds for a whole week. Instead she’s been holding them under her tongue and then stuffing them in her pocket when no one was looking. She’d stored them up and swallowed something like 25 pills at once—that is why she was throwing up on Tuesday. I hate this helplessness. I feel like throwing up. But I’m breathing in and out. Letting go, letting God. Trusting this process. Repeating that it’s out of my hands and out of my
control (Tina Marie, personal communication, 2014).

I no longer can distinguish the episodes from one another and she cannot either at this time but she remembers the content of the conversations:

Half of the time it was incomprehensible. It was in code with numbers. Or, key words that only made sense to you. At all hours of the night. Sometimes two in the morning, sometimes four in the morning. Non-stop. You’d hang up and call back in twenty minutes or five minutes. And start all over. Sometimes the calls were not you. Sometimes someone else is calling, ‘We have your sister here and we don’t know what to do. You’re her sister so you have to be responsible!’” (Tina Marie, personal communication, 2014).

As much as I reached out and tried to talk to Tina Marie, I also refused to talk to her. She experienced this as being on an emotional roller coaster.

She has called me just to scream at me for the last two days. The staff members who answer the phone seem surprised. Since I don’t receive regular updates from anyone on the staff, I have no idea what’s going on. I find myself wondering what I could have said or did that caused her to put me in the cross hairs. However, it’s been typical for her to misconstrue words or intentions and then stew on them, contorting them further with each angry rumination. Who knows what is going on in her head. I know I should not take it personally, that it’s the illness talking. That doesn’t change the fact that this whole giant situation is unfair. (Tina Marie, personal communication, 2014)

During episodic periods, people who regularly had daily contact with me like Yetta, Alison, and Julee feared for my immediate safety. They became frightened that my personality was going to be permanently altered. When I had very little contact with my sister, Tina Marie became aware of my condition through my friends calling her and through my nonsensical phone calls.
I asked Tina Marie what she remembers what my friends told her about those times and what her fears were:

You got rid of all your property and left your apartment. We wandered around the streets of San Francisco. You had just uncontrollable mania. You were calling all kinds of different people and not being able to function as a regular person in society at all. I thought you would go to jail. No, most dire situation would be if you killed yourself or get in a situation where someone killed you. Those things weren’t just probable. In the worst case when you were at your worst? Absolutely. More than probable—It was eminent (Tina Marie, personal communication, 2014).

Despite the fact my sister felt my illness put me in danger, she feels an important part of her role as a social supporter is to maintain strong boundaries:

Really, I get out a piece a paper and write down what I have control over and what I don’t. I let go of what I don’t have control over. That sounds very simple but for people who care about other people on a destructive path, mental illness, drugs whatever. You have to learn where your influence is and what you can do to help. Talk, keep talking. Get support as far as other people who might have been through similar situations and not be afraid to say, “You know what? This fucking sucks!” Half the people that love you they just want you to feel better. They say, “It’s going to be fine!” or “He’s getting better.” They don’t want to hear is that my sister may not ever get better. You may overdose tomorrow. You may slit your wrists tomorrow. It fucking sucks. So, I try not to be completely mired in negativity, but not to be mired in fake false positivity either. Self-care is really important. This is the most helpless situation you can ever be in—to watch someone deteriorate and to be unreachable. It’s the most helpless situation that you can
ever be in and it’s heartbreaking. There is no way to make that nicer, no way to fix it, no way to put a Band-Aid on it. It just sucks, it sucks hard. You just got to learn what you can help and do what you can the best that you can and then make sure you have time to vent and your own support system (Tina Marie, personal communication, 2014).

Tina Marie also told me about these specific self-care techniques. She tries to figure out what she has the ability to do to help and concentrate on what she can do rather than what she cannot do. She describes caring about someone who is mentally ill as heartbreaking and her self-care techniques surround managing her own emotional well-being:

Keeping boundaries are more than important, it’s vital. Because when someone else goes to crazy town, they don’t have boundaries so you have to have 7 or 8. I won’t talk to you if you aren’t on medication. I say “You sound manic, have you taken your meds. No? bye.” I also would like it to be that you are working on your shit. That might mean talking to a therapist but…the very least is you need to take your meds. And if things are too much on meds and if anyone is using me as the Band Aid. That is when I say, “No. you are draining me. Here is the line” (Tina Marie, personal communication, 2014).

Out of all the social supporters that I interviewed, Tina Marie had the most clear-cut minimum expectations of the people she has relationships with that are dealing with a mental illness. She feels the need to protect herself and her immediate family from the chaos. None of my other social supporters articulate their boundaries as having an immovable line. Perhaps, it is because we grew up with slightly different expectations than other children, maybe it is because she feels like she escaped that role when my parents moved out of state. Part of taking care of our disabled parents included taking on very adult responsibilities as young ages; both of us had more chores at a younger age than other children. We also both became hyper-vigilant, always looking-ahead
for something that might trip either of our parents. Even though I do not have the same perception, Tina Marie said she felt the added burden to take care of me. She feels that because of her early responsibilities she must have a rigid boundary system so she continues to enact caretaking obligations but with a much firmer sense of boundaries than my other social supporters.

**Auntie Wonda.** The final social support relationship I explore is the one with myself. I wrote the included letters to a child in my life who experienced similar mental health problems and had several periods of institutionalization. I describe these letters as being written to myself from myself for multiple reasons. First, the person I wrote them for was an at-risk youth and I do not feel as if I can ethically expose any of the details of his or her illness until he or she is capable of adult consent. Second, although I had another person in mind when I wrote them. I invoked memories of being in a similar position myself and, in providing advice and support to this young person, I also spoke to the younger version of myself. Speaking back to that younger Wonda allowed me to care for myself and heal some of the very old and deep wounds that this illness has caused. For the purposes of this project the letters are written to Wonda from Auntie Wonda—I finally chose myself as kin.

Wonda,

I wish I could help you understand that sometimes to get “better” we need to let go of the past, let go of the fear of the past and imagine an amazing future. Sometimes we have to let go of the crappy story we tell ourselves about ourselves even if at one point those stories were true. In my lifetime I have failed a lot. I barely passed high school. I have had a hard time holding down jobs. I have lost many friends. I even spent a period of my time lost on the streets of San Francisco too sick to even figure out how to ask for help. I
am gay—and you know that is challenging when your family is Catholic. I used to feel like no one would ever want to be my friend. I am going to tell you that you are not only lucky you are blessed—even though you can’t feel it or know it. I believe in you. I believe that this trouble you are in right now is just a tiny portion of your life and that you will be happy one day. And being happy is more important than anything else in the world. Its more important than having a fancy job, its more important than having friends, its more important that everything.

Love,

Auntie Wonda (2012)

This letter reminds me that all things are transitory including problems and mood swings. Life sometimes feels insurmountable but problems are permanent. I am not sentenced to a life of bleak depressing days. Sometimes it feels that way, but feelings are not permanent. Using coping skills is important.

Dear Wonda:

One of the ways I help myself when I am feeling down is to soothe myself. Learning to feel happy is a really difficult lesson. It is a really important skill that can make your life really full. When you express yourself you let those emotions out and they don’t have to control you. There are so many ways…I thought I’d share some ways I express myself and soothe. I talk to a friend or family member. I write in my journal. I sing, cry or read. I watch a movie. I get active—I love to swim. I cook. I play with my dog. I find something to laugh about. I travel. I make lists of things I am grateful for like: friends and family, medication, my dog, snow, sushi, the ocean, having enough food and a nice place to live, and flannel pajamas!
Love,

Auntie Wonda (2012)

The previous letter gives some strategies I use to combat depression. The next one expresses how much I hate being in the hospital:

Wonda,

I know you are sick of being in the hospital and that it really, really sucks; I remember what that feels like. I know it is hard for you to believe, but it does get better. I know it is hard to continue to have faith when it has been so hard for them to find the right medication for you. But, it is worth the fight because you are worth the fight. You are the most important person in my life and I love you unconditionally. Remember what that means? I love you no matter what. There is nothing you can do to break my love for you; there is no way you will ever convince me to stop loving you. You are a big reason why I try so hard to meet my goals. Despite all the hard times, life can get better. I found ways to feel happy and to pick my own path in this world and I think you will too. My life would be so sad and empty if you were not in it, you are a blessing in my life. I love you.

Thinking of you every day—

Love,

Auntie Wonda (2013)

Talking to myself as if I were a child I loved creates the space for me to think of the younger version of me as what I was—a young girl, scared, lost and alone. Reminding myself that I am worthy of self-care and love is a complex process when I combat a mood disorder. My words are deceptively simple, but the effect and affect of them can be profound.
Living away from home because of mental illness is common. Besides hospitals I had no residential treatment, but living with Andy and Kathy during high school and my cousin slightly after is an example of my needed to find help outside of my family. The campground in later years functioned as a live-in treatment center. The following letter I explain:

Wonda:

I know you really don’t want to live away from home—but the house you are in seems comfortable and the people seem compassionate. I bet you want to know just how long you are going to have to be there. That is a good question. I know how one day can feel like an eternity when you have to ask someone to unlock the darn bathroom! I want you to really try to give this place a chance. I want you to try to stop focusing on when you will return home. I mean all those other places were interested in getting you to go home—but they didn’t really help you learn to heal and they didn’t really give your medication a long enough chance to work. I went to my parent’s campground in Arizona to heal. Having that time and space to be with nature was a GIANT reason why I was able to get so much better.

