

“PROZAC SAVED MY LIFE” VS. “PROZAC RUINED MY LIFE”:
INVESTIGATING THE ADOPTION, CONSTITUTION AND MAINTENANCE OF
DISTINCT INTERPRETATIONS ASSOCIATED WITH DEPRESSION
AND ITS MEDICAL TREATMENT

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Abstract

Beyond the brute pain of depression, individuals enduring this problem also commonly face a more subtle, added burden related to both societal and personal confusion about the basic nature of depression and its appropriate resolution. This dissertation study seeks to better understand diverging interpretations or narratives at play in the experiences of those facing depression by examining the language of actual survivors. In particular, the complexity of individuals' decisions regarding possible medication use is investigated. Through fourteen in-depth interviews with survivors reflecting diverse (both positive and negative) psychiatric experiences, three specific questions are explored: 1) How exactly do individuals come to *adopt* a particular narrative of depression and its treatment? 2) What are the most meaningful differences between varied narratives that arise? 3) After being adopted, how do particular narratives appear to be *maintained* over time? The first section of the report describes basic patterns across survivor accounts—first, in reviewing individual synopses of each narrative (Ch. 3), and second, in documenting key interpretive themes across all interviews (Ch. 4-5). The second section moves into more direct analyses of these narratives, taking up explicitly the three empirical questions in turn. Chapter 6 identifies multiple resources that individuals draw upon in the adoption of distinct treatment narratives (e.g., intense levels of confusion and urgency; comments from friends/family; drug effects). Ensuing moments are proposed as powerfully cementing and galvanizing specific interpretations of both depression and associated medication use. Chapter 7 explores several issues underlying some of the most meaningful differences between narratives (how participants interpret the role of biology, agency, medication and surrounding relationships). In Chapter 8, strategies that appear to be associated with the maintenance of particular treatment narratives are examined. Among other things, analysis of patterns across accounts points to a striking role for diverging narratives in the unfolding treatment experiences of those facing depression. Since such individuals typically have little awareness that their treatment experience can be interpreted in fundamentally different ways—nor that these distinctions may have substantial implications for how their experience ultimately unfolds—a more thoughtful and broad-based deliberation involving both professionals and those facing depression is subsequently proposed.

Dedicated to Elaine Dubois and Mary E. P. Hess

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Chapter 1

Introduction

I have had . . . beatings to the point of unconsciousness--ripped, broken, arms taken out of the socket and that compares *nothing* . . . doesn't even *begin* to be the pain that became every day, just right here (*pointing to chest*)--this thing that wouldn't come off—that made it hard to breathe . . . like, I would rather have every day, just hours and hours of people beating the shit out of me than to [have] been where I was just inside. It *hurt* that bad. . . . there were times I thought it *would* kill me—all on its own, that I wouldn't have to do anything. (6)

As its victims can attest, the experience of depression can be agonizing to a terrifying degree. The woman cited above compares her recent depression encounters with earlier vicious child abuse.

Indicators suggest that in a given year, serious depression affects 14.8 million Americans ages 18 and older--approximately 6.7 percent of the U.S. adult population (Kessler, 2005). According to a 2004 World Health Organization report, depression is the “leading cause of disability in the U.S. for ages 15-44” (see National Institute of Mental Health, 2009). On an international level, Hyman and colleagues (2006), report that depression is now the fourth highest source of the “global disease burden” and the “leading cause of disability worldwide.” It was the assault of depression on one of my own dear ones that motivated my attention to the questions explored below.

In 2002, lymphoma took the life of my 22-year-old brother. Sam looked forward to a promising career in filmmaking and was well-loved by everyone who knew him—most especially his high school sweetheart and then fiancé, Mary¹. Soon after his passing, Mary fell into severe emotional challenges that included depression. At the time, as a new graduate student in psychology at the University of Illinois, I joined others in actively encouraging her to get help and seek treatment from psychologists and doctors. Over the next three years, I watched as Mary, in spite of both therapeutic and medical help, faced deepening pain and distance from us all.

During this period, I began to notice how difficult it was to tell what was really going on. Her eating disorder and depression continued, and I started to wonder what impact her treatment was having—particularly, the combinations of anti-depressant and anti-anxiety medications being tried. As I learned some of the latest insights on the brain, I started raising questions with family members on trips home to Utah: *Did the medications seem to be helping? How were the side-effects affecting the situation?* Once, I attempted to engage some of her treatment providers at

¹ Mary, who has become in every important sense my sister, has given her permission for her name and this story to be shared.

an inpatient facility around the same questions. In literally every case, I was most struck by their response to questions. When I wasn't ignored, individuals either minimized the concerns I raised or acted defensively.

Back in Illinois, I met with Wendy Heller, a neuroscientist who would eventually become my dissertation chair. After hearing my expressions of frustration, she emphasized that certain mindsets or ways of thinking carried great power and that, from her own observations and experience, they were not always readily open to serious questioning. She told me to be patient and encouraged me to keep exploring.

It was in the weeks that followed that I came across a notice for a conference in Chicago sponsored by the *International Center for the Study of Psychiatry and Psychology (ICSPP)*. I knew this organization was infamous for its persistent criticism of traditional medical treatment for emotional problems. The psychiatrist Peter Breggin, a long-time critic within his field, would be presenting at the conference. In spite of what I had heard, I decided I needed to hear these concerns for myself—dropping my plans that weekend to get in the car and head north. My response to the conference was mixed. Although it was refreshing to hear others directly examining the kinds of questions I had been wondering about, very often their rhetoric reflected sharp attacks on entire institutions and challenges to the motives of those involved in treatment. At the same as I was introduced to credible research from people such as David Cohen and Jeffrey Lacasse, I found myself distancing myself from many of the others for their fierce *anti-psychiatry* rhetoric.

From this vantage point, I decided I wanted to try to deliberately position myself in the middle of the conversation so I could try to listen and better understand both sides. I was struck in an uncomfortable way at how certain and absolute both proponents and critics of psychiatric treatment seemed to be—both citing scientific evidence and deconstructing the “faulty studies” on the other side. How could each side be so convinced that they were right? What lead individuals to such polarized views—and why was there such emotional intensity and anger associated with these questions?

I decided I would have the best chance of finding some answers if I went to the real *experts*—those with first-person, front-line experience of depression itself. It had been the experience of my sister that had raised so many questions for me in the first place. While curious about depression accounts generally, my primary interest came to be exploring what underlay the polarized views about *treating depression*—especially medical interventions, given the particular research debate on that issue. In my continued observations of Mary's situation, I began to notice a significant confusion in our family when treatments failed to resolve the problem. While the

pain of severe emotional problems is frightening enough for individuals and families, I wondered if the confusion and even panic regarding *what to do?* (linked to the surrounding research/professional confusion) wasn't, at times, even harder to bear. Once again, I asked myself, where do the competing treatment views originate? And what does the debate and controversy mean for the experience of those individuals actually facing depression?

In what follows, these questions will be explored across in-depth accounts of multiple depression survivors.

Stepping Back: Where Do Diverging Treatment Views Originate?

From the outset, I realized that one of the most common explanations for diverging views regarding medical treatment for depression emphasized physiological differences—"drugs work for some, and not for others . . . it just depends on your biology." Clearly, as a logical explanation for variation in treatment outcome, biological difference may also play a role in diverse opinions on medical treatment for depression.

One problem I saw with this explanation, however, is that other conditions also involving physiological variability *do not* reflect the same degree of public and professional discord. While biological differences also lead to variation in cancer treatment, for example, there is no comparable "anti-oncology" consumer movement. Cancer survivor groups? Yes. Cancer-treatment survivor groups? No. What leads citizens and consumer groups involved in mental health to such strong feelings in relation to treatment? While a meaningful role for physiological differences seems obvious, this factor alone does not seem to explain clashing views about treatment entirely.

In light of this, my own early hunch was that there had to be something significant *beyond* physiological differences that contributed to the public and professional confusion. At the Chicago *ICSPP* conference mentioned earlier, the influence of pharmaceutical companies on research and practice was a frequent topic of discussion. Indeed, recent years have seen big business interests in health care and pharmaceutical companies come under increasing scrutiny from watch-dog groups and researchers alike, including sociological examinations of associated power structures (McCubbin & Cohen, 1996; Cohen, McCubbin, Collin, & Perodeau, 2001; Williams, Birke & Bendelow, 2003).

While concerns with both pharmaceutical companies and psychiatry itself made sense overall, as noted previously, I was hesitant and uncomfortable with some of the rhetoric. While many of the arguments were fair and measured, in other instances these institutions were portrayed by critics as something of an "evil empire" deliberately causing pain and ignoring the

well-being of those facing depression. For instance, the *Citizen's Commission on Human Rights* has commissioned DVDs that include “Psychiatry's Prescription for Violence” and “Psychiatry: An Industry of Death.” In a recent one entitled “Making a Killing: The Untold Story of Psychotropic Drugging,” the *American Psychological Association's DSM (Diagnostic and Statistical Manual)* is essentially claimed to reflect “made-up” categories created to convince people they need medication.

From my own personal experience with those involved in medical treatment for depression, I had observed what is perhaps obvious—doctors with sincere interest in their patients' well-being. Similarly, I came to believe that most of those involved in developing and marketing drugs also maintained an authentic desire to help others. In short, accusations of sinister motivations permeating both pharmaceutical and medical institutions and driving all their actions did not “add up” for me. Similar to physiological differences, then, the influence of institutional profits, while also clearly relevant, did not seem to explain all the polarization and confusion. In my mind, a more comprehensive and satisfactory explanation for the confusion regarding medical treatment for depression would need to account for generally beneficent motivations among its primary stakeholders. Rather than simply accuse one side of being malevolent or completely “biased,” the question became how are we to understand individuals equally interested in depression recovery holding such intensely and deeply disparate (even mutually exclusive) views on what to do?

At this point, I began to discern the contours of some other possibilities—namely, that the polarization might have something to do with divergent interpretative frameworks or narratives.² In my undergraduate work at Brigham Young University, an early mentor, Brent Slife, had made me aware of subtle implications ensuing from distinct assumptions or interpretations operating throughout the social sciences (Slife & Williams, 1996). In my first year at Illinois, Julian Rappaport taught me how narratives could be seen as “community resources” upon which individual citizens drew in the creation of their own personal stories (Rappaport, 1998). Could diverging interpretive frameworks for treatment have something to do with the competing professional/research certainties and associated confusion? Whether for doctors, scientists or distressed individuals themselves, what role did one's interpretive framework or overall narrative play in the conclusions eventually reached? If competing narratives were, in fact, significant

² While there are meaningful nuances in formal definitions between words like interpretive framework and narratives (see discussion below), throughout the manuscript, these words are essentially used interchangeably: interpreting, narrating, perceiving, receiving, approaching, responding, making sense, understanding (as well as their noun forms: interpretation, narrative/narrative, perspective, way of thinking, perspective, view, approach, response, understanding).

overall—how especially did those facing depression navigate and negotiate differences in their own situation and arrive at a particular view?

Preliminary curiosity: Why hasn't science settled these issues already? As I found in my own preliminary conversations with people, many individuals had come to believe that science had already settled on answers to questions about treatment and etiology in a conclusive and definitive way. If this was the case, then the study I was planning would seem to be a distraction from the more important work of simply spreading the established “truth” about depression and its treatment.

My chance to spend six years as a graduate student in one of the leading psychology departments in the nation, however, left me with no illusions on this issue. In particular, I was influenced by my interactions with three neuroscientists, Greg Miller, Janice Juraska and Wendy Heller. Each made admissions about ongoing, fundamental questions still contested in their fields. More than simply technical details or nuances of interpreting a particular physiological state, they highlighted fundamental distinctions in underlying interpretations and portrayals, such as how reports on the physiology of emotion itself were being framed (e.g., Miller, 1996).

These interactions confirmed my own observations of clashes in the larger discourse that science had not, in fact, settled many fundamental questions in this area. The more I explored the research on depression and its treatment, in particular, I found the conflict striking. In addition to debates on the framing of biological contributions (Valenstein, 1998; Joseph, 2000; Miller & Keller, 2000; Slife, Burchfield, & Hedges 2002; Leo & Cohen, 2003), the general effectiveness of psychotropic medication had also become deeply contested (e.g. Kirsch & Sapirstein, 1998; Kirsch, Moore, Scoboria & Nicholls, 2002; Cohen, 2003; Breggin & Cohen, 1999; Moses & Kirk, 2005). Even on the tangible question of whether medication increased or decreased suicide risk associated with depression, researchers remained in disagreement (Healy & Whitaker, 2003; Harris, 2003; Gibbons et al., 2006).

It was thought-provoking to see scientists who presumably applied objective, fair methods coming to such widely divergent conclusions. While celebrities, businesses and social pundits would be expected to disagree intensely, that it was happening so often among scientists initially puzzled me. Laying aside the issue of *whether or not science* had reached conclusive answers, my curiosity came to center on *why they had not?* With so much collective research attention, how and why did so much confusion remain? Answers to this broader question affected how I eventually designed my own specific study of depression narratives.

Two studies, in particular, gave me insight on this larger issue—each a major and influential randomized controlled trial (RCT) of depression treatment published in the last ten

years. In spite of being seen as a “gold-standard” for establishing valid conclusions in psychology, fundamental problems were discovered with each study that reaffirmed some of my hunches about the ongoing contest between researchers.

In 1997, Emslie and colleagues published a study that was received as the first evidence that antidepressants work for children—making a dramatic and almost immediate impact in justifying expanding these prescriptions for children. After parents began to report adverse effects such as suicides to the FDA, however, the data were reanalyzed. This led to the discovery that although five different measures were made in the study to compare medicine and placebo (three self-report--parent and child--scales and two clinician ratings), Emslie’s original conclusions were largely drawn from clinician ratings, which were notably different from parent/child ratings, but judged to be more reliable. A reanalysis giving equal weight across measures reached more guarded conclusions (see Safer, 2006).

In another recent study published in the *Journal of the American Medical Association*, the “Treatment Adolescent Depression Study” (TADS) (2004) compared Prozac and Cognitive-Behavioral Therapy (CBT) separately and with a combination of Prozac/CBT in treatment for depression. Among other things, the well-publicized study concluded that “medical management of Major Depressive Disorder with fluoxetine, including careful monitoring for adverse events, should be made widely available, not discouraged” (p. 819). Once again, however, in the wake of parental complaints to the FDA, another team of researchers reviewed *the same research findings* and by interpreting the measures differently, reached different conclusions. The second team noted that in the study’s primary outcome measure—change in Children’s Depression Rating Scale-Revised Total score--Prozac alone resulted in minimal benefit over placebo, with placebo effects 86% of Prozac (change of 19.4 compared to 22.6 points). At the same time, other measures showed Prozac causing significantly higher rates of harm-related events—suicidal ideation, physiological effects (diarrhea, insomnia, sedation)--compared with placebo or CBT alone, as well as higher rates of psychiatric adverse effects (irritability, mania, and fatigue). Based on this re-analysis, one research team recommended that psychotherapy treatment, rather than drugs, be offered as the first line treatment for adolescents (Antonuccio & Burns, 2004).

On one level, of course, it is unsurprising that interpretations differ between different researchers. Ongoing testing and the differential interpretation of findings is a well-acknowledged basis upon which the community of researchers seeks to advance theory. That findings *within the same RCT* allowed such diverging interpretations and conclusions, however, raises some important issues—especially in light of the ensuing public response.