Love,

Auntie Wonda (2013)

Unfortunately going to the hospital is sometimes the only answer for medication tweaks. I always have a difficult time getting adjusted in an institutional environment and tend to resist treatment or feel as if it is punishment. When I am lucid I understand that resisting treatment only makes it more difficult.

Wonda,
I heard that you were in the hospital in San Francisco. I just wanted to take a little time to let you know I am thinking about you all the time and that I love you so much. Please don’t think of going to the hospital as punishment…try to think of it as a vacation from all the stress you have at home and at school. I am sure that this is about getting the right combination of medication for your body. It totally sucks, but this is 100% normal—we all have to go through medication tweaks. I want you to understand that you do not have to go in and out of the hospital for the rest of your life. You can have a good life even though you’ve had these problems. Because you are confronting these issues now and trying so hard to develop coping skills at such a young age—I think you have a really decent chance at a great life. There is no way I could have known my life would turn out so great when I was fifteen. The struggles you are dealing with now will prepare you for many challenges—challenges that you will already know you can handle because you can handle this illness.

Love,

Auntie Wonda (2013)

In the letter above I try to take a positive spin on the challenge of being in the hospital. The experience often feels punitive especially because we as a society often use the police force as the people who escort mentally ill people to emergency rooms and transport people to mental hospitals.

Wonda,

I know you are having a super hard time remembering things clearly and that sometimes your memories are more negative that the past really was. I don’t always remember things correctly either. It’s very frustrating. But, then, I started to think about the nature
of memory and what it really is and why we give it such power over our present. What is memory? It is like a video we replay in our heads. Sometimes that video gets erased and a new more negative, or more positive video gets put in its place. But why do we need memories? We need them to feel connected to people. We need them so we don’t keep making the same mistakes. When we experience trauma, sometimes those memories get extra stuck and keep popping up over and over. Going to the hospital is traumatic. Being locked away from your house, your things, and your family under the control of strangers sucks big time. It is scary and unfair and it hurts. Right now those memories are painful and raw—like a new wound. But, time does heal. And these awful memories might actually inspire you to help other people who are being treated unfairly. Sometimes we get stuck in memory and we play those tracks over and over in our heads. Try to find a way to distract yourself and live in the moment. Try some deep breaths or some meditation. Maybe go for a nature walk or create some art or write a letter to a friend. Remember, memories and feeling don’t really have any power to stop you from living the life you want.

Love,

Auntie Wonda (2013)

The letter above questions how memory is affected by mental illness and by the medications used to treat it. It also suggests that negative memories can either hold someone back from recovery or play a role in creating compassion for other people. It shows that managing perspective is imperative in self-care.

Wonda,
Always remember that mental illness is different than other kinds of diseases. When someone tells you that you have a personality, mood or conduct disorder—it can feel like they are just saying you are a jerk or an asshole or unlikeable. It is hard to separate who we are as people from our thoughts, feelings and behavior. It’s hard for even us to recognize that those things are symptoms rather than who we really are.

Auntie Wonda (2013)

The final letter I include articulates a problem that almost all people with mental illness must face. Often people conflate the symptoms of a mood disorder with fixed character traits that make a person who they are. It is specifically hard to sort out the way someone behaves and the way some displays emotions from the actual person. I believe most people with mental illness suffer socially because of it and are even misjudged by their closest allies.

Voluntary kin provided and continue to provide me social support in many ways. Each of the women supported me in similar yet specific ways. All of them communicated with me over the telephone and most also used some form of written correspondence. The artifacts that remain show mostly superficial updates about relatives, entertainment, health, travels and common interests. The communication served another purpose. Its purpose was to demonstrate that, although I was out of sight, I was not out of mind. The letters, emails, and postcards are proof that they thought about me highly enough to contact me. The telephone is my preferred long-distance form of communication and I certainly did not take notes of our phone conversations, but I remember some well. The phone calls are where the vast majority of social support was enacted. In those calls I talked of my hopes, my dreams, my fears, and my symptoms. Those countless hours of talking helped me realize that my life was not over and gave me the will to live.
My friends and family enacted an ethic of care in my times of need and continue to care for me even when I moved out of state. They all felt obligated to help me because we had previously established relationships before I became sick. Several of them also mentioned that caring for loved ones is part of how they were raised or is part of their spiritual imperative. Alison states:

When I was a kid I went to church a great deal and we were Lutheran—that’s more about your responsibility to others, and your responsibility to behave in a certain way in gratitude for you existence. I mean that is it, I think on some level I guess your spirituality is about what kind of life are you going to life and what kind of person you are going to be, you know? It defiantly effects [how you care for people]” (Alison, personal communication, 2014)

Kathy also spoke about her spirituality. She mentors and is in relationships with hundreds of people, including me. I ask her if she felt spiritually mandated to care for others and she replied, I don’t feel like I have to, its part of my nature. Its part of everybody’s nature. We all need each other. And the more you give you get it back tenfold. That’s not what I do it for but it feels very good to give (Kathy, personal communication, 2014).

For Alison, caretaking is part of the definition of family, “I have a certain amount of tradition in my family that comes with certain responsibilities. Family are people you have certain caretaking responsibilities towards” (Alison, personal communication, 2014). Although none of them mentioned the fact the way they care is because they are women, four of the five are mothers, so caring is part of how they enact their love on a daily basis:

What makes it doable and better and life affirming instead of soul crushing is that I do think that I am free to walk away. An offering has to be freely giving, it’s not something
that you give with a gun to your head. Right? Like, I choose to take these actions and when I start to feel like, “This is hard!” I have to think about this—I can get on a bus tomorrow. I can leave. I chose not to because you know because I say responsibility a lot, but that isn’t the only thing. It’s like (long pause) we all have the same ingredients, we all make the same mistakes. We all do the same things—so I make all those same mistakes, I need that same amount of forgiveness and I am going to manifest it into the world by giving it away to other people. You know?” (Alison, personal communication, 2014).

Alison also believes that while caring for people is part of her role in her family and part of her religious tradition, knowing that she can walk away empowers her to continue making the conscious choice to be a caregiver even though she struggles with the burden. Tina Marie’s faith allows her to live with the uncertainty of caregiving for someone with mental illness. She is able to release responsibility and worry trusting in God. The action of surrender when she gets overwhelmed helps her find strength to carry on:

My relationship with God is everything and permeates all aspects of my life. The number one thing with the crazy people in my life—what I’ve learned is surrender. In the twelve steps they always talk about surrendering to a higher power. Ultimately, I can’t control any of this, but my understanding of who God is and who these people are to God—his precious children and he hasn’t abandoned us and that is where my comfort is. I know, I just turn it all over to prayer, constantly, daily, sometimes hourly. All the people in my life. I carry them in my heart all the time and I just surrender it all the time. I put it in a box with a bow on it and I say, “This is yours. It is not mine, you are way bigger than me. Here you go!” That allows me to take on the day (Tina Marie, personal communication, 2014).
My social supporters did not care for me in hopes of reciprocity (although later I have been able to return their care), but enacting an ethic of care should not always be conceived as only a unilateral self-sacrifice. Engaging in social support relationships can be rewarding when given freely. Alison finds power in her ability to care as a choice rather than an obligation. Kathy feels as if caring for other people is part of not only her human nature, but that it is part of our universal natures. Tina Marie understands that God requires her to take care of people, but also believes part of the way she can actively care for people is by managing her stress by relying on God. Julee and Yetta did not specifically mention care in terms of ethics or spirituality, but in terms of friendship. Julee dedicated her time and energy taking care of me because she sees herself as a loyal friend. Yetta experienced a renewed connection with me when she communicated with me, but was unwilling to give up on our relationship.
CHAPTER V: BARRIERS TO RESILIENCE: STIGMA AND TREATMENT

Ultimately I submitted to medical treatment and have responded very well. With the support of my chosen family, I found the motivation to keep taking my medication, keep showing up to doctor’s appointments and to keep working on doing everything I can do to stay stable. I am very pleased that after years of treatment and much time spent recovering I became well enough to spend the last ten years in college. But my journey is not typical and treatment is not easy, simple, or fast. One size does not fit all. There are many barriers to treatment and recovery. Here I discuss some of the typical barriers I faced that are loosely grouped into two major intertwined categories: stigma and treatment.

One of the most common and most insidious barriers to treatment is the stigma surrounding mental illness. Stigma manifests in several interconnected ways. For me, initially I rejected the diagnosis. I did not want to be crazy. The doctors had it wrong. Maybe I smoked too much pot, maybe I had LSD flashbacks. I denied that the disease would affect me like it had affected everyone else, for me it would be a one-time thing. Because I resisted the diagnosis, at times I rejected medication, compounding the problem. Stigma and fear of disclosure to my employers and classmates created problematic situations that at times contributed my embarrassment as well as my refusal to comply with medical advice.

Medical treatment itself became another barrier. For me, I experienced the justice and health care systems as oppressive. The ordeal that I experienced as a young patient at an inpatient facility felt like punishment directly contradicting my identity as an American citizen deserving of civil rights. It became difficult for me to trust that police and doctors had my best interest at heart. Negotiating the medical system and finding practitioners can be time
consuming, intrusive and complicated. Finding the right combination of drugs is often a trying process that takes years and requires a commitment to keep trying despite potentially uncomfortable and dangerous side effects.

**Stigma**

Erving Goffman (1986) describes stigma as a process by which people are singled out as different and “othered” because of it. The stigmatized are “marked” by difference perceived as deviance that targets them for mistreatment; this is called a cue. In the case of mental illness, the cue can be either a difference perceived or knowledge that the person has the difference. The cue can be perceived by a behavior the mentally ill display, or by the knowledge of the diagnosis or label. All stigmata are not created equal. Some mental illness diagnoses carry more stigma than others. People who are depressed for example might not be perceived as deviant as someone experiencing psychosis (Ober, Granello, & Weaton, 2012). After a non-stigmatized person meets someone with a stigma, stereotypes about that stigmatized identity materialize. Stereotypes are ideas about a stigmatized identity that people in any social circle are exposed to even if they do not believe them.

Mental illness is one of the most stigmatized identities in our society, so much so that Falk (2001) subtitles his chapter on mental illness, “the ultimate stigma.”

Nevertheless, the stigma attached to mental illness is severe because we live in a world in which the ability to think and act rationally in a meaningful fashion has been declared mandatory by public opinion since the Age of Reason began in the early eighteenth century. Included in this demand is a necessity in the post-industrial society for each of us to perform independently the daily tasks assigned to us by our occupation, family obligations, and community membership (Falk, 2001, p. 40).
Because of the fluctuating mood swings present in BPD and the periods of relative normality, BPD sufferers have both discredited and discreditable identities. According to Goffman (1986), there are three types of stigma: physical abnormalities, blemishes of character, and tribal stigma of race, nation and religion. Several of “blemishes of character” he describes have applied to me over the years including: mental disorder, homosexuality, unemployment, suicide attempts and radical political behavior (p. 4). Even when embodying these stigma, I do not always identify as part of the larger group of people who also suffer from the markers. Even in my recovery, it has been hard to accept the label of mentally ill largely because of the stigma surrounding it.

The words flash in my mind. Mentally Ill. I picture a smelly person babbling on the streets homeless wearing mismatched disheveled clothing and pushing a cart full of random trash. She is frightening normal people with yelling preaching and responding to voices no one else can hear. I see her swat away invisible attackers. Mentally ill, me? No, I guess. Everyone walks around and by me too annoyed to care about my suffering. They can’t see the normal me. And I can’t reconcile my image of homeless and crazy me with the capable, caring me. I don’t want to blend into the garbage on the street (Baugh, 2000, p. 116)

City dwellers walk by destitute, mentally ill people every day as they navigate the landscape. It is impossible for individuals to continue about their lives and confront the horror that we allow ill people to languish outside. Stigma becomes a useful coping mechanism. We think that homeless or mentally ill people are somehow less than or different from us. Stigma surrounding mental illness include: mental illness as a personal weakness or character flaw, a moral deficiency, or a behavioral choice. This exemplifies the theory of stigma Goffman (1986) espouses:
The stigmatized by definition, of course, we believe the person with a stigma is not quite human…The stigmatized individual tends to hold the same beliefs about identity that we do; this is a pivotal fact. His deepest feelings about what he is may be his sense of being a “normal person,” a human being like anyone else, a person therefore, who deserves a fair chance and a fair break (p. 5).

If having a stigmatized identity encroaches on the ability to be credible, it only makes sense that people would not want the negative connotations of that identity associated with their personhood. This becomes a complex problem when it comes to treatment because doing well in treatment requires accepting a label. Not wanting to be “crazy” can stop people from complying with their medication regimens. Stigma impedes people’s ability to accept diagnosis and that inability to identify oneself as mentally ill creates a host of problems when it comes to treatment. Similarly, living in denial, which is also a symptom of many mental illnesses, convinces people that they were somehow misdiagnosed and therefore do not need to take their medications.

For me, refusing a label or diagnosis made complying with treatment plans and medication almost impossible. Trying to avoid the stigma surrounding mental illness motivated me to initially refuse the illness as part of my identity. Refusing to accept a diagnosis created a worse situation. Ultimately, when I accepted of the diagnosis of BPD, it allowed me to comply with medication that paved the way for my (re)integration into society.

I struggle with stigma when it comes to disclosing my health status to coworkers and new friends. I believe that my last major manic episode could have been prevented if I did not let shame stop me from standing up for my right to go to the doctor. Fear of disclosure and denial stopped me from advocating for myself in employment. I still struggle with how to disclose my health care status to new co-workers and friends, the following account happened in graduate
The keynote speaker was David. W. Oaks, the director of MindFreedom International. I was a little curious because the organization’s website says that they, “Win human rights in the mental health system!” Oaks, diagnosed with schizophrenia as an undergraduate experienced being medicated and held against his will in multiple institutionalized settings. He graduated from Harvard in 1977 and since then has spent his energy and time trying to agitate for human rights inside the psychiatric field. He remains unmedicated today. At the reception prior to his talk, I greeted him and listened to him a bit before disclosing the fact I had also been (mis)treated in the system. I had never met anyone else who perceived treatment as problematic and I wanted to lend him some support. I did not give him much of an explanation or any details, but admitted to the fact I also found myself hospitalized against my will.

He delivered a rambling speech peppered with power point slides making comments like, “This is Sally Brown; she is a survivor” before clicking to the next slide of another person, introducing the person by name and identifying them as a survivor. The presentation largely compromised of his scattered thoughts and pinpointing members of his movement by name. I became immobilized with shock when he gestured to me and said, “We have a psychiatric survivor in our midst!” I am certain in his head he anticipated me jumping up and taking a bow to thunderous applause and even sharing my testimony. Instead, I did not move a muscle, completely unwilling to come out in the middle of a room full of new colleagues and professors. A few minutes later, in his conclusion, he gestured to me again as if he rehearsed it with me and I just forgot my
cue. I can’t remember his exact words because by then hot salty tears of humiliation rolled down my cheeks notifying my companions of my obvious distress. Getting up and leaving would have only brought more attention to my stigmatized identity, so I stayed and tried to quell the tide of overwhelming emotion. When the speech finally ended, one of my cohort members responsible for organizing the event came and hugged me, obviously unnerved by seeing me upset. “I’m sorry, Wonders.” He looked genuinely concerned. I mustered up a smile and said, “Sometimes when you invite unmedicated crazy people to an event they behave like unmedicated crazy people and do crazy shit!”

My ability to understand that I should not have expected Oaks to understand the nuances of personal conversation and have compassion for him in the moment represents years of personal growth on my part. I believe I should be the person who discloses my mental illness, but my discomfort of the disclosure is proof that I feel the effects of stigma. Had I learned to negotiate my stigma earlier, my life would have been different. Had I not been afraid that the disclosure would make my boss think I was less capable or less promotable, I could have prioritized my doctor appointments over my job. Instead, I have thought of my mental illness as a disease rather than an identity.

Presumably the more allied with normals, the more he will see himself in non-stigmatic terms, although there are contexts in which the opposite seems true (Goffman, 1986, p. 107).

Newly accepted into a doctorate program, I felt like my BPD status (and my tears) carried with it a reason for my classmates to discredit me or question my academic wherewithal.

Whether closely allied with his own kind or not, the stigmatized individual may exhibit identity ambivalence when he obtains a close sight of his own kind behaving in a
stereotyped way, flamboyantly or pitifully acting out the negative attributes imputed to them (Goffman, 1986, 107-8).

The instant that Oaks exposed my mental health status to a group of my new colleagues, I did not identify with him but I was also unable to identify with the people staring at my mute self. I did not want to be associated with Oaks. Clearly, I have a sense of ambivalence with my “own kind” as Goffman refers to another person with shared stigmatized identity. By disclosing aspects of my story to Oaks, I reached out to someone with a similar background and story. However, because I interpreted his behavior as both unethical and unprofessional, I did not want to be associated with him. Moreover with him openly aligning with me, I felt he negatively reflected on my own professionalism.

This event happened before I settled on doing this dissertation and before I presented at professional conferences. I eventually understood these actions as part of a larger body of mental illness narratives, and as part of my own political advocacy. Although this project might be confused with other memoirs about bipolar disorder it is unique in two key ways. This project highlights my social supporters who have remained in my life in long lasting friendships and became chosen family members. These women who have consistently written to me, answered my phone calls, and made the time to visit with me were not bound by traditional social mores. Instead, the women unrelated to me by familial or legal obligations emotionally supported me even when I was unrecognizable and even when I could not communicate. They had periods of doubt; they sometimes thought it was too much, but our relationships persevered. My identification with my chosen kin sets my work apart. It is unusual for anyone with BPD to retain so many relationships after being psychotic. I believe I owe my resilience and unusually successful reintegration to these women. Their willingness to participate in my research without
taking pseudonyms also shows that they are unconcerned that my stigmatized identity will
transfer to them. I believe this is because I have been resilient for so long and they are proud of
my academic success.