The initial report of the 1997 Emslie study was uncritically received by the media and general public as exciting evidence that “Prozac worked for kids.” According to subsequent indicators, prescriptions of anti-depressants to children shot up in the years that followed. It was only years later, after reports of problems to the FDA that the data were reanalyzed as described above. In light of later implications, the uncritical embrace of one RCT as presumably “settling” a question is an evident problem in the way science is viewed. While the high level of control may offer certain benefits as one method of studying treatment outcomes, this control obviously does not eliminate the critical role of researcher interpretation. At a minimum, this suggests more cautious portrayals of conclusions from any one study or type of studies (see Jacobs, 1999). While this problem is certainly most pronounced in media portrayals of research, scholarly meta-statements across the RCT literature can also be benefited by simultaneous considerations of the quality and nature of the evidence itself.

While RCTs remain one helpful way of gaining insight into these kinds of questions, their limitations thus suggest a need for supplementation with additional methodologies. Beyond simply more methodological controls against bias-intrusions, I became intrigued by another methodology operating from an entirely different basis.

Studying Interpretation: A Case for Qualitative Methods

Over recent decades, qualitative researchers have begun to illustrate the potential of methods that investigate language and interpretation associated with depression and other severe emotional problems in a comprehensive, direct way via interviews, ethnography, archival analysis, and so on (e.g., Capps & Ochs, 1995; Drew, 1998; Gammell, 2004; Bilic & Georgaca, 2007). While still caring about objectivity in the basic sense of fairness, qualitative methods seemed distinct in two important ways:

First, although striving for systematic and rigorous design similar to more conventional studies, qualitative research seemed to more readily acknowledge the bias and standpoint of the researcher as a meaningful starting point for the study to be openly acknowledged. Rather than only seek to minimize or control a researcher’s own bias, a-priori interpretations were acknowledged so that their “play” in the study could be transparently observed by readers (Denzin & Lincoln, 2000)³.

³ This explains why I have shared so much of my own narrative to this point. While the following chapters explore challenging questions about medical treatment that reflect personal concerns regarding its role in recovery, it is important also to acknowledge openly that I am not “anti-medication” nor am I opposed to biomedical explanation, per se. Medical treatment saved the life of another brother who faced cancer—and I know there is value in it when used appropriately.

Second, more importantly, qualitative researchers saw diverging interpretation as a legitimate object of study in itself—including competing views and narratives of actual citizens facing depression. Ten years ago, David Karp (1997), a sociologist at Boston College who has pioneered interviewing research for depression, commented that “the essential problem with nearly all studies of depression is that we hear the voices of a battalion of mental health experts . . . and never the voices of depressed people themselves.” In his review of the *Journal of Affective Disorders* over a period of several years, he noted that in twelve volumes of this journal, he could not find *one word* spoken by a person who lives with depression. He concluded that “research about a feeling disorder that does not get at people’s feelings seems, to put it kindly, incomplete” (p. 12). As further detailed below, until recently, first-person accounts of those facing severe emotional problems have received little systematic attention within psychology. While autobiographies have been a historical outlet for these narratives, they have generally been seen as having little relevance to scientific knowledge and subsequently received little rigorous examination.

This study aims to contribute to the growing literature on public interpretations of depression—specifically, to better understand conflicting evaluations of its treatment. Going beyond autobiographical studies, this project joins Karp and others in examining themes across first-person accounts of the experience of depression and its treatment. Participants with diverse treatment experiences were recruited with the help of advocacy organizations on contrasting sides of the debate (*National Alliance of the Mentally Ill* and *MindFreedom Support Coalition International*). By comparing participant narratives, insight was sought on how people came to adopt such contrasting interpretations and evaluations of depression and its treatment.

Key terms: Interpretation and narrative. Before going further, it is important to say something more about how I understand my primary objects of study, “interpretation” and “narrative.” As reflected in narrative theory (Bruner, 1997; De Rivera & Sarbin, 1998), the impulse to interpret or “make sense” of one’s life may be seen as inherent to humans—universal to one degree or another. Rather than approaching interpretation as a static snapshot or mere “perception,” however, human beings are here understood to be continually interpreting or making sense of their experience, packaging and ordering thoughts as they navigate surrounding circumstances. Naturally, these interpretive choices and adjustments take place in the flow of previous interpretations and predispose those that follow. Furthermore, individual interpretations do not exist in isolation—but instead, link to other interpretations in web-like frameworks such as a story or *narrative*.

In the context of illness, Kleinman (1988) defines narrative as a “story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering” (p. 49). While coming in diverse forms, all narratives are characterized by a temporal ordering of events associated with change of some kind (Hydén, 1997). As what one proposed as a new “root metaphor” for psychology as a whole (Sarbin, 1986), narratives have also been argued to reflect “the preferred mode for understanding how human intentions and desires get translated into human actions and how those actions play out over time” (McAdams, 1999, p. 480).

Like the individual interpretations that make it up, narrative or “narrating” may also be understood as a kind of holistic interpretive *practice* that is lived and continuously accomplished moment-by-moment (T. Schwandt, personal communication, 2006). More than a “subjective overlay” or “perception” of experience, narratives thus have an existential quality to them. In addition to *telling* stories, for instance, individuals are understood to be *living them out* in tangible ways (Fay, 1996, p. 178). As Kleinman (1988) adds, “the personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering” (p. 49).

To further preface the study, the particular relationship between interpretation/narrative and other factors (physiology, environment, relationships) is also important to address. More than simply “interacting” with these conditions, both interpretation and narrative are proposed here to “transact” with physiology and context. In 1984, Altman and Rogoff proposed a “transactional model” that called for “the study of the changing relations among psychological and environmental aspects of holistic entities”—the unit of analysis being “holistic entities such as events . . . not composed of separate elements but a confluence of inseparable factors that depend on one another for their very definition and meaning” (p. 24). A transactional account of the “event of depression,” then, would attend to logically distinct elements—body, context, interpretation, time—as inseparable aspects of the same holistic entity. From this perspective, a depressed person is understood to be “always already” embodied (“biological aspects”), embedded in an external physical and social context (“contextual aspects”) and continually acting and making sense of the experience through time (“temporal” and “interpretive/narrative aspects”).

This becomes an important theoretical backdrop for how interpretations and narratives are approached in what follows—namely, as intimately connected to a complex mixture of physiological and ecological context. For instance, since interpretation is an embodied act, its study cannot be neatly abstracted from attention to known variation in physical phenomena.

Moreover without a particular context and community in which an embodied interpreter resides, there would be no interpretations in the first place. On the flip side, of course, it might be similarly argued that without the ongoing, evolving interpretations of human agents themselves, particular contexts, communities and physiological experiences might have little meaning at all.

In all these ways, this study attempts to investigate depression as a holistic event, constituted by biological and contextual aspects interpreted as they develop and change over time. Specifically, I attempt to examine the complex ways that human interpreters navigate through the host of these objectively diverse experiences via the lens of interpretations themselves. In doing so, rather than minimize external factors, I seek to better understand the interpretive backdrop against which they become significant.

Precedent in the Study of Depression Interpretations: A Review of the Literature

Interpretation associated with serious emotional problems has often been minimized in traditional psychopathology investigations--relegated to the realm of *subjectivity* that if to be studied, is to be done so only with tight methodological control. Indeed, where human interpretation has been studied directly, it has typically happened through cognitive studies or surveys with high levels of control. While interesting insights have been gained through these approaches, there are a variety of other ways to approach the study of interpretation.

On a general level, the broader discourse of depression has been explored in interesting ways. For instance, large scale marketing studies examine the dissemination of dominant interpretations in the form of pharmaceutical company advertisements (Montagne, 2001; Cline & Young, 2004). Large-scale survey studies have attempted to document community/public attitudes towards medical treatment for depression (e.g., McLeod, Pescosolido & Takeuchi 2004). Historical researchers have also examined the development of a variety of associated constructs in public discourse over time (see Healy, 1997 on psychopharmacology; Rousseau, 2000 on depression; Baldwin, Williams & Houts, 2004 on PTSD).

Beyond these examinations of general interpretation in public and corporate spheres, other studies have moved to investigate interpretations of those more immediately involved with depression itself—including doctors and mental health professionals; friends, family and caregivers; and those individuals facing depression. When attention is paid to the voices of individuals facing depression, it has typically been through survey research--dating back to the “Custodial Mental Illness Ideology Scale” (Gilbert & Levinson, 1956) to the more recent “Reasons for Depression Questionnaire” (Addis et al, 1995) and “Perception of Depressive Illness Questionnaire” (Manber, et al., 2003).

Where qualitative research has been applied to depression in the past within psychology, it has been largely focused on case studies as a way to gain insight into therapeutic dynamics. When attention is paid to the *patient's* views in this way, it has therefore often been conceptualized as an exploration of underlying psychopathological irrationality. Cognitive researchers, for instance, have investigated disordered and irrational thought patterns underlying psychological problems in order to address these patterns in psychotherapy. The psychiatric compliance literature, as well, attempts to understand the faulty logic of those who resist medication (Kirk, 2005; see Navon & Ozer, 2003). In a recent review of medical compliance literature, for instance, Moses and Kirk (2005) note a consistent ambivalence towards medication in youth, with large numbers embracing medication and equal numbers resisting it. Whereas some are extremely positive about its impact, others express concern about harmful side effects. Even those believing in positive effects often show other concerns about control and identity.

The historical exception to this pathology-weighted study of patient perceptions and interpretations has been the rich autobiographical literature on severe emotional problems, including depression, noted earlier. This literature is enormous, with one bibliography of mental illness autobiographies listing literally hundreds of titles (Hornstein, 2003). Specific to depression, one search of Amazon turned up 17 biographical works in the year 2008 alone:

- *Shoot the Damn Dog: A Memoir of Depression*, Sally Brampton
- *The Devil within: A Memoir of Depression*, Stephanie Merritt
- *Out of Focus...Again: A Journey from Depression to Recovery Through Courage, Love and Commitment*, Sandy MacDonald and Ann Kochenberger
- *Hide and Seek: How I Laughed at Depression, Conquered My Fears and Found Happiness*, Wendy Aron
- *Blue Genes: A Memoir of Loss and Survival*, Christopher Lukas
- *Gray and Red: An Internal Struggle of Depression and Self-Injury*, K. A. Proveaux
- *My Life...Welcome to It: Living with Bi-Polar Disorder (also Known as Manic Depression)*, Ivy Berry
- *Moving On From Depression*, A. Brocklesby
- *Surviving Depression: My Agonizing Struggle with Sanity*, Robert L. Hamlett
- *My Sisters Three: A Tiny Glimpse of Abuse and Neglect Viewed Through the Eyes of Someone Now Living with Major Depression*, Dearis
- *Depression Saved My Life*, Brian Michael Joyce
- *Madness: A Bipolar Life*, Marya Hornbacher
- *The Other Great Depression: How I'm Overcoming, on a Daily Basis, at Least a Million Addictions and Dysfunctions and Finding a Spiritual (Sometimes) Life*, Richard Lewis
- *Something In My Childhood: A Personal Journey with Depression*, C. Gorrie and A. C. McKessock
- *Why I Jumped: A Dramatic Story of Finding Hope Beyond Depression*, Tina Zahn and Wanda Dyson
- *Silently Suffering with Anxiety, Depression, and Agoraphobia*, Julie Auriana
- *Forever the Fat Kid: How I Survived Dysfunction, Depression and Life in the Theater*, Michael Boyd

Unfortunately, this literature continues to be largely dismissed by psychologists as not offering a legitimate grounding for knowledge; with one interesting exception (Clark, 2008 “Depression and narrative: Telling the dark”), I have seen no systematic attempts to analyze themes across autobiographies. In that unique project, Clark, a professor of English, draws together contributors from a number of disciplines to examine “the stories we tell about depression: its contested causes; its gendering; the transformations in identity that it entails; and the problems it presents for communication.”

On a more optimistic note, there is currently a flowering of interest and activity in diverse styles of qualitative research taking place across a variety of problems, including depression (Hurst, 1996; Curtis, 2001; Walker, 2001) attention-deficit hyperactivity disorder (Navarro & Danforth, 2004) post-traumatic stress disorder (Baldwin, Williams & Houts, 2004), agoraphobia (Capps & Ochs, 1995) and eating disorders (Malson, et al., 2004). In addition, novel areas of interpretive investigation are being forged including “phenomenological psychiatry” and “hermeneutic psychopathology” (Schmidt-Degenhard, 1997; Schmidt-Degenhard & Feldmann, 2003; see also Mijuskovic, 1996; Hedelin & Strandmark, 2001).

McAdams (1999) points to an upsurge of interest in narrative beginning in the mid-1980’s across multiple areas of psychology. Figures 1 and 2, created by the founder of a narrative psychology clearinghouse on the internet (www.narrativepsych.org) illustrate the change over recent decades:

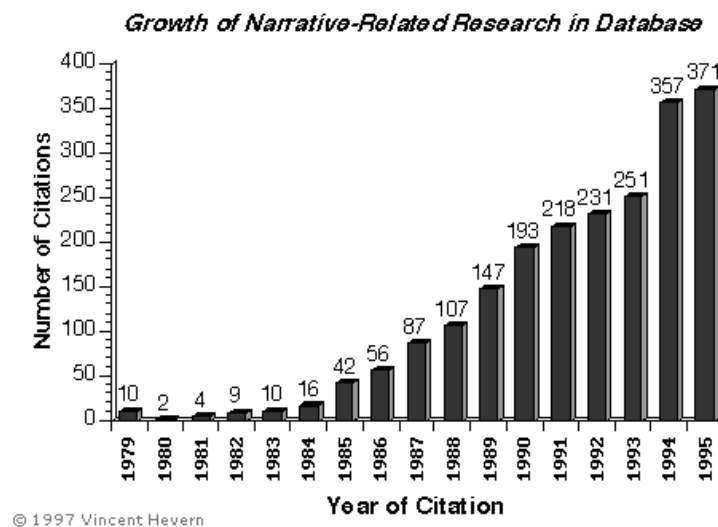


Figure 1. Taken from Hevern, V. W. (2004). Introduction and general overview. Narrative psychology: Internet and resource guide. Retrieved [March 22, 2004] from the Le Moyne College Web site: <http://web.lemoyne.edu/~hevern/nr-pbiog.html>

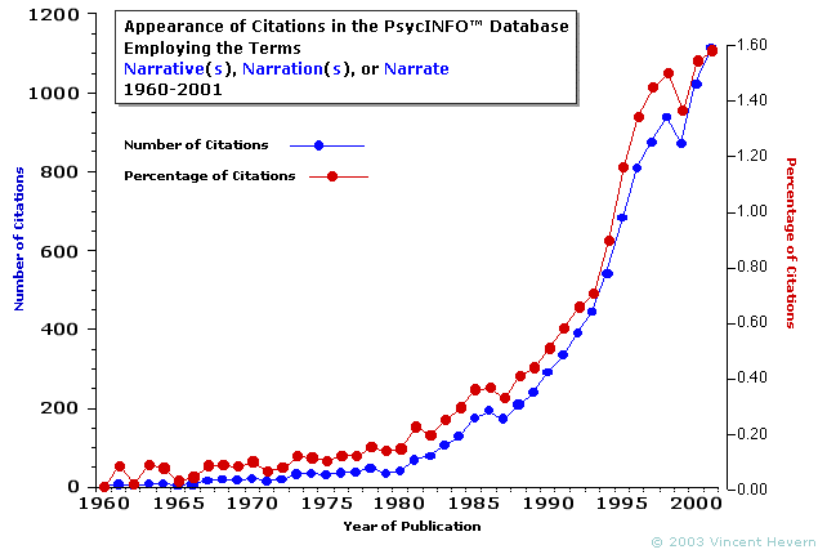


Figure 2. Taken also from Hevern (2004). (see reference above).