Everyone involved in this project hopes that our story might help other kinship systems
to cope with this disease and that our collective pain and hope can somehow end up serving other
people through their own hardships. Beyond revisiting my own trauma to reclaim it, this project
gave my voluntary kinship circle and social supporters an opportunity to record their memories
about my symptoms and illness. Although we had individually spoken about some of these
scenarios in the past, this has been the first time I gathered these stories, their interviews, and
some of the written correspondence together in one place. This document builds a history
important to my individual family’s healing as well as a document where I purposefully disclose
my BPD as a political strategy to resist stigma. Like other mental illness narratives, we hope the
story is helpful to other people dealing with similar issues.

Although this work ultimately discloses my mental health status, I still do not identify
with words like “victim” or “survivor”. The premise of Mind Freedom International is creating
avenues for psychiatric patients who consider themselves survivors of the medical system to find
support and help in reclaiming their identities as “mad.” Modeled after gay pride they host, “Mad
Pride” rallies and events to bring awareness of the deplorable conditions of institutions and
create visibility for the injustices inherent in the care that people labeled mentally ill are
subjected to due to ignorance, stigma, and capitalism. They actively rail against medical
hegemony and, although they claim not to be anti-medication, they cannot be considered “pro-
medication.” Traumatized by their treatment, they believe people should not be forcibly
medicated against their will.
I do not appreciate the language of victim/survivor applied to me. I believe that those kinds of identifications have the ability to hold a person in the worst moments of their lives and potentially stop them from growing. That being said, I am a product of my family of origin. My relationship with disability is complex. Both of my parents have physical disabilities, yet they do not identify as part of a disability community nor do they use the label (or any of the euphemisms) disabled. Our vocabularies did not include those words. My parents’ Otherness did not enter polite conversation.

My mother taught me her “walking funny” was just how she was born and there was no discussion after that. In my mother’s defense she was never given proper medical care or a diagnosis until she was over forty. Her gait was what it was. Mom does not roller skate. Similarly, my father’s low vision and his inability to distinguish colors was a fact. Dad does not drive. Their refusal to identify as disabled has been both a blessing and a curse. A curse because it has stopped them from getting the medical care they deserve. It has been a blessing because their lived experiences provided me with two strong role models who never let one facet of their beings dictate how they saw themselves or limit what they could do. My parents enjoy the outdoors and we camped and hiked often. Even now that my mother can no longer walk more than a step or two, they still enjoy the outdoors even though my mother uses an electric wheelchair. My parents held jobs their whole lives and have owned their own businesses, where they worked together side-by-side, for thirty years. Their partnership has lasted over fifty years and they still enjoy each other’s company. Their example taught me that I am allowed to define myself.

Oaks’ traumatic treatment in 1976 defined him, and he dedicated the rest of his life trying change the system. He used the words “psychiatric survivor” to define himself and by proxy to
define me. I reject that language. I lived through that experience, but I have not incorporated it into my identity. I absolutely experienced treatment as traumatic and it made it difficult for me to reach out for help; for me, using the words “psychiatric survivor” to define myself would make taking advantage of treatment solutions impossible. I believe accepting it as my identity prevents me from moving on and being resilient. The word “resilient” is in the title of my dissertation to describe my ongoing action—not my identity. I also am not part of the disability community and have never gone to a support group; instead, I relied on my social support networks to help me.

I “get” that drug addiction, homelessness, victimhood, and survivorship are generally written in a specific way and my narrative does not follow the average narrative. Those things happened to me...but they are not me. I use the analogy of men who have sex with men (MSM) but are not gay. Like a MSM who uses condoms, I have to take medication and get treatment for BPD. I do not have to identify with a label that I feel is detrimental to my own self-image. It might be read as product of stigma but I believe my refusal to identify is one of those things has been helpful in my resilience. I know I have a disease that requires treatment, but I do not accept that my future is limited because of that.

I first identify as being a person in relationship with people I love and respect. That carries self-imposed obligations, including caring for myself as best as I can. For me caring for myself and being in relationship with non-mentally ill people does not include coding myself as survivor, victim, addict, or anything else. I am certainly not saying that should be everyone's path, but it is my truth. For me defining myself in relationship to people who love me and have known me in periods of both lucid thought and mania helps ground me and inspire me to continue to work on myself and get treatment.
Treatment as Its Own Deterrent

Like Oaks, I experienced the justice and health care systems as oppressive. I felt mandated hospitalization enforced by the police punished me to serve time for expressing my First Amendment right to freedom of speech. I never threatened anyone or anything; I just expressed unpopular opinions in ways no one could understand. I now understand that the police and my social supporters tried to get me the help I obviously needed. At the time, I experienced enforced treatment the way Oaks did—I felt held as political prisoner.

When involuntarily committed in California, the original hold lasts 72 hours. If the hospital staff believes someone is incapable of caring for themselves or if they deem the patient a danger they can petition the court to hold the patient another fourteen days. This process continues every fourteen days as needed. The court is held inside the hospital. I vividly remember looking up at the judge and thinking he and the staff were in cahoots. At my competency hearing I stated as if they were magic words:

I want to exercise my right to defect to Cuba. I am being held against my will in an institution that is corrupt because of its dependence on drug companies for free office supplies. They have a conflict of interest. My level of care is determined by my ability to pay. I demand to defect to Cuba! (Author’s memory, 2014).

This made such sense to me. I became genuinely shocked when mandated to stay another fourteen days. Because the justice system has been involved, my mental health episodes and treatment have felt punitive. Police came for me another time, and I physically struggled with them—knowing I would be heading to a psych ward. It became completely intolerable that the police were transporting me because I thought of my symptoms as unpopular political speech. The First Amendment guaranteed my freedom of speech; I believed I had a right to say things
that made people uncomfortable. I believed that my rights were violated, so I felt like a political prisoner. The first institution I stayed in stayed with me. The dismal conditions and the lack of safety reverberated in my manic brain. Cornered by the police, I expressed my fear through being combative. Similarly I refused to comply with the emergency room staff forcing them to inject me with tranquilizers. For me, being treated like a criminal instead of like a person suffering from an illness, only exacerbated the immediate situation. Furthermore, the bad memories of what I considered mistreatment made future compliance more difficult.

Over the years my perspective changed. In theory, I agree people should have the right to refuse treatment. But, I also believe that people should not be forced to suffer because they are experiencing symptoms of mental illness. These complex ethics have led to the patient’s rights movement. I understand the righteous indignation that Oaks and his ilk feel over ill-conceived treatments forced on them; I felt angry too. But “psychiatric survivor” is not part of my identity. In hindsight, I think the hospital helped me get treated and it gave me a reason to stay working towards resilience and reintegration. For years my goal was to stay out of the institution. I agree the system is hugely flawed and many times treatment feels awful but I no longer perceive my institutionalizations as torture. I view that time of my life as a painful interruption that ultimately allowed me to submit to treatment for the good of my family and myself.

The like the rest of the American medical system, the mental health care system is woefully flawed. Most communities do not have walk-in psychiatric clinics and, if they do, they are exorbitantly expensive. I walked into an immediate care facility in Louisville, Kentucky to get refills on a prescription and the bill was $250, no insurance accepted. For most people, finding immediate care is very difficult, with long waiting lists and intricate intake procedures. Sometimes it takes weeks or months to get help. Calling a county help line or finding a doctor
that accepts insurance can mean that people in dire need linger, often getting worse. Even if a person and their social supporters are actively seeking help, often symptoms escalate into an emergency situation. Police, not mental health care personnel, are the first responders. The mentally ill are triaged through emergency rooms or jail cells. This is traumatic for everyone involved.

Patients and social supports must find ways to cope and manage in an imperfect system where the resources are too scarce. There is lack of affordable and efficient programming for people struggling with mental illness. There is simply not enough help. Sometimes the doctors do not have any answers. For many people, their lives become a near endless cycle of altercations with the police and hospital staff. Overburdened psychiatric wards are filled to capacity and on any given day the administration tries to discharge the least acute patients to other environments. For me, that was a transient whorehouse, a dangerous environment that I am certain most citizens of San Francisco would agree inappropriate for mentally ill women to live in. The (mis)treatment of the mentally ill by the justice system and by the hospital staff can, for many reasons become the reason to believe all aspects of medical treatment are oppressive. Therefore the notion of “getting help” itself becomes another barrier to effective treatment or compliance.

The ordeal that I experienced as a young patient at an inpatient facility felt like punishment directly contradicting my identity as an American citizen deserving of civil rights. It became difficult for me to trust that police and doctors had my best interest at heart.