For depression research, in particular, one aspect of this development has been to reverse the past gender bias of autobiographical work, which was largely written by men. Current interviewing research has been more directed at women’s experience, including adolescent women (Hetherington & Stoppard, 2002; Gammell, 2004), middle-aged women (Hurst, 1996; Scattolon & Stoppard, 1999; Amankwaa, 2000; Scattolon, 2003) and elderly women (Hedelin & Strandmark, 2001). Interviewing studies of depressed men exist, but are less common (Elder, 1979). Even with this upsurge in interest, however, the relative contribution of these approaches still remains dwarfed by the broader psychological literature on mental and emotional problems (Stoppard & McMullen, 2003).

What is only now being “discovered” in psychology, has long been embraced in the field of anthropology. Medical anthropology, in particular, offers a rich literature about the role of diverse cultural interpretations in the experience and treatment of medical problems. Arthur Kleinman (1988) has been a pioneer in his investigation of “illness narratives” and the meaning around pain, sickness and healing. While some dissertations on these issues exist in psychology, medical anthropology regularly produces volumes of this kind of investigation, with titles such as “medicine as culture” (Lupton, 1994) and the “social and cultural lives of immune systems” (Wilce, 2003). These studies explore the interpretive dimension of many physical and mental problems (see Hahn, 1995; Telban, 1995; Castillo, 1998; Skultans & Cox, 2000; Finkler, 2000; Mattingly & Garro, 2000), including depression. Anthropologists perhaps also deserve credit for pioneering the investigation of *professional accounts as narratives*, rather than as reflections of

undisputed reality they are often taken to be (e.g. Thomas-MacLean & Stoppard, 2004). Within psychology, cultural psychologists increasingly seem to reflect anthropological sensitivities in their research of different cultural portrayals of mental problems (see Angel & Thoits, 1987; Tsai & Chentsova-Dutton 2008; Amankwaa 2000; Walker, 2001).

A common thread running across all these literatures—from psychology to anthropology, sociology and history—is the reminder of the *situatedness* of individual experience in these larger interpretive frameworks or discourses—called “narratives” in this study. Rappaport (1998) clarifies that narratives are not created “whole cloth”—but are, instead, drawn from the larger cultural narratives available in communities—called a “dominant cultural narrative” when a particular narrative is shared by many people and institutionalized in policies and procedures. The biomedical model of understanding emotional problems could arguably be labeled a dominant cultural narrative (Crossley, 2003; Landers, 2004).

As the interpretations of individual survivors of depression are investigated in light of this dominant narrative, insights emerge regarding their relationship—namely, the way a prevailing biomedical narrative might influence individual decisions and practice. For instance, Gammel (2004) explores how adolescent girls draw on different discourses to make sense of their experience—including an “adolescent girls’ lives” discourse and a medical discourse. She reviews how girls make different strategic decisions to reconcile contradictions between different understandings of depression—discarding one account in favor of another, combining explanations in seemingly contradictory ways, and sometimes pursuing an integration of ideas. She notes that a medical discourse is more likely to be adopted when the depression is judged to be severe and when life stressors do not seem to be relevant. Given the potential implications of such narrative patterns for the actual experience of distressed individuals, research such as this deserves more attention.

Stoppard and Gammell (2003) describe a feeling of relief accompanying diagnosis as individuals come to see difficulties as depression, rather than personality flaws. This shift makes the depression experience more acceptable to some: “[It’s] the same as any other illness. You’re depressed; well you’ve got a bad heart so what’s the difference . . . it was a natural occurrence . . . People aren’t ashamed to walk around with diabetes or a heart attack. . . It’s the same thing (p. 51).

The same authors go on to note that part and parcel of diagnosis for all interviewed was adopting a personal understanding of depression as largely a chemical imbalance in the brain. Stoppard and Gammell (2003) have explored “medicalization,” the progressive translation of problems as diverse as child birthing, adolescent delinquency, homelessness, old age, menopause,

and race, into a biomedical language. Medicalization has also taken place with most major psychological problems—including depression.

This shift in explanation, in turn, has been linked with accepting medical prescriptions—emphasized by many survivors as an important part of treatment. Moses and Kirk (2005) note that many experience positive “psychosocial side effects” with medicine, including increased self-confidence and the alleviation of guilt (pp. 392-393).

On the other hand, a general reluctance to proceed with medical treatment has also been examined in the narratives of depressed individuals seeking help (Karp, 1997). Through in-depth interviews, Karp explored the intense and ambiguous internal process of accepting new definitions of self accompanying diagnosis and treatment. He portrays depressed people as engaged in a continuous process of trying to make sense of their experience: “the experience of taking antidepressant medications involves a complex and emotionally charged interpretive process in which nothing less than one’s view of self is at stake” (p. 102). Moses and Kirk (2005) cite a patient interviewed by Goldstein “I need to know what is my personality and what is caused by the pill. I don’t know whether my feelings are what I feel or what the pill causes me to feel” (p. 391).

Feminist researchers have investigated the way medical treatment and its implicit narrative may be potentially disempowering for women. This includes the suggestion of conditions over which people have little or no control, the limited attention to social context, and the typical reliance on doctor judgments during treatment. These qualities contribute to personal narratives of depression reflecting minimal personal power. Moses and Kirk (2005) review conflicting conclusions in the literature examining learned helplessness within depression treatment, but note a consistent link between conventional treatment and notions of an external locus of control. They explore how psychiatric treatment may undermine autonomy, control and a sense of efficacy. Of course, the experience of depression itself is also experienced as disempowering. A woman interviewed in Stoppard and Gamell’s (2003) study said: “you’re going to have to acknowledge that sometimes, you know, it is going to invade your life . . . and at times like that you have to ride it out” (p. 52).

Consistent with previous reviews of traditional outcome literature, patient anecdotes, and the medical compliance literature, these interview studies confirm a fairly consistent ambivalence about medical treatment for depression. Karp’s (1997) study examines how this ambivalence may change as attitudes shift. In the majority of individuals interviewed, the initial reluctance of patients towards biomedicine is eventually overcome in a process he compares to religious

conversion. He explores how the bulk of individuals experience later disillusionment in coming to understand the potential of medication more realistically.

As reviewed above, those adopting the biomedical narrative often center their understanding on physiological responses to medication. In contrast, those resisting a biomedical narrative often turn to the context of daily living as a consistent theme. Stoppard and McMullen (2003) note that rather than seeing depression as an extraordinary event, most women interviewed naturally understand their depression as arising in the context of their everyday lives—a normal taken-for-granted consequence of life. These researchers note the disjuncture between this indigenous commentary from women and the prevailing biological narrative of what underlies depression.

A central part of a context of daily living, perhaps, is relationships. For individuals experiencing depression, this often includes disconnection and isolation—even when social connection is earnestly desired (Karp, 1997). Susan Hurst (1996) has investigated “profound betrayals” from close figures as prompting a demoralization process constituting depression. Also common are narratives of families not talking about “the problem”—simply not acknowledging it. Individuals hide ill feelings at home, put on a mask, play a role and exhibit two sides. In this case, a professional is welcome relief in order to be able to talk to *someone* about feelings—since it has been too difficult with family or friends. Finally, those seeking relief are rarely made aware of other sources of help—having to request such help or seek it out themselves (Stoppard & McMullen, 2003).

While the literature offers important initial insights into the interpretations of depressed individuals generally, there is still relatively little attention being paid to interpretive research on medical treatment overall. There have only been rare investigations, for instance, of the more subtle effects of psychiatric treatment on meanings and relationships (e.g., Nevins 1990). Moses and Kirk (2005) lament:

We know comparatively little about the overall experience of being treated with psychotropic drugs. In addition to symptomatic physical changes produced by medications, what is the subjective experience . . . of taking psychotropic drugs? Are there direct or indirect social and psychological effects on esteem, identity, and other views of the self? (p. 387).

For these reasons, additional research on these questions appears to be justified. Calls have even been made to employ qualitative studies as a formal part of the outcome research for psychiatric treatment (Crawford, et al., 2002).

As the dominant biomedical narrative has grown in power, so also have counter narratives. These alternatives vary in how sharply they break from dominant explanations and to

what degree they are critical of these explanations; likewise, individual narrators vary in how they draw on different, sometimes contradictory narratives. For instance, many women interviewed have positive judgments of medical treatment while also leveraging non-medical “everyday life” explanations—including poor interpersonal relationships, difficulty coping with a job, school related stress and heavy workload contributing to depression (Stoppard & McMullen, 2003). Other individuals, however, adopt fierce anti-psychiatry narratives that rebel against any kind of medical explanation. While variation in narratives across cultures is studied within anthropology, there seems to be less research on why narratives within a restricted locale can be so remarkably diverse. The current project aims to understand interpretive differences existing even within one cultural location (two states in the U.S.) at one time period.

Theoretical Questions

As noted above, on a broad theoretical level this study aims to better understand the “transactions” accompanying the development of diverse accounts of depression and its treatment. Awareness of the relations between narrative and biological/contextual variability constitutes an important backdrop for three specific empirical questions described below. In short, each aspect of this transaction is understood as a potential prompt for the active interpreter or narrator, who is necessarily encountering and making a constant, ongoing flow of decisions. By examining more carefully how narrators adjust their interpretations and larger stories over time in the face of evolving conditions, the project aims to gain insight into how narratives come to be polarized so sharply. Furthermore, the way individuals *make sense of their experience* via hypothetically distinct narratives was theorized as having potentially tangible consequences for the *actual experience* of depression—i.e., how are emotional problem experienced and treated differently when interpreted and narrated in distinct ways? Better understanding of these interpretive processes is thus proposed as potentially offering further insight into the nature of the larger transactions involved in depression, as well as its basic nature and appropriate treatment. In all these ways, a more complex social scientific understanding of the “interpretive event of depression” is sought.

Empirical Questions

As a dynamic activity over time, interpretation can be studied in different time periods across distinct contexts. Given this, the research will center around three empirical questions:

1. *Narrative arrival/creation.* How do these narratives arise? What resources do participants appear to draw on in the initial adoption or formation of a personal narrative? How

are different features of past experiences (physiological responses to medication, reactions of surrounding community) taken up to prompt an evolution or disruption of previous understandings? How might narrators adjust differently to these common experiences?

The process of arriving at a particular narrative was anticipated to be complex—if only by virtue of the amount of time preceding it and the possible contributors available. Sheer number of contributors multiplied by the time of life prior to the interview means the amount of contributing events may literally be infinite. While impossible to research, this becomes an important acknowledgment to make. Each individual interviewed has been immersed in a sea of emotional states and messages for the duration of his or her life. These promptings as a whole constitute the available ways of thinking, making sense and approaching their ongoing experience. From these available ways of thinking, they have made choices throughout their lives of ways to make sense of their current experience. Sometimes these choices have been made explicitly, in a deliberate way. More often, however, I believe they have been made implicitly as a function of living. Over time, these choices—deliberate or otherwise—have led to their current state of thinking and being. After reviewing the content of participant narratives in Chapters 3-5, Chapter 6 will focus explicitly on an analysis of how particular stories appear to be created and arise over time.

2. *Narrative constitution.* What is the nature of differing narratives of depression? This question includes a focus on both what is presented in the narrative and how it is presented: what is the content of these narratives and how is this content structured differently across narratives? Once again, after reviewing content of our participant narratives in Chapters 3-5 and briefly exploring structural patterns in Chapter 3, I focus in Chapter 7 more explicitly on key issues that appear to underlie the most meaningful content differences between narratives.

3. *Narrative maintenance.* Given adoption of a particular narrative, how is it maintained over time? Once a personal story has formed what are the processes or strategies that contribute to its continuity as a narrative? This question goes beyond the structural nature of narratives (how are narratives presented) to ask what particular actions appear to help *perpetuate the narrative over time*. When narratives are challenged, what strategies are employed to preserve the story? What constitutes these strategies and how do they function to sustain narratives? Chapter 8 examines the maintenance of narratives over time.

On one level, all three activities (narrative creation, constitution and maintenance) appear to be inseparable—each fundamental acts of narrating life experience. On a finer level, however, given the dynamic and temporal quality of “narrating,” each may be separated by temporal

progression—early events leading to the creation and adoption of a narrative, with later events accompanying the present narrative presentation and perpetuating its maintenance over time.

The following chapter lays out the methodological design of this interviewing study of depression survivors. Following this discussion, analysis begins with a brief synopsis of each of the sixteen participant narratives (Ch. 3). Next, the text moves to an overarching review of key themes across narratives relevant to the three empirical questions. This thematic review is divided into two chapters: one taking up themes relevant to how individuals come to define and interpret the problem of depression (Ch. 4), a second focused on how individuals come to frame and interpret depression treatment, with a particular focus on medical treatment (Ch. 5). Interview excerpts across this section are arranged in a roughly linear temporal sequence to help make sense of the themes more broadly. Although addressing empirical questions implicitly, this section aims to be primarily descriptive—a walk through of interview excerpts relevant to these questions. In the following section (Chs. 6-8) empirical questions are taken up more explicitly: how do narratives arise (6), what major differences are evident across stories (7) and how are they maintained over time (8). Each of these final chapters includes more deliberate discussion of previously reviewed narratives and themes for both empirical and theoretical questions taken up in the study. In the final chapter (9), implications of findings for the larger discussion on depression treatment are explored.

In order to connect with the rich vein of related investigations, findings will be presented alongside insights from other research teams in a way that highlights salient and re-occurring themes across the growing literature (Chs. 6-8). In this way, the presentation also aims to contribute to synthesizing of findings from the literature—a need emphasized as critical within the qualitative study of medication experience (Pound et al., 2005). Finally, by better understanding in what ways depression and its treatment are being interpreted differently, this study aims to facilitate a more thoughtful collective deliberation regarding severe emotional problems and their treatment (see Schwandt, 1996).

Chapter 2

Methods & Analysis

Methods

In order to examine interpretive processes associated with depression treatment, this study investigates the language of actual depression survivors through the method of interviewing. Interviewing is here approached from within a narrative/interpretive methodology that highlights the “dialogic process of communication” and the “joint construction of accounts of social life in conversation and reflection” (Schwandt, 2007, p. 195).

Sampling and recruitment. The aim of sampling was to recruit those with diverse experiences of depression and its treatment, ranging from very positive to very negative evaluations of traditional psychiatric treatment. The key sampling characteristic was *diversity of treatment experience*. I aimed for participants with glowing testimonials of treatment and recovery, those with tragic rants against the treatment system, and those in between. In doing so, I sought to explore the broad scope of the continuum of how people evaluate their treatment experiences. My research questions did not necessarily call for differences across other demographics, so there was no particular recruiting strategy to gather men versus women, particular ethnic groups, and so on (also unnecessary without a goal of generalization across groups). The exception to open recruitment was avoiding interviewing children, youth and adolescents (due to both ethical difficulties and sharp developmental differences that were not at issue in this study). I requested permission to recruit subjects in both Illinois and Utah, given opportunity and multiple connections in both locations. Although religiosity was also not deliberately selected or queried, ten of the participants, to my knowledge, identified with the Church of Jesus Christ of Latter-day Saints (Mormons), with three identifying with other Christian groups (Catholic, Evangelical and Pentecostal) and three reflecting no explicit religious identification. As a whole, then, the sample was highly religious and Christian⁴. (See comment at the end of this section on how religion was understood in relation to this study’s questions).

Broadly, recruitment was aimed at anyone who had experienced depression at some time in his/her life, regardless of degree of exposure and involvement in the system (with no requirement that participants had received formal diagnosis or treatment for depression). Severity or exact nature of experienced depression according to official diagnostic criteria was not a

⁴ Since Mormons do not consider the orthodox view of God’s nature or the Trinity to be true, many orthodox Christians do not consider Mormons to be Christian. This demographic statement assumes the existence of different viable “narratives” of Christianity.

determining factor. In this way, anyone who self-reported to have experienced “depression” of some kind was recruited—both long and short durations and multiple kinds. My rationale for such a broad inclusion protocol was to not exclude individuals who self-identified as “depressed” but who, under more exclusive criteria, would have been excluded from sharing their experience. This ensured the desired diversity of voices. Although such diversity may be an obvious hindrance in other studies, my own research approach and questions required it.

The primary criterion for inclusion in the research was thus having experienced depression at some point and in some degree. Reported experience was typically, but not necessarily, in the past. Although participants continuing to fight depression in mild degrees were not excluded, when the current distress was of a serious degree, the person was excluded from the study (see exclusion protocol listed in “ethics”). Consistent with this protocol, I declined interviews with people in several instances who were undergoing intense treatment for depression.

In order to reach a fuller range of stories, organizations advocating for and dissenting from psychiatric care were contacted—including the *National Alliance of the Mentally Ill (NAMI)* and to the *Alliance to Stop the Influence of Psychiatry in Religion and Education (ASPIRE)*. [ASPIRE is a now-defunct group of lay persons concerned with psychiatry’s influence in dominant institutions of society (see www.aspire.us). The organization was headed by a Utah mother, Cassandra Casey, whose teenage boy killed himself soon after starting Prozac]. Leaders of each organization were contacted and informed of the research, with subsequent letters of support written for the project (see below). The purpose of each organization is to educate the public about its particular perspective on mental health treatment. Organization leaders were invited to contact possible participants in their networks, briefly describe the research and invite their participation. Flyers were provided with information about the study and contact information of the primary investigator.

In seeking this purposive sample, pluralistic recruitment strategies were employed—posting flyers at the local public libraries, posting notices to psychology listservs and asking acquaintances if they “knew someone with a story.” I anticipated some reluctance as health and disease issues are often reported to induce hesitancy in interviewing research (Adler & Adler, 2003). For this reason, I sought to “snowball” with every contact—“who else do you know that may have a story to tell about this?” This became a form of continuous “sponsorship” recommended in cases where there is not time for extensive relational groundwork (as would be the case in ethnography) (Adler & Adler, 2003). While doing so, I avoided interviewing persons

with close relationship to myself—friends or family. Most referrals for the study came from the help of personal acquaintances (see *Appendix A: Recruitment protocol and flyer*).

While recruitment progressed, I began interviewing participants. The plan was to interview approximately 15-25 persons or until the diversity of experience I aimed to understand had been adequately explored. While there was no pre-set number assumed to be necessary for validity (samples in similar studies have ranged from 1-50 interviewees, depending on the goals and research approach of the investigators), I planned on regularly assessing whether there was “sufficient coverage of experience” by analyzing interview data as I went along. Data generation and analysis thus overlapped, with transcription and review of interviews proceeding simultaneously with ongoing efforts in conducting further interviews.

Given the prevalence of depression, finding subjects for this study was not difficult. However, in light of the prevailing biomedical view of depression, these snowball recruitment strategies were not anticipated to yield as many accounts critical of medication. While the director of the Utah chapter of the *NAMI* was extremely helpful in putting me in touch with participants, it remained remarkably difficult to find individuals from an alternative perspective—even with *ASPIRE*’s help. Indeed, after conducting 9-10 interviews, I was having difficulty encountering the broader diversity of perspectives, and so took steps to deliberately pursue greater contact with additional referral sources. The director of *ASPIRE* referred me to Anne Blake Tracey, leader of another anti-psychiatry organization centered in Utah, the *International Coalition for Drug Awareness* (<http://www.drugawareness.org>). When Tracey had no referrals, I turned to a third source, *Mind Freedom International* (www.mindfreedom.org), a prominent “anti-psychiatry” group across the nation. After sending an e-mail to their listserv in Illinois, I got in touch with two people living in Chicago who were willing to participate.

As a result of this broad sampling approach, the sample turned out to be notably complex. While some participants came from abusive families, others spoke of happy childhoods; while most described what appeared to be classic unipolar depression, a few reported clear bipolar tendencies. In spite of these benefits, it is important to clarify that not all depression accounts were included. While not verified through diagnostic criteria, two individuals shared accounts that seemed distinct and not of the same fundamental kind as the others—i.e., not serious enough to be classified as clinical depression, reflecting “passing blues” easily shaken off. To have included these accounts, I judged, would have pushed the “diversity” of depression narratives so far that “depression” would cease to have a common meaning. For this reason, these accounts were only peripherally included in analysis as exemplars of sadness narrated-as-depression (leaving the total number of narratives fully analyzed at 14).

On the most important criteria—diversity of treatment experience—the sample was generally sufficient, although more participants critical of treatment would have strengthened the study. While four participants eventually refused medical treatment, only two of these were expressly critical of that treatment. The majority of participants were either strongly in favor of medications, generally in favor, or ambivalent. As a result, the sample tended towards a generally favorable position on medications (much like the general population). Even among this majority expressing favorable leanings towards medications, however, most expressed significant ambivalence. Consequently, the sample could be understood as ranging between 2 unconditionally in-favor of medical treatment for depression, to 8 ambivalent, but generally in favor, to 2 ambivalent, but generally opposed, to 2 unconditionally opposed.

Two other demographic characteristics deserve some further mention: gender and religious faith. As noted previously, the sample is fairly religious—especially Christian (Catholic, Presbyterian, Evangelical and Mormon). Although faith clearly matters for how one narrates any experience, I did not believe initially that faith would necessarily have much bearing on my three main empirical questions nor did I deliberately sample individuals to select for a particular variety of faith. Instead, I assumed that any human being facing depression would narrate depression and its treatment in varied ways that could be compared and from which interesting insights would come. That individuals also believe in God (or not), while obviously reflecting an interesting aspect of individual narratives, was not presumed to be so influential that it prompted wholly different forms or patterns of narratives. (Another reason for this belief was my privileging of questions regarding how psychiatric treatment was narrated—a cultural experience fairly universal across other differences).

Having said all that, it is important to acknowledge that this is a highly religious (especially Mormon) sample. With one major exception, I think analysis bears out my general initial assumptions. As reflected in descriptions of recovery in Chapters 3 & 5, individuals referenced God's hand and help in multiple ways during their narratives—especially in guiding them to healing. Chapter 8 summarizes the potential role of this faith as a strategy for maintaining individual narratives, and later, as an explanation for the high rates of anti-depressant use in Utah (moderated by a trust in doctors). Perhaps the most likely pattern is that conservative religion seems to make people more likely to adopt and maintain a biomedical narrative of depression—a pattern that has obvious relevance to the study and that I believe deserves further attention (my own explanation is included in Chapter 8). This becomes a notable exception for the rationale to disregard religion as a crucial sampling variable. In spite of this qualification, my broader observations to date (hearing and reading many other accounts) lead me to believe that

the general findings and patterns presented in what follows would likely be seen across many other demographics.

Given the value on transparency in qualitative research, I would mention my own identification as a member of the Church of Jesus Christ of Latter-day Saints (“Mormon”). On many levels, the Church of Jesus Christ has instilled and shaped what I have come to view as important in ways that I value—including, no doubt the questions involved in this study. Having said this, while active in my faith, I have some concerns with how many of my religious brothers and sisters have come to approach questions discussed in this study (see Chapter 8). In terms of the interviews, although I did not always reveal my religious faith, those who knew of it perhaps spoke more openly of their own spiritual experiences.

Moving on to other demographics, I similarly did not believe gender would fundamentally skew data that aims to document how medical treatment is narrated. Of the original 16 participants, 13 are women. Although women have well-documented higher rates of depression and also seem more willing to talk and share, the kinds of patterns and dynamics I saw in male participants like Kyle and Peter did not differ significantly, in my mind, from those I saw in female participants, Esther and Sarah, respectively (pseudonyms are used throughout). Of course, if my questions were focused on attending to unique ways men and women narrate depression, I believe interesting patterns would definitely emerge. For questions attending to medical treatment, however, I did not assume meaningful differences would necessarily vary by gender.

Ethics. Multiple steps were taken to minimize potential discomfort or distress—especially through recruiting procedures carefully designed to exclude individuals who were experiencing *serious depression*. The goal of my inclusion/exclusion protocol noted earlier was to only include participants who were currently stable. Although persons recruited for research may have incidentally been in contact with professionals recently regarding their depression (doctors or counselors), when this contact constituted a regular ongoing treatment for depression, the person was excluded from the study.

While formal criteria are limited and no official diagnosis of depression is needed, the following basic protocol was used to systematically exclude persons who were currently experiencing depression to a significant degree. While not identifying as a clinical psychologist, as part of graduate training in a combined clinical/community doctoral program, I took a class in basic psychological assessment and received specific training in assessment for suicide risk. At the time of initial contact, potential participants were asked the following basic screening questions prior to confirming their inclusion in the study:

“Before confirming your participation, I need to first ask you some basic questions about your current situation related to depression before we start. The reason for this is that this research does not apply to all circumstances—and I need to make sure the study fits your situation. There is a chance this study may not be a good match for you. Will that be okay to ask a few general questions about your situation?”

(If “yes”): *“Are you currently receiving any treatment for depression?”*

→(If “yes”): *“Can you describe how regularly your treatment visits take place?”*

[If treatment was on a fairly regular--weekly/bi-weekly basis--(such as intense psychotherapy or psychiatric supervision)--the participant was told the following]—*“In order to make treatment a priority--as it should be—I won’t be able to include you in this current research study. Let me assure you that this will in no way harm the research, and thank you for being willing to participate regardless!”*]

[If treatment was infrequent or sporadic—such as monthly visits to a primary care physician to monitor medication or follow up visits to a counselor twice a year—the participant was told the following]—*“I want to be careful not to interfere with any treatment—which should be seen as the priority. It looks like this won’t be a problem—but I want to check in with you to make sure. Do you feel okay about participating?”* [More details about what the study entails were reviewed in the informed consent at a later point; this simply functioned as an initial, general screening question for those in light contact with professional services (typical of many stable Americans and not be interpreted as evidence of instability unless further signs indicated otherwise).]

→(If “no”—the person did not currently receive treatment for depression, the person was asked the following): *Have you been experiencing any significant increase in symptoms or struggles with depression currently?* [This question represented a secondary screening precaution beyond whether the person is in intensive treatment or not, since it is known that a good number of people fighting depression do not receive or seek any treatment or help.”]

→(If “no”—there was no significant increase, I confirmed details of their participation)

→(If “yes”—there was a significant increase in symptoms, I informed them I wouldn’t be able to include them in the research, but thanked them for their willingness to participate. At this point, I explained that getting better is a more important focus than research. I also asked participants if they had considered getting help and presented them with information on basic referral sources (the same information leveraged in the case of any distress during the interview; see *Appendix B: Additional plans in case of distress during interview*).

As a result of this screening, participant stories were largely expected to be chronicles of experience in participants’ past (with the exception of mild ongoing struggles⁵). Because recruiting naturally targeted people more interested and willing to “share their story,” it was not

⁵ While being careful about these exclusion criteria, I sought to avoid the other extreme which would unnaturally limit my sample. Specifically, I sought permission in my protocol to contact individuals who were still mildly depressed currently (a vulnerable population). The goal in doing so was to allow my interviewing sample to include voices of these individuals. Especially given the commonality of relapses and the difficulty in defining when depression is actually gone, it seemed important to obtain permission to be able to speak with these individuals.

anticipated that serious discomfort would be a regular aspect of sharing for participants. Still, participants were monitored throughout the interview to assure that they were comfortable. Since recruiting procedures could have failed to detect a person currently fighting serious depression and because even recounting past or mild depression is not without the possibility of real discomfort, plans and steps were put in place in case they were needed (see *Appendix B*).

The only other risk of note was basic privacy (particularly since experiencing depression can be viewed as stigmatizing by some). In addressing confidentiality, participants were assured that recordings made during these interviews would be confidential and secured in a locked office when not in direct possession of the investigator and that any publication, report or presentation of research that may result from this inquiry would not identify him/her or any other participant.

Beyond the avoidance of seriously depressed participants, additional basic ethical protocols were followed for everyone—including voluntary consent obtained from each participant prior to beginning an interview. Consistent with Adler and Adler's (2003) recommendation for sensitive interviews to "be overt about intentions but remain oblique or vague about their specific purpose" (p. 163), I did not go into detailed description of the exact research questions within the informed consent (see *Appendix C: Informed Consent*). Because important aspects of informed consent documents often remain obscure to participants, however, I made sure the consent procedure functioned as a conversation—verbally highlighting significant issues and probing for any questions or concerns. As noted on our university IRB site, the consent process also aimed to "involve answering questions that arise before, during, and after the subject's participation." Copies of the consent forms were given to participants for their records.

While participants gave consent for their own sharing to be recorded and used as data, other kinds of data also became relevant. Several participants offered written material as a supplement to their verbal sharing—including pictures from a book that had been influential and writing they had done about the subject. Each gave their permission for the written material to likewise be included in the research. In one instance, family members spontaneously entered the interview, adding important elaborations to and exchanges with their mother's narrative. These family members also gave their verbal consent for their comments to be included.

While denying that I was offering any immediate benefit, I acknowledged a general benefit of potentially improving the way we respond to depression in communities by better understanding how and why people narrate their experiences so differently. A ten dollar bill was offered at the beginning of each interview, alongside an emphasis that remuneration was not compensation for their time after the interview is over, but a simple expression of appreciation for assistance in the first place.

In making follow-up calls, I once again sought to be careful about emotional stability of participants, since there was a possibility that participants originally screened for interviews had lapsed back into depression in the interim. Anticipating this possibility, the following three safeguards were in place as an expansion of my original protocol for distressed participants:

- a) General screening: Given the brevity and generality of the call, it was not necessary or appropriate to do a more in-depth screening (as done previous to interviews). Rather, the goal was to specifically assess whether a person currently felt well enough to speak. Following an explanation of the purpose of the call, I would ask “*are you feeling up to answering these questions?*” This would function as a general screening which served its purpose for the purpose and nature of the call.
- b) Maintaining summary nature of the call: Importantly, as reflected in the phone script, this follow-up call explicitly avoided delving into experiences to the depth of the original interview—remaining general enough that it did not elicit very emotional descriptions.
- c) Preparation for worst case scenario: In the worst case scenario that a past participant had now lapsed into a bout of serious depression, I planned to apply step four of the plan for distressed participants from the original IRB protocol: “*if responses indicate significant challenges in recent experience or increasing level of depression, I will recommend immediate contact with a health care professional or some other support in their community—for additional assessment and assistance. If they have no previous contact or have interest in additional resources, I will provide information on the following resources as well as any additional resources that appear to be relevant*” (See Appendix B: *Additional plans in case of distress during interview* for further details including provider names and numbers).

In spite of these risks, it was concluded that the potential benefits of improved ways of understanding and responding to depression were significant enough given the increasing human toll of depression in our society. These benefits outweighed the minimal, inherent risks associated with disclosing personal information (discomfort, assuring confidentiality). While participants were regularly emotional in recounting their experiences, it never reached a level of serious distress which made the emergency protocol necessary.

Audio files, written notes, and electronic files of transcription were kept secure on a flash drive in a locked office when not in direct possession of the investigator. Digital audio files of interviews were coded numerically and kept on a secure flash drive prior to transcription. Written “memos” from the interviews were also kept secure. Data collection was confidential, but not anonymous, since I still had the ability to trace responses to subject identities—and retained the ability to contact participants at a later date. These transcribed files, however, were coded with numbers replacing names, and thus only identifiable to me. The identity key was stored in an office separate from the files. Signed informed consent documents were stored in third secure location separate from both audio files and identity key. Once all files were transcribed, these electronic text files were also kept secure on a flash drive. All undergraduates assisting in the

transcription process were trained on the importance of confidentiality and the specific ways to protect this throughout the research.