I experienced hospitalization as traumatic. California changed the laws regulating mental institutions since the 1980s. Patients under the age of seventeen are no longer housed with adults. Unfortunately, when I experienced my first hospitalization when I was fifteen that law had yet to
be passed. That hospital operated as a holding tank for ill people. It kept undesirable people off the streets and alive. Treatment only included anti-suicide tactics, a smoke filled room with a television, and some crusty cosmetics. Partially because my parents refused to consent to my taking medication and partially because of the assault; I remember the whole experience as purely negative. That facility did not help me; if anything it compounded my problems. The reoccurring memories of that hospitalization made it much more difficult for me to ask for or accept help when I really needed it. It made me more reluctant to ask for help and it made subsequent hospitalizations more problematic then they needed to be.

All these years later, every once in awhile a smell or a sound takes me back there against my will again. The scenes rewrite and invading my present into a play I am forced to see...the sound is terrifying, yells and screeches horrendous. A tortured woman screams in staccato, “I demand to see my counselor! I demand to see my counselor! I demand to see my counselor!” She is a tiny four-foot tall woman who can’t weight more than eighty pounds. Three big orderlies tackle her to the ground and plunge a needle into her right buttock. Her thin frame struggles against them with surprising vigor and strength while they carry her off to a mystery room, one I imagine has padded walls. From another far off room with a closed door I can hear the screams of a man, or maybe a cat. These noises bubbled up from his poor, sick core and it is clear to me that he is possessed by the devil. The curtain closes and reopens again onto the Thorazine Shufflers taking baby-steps and not really lifting their feet—they, circling the perimeter of the room heads slightly bent eyes downcast. A few are repeating phrases like “Do fries come with that shake? Do fries come with that shake? Do fries come with that shake?” and “Gotta, gotta, gotta go!” “Gotta, gotta, gotta go!” Others are slouched
and slumped down on the floor or on chairs almost passed out because of their various
chemical restraints smelling like sweat and urine. Almost thirty years and it still terrifies
me. Being completely and totally at someone’s mercy makes me suffocate. No, it’s worse,
it’s being at the mercy of a faceless, godless institution locked without any real ability to
reach for a lifeline. I felt like I did not belong there at fifteen. Over forty, I still try to
click my heels like Dorothy to get out of the confinement…I don’t have my ruby slippers
now and I didn’t then (Baugh, 1994).

Even though I have come to terms with the necessity of my multiple institutionalizations, I
continue to experience them as traumatic and stigmatizing. I have occasional flashbacks and I
have been diagnosed with Post Traumatic Stress Disorder (PTSD). It seems counterintuitive that
a hospital can been traumatizing in this way, but for me it has been the site of abuse and a place
where I feel my civil rights have been repeatedly violated.

Because I feared the institution, I felt safer living as a transient on the streets of San
Francisco. When I experienced that episode, I became fixated on freedom and became very
frightened of going to the hospital. I put myself in exceedingly dangerous situations and blended
into the marginalized population. I could not care for myself. I barely slept and I barely ate. I had
no ability to tend to basic hygiene or navigate San Francisco’s social services. I kept moving
around and hiding like a feral animal. Fear of being confined is a strong fear indeed. When I did
get help, I cycled through the system into a living situation that was arguably worse than
sleeping outside. I luckily found a way to get to my social supporters who could help me. If they
had not been there I am certain I would not have ever made it off the streets.

Negotiating the medical system and finding practitioners can be time consuming,
intrusive and complicated. Choosing to comply with medication means that I have spent a great
deal of time and money going to doctors and specialists to obtain my prescriptions. Each time I change to a new doctor or need to get set up with a new office or system I am forced to rehash my medical history from scratch. At the billing rate of several hundred dollars an hour, maybe they could read my chart. Each time this happens, I have to plan to take the entire day off because of the effect of it all. It upsets me to have to talk about chapters of my life that I consider closed simply to get the same medications I already take. It is invasive and I have found that many professional mental health care workers are less than sympathetic.

11/2013.

The desk is cluttered but not too messy. She turns to me and asks me the litany of questions. I answer the same questions read off a checklist that I answer every time I move or change doctors. The revisiting of these questions triggers unpleasant memories and I have learned to schedule these appointments at the end of the day, when I have no other appointments. This woman is specifically methodical in her approach; it is as if she is a mechanic asking me how many miles I have on my car. And then she gets to the question I never know how to answer. “Have you been abused?” I am uncharacteristically silent. “Have you been abused?” She repeats. I just want my prescription. I size her up decide which of the multiple answers. I know it seems like a yes or no question, but for me it’s a very complex. I have not been abused any more or less than anyone else raised under the threat of a wooden spoon. I’ve most been abused mostly by capitalism and the patriarchy. I’ve been abused by the mental health system and stigma. I don’t know. It depends on your definition. And how I tell my story depends on my mood. I tell her “No” because it seems preferable to dragging up stuff from so many years ago (Author’s memory, 2014).
This winter I received a new diagnosis to add to the growing list. Seasonal Affective Disorder (SAD). After long months of gray skies and snow, I sank into a low depression that almost killed me this year. Grateful I taught online, I hid from everyone. I turned into a hermit living in the basement, keeping odd hours feeling as if this project might be the end of me:

2/2014

*When I have down days, down, down days like today I feel how much I have lost. I have been marking every morning and every night with a hand full of pills for years. The swallowing is the most constant thing in my life. I wonder if this hasn’t all been one giant mind-fuck of a mistake—the last fifteen years of swallowing and refilling prescriptions and retelling my story and disclosing my disability status. What about the less obvious ways these chemicals poison me—besides the hundred pound weight gain, the high blood sugar and the failing liver—that is? Memory loss, lack of libido, change in hair texture, heartburn…where do side effects end and middle age begin? On the down days, down, down days I struggle to pull myself out of bed or think anything in the world matters. I lose desire to interact with anyone, even the people I love. I can’t pull up the motivation to care about anything or find any compassion. I unsuccessfully battle pessimism; I can’t control my tone. I don’t recognize the snarky comments that come out of my mouth. Willpower is an ineffective tool against the monster depression that sits on my chest pinning me to my bed in the basement. The world tastes like cardboard. My work is a farce. Why have I spent the last ten years is school? Anxiety cripples me; graduate school left me with debt and probable unemployment. I can’t even recognize the thinker behind my thoughts—where am I? It’s so hard to understand where my cancerous personality begins and where my symptoms begin. I pull into the one car garage and contemplate*
how easy it would be to close the door with my engine running. How fast? Instead I just decide to stay in the basement unit and wait for a doctor’s appointment. Always already waiting.

I thought asking for help was supposed to be the hard part. I do not have a therapeutic relationship with my current doctor. It is more adversarial. But I do not have the luxury of shopping around; it took me months to even get into see a doctor. With Medicare, I take what I can get. No family practitioner will prescribe my medications, so I have to be in the psychiatric system. My interactions with doctors and nurses have been varied. Occasionally, I get a doctor who treats me like a partner in my own health. When that happens I find a way to afford them; when the last one moved practices, I drove over an hour to see her. More often than not, I am stuck with a capable enough pharmacologist whose personality annoys me. It sometimes becomes a barrier to treatment, because I am more apt to cancel or miss appointments if I dread going.

3/2014

When I finally get into see the shrink and tell her that I am depressed she asks me to describe my symptoms to her. I feel like screaming because I am doing the right thing, I am advocating for myself but she is not making this easy. I know what the fuck depression feels like! I tell that I’ve all but abandoned my lover upstairs to live like a creature of the night in my basement. I tell her I’ve gained like six pounds in a week. I tell her I am fairly certain I’ve just wasted ten years of my life in graduate school. She makes me beg. She wants to know if I am certain that it’s not a problem with my bad behavioral habits. She lets me know that everyone is having a hard time this winter. I want to scream that everyone is not paying her to help them and that everyone is not forced to wear pants
with elastic bands because they are so bloated. Surely not everyone is living underground! Then she asks me what I want her to do for me. I manage to not blurt, “Write me a script you cunt!” She literally asks me what medication I want. My mouth drops open and I say, “Speed might be nice, that or an antidepressant?” She smacks her lips and silently charts the fact she has decided to bump up my antidepressant by one half a dose.

My anger is disproportionate to the situation. Suddenly this woman becomes every single person power-tripping in the medical system I have ever met: the nurse who will give me lotion, the people who tied me down, the ones who shot me up, and the ones who failed to protect me. My stomach lurches and a switch flips inside my head. I am obligated and honor bound to navigate these situations out of respect for the people who have invested their time, money, and hearts in me. I find a way to swallow my pride like I have been swallowing pills all these years.

It can be difficult to find any doctor, let alone the right doctor. The doctor-patient relationship should be one of teammates, working toward a common goal of optimum health and independence. Unfortunately, that is not always the case. Doctors are fallible human beings who are not exempt from personality struggles and judgments when it comes to their clients. They all have personal treatment philosophies and have their own interpersonal communication styles. One patient might respond to nurturing compassion and another might respond to a more authoritarian dynamic. Sometimes there is not any help. Sometimes doctors are stumped, sometimes medications do not work, and sometimes individual’s circumstances make treatment unusually difficult. Sometimes there just is no help available.