Interviewing. An IRB protocol was approved the year prior to the formal launch of the dissertation study in order to do piloting of my interview questions. The interview schedule was subsequently refined during this preparatory time through both practice interviews and exchange with committee members. The interview schedule became increasingly unstructured as it developed, anticipating that once participants felt comfortable sharing openly, they would need only intermittent prompts in relaying their story. After the initial main question, “tell me your experience of facing depression,” possible probes were listed as needed to prompt further elaboration into the three central empirical questions. These probes included: a) questions to further investigate events or features contributing to the *adoption/formation* of a narrative; b) questions that prompted further exploration into the *nature of the narrative*, including probes targeting both the content and structure of individual narratives; c) finally, a few probes to prompt further discussion of how an individual has *maintained their narrative* over time. In practice, depending on how much individuals shared from the initial open-ended question, only a subset of probes were used for any given interview (See *Appendix D: Interviewing schedule*).

My interview with participants constituted only two short hours of their lives—only a brief, concentrated period in which I was able to directly inquire into their *current understanding* of their *past experience* with depression. As such, I engaged as best I could to understand how they currently thought of their experiences. As part of my inquiry, I sought to investigate how individuals arrived at their current understanding by asking individuals themselves to select among past experiences and share relevant contributors to their current understanding. In multiple ways during the interview, participants were asked to comment on influential events, persons and aspects of their past experience (medication outcomes, media), as well as to respond explicitly to how their perspectives had shifted relative to the past. Combined, this set of questions probed (as much as possible within the limitations of a two hour interview) into that individual’s current perspective on how he/she arrived at his/her current understanding.

In my IRB protocol, I reserved the option to modify the schedule as the interviews proceeded since I *expected unexpected* dynamics to emerge (Kvale, 1996 p. 100). After several interviews, I saw a better organization for the questions and laid them out in a more linear way. As interviews progressed, I also found several questions that were not working and either revised them or dropped them entirely.

Given the subject matter, it felt especially important to be sensitive to rapport issues. Seidman (1991) recommends avoiding extremes of too much versus not enough rapport, arguing for appropriate distance on sensitive topics in order to assure answers have sufficient autonomy and to avoid a therapeutic relationship. This caution seemed particularly important with interviewing about depression experience. Indeed, one woman quipped after the interview, “It’s good to talk, you don’t charge me.” I answered in good humor, “No, I’m actually paying you. Is it alright to ask a few more questions?”

Overall, the tone of participants’ voice spanned a surprising range both across and within interviews--from talking very, very slowly or in a monotone way, to exquisite emotion evident in a pained voice, or one that was happy and content. While selection criteria required the person be stable and not currently in intense treatment, pain was still evident in most interviews; the intensity of emotion and feeling across stories was striking and humbling to witness. As interviews progressed, I reflected on how participant stories were a real gift; the more I learned, I realized that it was a real *honor* to witness them.

After passing my preliminary examination Wednesday, May 11, 2005, I submitted a final IRB proposal in order to receive approval to begin formal research by June. In the meantime, I revised my dissertation proposal based on feedback from the dissertation committee—structuring it around the three empirical questions reviewed earlier in the introduction. In August of 2005, after receiving approval from both the IRB committee and my dissertation chairs on the revised proposal, I began conducting narrative interviews in Utah. Participants were contacted directly by the investigator and invited to participate in an interview at a time and location convenient to them. Half of the interviews took place at an individuals’ place of residence, with the remainder happening at multiple locations, depending on what was most convenient for the participant. Two interviews happened at work sites, one at a park, one at a church, one at a library and two at the psychology building. Individual interviews took place face-to-face and were audio recorded. For the main interview, I decided to try to avoid phone exchange, believing the costs would outweigh their benefits for the questions I was asking. One interview, however, had to be finished on the phone when face-to-face time ran out. All original interviews took place between July and December of 2005 in Utah and Illinois. Nine interviews were conducted by the end of the summer before returning to Champaign. Six more interviews took place over the coming two months in two Illinois cities—Champaign-Urbana and Chicago. One more interview took place in Utah in December, 2005.

As noted previously, the decision to stop interviewing was connected to my early, ongoing analysis of the interviews to date. As interviews progressed, I monitored the tenor and

themes of interviews and attempted to adjust additional recruiting to target more areas not yet sampled. While this led to a broader diversity of stories, there was a growing realization that the variety of stories was literally endless—realizing that my goal was not to make sure my sample was broad enough to capture as much of the variety as relevant to my questions. When, in my last cluster of interviews, I found three individuals with views more critical of traditional treatment, I concluded my sample had reached sufficient qualitative diversity. Even in a sample of fourteen individuals, I came to realize that powerful insights could be gained from even just a few stories.

There were sixteen participants: 10 participants from Utah and 6 from Illinois. There were 10 interviews in the Salt Lake Valley, 3 interviews in Champaign and 3 interviews in Chicago. The average interview time was 1 hour, 31 minutes, with a range from 39 minutes to 3:05 hours (a mode of between 1 and 2 hours). The total time across interviews was 24 hours, 23 minutes.

Interviews were tape recorded for transcription purposes, which took place beginning in fall of 2005 over the next nine months with the help of six undergraduate students: Diana Brahm, Mary Moore, Kim Brookens, Nate Walsh, Jesse Taylor and Asma Siddiqi. There were 199 single spaced pages of transcription (average of 12.5 pages per interview). In supervising the transcription, students were instructed with the following basic guide: *“Aim for a transcription to be quality in really capturing what was said:*

- *In general, try to capture everything said on the transcript—including significant silences or gaps.*
- *Record these meaningful gaps with a series of periods.*
- *Example: “The thing about my father is he . . . I don’t know, you know?”*
- *Record significant emotions heard on the transcript in brackets [sigh] [crying] . . use whatever word seems to describe the emotion! (;*
- *Use periods to naturally reflect the endings of their thoughts (rather than the ‘grammatically correct’ endings)—i.e. follow the flow of their thoughts.”*

As I read through transcribed texts to code them, I simultaneously listened to the interview through headphones. In this way, I was able to conduct a general quality check on the transcription itself—correcting it in places where significant errors were made.

Personal memos were also recorded throughout the process of interviewing. Schwandt (2007) describes memoing as an “analytic procedure . . for explaining or elaborating on coded categories . . captur[ing] the thoughts of the inquirer while he or she is engaged in the process of analysis.” He adds specifically that “memos are conceptual in intent, vary in length and are primarily written to oneself. The content of memos can include commentary on the meaning of a coded category, an explanation of a sense of pattern developing among categories, or a

description of some specific aspect of a setting or phenomenon” (pp. 188-189). My memos included notes of possible themes, key issues based on participant insights, aspects of interviews that stood out and excerpts of verbatim quotes from interviews—as well as beginning hypotheses and conclusions to test in later analyses. These were transcribed for use in an early phase of analysis, suggesting avenues to pursue in more comprehensive analyses (see analysis section for details below).

Analysis

Fundamentally, I view analysis as a continuation of the interview conversation—a seamless extension of the exchange with participants’ words. Rather than just asking questions and listening once, qualitative research is constituted by multiple waves of listening, hearing and thinking about responses. In this way, it makes sense to think of “waves of analysis”—with the first wave of analysis happening during the interview itself (see “memos” above), with multiple waves following.

Broadly, I take a philosophical hermeneutic approach to analysis, which sees interpretation and language as inseparably connected to the observable, empirical world. From this perspective, as delineated in the introduction, humans are understood to make sense continually of their experience as they navigate surrounding circumstances—in this case, active engagement in interpreting encounters with depression (Lewis, 1995). As meaningful physiological and contextual conditions change over time, individuals make ongoing choices in how to think and be, adjusting overall interpretations in the process. In contrast to strong constructivism or realism, however, hermeneutics sees language as neither “reflecting” nor “producing” experience, but instead *partially constituting* it (Taylor, 2002). As a viable alternative to both essentialist realism and anti-realist relativism, a hermeneutic approach to research—including within qualitative inquiry—has become increasingly common within psychology (Martin & Sugarman, 2001).

Consistent with these portrayals, a hermeneutic analysis of depression narrative moves beyond an attempt to grasp the “objective experience” of depression itself (i.e. “factors contributing to the problem”) to understand how individuals frame and interpret/narrate the experience. In this way, rather than seeking a reality “behind” the narrative—i.e. “what really happened” (whether medication works or recovery is possible), understanding is sought for the way individuals come to make sense of happenings through distinct interpretive frameworks.

This analysis section is divided into two sections—first, an explanation of the analytic plan established before the study and second, a summary explication of how the actual analysis played out over time.

Analytic plan: Seeking answers to the three empirical questions.

Overall analysis for the research project involved careful exploration of the three empirical questions reviewed earlier: How are distinct narratives created (or how do they arise)? What constitutes the essential nature of narratives (including meaningful differences between them)? And how do these narratives appear to be subsequently maintained by individual interpreters?

1. The creation of stories: How do these narratives arise? Before inquiring into the nature of narratives, assessment first targets how current narratives came to be—exploring evidence for what led to the creation or adoption of the narrative. How did individual narrators speak of arriving at their current understanding—including any events (with doctors, biology, community or media influence, etc.) that “had an impact” on them or “taught them”? How did different narrators make sense of various physiological and contextual aspects of experience (starting medication, family interactions) and how might these aspects have contributed to the overall evaluation of the experience they adopt? The anticipation was that many factors would be involved in the adoption of a personal narrative—interaction with community members, professional helpers, good or bad physiological responses to drugs, and so on. Given this, analysis aimed to investigate how narrators navigated through multiple (often conflicting) prompts in settling on their current account of depression and its treatment—the “complex and emotionally charged interpretive process” Karp (1997) highlights in studies of individuals seeking to understand their depression experiences (p. 102). In this process, were there episodes that appear to have galvanized the current narrative—turning points leading to the adoption of the narrative? How do some narrators come to portray their experiences in medical terminology while others reject the same? (and vice versa) Were there conditions that seem to make adoption of a medical narrative more likely than others, such as the severity of depression? (see Gammel, 2004).

Implicit in understanding how a particular narrative arises is grasping what came before it. This includes both previous understandings that may have been modified or rejected and critical events that may have prompted these decisions. To what degree were current narratives preceded by other articulated ways of understanding experiences? (i.e. did participants

describe their interpretations changing over time as their experience developed?). Were there episodes that appeared to have unsettled these past narratives--perhaps prompting evolution towards its current state? If so, what were these turning points like? In light of these past understandings, how did individuals appear to embrace their current narrative?

Importantly, this analysis also aimed to attend to both cognitive and emotional experience. Was the process of narrative acquisition primarily characterized by reluctance and ambivalence, relief and excitement, or perhaps a mixture of emotions? A special focus of analysis was investigating the adoption of particularly polarized (and emotional) narratives of participants. Were there patterns in how these narratives are adopted or rejected—perhaps similar to Karp’s (1997) articulations of conversion and disillusionment in his interviewees?

After reviewing memos from interviews, several themes were selected in “how did they arrive at their current understanding”? Particular attention was then given to these themes in coding—such as events where an individual was influenced by a particular community member, by a book or other media, by events related to their biology (with doctors or medicine) and by traumatic events. After illustrating trends in actual verbatim text across Chapters 3-5, Chapter 6 examines explicitly themes in how stories appear to arise over time.

2. The nature of stories: What is the nature of differing narratives of depression?

After examining how a particular narrative appears to arise over time, this question focuses on how participants are *currently* thinking about and framing their experience. Clearly, any narrative itself is complex and may be analyzed in a variety of ways. As reflected in interview questions, the following aspects of individual narratives were examined: Where most basically do individuals see depression as coming from? How is the role of biology seen by individuals? What is the role of abuse/traumatic experience? What reportedly leads to recovery? What does it mean to “get better”?

More broadly, analysis relevant to this question included attention to both the content and structure of the narratives—moving from a basic content analysis of “what is being said” (narrative content) to a more sensitive narrative analysis of “how this is being said” (narrative structure). The following questions were important from the outset of the study:

a. Story content. First, were there patterns in the content of narratives? Three areas—biology, agency and context--were of particular interest:

i) The interpretation of biology and depression. This refers to how participants speak of biological aspects of their condition and how this changed over their experience of depression. This may range from a full adoption of a language of biological bases for depression, to a mixed reception of this language, to a complete rejection of this language. Alternatively, there may be

multiple ways of talking about biological contributors—with meaningful differences between them. In cases where psychiatric drugs are used, the following issues were earmarked as important to analyze:

- How often do narrators attribute improvement or deterioration to a primarily biological change (response to the drugs) versus something else (life experience, relationships, the depression itself)?
- How are uncomfortable effects of the drugs portrayed in the narrative—especially the milder discomforts such as numbness?
- What is the person’s lay definition of “getting better”? What is their personal definition for when a medication “works”?

ii) The interpretation of agency and depression. This refers to how individuals generally speak of having capacity to manage, resist, or be free of depression in the course of their experience (and how this changes over time). This includes biology talk, but goes beyond it—ranging from an “intrinsic locus of control” highlighting their personal agency, to an “extrinsic locus” emphasizing external determinants (as well as to middle ground combinations of agency and constraints) (see Stoppard & McMullen, 2003). This quality will be reflected in how they talk about what depression is, how it began and whether or not it ever ultimately ends. Are improvements and downturns in depression attributed to areas within their control or outside of their control?

iii) The interpretation of context and depression. This refers to how the person generally talks about surrounding contextual factors. I was particularly interested in how participants would speak of their community context. Sarason (1974) called on community psychologists to make “sense of community” a central focus of research and practical attention. This sense encompasses feelings of “belonging, identity, emotional connection, and well being” (Fisher, Sonn, & Bishop, 2002). I sought to understand how participants interpret their sense of community over the course of the depression—including feelings of belonging, identity and emotional connection. Do they report relationships growing stronger or weaker through the experience of depression? Did taking a medication affect their relationships at all? Where has the individual gone for support over the course of their experience? Whom has he/she trusted and relied on (and how has this changed over time)? To what degree does the person rely on professionals versus the natural community? How well do they judge members of their natural community as understanding and empathizing?

b. Story structure. Besides examining basic narrative content, I also planned to investigate the structure of stories—how each individual presented and framed his/her experience. This would include attention to structural elements in how the story is organized or “packaged” and how the tale is developed—i.e. plot, characters and themes (Coffey & Atkinson, 1996, p. 57-

58). Where is primary attention focused in the narrative—to ‘everyday life,’ to biological changes, to professionals? Who are the main characters and how do the basic “plots” compare?

After illustrating trends in actual verbatim text across Chapters 3-5 and briefly reviewing structural patterns, Chapter 7 examines more in-depth meaningful differences in the nature and content of differences across participant stories. (As reflected in this Chapter 3, direct examination into the narrative structure itself was much less extensive than other types of analysis. For reasons described there, investigation of narrative structure across accounts ultimately remained only at a most basic level).

3. The continuity of stories: How are narratives maintained? I was lastly interested in exploring what processes contribute to the narrative being maintained over time. This analysis extends the previous exploration of narrative structure (how narratives are presented) to examine how particular presentations *function to perpetuate the narrative over time*. What constitutes the active strategies that reinforce or cement particular narratives and how do they function to sustain them? These may include denial, reliance on authority, resistance, and intense dedication characteristic of “conversion” (Karp, 1997)—as well as basic choices in whether to discard one account in favor of another, combine them in seemingly contradictory ways, or pursue some kind of integration (see Gammel, 2004). These strategies may become especially evident when participants discuss events that challenged their understanding. In these instances of challenge, how did narrators interpret experience to preserve their stories? What aspects of narratives serve to immunize narratives against change or further entrench them?

As noted in the literature review, individual engagement in experience is not solely a cognitive affair. Analysis of this question thus addressed emotional aspects of narrative maintenance. For instance, how might emotional “clinging” (Karp, 1997) to biomedical interventions cement a particular narrative? On the other extreme, how might fierce anger against psychiatry stabilize a certain counter-narrative? Beyond structural aspects of the narrative, analysis on this point has aimed to address contextual and biological aspects of the experience that may be contributing to maintenance. Are there patterns of physiological or contextual experiences (particular responses to medication or family reactions) accompanying the sustaining of a particular narrative over time? How are ensuing experiences taken up to reinforce narratives? After illustrating trends in actual verbatim text across Chapters 3-5, Chapter 8 examines explicitly themes in how stories appear to be maintained over time.

To be clear, any themes identified in these questions areas are not reflective simply of the objective occurrence of events or experiences, as would be the case if analysis had centered on event-based questions such as “how many resisted medication?” Neither, however, are these

themes mere interpretive patterns, as would be the case if analysis had exclusively centered on the question, “how are participants framing/interpreting their experiences?” While both of the above questions play into the overall analysis, themes identified in the upcoming chapters largely center on the *interplay* between interpretation and experience across accounts. In addition to asking how varied *experiences* are *being interpreted* across accounts, analysis explores the circumstances, contributors and processes associated with these interpretations *arising* and being *maintained* over time. These latter questions require attention to nuanced patterns in the interplay between common experiences and interpretations over time. In this way, the themes identified in upcoming chapters systematically articulate evidence of salient patterns in how particular interpretations arise and are maintained by participants over time.

Analytic process: Phases in the examination. Moving on from the analysis plan, how did examination actually proceed? After completing interviews and transcription, analysis began gradually over the coming year, with an analytic structure for chapters beginning to coalesce late in 2006. During this period, I listened to the interviews while reviewing the transcripts, then coded the interviews (as detailed below). Finer-grained analysis of these codes began in November and December, with follow-up clarification/update calls to participants taking place one year later in early 2008. During this time, I finished writing up results, submitted a draft to my co-chairs, and revised this draft based on their feedback towards preparation for my defense.

As noted earlier, analysis proceeded in “waves”—ranging from memos in the interview itself, to early analysis of the memos transcribed to produce a preliminary coding tree, to comprehensive analysis of the interview text based on this coding tree. Descriptions below review early- to mid-analysis and writing decisions, then finally the summative decisions made on how to analyze and frame the results.

1. Initial analysis: Making and examining memos. Memos recorded during interviews were transcribed and analyzed for each participant, including first of all, salient patterns and themes within each individual. Next, I identified “things to look for” more broadly across accounts, including preliminary conclusions on salient differences and commonalities in stories. Many of the specific “codes” used in the formal coding tree were generated in this initial analysis of memos.

2. Main formal analysis: Coding of transcribed interviews, followed by analysis within codes. As a rough initial coding “tree” was organized, the second formal wave of analysis began as this framework was applied to the transcribed interview text. Rather than remain “set,” this coding tree evolved throughout the analysis as additional codes were generated and some initial

codes were abandoned—expanding and elaborating upon the rough initial coding frame. In addition, I would record additional memos as I coded—keeping a blank document open where I would write additional insights, comment on particular verbatim excerpts coded, or make note of anything not fitting in the current set of codes (and not calling for the creation of an additional code).

Since there are many ways to approach coding, it is important to clarify how I approached the actual task of coding. For a sample of participants selected randomly or in a way representative of the larger population, very often coding centers on identifying the frequency of particular ideas or themes. As noted earlier, however, rather than aspiring to general representativeness, my sample was purposively selected to maximize variation. While the range of views was consequently diverse, certain views were not reflected as much as others; only two participants (of 14), for instance, were strongly concerned with psychiatric treatment, with the majority generally favorable to medical treatment or ambivalent. Given this set of views in the sample, basic frequencies did not appear to be as valuable a part of analysis.

For this reason, more than the frequency of particular themes, coding primarily aimed to capture the *variety* of themes available—exploring the nature and qualitative differences between accounts. For instance, I sought to explore varied reasons cited for resisting medicine and wanting to taper it. Overall, I found different participants offering unique insights and lessons across accounts. While one individual elaborated on her sharp ambivalence about treatment, another shared exquisite detail about his growing conviction of the importance of medication. As a whole, this group of participants offered a rich variety of views and emphases—a smorgasbord which seemed a good match with a thematic, qualitative approach. This kind of an approach to thematic inquiry is consistent with the way Karp (1997, 2006) has analyzed his interviews with depression survivors.

To concretize the approach I have taken, a tangible comparison is helpful. If depression treatment interpretations were African wildlife, this project would be an attempt to identify the *kind and varieties* of species (and perhaps glimpse something of how they came to be different), rather than an attempt to “chart the prevalence” of different species. I looked to other kinds of studies—large-scale surveys of public attitudes, for instance—as more well-positioned to assess the quantitative scope of a particular interpretation. (As evident in Chapters 6-8, many of these broader survey studies form an important backdrop for my final analyses as well).

Throughout analysis, I sought to be careful of perhaps the greatest danger of qualitative research: over-eager self-narration of others’ stories —“using them” to justify the researcher’s

own views. Was I really listening to what experience means to them, or just “overlaying” my initial analysis?

Typically, this danger is addressed through attempts to be objective and control one’s own subjectivities in different ways. In this case, rather than seek to escape my a priori views, I sought to acknowledge my own interpretations as a critical and inescapable backdrop for analysis. Specifically, I began this project with concerns with the general societal confusion about medical treatment, and questions about whether the medications were really helping or not. I also wondered as to whether medical treatment might potentially prolong depression in the long-run.

While acknowledging the role of researcher pre-understandings in this way, they need not set the “agenda” for analysis. That is, the fact that I began with these pre-understandings *did not mean* my analysis had to center around finding evidence to fit my views. On the contrary, acknowledging researcher views at the outset, allowed, I believe, a more transparent and public accounting of whether and how these views were open to being tested and challenged in the study itself. In other words, if an audience knows what a researcher’s general inclinations are, they may adequately judge whether the study was an honest and fair examination of the subject matter (in spite of these biases).

As another way of holding myself open to being contradicted, I adopted a *particular way of engaging* text in which expectations are held “gently” enough to allow the text to jump out and teach the researcher—a kind of “dialogue with the text.” As noted in the introduction, this project centers on both theoretical and empirical questions. Overall, transcripts were analyzed in a dialectic fashion—moving back and forth between “tracks of analysis” theoretically and empirically (Alford, 1998). In other words, as I examined how data informed my empirical questions (nature, adoption and maintenance of narratives), I “zoomed out” to explore implications for larger theoretical questions (nature of depression transactions; nature of depression). From this perspective, analysis was about letting go of rigid pre-categorizations in my immersion in text—letting myself be taught.

My specific methods of doing so varied. Sometimes I would cut and paste a paragraph of text that puzzled or challenged me into a blank document, then begin writing my thoughts and questions in an attempt to find an interpretation-of-their-interpretation that was satisfying. Other times, I would actually dissect a piece of text, getting close up and taking it apart, looking at its parts. As noted previously, throughout analysis, I continued to memo about ideas that came to me during the process—both in direct encounters with the text (interview events, coding transcripts) and in random moments unassociated with the dissertation.

Preliminary themes were created from this preliminary analysis of memos, with additional ones added as coding continued. Eventually 30 coding categories were created and classified into clusters to facilitate the progression of the coding process. There were 648 coding references total, and 16 possible sources cited. A detailed description of nodes, their meaning and the number of references and sources for each node is elaborated in *Table 1: Meaning and frequency count of interviewing nodes*. After coding was completed, analysis moved to a more fine-grained analysis within codes, examining the various patterns across comments. The following five chapters (3-7) are all dedicated to the sharing of resulting patterns and conclusions from interview analysis.

3. Final analysis: Examining the broader meta-story. As part of this final analysis, I wrestled with how to make sense of diverse interviews of people with such remarkably complex and variable experiences. Originally, my intention had been to compare whole narratives. Since accounts were so diverse, however, and limited to 14 people, I opted against comparing them exclusively or primarily on the level of “whole narratives,” relying more centrally on thematic analyses instead. The exceptions to this are Chapter Three’s synopses of all narratives and a short section in Chapter 7 examining overall narrative structure. In this way, most of the analysis of narratives is carried out in a thematic way, rather than a traditional structural/functional approach. Eventually, I settled on two primary ways of trying to capture and present my understanding of this complexity:

First, I sought to identify themes of major events highlighted within participants’ narratives, especially those that seemed relevant to the formation and perpetuation of those same narratives. These ranged from vignettes of initial confusion at facing depression and early influential encounters with friends and family, to moments of personal crisis and varied experiences of medical treatment. After identifying these patterns or themes associated with events, I decided to order them (in Chapters 4-5) within a general temporal framework according to what point in time they seemed to be relevant to the adoption and maintenance of particular depression interpretations (rather than merely listing them thematically with an arbitrary ordering). In this way, glimpses of broader patterns could be seen across stories. Although in a sense, the contours of a “meta-narrative” across stories may be evident, I resist claiming to identify an underlying, essential “story of stories.” Instead, this chronological, linear structure for presentation serves as a helpful backdrop to organize and make sense of the most salient, meaningful characteristics of individual stories and patterns across accounts (both similarities and differences).

Once again, to be clear, it is important to emphasize that the themes which follow do not reflect the “full story” across participants. As explained above, this was not my aim. Instead, since my particular questions relate to the experience and interpretation of medical treatment for depression, I gave preference in analysis to any events, circumstances and interpretation that seemed relevant to this area. I decided that an attempt to address “all interesting themes” at once would distract and dilute from the central line of questioning. Given this, other more peripheral themes, such as the role of community, are addressed in other places, such as the broader discussion of the nature of narrative/interpretive differences in Chapter 7.

Since a central value of this research is the richness and power of stories themselves, the central chapters (3-5) focus primarily on accounts of participants themselves—serving as a platform for individual narrators to largely⁶ speak for themselves. As will be observed in these chapters, the complexity, diversity and richness of individual accounts is remarkable.

Even while attempting to maximize interview text and minimize my own interjections in these early chapters, of course, my own voice as a researcher is never absent. I alone made decisions about which text to include, how to order it in general themes and present it in a temporal ordering. In this way, my own research voice comes through in this first section as the narrator of the skeletal “meta-narrative” across accounts, a counterpoint voice walking through this meta-story like a tour-guide.

To be clear, however, little effort is made in these initial three chapters (3-5) to explore and parse out explicitly what these key events and narrative aspects have to say about the broader empirical questions. Instead of analysis and deliberate discussion, this first section centers more on the text itself, aiming to offer a felt and concrete sense of individual narratives in both close-up examination of two whole accounts and then across narratives. Although empirical questions are each addressed within this section, possible answers remain largely implicit, allowing explicit attention to remain largely focused on the actual narratives themselves. The presentation of individual synopses *within narratives* (Ch. 3) and themes *across narratives* (Ch. 4-5) becomes a dual platform for the analytic chapters that follow.

Subsequently, later chapters explore insights relative to empirical questions more explicitly. In individual chapters, the adoption (Ch. 6), constitution (Ch. 7) and maintenance (Ch. 8) of stories are addressed, with overt attention to what key events and aspects across individual narratives might mean for each of these issues. It is in these chapters that the implications of

⁶ I say this while acknowledging that a goal of having participants speak for themselves *completely* is impossible, unless I deny the role of my own interpretations (even in these first descriptive chapters, they underlie the design of the study, the formulation of its questions, the choice of which comments to highlight, how to cluster quotes, how to order them, etc.)

narrative patterns for the broader empirical questions are examined in an explicit way. In these later chapters, findings from this study are juxtaposed with insights from the broader literature on treatment interpretations/perceptions in a montage or “patchwork of voices” (Rich, 2006, p. 286).

This structure reflects roughly the “results” and “discussion” format of traditional research reports. The first section (Ch. 3-5) largely centers on the “showing” of narrative excerpts relative to the adoption and maintenance of particular narratives both thematically and within individual accounts. The final section (Ch. 5-8) moves to a more overt “telling” of what these excerpts might mean for the adoption, constitution and maintenance of depression narratives. “Discussion” in the traditional sense thus emerges in the latter section, culminating in the final conclusion section (Ch. 9).

Chapter 3

Summarizing Individual Narratives of Depression and its Treatment:

“So tell me your story. . .”

This and the subsequent two chapters describe the actual narratives themselves. This review is carried out in two ways. First, in this current Chapter 3, a brief synopsis of each participant narrative is presented--a summary sketch of how each individual essentially sees his/her experience with depression and its treatment. Second, in Chapters 4 and 5 salient themes across participant narratives are presented. Subsequent analytic chapters draw on these three more descriptive chapters in discussing more overtly how narratives arise and are maintained over time.

To preface this chapter, three qualifications are noted. First, rather than summarizing what a person “experienced,” these synopses attempt to summarize how each individual generally *packages or narrates* what they experienced. Second, rather than convey an in-depth, detailed narrative analysis, the following chapter simply reviews synopses reflecting basic sketches of individual accounts. The reasons for this are that a sample of 15 felt too small to form the basis for very compelling comparisons across whole narratives. Also, I thought that thematic analysis across accounts (the focus of Chs. 4-5) would better capture the insights needed to inform my main empirical questions. Third, because diverging interpretations for the medical treatment of depression are central to this study’s questions, how individuals see medication within their overall narrative is privileged in what follows (relative to how they see all kinds of other aspects of their depression experience). This was an additional reason for relying on thematic analysis more than that of full-narratives, with the latter arguably more appropriate when equal emphasis is given to all possible aspects of a narrative (i.e., how individuals narrate psychotherapy, surrounding friends and family, etc).

While some stories were relayed in a coherent, flowing narrative, others shared their experience in disjointed bits. Among other things, this difference may have reflected how often individuals had received the opportunity to share their story previously (with several admitting they had shared their story in forums on multiple occasions). Another difference was reflected in the amount of insight and self-understanding individuals seemed to have into and about their own story. While some individuals offered a running commentary of serious contemplation on the events being relayed, others primarily conveyed details of the events themselves, with much less self-interpretation.

Pseudonyms are given to each person. Since a great deal of verbatim from each person will be shared, and since these excerpts are scattered across seven chapters, I hope names may also assist readers in discerning individual story-lines across chapters. In order to protect their identities and maintain confidentiality, I also avoid sharing too many details of demographics or extraneous background information of participants. Instead, synopses reflect summaries of key themes and highlights from each participant's narrative. To conclude this chapter, a brief analysis of the narrative structure across accounts is given (with a more extensive analysis of narrative content awaiting Chapter 7).

Individual Narrative Synopses

Laying aside two individuals excluded from analysis (see section below, participants 1 and 14), the following summaries reflect snapshot accounts of individual narratives of depression and its treatment.

(2) *Elaine*: This married woman in her 50s, with grown children, spoke very slowly with dramatic, emotional language and deep pain still evident in relating her account of facing bipolar depression and anxiety. Much of Elaine's depression narrative referred to a mixture of ebbing, but ongoing confusion and fear. To begin, she elaborated at great length on the intense confusion she experienced at what she was initially experiencing when depression first hit. This included reports of personal perplexity at no seeming explanation for the emotional paralysis of depression, as well as emphasis on the confusion of surrounding friends and family as a burden for her as well. The pain and confusion got so bad that she joked to her brother that she wanted to get in an accident—prompting family pressure to seek treatment. The doctor's explanation of chemical causes for depression relieved her confusion and she experienced an almost miraculous initial effect of her first anti-depressant in helping her cope with and handle her emotions, as well as sleep well for the first time in a long time.