Finding the right combination of drugs is often a trying process that takes years and requires a commitment to keep trying despite potentially uncomfortable and dangerous side
effects. Medication is exorbitantly expensive and unless there is insurance or some kind of patient assistance program, having help that costs upwards of eight hundred dollars a day is the same thing as having no help. It is only because I was inpatient for three months at a facility that negotiated disability and Social Security paperwork for me that I have been able to comply with my medication. Even with those advantages, there have still been times when through some glitch in my Medicare, I relied on my parent’s ability to pay for my medication rather than stop taking it. I fully understand that to be a product of my privilege.

Luckily, I have had people along the way to help me negotiate these difficult situations. For me having a social supporter on the other end of the phone helped me show up to an appointment I did not want to be at, fill a prescription I did not want to pay for, and drag myself out of the bed on days where I felt like I would rather sleep the day away. My journey would not have been as successful as it has been without the love, guidance and support of a whole team of people. But that support does not make me immune to side effects I have experienced. The system is flawed for several reasons. It is hard to get an appointment to get medication and it is also hard to obtain the medication itself, even with a prescription. Although this is rapidly changing with computers where doctors directly communicate with drug stores, doctors have handed me a paper prescription that had to be delivered to a pharmacy. Unable to care for myself, I have lost the piece of paper before. Also during one manic episode I asked for my medication to be in liquid form, convinced I could not swallow pills. The doctor complied, I made it to the pharmacy, but that pharmacy did not carry the medication in liquid form and could not change the prescription back to pill form. The problem was too complex for me to handle, so I went without anti-psychotic medicine, prolonging mania by weeks. The process of obtaining, retrieving and taking medications is difficult. I also battle with the side effects of the medication.
Long Term Side Effects

I am at least one hundred pounds overweight. I do not claim that I am not partially fault for letting my weight get this out of control, but the fact remains that the majority of the medications I use to control my mental illness also have weight gain as a side effect. When I got to Arizona, I weighed about 120 pounds. I am comfortable at about 150. When I first started gaining weight I did not worry about it. I did not care too much because complying with my medication regimen became paramount rather than worrying about my weight. I felt if I had to pick between being fat or crazy, that I would pick fat.

My weight fluctuated up or down forty pounds for a few years. Then one day, sitting in a doctor’s office the nurse said, “183.” I almost fell over. I am 5’2. I became as heavy as my father, who at almost six feet could handle the weight. I cried to my psychiatrist at the time who gave me a great drug, Topamax. Finally, I felt like a normal person. I ate a small breakfast and spilt one entrée between lunch and dinner. I began swimming religiously. I dropped weight rapidly. I felt great, until my eye-doctor said it caused incredibly high eye-pressure that threatened my eyesight. So I picked fat over blind. So here I am now, middle aged and morbidly obese. But in all honesty, I would rather be fat than crazy.

Beyond the weight there are other side effects:

2/2013.

I awake to the ringing of my phone; it is the shrink’s receptionist telling my voicemail that she’s called off. Called off is Midwestern for called in sick. I wonder a bit about geography of prepositional usage before rolling over and going back to sleep. I bolt up awake remembering I really needed to actually talk to my doctor today. She switched my medications around because my liver enzymes levels came back four times higher than
normal. Going off one mood stabilizer and beginning another frightens me because switching medications can create mania. Now the follow-up appointment to discuss my liver has been canceled. But she’s not there. I am traveling soon to a conference. I call back. The office is closed for lunch. Waiting. By mid-afternoon I finally get a nurse to tell me my test results. She can’t interpret them, but she tells me anyway. The high end of normal is 40, and 500 is liver failure. Two weeks ago I heard the number 190. I wait for the words 75 to form in her mouth; instead she says 270. Liver failure is 500. Does that mean that my liver is more than half failed? Does it mean that if these numbers continue to climb at this rate I will be dead in two months?

I thought fat and medicated was a better choice than crazy and thin. The nurse told me to make an appointment at my regular doctor; I wish I did not have to rely on my campus’ health center for a doctor. My liver is messed up. The results of my liver ultrasound are that I was diagnosed with non-alcoholic steatohepatitis (NASH), a fatty build up in the liver that can cause cirrhosis. It is probably because of my obesity or the medication. My shrink tells me the bad liver enzymes number should come down with a switch off the Depakote and onto lithium. I took Depakote for well over a decade and remained stable. I am concerned about changing onto an unknown substance. This time I pick my liver over my sanity. Normal people do not have to make these choices. The lithium seems to work fine and the enzymes are better under control—everyone seems relieved.

A year later, I am in a health care system that automatically sends the results from the lab work my psychiatrist orders to my general practitioner. It is March 2014, about a year since the liver scare. The receptionist from my general practitioner’s office calls, “Hi, this is the doctor’s office. The doctor would like you to take another blood test for your liver function…it’s a little
too high.” The fact I stopped drinking over a decade ago but might have cirrhosis is an irony not lost on me. I am sure they have not read my previous records and do not know that I am okay. I reorder the records from BGSU and wait some more. In five days they take my blood test again and want me to consult with a gastroenterologist. They make the appointment for me.

June 2, 2014.

ANOTHER new doctor takes his own blood test. I am asleep on my parent’s floor—I am instantly alert when I hear the words, “We are scheduling a biopsy as soon as possible.” My travel plans ruined, a one-way airline ticket already bought for my friend’s daughter to drive with me cross-country must be forfeited. The phone call is urgent. I was sure the numbers came down since the last test because I lost a little over twenty pounds since the last month. I don’t think anything of it, I had a needle-biopsy before on a tumor behind my ear. It didn’t hurt. I never have an appointment to discuss the test…instead I have a number of phone conversations that begin to alert me that this is an actually serious procedure.

I totally underestimate the pain involved with the biopsy. The nurse offered me Xanax for my nerves, and even though I did not feel particularly nervous, I took it. She stabbed my hand to make an intravenous line. I notice the white lights on the ceiling as they are wheeling me into the CAT scan room. I am calm. I lay down and the machine sucks me half inside. I feel a cold-wet swab cleaning under my breast. They write on my with a Sharpie and I think of all the people who accidentally get the wrong organ taken out. My spirits are high, can’t wait to go to the movies with my mom. The doctor warns me there will be a “bee sting.” I have no idea what kind of bee this person has been stung by, because this feels exactly what it is an eight inch hallow needle invading my body.
The poke radiates up to my shoulder and I feel like I am going to puke. Oh my God, I’m stuck in a tube and I am going to puke! I cry out that I am going to barf. I have never had this kind of reaction to medical procedure. I feel sick and release a flood of tears and pent up emotions. Today I am tired of being strong.

I have had other serious side effects that have hurt my physical health. Beyond the weight gain, and the liver problems the medications left me with raised my blood sugar and bad cholesterol. The medications changed my biochemistry making me hypersensitive to the sun and easily dehydrated. This limits my ability to participate in physical and outdoor activities. Over the years, the side effects changed almost every part of my body and mind: my muscles became palsied, my vision blurred, and my feet swelled. I recently wrote:

I want to stop swallowing the pills. I don’t want to show up to talk to one more professional as much as I want to turn over and go back to sleep. When I look at my sagging, flabby body incapable of moving in ways I once took for granted I falter. A doctor tells me that my liver is dying and my eyes are failing and my pancreas is next—I get angry. I show up to the pharmacy and my insurance isn’t working so I use my student loan to pay for the seven hundred dollar fee. Social Security cut me off because I am “employed” as a teaching assistant. I am so frustrated.

In these moments I think of the women who make my life worth living: Alison, Tina Marie, Kathy, Julee, and Yetta. Even though I feel frustrated, sad, angry and dejected—I persevere. My life is not only mine, I am lucky to have people who love me. I reach out to my social supporters. I pick up the phone or jot off an e-mail and ultimately know that I am not alone. I have a renewed commitment to take care of myself, especially when it is hard.
CHAPTER VI: CONCLUSION

In this dissertation, I (re)told my BPD narrative using several different sources including poetry, blogs, and trauma writing/autobiographical fiction. While I hope this final autoethnography is evocative, the project itself has been emotionally and potentially professionally risky for me. Although the academy gives lip-service to diversity, every time I present my research at an academic conference one of my peers expresses their concern that it might negatively impact my future employment opportunities. For example, at the National Women’s Study Conference a professor who works as the head of a gender studies department warned me that I should consider pursuing another research topic to make myself more marketable. Originally, I thought that the professor underestimated her colleagues. After an unsuccessful academic job search, I sometimes doubt my own decision. However, when I told some of the people in my personal life about my story, they have been positively affected. I believe that the risk is ultimately worth it for me. This work is my activism and it is worth it if it can combat stigma and help shed some light on the fact that resilience is possible with the help of a strong social support network. If this work is published and used outside the academy and in the mainstream population, I hope individuals will understand that although BPD can seem like a behavioral symptom it is a disease. I hope it can foster understanding not only of the symptoms and how they are experienced, but some of what was helpful to me that almost any social supporter can provide.

The Process of the Project

I included written correspondence from and to several people who were all my voluntary family members before seeing me in the throes of a major psychotic mood swing. For this
project, I interviewed those same social supporters and asked them to share their experiences from those time periods. This dissertation provides a glimpse into 1) symptoms of BPD from multiple perspectives; 2) homelessness; 3) psychological treatments including mental institutions; 4) feminist awakening; 5) stigma and stigmatized identities; and 6) social support. Because of my desire to help other families, I intend this manuscript to be useful outside the academy. I hope that people affected by BPD and their social supporters might find some comfort in this autoethnography. I hope people facing this diagnosis can read my words and feel through time, love, and treatment (re)integration back into life is a reality.

I know revisiting trauma is never easy, but writing such a personal autoethnography proved to be very difficult. I uncovered feelings that wish remained buried, both negative ones and positive ones. There were so many things I did not tell; I learned much hanging out in a city for a month with nowhere to go. I tried to focus largely on my relationships rather than life on the street. I purposefully chose not to stir up problems in my family because that does not serve me or the project. I wanted to highlight this incredible gift of good health and better friendship. I remember sitting in the dessert longing for another postcard from Yetta. I felt so grateful for when Alison drove to a pay phone to call me, or when I received one of Kathy’s handwritten letters. I appreciated Tina Marie’s understanding when I showed up at her party in pajamas. When Julee stayed home with her newborn, we kept each other company over long-distance calls. These social supporters are not the “support” of my life—they are the people for whom I live to love.

Everyone involved viewed this project as a worthy cause. For each of us it became a personal expression of friendship and, at times, an experience that fused us even closer together. It is also a political action that speaks back to the overwhelming stigma attached to being
mentally ill or being a person willing to stay in relationship to someone with mental illness. Because so many years have passed between my being symptomatic and the interviews my chosen kinship members participated in, the retelling of our collective stories was easier to unpack than if the interviews had been done while emotions still ran high. That being said there were many tears shed, primarily of relief. The women who spoke to me about our past knew my story so far has included an extended period of resilience that we hope will continue. They felt comfortable with sharing their perceptions with me because they knew they were not risking our friendship or my mental health.

Acceptance

My own acceptance of my diagnosis was not instantaneous. Like most BPD patients, treatment and medication worked and then I stopped taking my medication only to relapse. That relapse cost me my job, my home and some, but fortunately not all, of my friends. I am lucky because I realized without my chosen kinship circle I would have remained on a merry-go-round of being not/symptomatic, in/out of institutions, and un/employed. I decided to trust them. The identity that became most important to me was my identity as a person in relationship to my chosen family.

Accepting a diagnosis of a life-long, chronic illness requires a consistent commitment to caring for one’s health. I started accepting other factors of my identity in the two years before my hospitalization in my twenties. I wanted my friends and family to know my authentic self. I did not allow shame, stigma, and secrecy torment me. Instead I opened up my true self to my family and friends. The rhetoric of “silence equals death” influenced my decision to come out. To me those words are equally true for people suffering with mental illness as they are for people suffering from sickness and the effects of homophobia. I saw that the two concepts were
interrelated and mired in stigma. Just as I refused to be silenced about my sexual orientation, I refuse now to be ashamed and silenced about my mental illness.

At some point I started understanding that my own mental health was fragile and that I needed to prioritize it above all. I began saying to myself that my mental health was my baby. For me that meant that I needed to care for it first. I needed to be forgiving. I had to take care of it at all costs and I needed to advocate for it fiercely. This metaphor was extremely helpful and, although I certainly needed to pick myself up quite a few times after making foolish mistakes, once I began to visualize my mental health as my baby I found a way to be more forgiving of myself and ultimately make small steps toward reintegration and resilience. For the first several years after my homelessness, I only had one goal: I did not want to return to the mental institution. After I spent several years learning to stay outside of the world of inpatient treatment, I decided that I could venture out to the local community college with the goal of making some friends. After seven years of small steps, I challenged myself further, with the help of my treatment team and with the advice of my social supporters, to be the first person in my family to attend college.

For me it was imperative that as I moved towards reintegration that I not disguise my mental illness status. Somewhere, already ingrained in me from my personal identity politics, I understood that keeping my mental health status secret would only compound its detrimental effects on my life. Succumbing to stigma would not serve me. I personally cannot be well while living in the closet. For me, telling people that I have BPD is not the same as identifying with the larger mental illness community. I am not ashamed even though I do not that I identify as a victim of the system or participate in the Mad Pride movement.
I have never formed a relationship based on my mental health status and I have never attended a support group based on my diagnosis. I have never utilized the internet to find associates who are dealing with similar issues, nor have I joined any awareness campaigns or participated in any organized activism. My sole form of activism is coming out about my own experiences both in person and in writing. Although I have friends with various mental health diagnoses and they benefit from my knowledge of the system and medications, mental health status has never been the thing that bound us. For me, my support system lies with the people who already knew me. I lean on my chosen family rather than a formal organization.

This is not to say that organizations working towards education, activism, and advocacy are not helpful to many people. NAMI provides support groups and education for patients and their friends and families; other organizations help counter stigma and the medical industry (Icarus Project, No Kidding, Me Too!, Freedom Center). While I personally did not feel that I needed their assistance, I am certain that these agencies help people handle what can be a devastating blow to their identities.

Identity

This project has made me really ferret out my own sense of identity. In many ways I had a complex and pluralistic sense of identity before getting diagnosed with BPD. I already had a firm identity as a liberal, a member of the LBQTQ community, a daughter of two people with physical disabilities, a child worker, and a member of an invisible ethnic group. Adding gravely disabled, mentally ill, or person with BPD was not easy. Considering myself disabled is antithetical to how my parents raised me.

Both of my parents have physical disabilities and their sense of pride does not come from identifying with disability or the disabled community; they are defined by their relationships.
Clearly, my own notion of identification was heavily influenced by their identities. While my parent’s own lack of identification with the disability community might be predicated on their not wanting to be stereotyped or it might be rooted in their own internalized stigmata, I grew up thinking that their bodies worked differently but that those factors ultimately did not matter. Their refusal to identify as disabled has been both a blessing and a curse. A curse because it stopped them from getting the medical care they deserve, a blessing because their lived experiences provided me with two strong role models who never let one facet of their beings dictate how they saw themselves or limit what they could achieve. Their example taught me that I am allowed to (re)invent myself.

This allowed me to shift my identity enough to stay in treatment. My primary goal for years was to stay out of the mental institution. While I do not identify as being a victim of the system, I am certainly in no hurry to re-experience being locked up. Doing this project made me understand why I do not consider myself a victim of the hospital or any other aspect of my life. I believe it is rooted in my upbringing having two disabled parents who refused to identify as such. The word “victim” in my family means a lack of control over fate and a sense of being stuck in the past by circumstances beyond control. Certainly for some people there is power and unity when they express their identity as a victim or a survivor, but I was raised that victims and survivors allowed those factors to dictate their identities and their futures. Therefore a tension exists in my own identity and in my own narrative. I am empowered to write about my life and I think it is important to expose what living with BPD feels like, but I must be careful which labels I accept. For me, there is a balancing act between being in charge of my own story while actively trying to decolonize medical knowledge, and accepting and organizing around labels that make me feel identified by slivers of my life. In other words, I am not the worst thing that ever
happened to me. I am not an illness. I am a person who deserves to be in relationship with people who support me but do not only define me as a victim, survivor, or patient.

Social Support

Proper treatment of mental illness is imperative, but so is a strong social support network. In my life, the quality of my relationships is dependent on my willingness to get treatment; conversely, my willingness to get treatment has historically been dependent on the quality of my relationships. For me the living in an institution and even living with my parents as an adult often felt invasive. Certainly, in the beginning, I found it tiresome to try dozens of combinations of drugs. The side effects of being a human guinea pig did not always feel worth it. I wanted to give up. What got me through those times was the value of my relationships. My social support network gave me the motivation to continue with the medical treatment that felt experimental. My social supporters made me feel as if I deserved to be better and, even if I never worked again, I had something to contribute to the world. I have relied on my social support network to help me feel like a person deserving of love and friendship. For me acceptance of my illness began with understanding that I had a responsibility to be the best person I could be because choosing to be unmedicated created undue hardship for the people I loved most. I felt a strong sense of responsibility to set myself up to have the best mental health that I can have not only to make my social supporters proud of me, but also so I could participate fully in my relationships with them.

For me, my chosen kin have included people who met me from different stages of my life. Kathy is like an extra mother, and has known me since I was a child. Tina Marie and I choose to be in a positive relationship with each other after years of a tumultuous relationship. I have known Alison for almost thirty years. I met Julee and Yetta in my twenties. Each of these
women and each of these relationships have proven strong enough to deal with the triumphs and tribulations my moods. These women have all been available to help me and be honest with me. All have expressed to me, in their own way, in their own communicative forms, that my disease and my stigmatized identity does not disqualify me from being in healthy relationships. The women in this dissertation love and support me unconditionally.

Unconditional love does not mean that these women support me without boundaries. Tina Marie does not withdraw her love from me, but she requires that I am complying with my medication regimen if she is going to interact with me. Kathy certainly loves me unconditionally, but she needs me to respect that she has a very busy schedule. I need to respect her time and understand that I am not her only priority. Julee and Yetta both have busy careers and, although they are both willing to talk to me, sometimes it means that I have to wait several days before I can talk to either of them on the phone. Alison has a child who also has mental and emotional problems and I am not first priority. Part of each of our relationships is predicated on my trying my best to take care of myself while respecting that they all have other obligations.