After this climax, she related the effects of medication fading and the long search to find the right next medication and dosage level that would duplicate the earlier effect. She also expressed intense fears about the future—especially what she would be like without the medications. Although recounting her first encounter with depression as a time of intense stress (raising seven children, running two businesses and going back to school), her external environment remained largely in the background of her narrative of facing depression—with her attention given to how she came into contact with doctors, what the medications had or hadn't done, and what she hoped they would do for her in the future. Although still searching for a

return of the treatment relief, frustrated with the number of current medications and expressing some interest in tapering, her story remained one of general redemption⁷ by treatment.

(3) *Camille*: This middle-aged married woman with younger children also spoke slowly and quietly about her experience with anxiety and unipolar (seasonal) depression. Similar to Elaine, Camille spoke frequently of the emotional burden on her, associated with surrounding family members' confusion. In her case, she was directly challenged as to the reality of her experience—including insinuations that she was just lazy and should “snap out of it.” Camille's account seemed to center more around the trauma of these kinds of comments—reflecting a story of being a victim of this surrounding stigma.

Similar to Elaine, Camille found the biomedical explanation to be deeply relieving—even prompting her to travel to California to receive a SPECT scan providing visual evidence of her biological deficit. If there was a protagonist/hero figure in the story it was this practitioner, effectively addressing the antagonists (those critical of her behavior). Although having mixed results with medication, she was largely comfortable continuing treatment. In the face of surrounding stigma, it was biomedical diagnosis, rather than medical treatment itself, that seemed to function as Camille's major vindication and redemption.

(4) *Sarah*: This middle-aged woman with older children spoke in an animated, energetic way about her experience facing and managing post-partum depression and occasional anxiety. The beginning of depression in Sarah's story was a period after a pregnancy. Like Elaine, Sarah recounted poignant moments of confusion both personally and for loved ones about what she was facing. Similar to Camille, Sarah highlighted being questioned by her ex-husband about the nature of depression—and contrasted this with unconditional support from friends and other family members. A first turning point came when a neighbor friend introduced the idea that depression could be caused by a chemical imbalance. Though initially fearful of the related notion of chemically treating depression, this ongoing relationship was mentioned multiple times throughout the narrative. Sarah emphasized her own surprising aggression toward her children as a climactic, crisis moment prompting her to seek treatment.

A spiritual experience in the hospital was a turning point in accepting medical treatment and believing she was called to help others facing depression learn to do the same. This was a second turning point in her story—reporting that it galvanized her commitment to continue treatment. Although her initial experiences on medication were not as dramatically positive on

⁷ As detailed in Chapter 6, “redemptive” sequences have been defined by narrative researchers as “an affectively negative or bad life-narrative scene . . . followed by an affectively positive or good outcome” with “the good ultimately redeem[ing] or salvag[ing] the bad that precedes it” (McAdams & Bowman, 2001).

others, she vividly recollected the first really good sleep she had after starting a second drug. In addition to her family, the influential neighbor was the major protagonist in her account—helping to reassure her and help her stay the course after experiencing difficult states concurrent with treatment (her ex-husband being the major antagonist). Although Sarah also spoke of learning major lessons as part of her recovery, it was her evolving openness to and relationship with medication that occupied the foreground in her narrative. Sarah’s story centered on the process of overcoming her own resistance and fears regarding anti-depressant medication through a series of events that gradually cast away her ignorance in the process of coming to a personal acceptance of medication as key to her recovery. A major part of that embrace was becoming an advocate to help educate others. Along with Peter’s story related below, Sarah’s account went beyond the typical pattern of redemption to an especially vivid account of conversion to medical treatment.

(5) *Victoria*: This middle-aged married woman with one small child spoke quietly and deliberately of her experience with unipolar depression. Like others, Victoria highlighted the confusion of depression and initial struggle to explain it. A first turning point came, like Sarah, in a conversation with a friend who encouraged her to seek medical treatment. Although acknowledging some difficult side-effects, her emphasis was on dramatic initial improvements in emotional control on the medications. At a point where side-effects led her to consider tapering, she spoke of a second turning point/defining moment of being taught by a doctor that she should be grateful that she could be on medications the rest of her life. In a pattern seen with Sarah and Peter as well, Victoria spoke of learning to deal with major life changes, while retaining a major focus on medication itself.

She spoke often of her husband’s amazing support for her. He, along with an influential neighbor, were cast as protagonists in the story—with God being emphasized as the main protagonist throughout (no major antagonists). In a way very similar to Sarah, Victoria spoke of a divine hand she saw as guiding her first to diagnosis, and then to the right doctors and treatment levels. Like Sarah, she also emphasized a sense of calling to share what she had learned with others. Two climaxes of her account both involved painful moments emotionally and physically where, in both instances, help came that she saw as miraculous. Although not as intense as Peter and Sarah’s telling, Victoria spoke of a redemption through treatment that included a long process of conversion as well.

(6) *Lucy*: This younger married woman in her twenties shared an especially painful story—spanning vicious abuse as a child, to a terrifying burden of depression and other severe emotional problems later on, including auditory hallucinations, attention problems, obsessive-compulsive disorder (OCD) and bipolar depression. In the middle of her early abuse, she

recounted being taken to the doctor and put on Prozac. Although critical of her doctor for not picking up on the abuse, Lucy herself also consistently downplayed the role of past abuse in her ongoing emotional problems. Instead, Lucy's story centered on the experience of seeking a correct diagnosis and finally receiving better treatment support.

A turning point was when she was introduced to a mental health advocacy organization that helped educate her about depression. Subsequently, a major theme of her story was the failure of surrounding professionals to accurately identify her correct diagnosis and supply adequate treatment (mentioning several friends who killed themselves due to a lack of treatment as well). In different ways, then, bad doctors were the antagonists of the story. Three times during the interview, Lucy mentioned the lack of a proper diagnosis and consistently emphasized her suffering as needlessly resulting from not "getting med levels right" in the last three years. The experience of receiving a correct diagnosis, although described as rocking her identity in profound ways, was clearly a defining moment of her account. One good doctor and her mother were mentioned as protagonists of the account—offering her the support she needed at the right times. A climax of the story was her mother rushing home at the right time to find her after she had cut her wrists. Although Lucy acknowledged difficulties with the medications and questions about biomedical explanation, she also became an advocate for the medical treatment of depression and had frequently shared her story with others to encourage them to seek help. In a way similar to Elaine, although Lucy had some ambivalence at the level of treatment relief, her story remained one of general redemption by treatment.

(7) *Jill*: This middle-aged married woman with older children related an account of facing unipolar depression for many years. In spite of a "dread" at being tied to pills, the combination of a local woman killing herself and aggressive behavior to her children lead her to become fearful and reach out for help. Like Elaine, Jill spoke of receiving a diagnosis as comforting--especially being able to offer an explanation to surrounding family members.

Although mentioning a positive impact of her anti-depressant, she spoke even more of sexual side-effects and her lack of being able to "feel deeply" in a spiritual sense (the latter, a theme that arose several times). Overall, Jill's narrative reflected striking ambivalence about treatment. At the same time she expressed conviction that recovery wasn't possible without medication and encouraged psychiatric treatment for others in her family, she struggled to justify the same for herself and remained, in her words, "sitting on the fence."

Like Victoria, Jill recounted a doctor encouraging her to be thankful she could be on medication for the rest of her life. In contrast to others, however, Jill's initial resistance to medication did not appear to abate. Rather than a long process of conversion, Jill's account

reflected a long process of limbo-like ambivalence and tension. In a way similar to Elaine and Lucy's lingering frustration (but more intense), Jill's story seemed to have less of a definitive end—instead, remaining open-ended in the presence of ongoing worries, questions and resistance. Among those who spoke of medication as having lifted them to some degree, Jill's redemption account was the mildest. As she started feeling better, her desire to taper would frequently return, although failing in her occasional reported attempts to do so.

Aside from a brief criticism of public figures (Tom Cruise) who criticize those taking medication, there were no major antagonists. Encouraging family members, including children and her husband, were protagonists.

(8) *Debbie*: This middle-aged married woman with children recounted a long fight against dysphoria and anxiety associated with challenging times. After being offered Prozac as part of a study, she tried it and reported feeling like “Superwoman” with energy to do everything she wanted (a climax to her story). After these initial effects faded, she joined Elaine in detailing a journey of trying to find a drug and dosage to duplicate Prozac's original effect. Similar to Jill, Debbie's narrative of depression treatment largely centered around ambivalence—wondering out loud at one point why she could convince others of the importance of antidepressant medication, while struggling with the notion herself. Also parallel to Jill, Debbie related desires to taper that ended in failure. For her, one such attempt was another turning point, as she saw emerging turbulent emotions as a return of depression; subsequently, she went back on her medication, convinced by the experience that her depression was undoubtedly chemically-based. Although not as intense in her questioning as Jill, Debbie's account was almost nearly as centered on ambivalence and reflected the second weakest story of redemption via treatment.

(9) *Robert*: This married man in his twenties described facing emotional downs his whole life—particularly unipolar depression and anxiety during times of great stress. Although struggling with blues much of his life, it was during his religious “mission” that he started to be especially bothered by it and was recommended by his religious leader to try medication (a first turning point). After a scary period of considering suicide (second turning point/climax), Robert recounted his family pressing him to begin treatment. A series of these difficult, stressful experiences were emphasized as prompting the emotional turbulence he experienced.

Compared with his reported skepticism regarding early treatment, it was the noticeable impact of a later medication that began to change Robert's mind (third turning point). In the pattern of Sarah, Peter and Victoria (but to a much less intense degree), Robert's story reflected a redemption via treatment following a conversion process of coming to embrace his crucial and ongoing need for medication. Although Robert continued to highlight the role of stressful

situations, like others, the medication was emphasized as the major solution. Aside from a supportive family, no major protagonists or antagonists were mentioned.

(10) *Peter*: This single man in his twenties had also faced emotional problems his whole life—including challenges with panic, anxiety and unipolar depression, as well as some attention difficulties. Peter was the only participant that emphasized early confusion with depression as much as Elaine—“why was I feeling this way!?” Like Sarah, Elaine and others, he subsequently experienced significant relief from biomedical diagnosis. He remained, however, reluctant to try medication until a major break-down at his workplace lead him to a willingness to “try anything.” This break-down moment was both the climax and turning point to Peter’s story.

After commencing treatment, he reported experiencing huge improvement—with improved emotions directly correlated with an increase in dosage and coming to feel his best on its maximum dosage. Peter spoke of remarkable support from protagonists such as friends and family, and highlighted help from God multiple times as well (like Sarah, Kellie and Victoria). Although also reflecting on personal changes involved in recovery, for Peter, medication was clearly emphasized in the foreground as the basic building block on which other components of recovery rested. Alongside these other changes, it was the results of finally giving medication a chance and the process of coming to an acceptance of treatment (like Sarah & Robert) that occupied the centerpiece of Peter’s narrative. With Sarah, Peter’s account likewise went beyond the typical pattern of redemption to an especially vivid account of conversion to medical treatment.

(11) *Fern*: This older divorced woman with grown children spoke of long-term dysthymia associated with stressful occasions—especially, the serious marital trauma of her husband’s unfaithfulness and eventual abandonment after many years (major antagonist/climax). Unlike many other accounts, the grief and pain of this stressful experience for her children and herself occupied the foreground of her story. While generally “not a medication person,” Fern spoke of betraying her “personal code” at one point and seeing if anti-depressants would help. After experiencing some benefit in avoiding negative thoughts for a period, she started to feel out-of-body and less control. This upset her enough to stop medication for good. This whole experience was related as a minor, secondary event, compared to the tremendous emotional cost of her husband’s betrayal on the family. While there were major turning points related, she did speak of finding help and some degree of redemption in spiritual experiences.

(12) *Kyle*: This middle-aged married man with children recounted relatively recent experiences with bipolar emotional challenges—severe bouts of depression accompanied by manic episodes during stressful times. Like Elaine, Kyle recounted his first bout with depression

as having a defined beginning, being “smacked” by depression in the middle of a busy period where he was trying to complete renovations on his home by himself. During a period of mania, his wife signed papers to forcibly commit him to a hospital for treatment. Combined with negative psychiatry encounters prior to entering the hospital, this uncomfortable experience was a climax that raised many critical questions in his mind. Although Kyle recounted a period where he tried medications with some degree of success, a turning point came when he experienced fairly severe side-effects and went to consult with a psychiatrist. When the doctor suggested they add Wellbutrin to the current treatment, Kyle felt uncomfortable and said, “I’m not going to be a poly-pharmacy experiment.” He left the appointment and began to read literature from those critical of psychiatry. While challenged by family members in his rejection of treatment (wife and father were antagonists), Kyle reported growing interest regarding non-medical treatment options (in her support to introduce him to alternative sources, his mother was a protagonist).

Similar to Michelle, a turning point for Kyle was coming across a professional who believed he could recover. After adding Omega-3s and adjusting his life-style to prioritize good sleep, Kyle’s depression subsided. Ending up as a volunteer advocate to educate people on the *harms* of psychiatry, Kyle’s story reflected a kind of mirror opposite to Sarah’s account, above. That is, rather than overcoming resistance and fears regarding anti-depressant medication, Kyle related a series of negative experiences with medication that galvanized growing and deepening opposition to psychiatric treatment. Similar to Sarah, Kyle’s account likewise reflected a story of having ignorance gradually cast away through learning experiences, albeit in the opposite direction and with an outcome of increasingly resisting medical advice. In contrast to many other redemption accounts, Kyle essentially saw his redemption in *avoiding* psychiatric treatment, alongside his embrace of non-medical interventions for his depression. Like Esther, the primary narrative plot was the learning process following negative treatment experiences—with personal research leading to a rejection of the system and the embrace of an alternative.

(13) *Michelle*: This older divorced woman recounted facing severe recurring depression and other delusional problems after a long, abusive marriage. Similar to Lucy, Michelle mentioned little or nothing about the previous abuse in her account—instead focusing on the nuances of treatment and overall recovery. Alongside several suicide attempts, her long process of treatment included multiple hospitalizations and electro-convulsive shock therapy (ECT), with doctors eventually concluding she had no chance of ever living independently. She spoke of that moment as a defining moment, that lead her and her family to believe for many years that recovery was not possible (the doctor who told her she would not live independently was an antagonist). A climax of her account came at an in-patient facility that showed some trust in her

to choose whether she could leave. This was followed by another defining moment/turning point of later hearing the story of a woman in a state even worse than she was, who had nonetheless come to live independently again thanks to a recovery program.

Michelle went on to emphasize her experience in the same Copeland “Wellness Recovery Action Plan” program as her literal redemption to regain the capacity to live again independently. Like Kyle, simply hearing that recovery was possible was a major turning point in her account. Those individuals who introduced her to the possibility of recovery were the clear protagonists/heroes of the story. Rather than coming to an acceptance or rejection of medication, the primary plot of Michelle’s story was coming to an acceptance of the idea of true recovery. While medication continued to be seen as important to her stability, it was the recovery program alongside other physiological changes (e.g., stabilizing her blood sugar) that were emphasized as the thrust behind her improvement. From this backdrop, the central theme and overall emphasis of her account was the importance of remaining open to recovery for those facing severe emotional problems. Like others, she had become an advocate for those struggling with depression; rather than advocating regarding medical treatment specifically (for or against), her educational efforts centered on spreading the message that recovery was possible.