On the surface this might seem as if this is only my story, but it is our story, co-created in both reality and in this project. While not all of the women in this story have met each other, the majority have and all attempted at times of crisis to create a community of care for and about me. Julee and Alison have been friends for almost eighteen years now, and their friendship blossomed over my incapacitated state. Kathy and Tina Marie obviously already knew each other but have had many lunches discussing strategies about how to help me.

Over the years, the intensity of my social support has varied. For many years Yetta mailed me a postcard almost every week, but when I enrolled in college, the postcards became less frequent. She felt I did not need as many reminders that she cared for me when I became less
isolated. Additionally, our correspondence moved to e-mail. Kathy sent me many hand-written letters over the years, but her contact with me intensified when I started college. As the only woman I knew who had a degree, she offered me encouragement and advice while helping me deal with the culture shock. Alison’s social support has been consistent over the last twenty years. Even when we were separated by time zones, miles, and cultures, we regularly spoke on the phone hours a week. Simple communication through e-mails, phone calls, or postcards helped me feel connected to those people I knew before my psychotic phases or during periods of remission. Those forms of communication did not need to be about anything relative to my illness. A simple “hello” was often enough to remind me that there was a time before BPD and that there would be a time when I was not so incapacitated. Anticipating a postcard from Yetta was sometimes the only thing I had to look forward to, but having her correspondence regularly delivered linked me to positive memories and to a healthy relationship with someone I loved and respected.

My social support network reflected back to me a positive image of myself at times when I felt very low. I relied on them to help me recognize when I was symptomatic. My chosen kinship circle knows me much better than the doctors and therapists that infrequently see me. Because of this, my circle is in many ways better equipped to alert me of mood swings. My chosen kinship circle is on the front line of helping me monitor my moods. They help me know when to get more medical help and when I need to use other coping skills. I have grown much stronger over the years, but I still lean on this dynamic group of women when I am not feeling well or my medications do seem to be working. It is times like these that I am lucky to be extroverted enough to reach out to any one of my large chosen kinship circle. For me, one of my methods for dealing with stress is to reach out over the phone. Tina Marie will tell me to go to
sleep or remind me what worked last time I had a specific symptom. Alison will remind me of a doctor’s appointment or remind me that I always cry when I am tired. Yetta regularly recommends that I go for a walk with my dog, while Kathy reminds me that graduate school is worth it. Even though my life circumstances are no longer dire, this group of social supporters still act as a team of voluntary kin that have helped me with my physical, mental and academic successes.

I truly believe my social support relationships served to help heal me. I define myself as in relationship with others. Their kind words allowed me to both comply with medical treatment and resist the limitations doctors predicted I would deal with indefinitely. I also want loved ones to know that small gestures, such as a phone call or a postcard, really can make a difference in a mentally ill person’s life. I believe my social support relationships motivated me to not only survive but to thrive.

I used this opportunity to (re)conceptualize and contest the notion that patriarchal families comprised of blood and legal relatives are always paramount in a person’s life as social support. The social support I received from my chosen family was in many ways more important and therapeutic than support given by my biolegal family. I am uncertain that I would be as resilient as I am without the support of my chosen family. This research revealed effective social support need not be from family that is biologically or legally related. Much of the social support research relies on a more traditional definition of family. Blood relatives of people with mental illnesses write most of the illness narratives. The vast majority of literature and hospital policies are written with a traditional patriarchal family in mind. My work highlights the fact that people can become family based on a relational model of identity and stands in opposition of the idea
that traditional patriarchal notions are the only versions of family that should be considered valid by academia, or the medical industry and society.

**Reclaimed Identity**

Part of the purpose of this dissertation is to articulate BPD symptoms in plain language to help people understand the medicalized language used to describe symptoms. Using my own words and the experiences of my social supporters, I believe that the action of writing and recording our own experiences in our language helped us both heal and reclaim our experiences from the colonization of medicalized language. When our lives are recorded in someone else’s jargon, the experience is objectifying. Retelling our (however imperfect) memories is a coping mechanism and an activist action that works to empower us to move from being an object to becoming a subject. Because we did this as individuals and as a collective, the freeing affect rippled through my community of social supporters. This project served as a space for us to heal and reflect as a social circle. It offered me a chance to be reflexive. This is not to say that this project was easy or that the process was always joyous. Retelling and reliving some of the more harrowing experiences created moments and days of discomfort, but ultimately we all thought that it was personally beneficial and all wanted other people to benefit from our lives.

It has served as a way for us to speak back to medical colonization and to reclaim our stigmatized identities. I wrote this project with a non-academic audience in mind, but I am interested in publishing a more theoretically rich excerpt as academic journal articles. This project is filled with instances where the medical system acted as governmental power and doctors worked as agents of the state. That treatment temporarily robbed me of agency and autonomy, leaving long lasting emotional scars. This work serves as a way to articulate resistance against the medical colonization of my identity. Ignagni and Church (2011) state,
“Through storytelling, disabled people can reclaim our experiences from medical hegemony” (p. 628). This autoethnography pushes back at the doctors, mental health professionals, and the disease itself. For example, there is a problem with the way a patient’s voice is recorded and talked about. Doctors, social workers, or therapists translate words into their own jargon for medical files and their own industry-specific billing codes. The institution and disease at times stifled my sense of autonomy, individuality, and free will. This process provided me a compelling and unique opportunity to struggle with and record my identity (re)formations after many years of dealing with BPD. Common symptoms of BPD include flat affect, grandiose behavior, auditory hallucinations, and hypersexual behavior. These words fail to convey the intensity of the symptoms that the patient is coping with and rather than helping her support systems to understand the illness, these words can also create confusion. My autoethnography counters ambiguous medical symptoms with lived experienced creating wider understanding and, I hope, compassion where it is sorely needed.

I specifically wrote this in an accessible way, limiting my use of academic words and jargon, because use of medical and academic jargon tends to create a gulf between institutions and the people who are trying to cope with the unfathomable. As Ardra L. Cole and J. Gary Knowles (2011) point out, “The language that the academy and all that it symbolized fell short in its ability to capture and communicate the complexity of human experience in all its diversity” (p. 57).

Using qualitative methodology to help demystify the symptoms of BPD and to creating a text readable by people who are not in the medical or academic industries is part of an activist project. Although there are many people who talk for and about the mentally ill, and a large body of mental illness narratives, I have used my position inside the academy to reclaim and
decolonize medical knowledge. I used a variety of qualitative methods and quilt them together to create a retelling of my story. Ideally, a large enough variety of data are used that the reader will find something that is both appealing to them in terms of style and evocative enough so that they can sympathize with people who are experiencing the symptoms. Because this work will be used inside the academy, this might eventually help university faculty and staff recognize and respond to the symptoms of BPD, which for many people appear during traditional college age students.

**Limitations**

Much of my story is typical. The psychotic symptoms of BPD I experienced were extreme but within the normal diagnostic criteria. I hallucinated, both visually and auditorially. I suffered from delusional thoughts. At times I exhibited hypersexual behavior and was hyper-verbal. I became lost—physically, spiritually and mentally. I struggled with accepting my diagnosis, and I struggled with being hospitalized many times. Over the years, doctors prescribed me dozens of medications in dozens of combinations. I experienced multiple short and long term side effects. Because hospitalization is expensive and BPD created long term unemployment, I remain poverty stricken.

While I am not of the “I am grateful for BPD” camp, I do understand that without it I never would have finished college. I also understand that I never would have repaired my relationship with my family of origin. There are many people that I would never have met and I certainly would not have my animal companion. I also would not be one hundred pounds overweight. I would not have needed a liver biopsy. My hair would not be thinning. I would not have nearly constant heartburn and I certainly would not have spent more than a year inside mental institutions, where some brutal things happened to me. While I am not grateful for BPD *per se*, I am grateful for the relationships it strengthened, and the wisdom I gained at a fairly
I certainly recognize my privilege. Several factors helped me be able to get as “better” as I have. Luckily, a social worker negotiated the government forms for me and I qualified for Social Security/Disability and Medicare. She filled out the endless forms that have helped me afford my treatment and medication while giving me a small stipend to live on. My parents allowed me to live with them and they happened to have an ideal location where I could heal and work in the sunshine. I did not have to worry about becoming homeless again, or how to pay for my basic needs. I had the luxury to take my recovery slowly. The doctors found medicine that works well most of the time. I do not have a learning disability, and once I healed and responded to medication I went to college. I learned how to negotiate the medical system, fill out endless forms, comply with medication, and manage my own moods.

Lastly, and most importantly, I found strength and support in my interactions with my social supporters and voluntary kinship members. These people have helped me by showing me that I matter to them in many ways. They have communicated support in letters, phone calls, and visits. They believe that I have the capacity to follow my dreams and have always encouraged me. Not everyone is as lucky. I fully recognize that many mentally ill people are not capable of maintaining healthy beneficial relationships and many non-ill people do not value relationships the way we do. So, my story can be read as a case study for resilience and social support with the understanding that it is as unique as it is typical.
REFERENCES