(14) *Esther*: This middle-aged woman spoke during a brief interview of depression emerging with life stressors. From the beginning, her encounters with medical treatment for depression were recounted as categorically negative—especially in having labels imposed, her questions dismissed and medication pushed. A climax in the story was when doctors decided her concerns were a sign of her mental illness and sought to contact her family to assist them in medicating her.

It was during this time, she reported starting to research on the internet for herself. She described recovery from depression as happening fairly easily—with no specific source of redemption, per say, except for a vivid emphasis on escaping “the system” in which she had been “ensconced.” Overall, these experiences were related as explanation for why she had become actively involved in advocacy efforts to educate others about the harm and abuses within the conventional mental health care system. Medical professionals and, indeed, the entire treatment system were framed as the antagonist within her account. Like Kyle, the primary narrative plot was the learning process spurred by negative treatment experiences—with personal research leading to a rejection of the system and an embrace of alternatives (see participant #15 at the end).

(16) *Kellie*: This single woman in her early 30s spoke of experiencing symptoms of low-level depression for much of her life. Like other participants, Kellie spoke of initial confusion

personally and in terms of explaining her feelings to her family. Also like several others, she related a process of coming to accept that she had a problem and needed help. Although expressing some appreciation for the legitimization of diagnosis, Kellie was unique in reporting never following that diagnosis to accept any medical treatment.

In spite of relating intensive encouragement from her brother in medical school to begin medical treatment, she resisted based on negative previous experiences with hormone medication and a feeling that depression would eventually resolve over time. Like Fern's account, medication thus remained largely in the background. With the support of a remarkably trusting and supportive family, Kellie sought to understand other reasons for her depression and reported gradual healing over time. Similar to Sarah and Victoria, Kellie emphasized divine support as key in her recovery—although, in her case, God's guidance never directed her towards medical treatment. Rather, Kellie spoke of learning major life lessons at different points throughout her experience that were critical in her recovery. Her family and God were major protagonists emphasized in the story. The overall theme of her account was the gradual, unfolding nature of recovery. Given the consistency of her views over time and relative stability of her recovery, there were no major climaxes or turning points recounted.

Individual Narratives Not Used in Analysis

(1) *Veronica*: This divorced woman in her late twenties shared an account of difficulties associated with the death of her father and other challenging transitions in her life. Many aspects of the narrative suggested the “depression” she faced was non-clinical and qualitatively different than other depression accounts. For this reason, as explained in the previous chapter, her account was eliminated from formal analysis.

Although recounting difficult events such as her father's death and a divorce, her comments never pointed towards depression invading her life as in other narratives. Instead, she spoke of “getting depressed” almost casually. The pain expressed in her account, compared to the others, seemed qualitatively different—as did the challenge of getting better (her recovery occurred fairly rapidly and easily—like a cold). In other accounts reviewed below, by contrast, life events almost necessarily remain in the background given the intense pain of something else concrete and terrifying occupying the foreground.⁸

⁸ Beyond the simple confirmation that “depression” means different things to different people, this illustrates on a deeper level, a critical qualification in the study: a reaffirmation of something existing clearly “beyond the narratives”—i.e., that depression is not something made by interpretations alone. Among those critical of mainstream psychology, it is popular to emphasize discourse or surrounding institutions as “making people sick”—and sometimes suggest mental illness is a “myth” (Szasz,

(15) *Alicia*: This single woman in her twenties spoke more of her experience facing eating disorder than that with depression, which was relatively brief and associated with one traumatic event. Different aspects of her story suggested her depression was likewise not clinical—and did not seem to appropriately compare with other participant narratives. Along with the first participant, her account was also eliminated from formal analysis.

Basic Narrative Structure Across Accounts

As a first basic way of examining the nature of narrative differences across individuals, we turn to basic patterns in how each individual presents and frames his/her experience—i.e., structural elements in how the story is organized or “packaged.”

As reviewed in Chapter 3, the themes and overall plots of narratives differed in interesting ways.⁹ Since the invited focus was their experience facing depression, stories were naturally oriented to their journey facing and seeking to overcome this problem. Most every account subsequently reflected some kind of general “redemption” sequence (McAdams & Bowman, 2001)—although the source of this deliverance varied in striking ways.

For the majority of participants, their account emphasized medical treatment as the central player in redemption. This emphasis ranged from the strong, enthusiastic testimonials of Peter, Sarah and Victoria to milder endorsements from Jill, Lucy and Debbie.

For a few participants, acceptance of such treatment was fairly easy. For the bulk of others who reported experiencing resistance, their accounts could be seen as variations around one similar plot: the journey towards fully accepting medication—translated for some as “finally giving treatment a chance.” While most had reached that point, those who had not were still aiming for that goal. Against this broad theme, the details of barriers varied—from personal

1960/1994). While attending to surrounding cultural factors and raising critical questions are both important, I believe this should be done without questioning depression itself. There is an external reality to depression without which the surrounding interpretations explored in this study would be irrelevant. While the way we *frame* this reality is one of my questions, this inquiry should not be confused with contesting the *reality of depression itself*. Amidst an exploration of diverging ways of interpreting depression, the entity of depression itself need not be seen as just a construction of these interpretations—“merely a construct” or a “figment” of the discourse. On the contrary, it is very real and tangible—so much so, that when other individuals such as Veronica and Alicia who have experienced a sorrowful time come to label and narrate this same event as “depression”—it simply does not fit. While drawing on similar language and terms, these personal narratives do not succeed in transforming a different experience into the kind of experience related by others. To conclude, this becomes an illustration of how interpretation is being approached in this study: inescapably linked to the “brute” reality of surrounding context, bodies and depression itself.

⁹ *Note*: As outlined elsewhere, my study design and specific questions lead me to conclude that thematic analysis would reveal answers better than whole-narrative comparisons. For this reason, only brief analyses are made below in how different tales are developed (see Chapter 7 for more extensive look at key issues underlying meaningful narrative differences).

resistance to family resistance and from improper diagnosis to incorrect prescriptions. In spite of such differences, a primary theme of these narratives was the growing acceptability and centrality of medications in resolving the problem of depression.

In addition to accepting and receiving medication as a primary solution, related themes included seeing the warning signs quicker (prevention) and spreading the truth about mental illness to the general public and families who misunderstand. Many participants also spoke of the importance of making changes to one's thinking, learning life skills and the importance of loving community.

A small sub-sample of participants likewise spoke of redemption, but as coming from other primary sources. For Fern, it was healing from an abusive relationship with God's help (11); for Kellie, it was receiving divine help to learn key lessons and make changes contributing to her depression (16); for Kyle it was tapering off medication and changing his lifestyle in terms of stress, nutrition and sleep; for Michelle, it was finding those who believed she could recover and getting her blood sugar stabilized (13); for Esther, it was largely becoming free of the mental health and medical system itself (14). Beyond the general theme of resisting the medical system, other related themes included personal changes, learning skills and the importance of loving community, as well as additional physical treatments that may impact depression.

Across accounts, the main actors ranged widely, with roles often portrayed in either a positive or negative light. Overall, those largely favorable towards medical treatment for depression spoke of positive "hero" figures that included a religious leader and mother encouraging treatment (Robert); friends and neighbors encouraging treatment (Victoria & Jill); a brother who is a doctor (Camille), good doctors (Lucy), validating, supportive parents (Sarah, Victoria & Peter), and a friend who faced depression before (Sarah). For this same cluster, negative "villain" figures included an apathetic husband (Elaine & Sarah), others critical of psychiatry—i.e., Tom Cruise or surrounding family/friends (Camille, Sarah & Jill), bad doctors seen as not giving competent treatment (Lucy, Michelle), an abusive husband (Michelle) and an abusive father (Lucy).

In contrast, for those generally unfavorable towards biomedical treatment, positive "hero" figures included critics of psychiatric treatment (Kyle), family members who introduce alternative interventions (Kyle) and supportive family open to the individual thinking for herself (Kellie). Negative "villain" figures included those encouraging treatment (Kyle & Esther), professionals pressuring individuals into treatment (Lucy, Kyle & Esther), patient advocacy groups encouraging treatment (Kyle), and a neglectful/abusive husband (Fern).

Chapter 4

Interpreting the Problem: Making Sense of the Monster.

The previous chapter reviewed brief synopses of each individual narrative. Accompanying this *within-narrative* review, I now turn to thematic results *across-narratives*. The following two chapters begin to orient the study more explicitly towards the main empirical questions—exploring key experiences and events across accounts standing out as especially relevant to the adoption, constitution and maintenance of particular depression interpretations.

Narratives of depression reflect characteristics similar to any story. Just as any tale involves an antagonist and protagonist, so also depression stories may be approached in two parts: the development, engagement and interpretation of the foreboding challenge itself (“problem definition/interpretation”) and the ensuing engagement and interpretation of helpful answers (“solution definition/ interpretation”). This chapter examines key events associated with interpreting the problem of depression itself, while the next explores events associated with interpreting possible solutions for depression. More specifically, this chapter includes the following areas and events identified as critical to the formation of narratives, called “problem interpretation” themes: 1) *The brutal reality of depression*; 2) *The added burden of confusion*; 3) *Answers offered*; 4) *Formal diagnosis* & 5) *Moments of climax*.

Rather than list these key experiences only thematically, they are presented below temporally in a way that highlights similarities and differences in helpful way. Once again, with the focus on offering a felt and concrete sense of individual narratives, no effort is made in these chapters to explore and parse out *explicitly* what these aspects have to say about the broader empirical questions—leaving this task to the overt analytic chapters which follow (Chapter 6-8). With “results” remaining largely implicit here, the attention in the next two chapters remains focused on the nuances and richness of experience reflected in the actual narratives.

Furthermore, whereas later chapters hone in more directly to contributors and strategies in the adoption and maintenance of narratives, these chapters take up themes across accounts in a broader fashion. That is, themes range from basic snapshots of reported experience to specific patterns of how these experiences appear to be interpreted. In this way, while these chapters are largely focused on what participants reported to have happened in their stories, subsequent chapters focus more exclusively on the nature, contributors and implications of how these happenings are variously framed or narrated.

Theme 1. The brutal reality of depression: “I thought it would kill me—all on its own.”

The terrifying pain that hijacks and saps its victims constitutes the basic backdrop against which individual narratives unfold. On average, participants spoke of facing some form of severe depression for an average of 9 years (range from 1-18 years). Reports often centered around states of overwhelming paralysis—“like I was trying to swim through mud” (7); “Day to day tasks like putting the wash from the floor into the washer . . . overwhelmed me and I would just start bawling” (2); “indescribable effort to force myself to do anything” (4); “even *simple* tasks, uh, just become . . . terrible, just unbearable (9). Elaine specifically linked this inability to accomplish anything to mental chaos—“My thinking at the time was really log jammed I mean I couldn’t produce coherent sentences practically and I had ideas that were just . . . coming from everywhere; I couldn’t put rational thoughts together. . . [I felt] totally out of control as a person.” She continued, “I just felt sick. I just felt like I was just wired just, totally, like I was just coming totally unglued all the time. Like I just couldn’t handle it, you know . . . and I was just spending days just bawling too, you know, just crying my eyes out and just totally, totally, totally stressed out” (2).

Two individuals spoke of lashing out at others—“I’ll say just about anything to just about anybody” (10); “Everything would make me frustrated . . . I would snap, start snapping at everybody and irritated all the time. . . You cry all the time; you’re snapping all the time, hateful (*laughs*), you’re tired, it’s just a terrible thing. Terrible” (7). Elaine commented on another common response:

Just a desire to..to just bury yourself.. To just get away from everything . . . To escape life, to escape thinking about what . . . needs to be done, what could happen, what... what is happening that I should be doing something to help with. . .What’s going on in life..just be..away, away from everything. And not have to think about anything, and not have to interact with (*sigh*) people . . . you kind of almost wish you weren’t there at all. . . .¹⁰ I feel like, I mean, I could sleep for days when I was going through the worst of it--just to get away, to not have to think about life.” (2)

Three others spoke of escaping the pain through sleep or watching television—“Crying comes easily, sleeping all the time” (7); “I didn’t want to get out of bed ever” (9). I forced myself to get out of bed . . . I’d come home from work, I’d eat some dinner, and I’d just go lay down (16). Peter said, “I was shutting myself off from everything. I would watch TV, but not really, you know. It was just noise in the background; I was not taking anything into my mind; my mind

¹⁰ Throughout, I have sought to be precise and consistent in my use of ellipses. Reflecting prevailing standards, four ellipses (. . .) suggests material removed between two sentences (in a few rare cases, one sentence has been reordered to come before another to reflect a more coherent overall statement); three ellipses (. . .) indicates material removed within one sentence and two ellipses (. .) generally reflects a natural pause or break by the speaker himself or herself. Italics reflect the emphasis of the speaker as well.

was so locked down in depression” (10). Peter further related his deliberate attempts to isolate himself and avoid attention from surrounding friends and family:

As I got older, I learned not to lash out but I learned to turn inward . . . and so what I would do is I would walk around with my sweatshirt on and my hood pulled down, you know . . . I’m a big guy and I’m easy to pick out of a crowd. But you’d be amazed how easily a person can disappear if they want to . . . the right combination of clothing . . . colors and keeping your head down you can become a ghost and I did and I got very, very good at it. (10)

Others likewise spoke of “faking” it to friends (16)-- “There was still part of me that was struggling all the time. Um, even though sometimes on the outside it seemed like I was doing pretty well” (9). The true pain, however, was readily acknowledged—called “hopelessness” (11), a “black hole” of “no hope for the future” (12) and “free falling” into a “a bottomless pit” (13). Robert said, “it numbs you and becomes the point that . . . you forget what being happy is like” (9). Camille said, “It’s like being enveloped in this thick darkness that no light can penetrate. . . . I would call it hell, like being in hell. There’s no joy, there’s no . . . no matter what you do you can’t find happiness. Who wants to live that way? I wouldn’t wish that on my worst enemy” (3). The most graphic depiction came from Lucy, as repeated earlier, a younger single woman who compared depression with her early encounter with vicious child abuse:

I have had very bad beatings to the point of unconsciousness, ripped, broken and arms taken out of socket and that compares *nothing* . . . doesn’t even *begin* to be the pain that became every day, just right here . . . like this thing that wouldn’t come off—that made it hard to breathe . . . like, I would rather have, every day, just hours and hours of people beating the shit out of me than to been where I was just inside. It *hurt* that bad. It hurt so bad that there were times I thought it *would* kill me—all on its own, that I wouldn’t have to do anything. (6)

Theme 2. The added burden of confusion: “I couldn’t figure out why”

While the brute pain described above is an inescapable starting point for these stories, it is an aspect of depression fairly well-acknowledged. At closer-view, there is another burden evident across accounts that is more subtle and far less recognized generally, namely, intense personal confusion at what one is facing. Not everyone mentioned confusion, such as those who had felt blue for so long they assumed it was a part of life (Kellie & Robert) and others who had experienced obvious reasons to be depressed (Fern, Lucy). 7 of 15 participants, however, spoke of some kind of confusion faced at the outset of their experience with depression. Said Peter, “The thing that made it so frightening (*pause*) and so . . . difficult to handle was that I couldn’t find where it came from. It seemed to come out of *nowhere* . . . I would wake up feeling sad . . . or wake

up feeling angry and I *couldn't figure out why*. How can you be sad when you *wake up*? Nothing *caused* you to be sad!" (10). Elaine similarly recounted:

It's always the same thing, you know. There's nothing really to say. There's no explanation; there's no reason that you're depressed really, I mean, like. . . I know that when I lost my little grandson, when we went through that [*Sudden Infant Death*]-and that's the most horrific kind of thing in the world, I mean, my daughter put him down for a nap at nine a.m. and he was gone at quarter after ten, you know--and I had all these daughters that were just heart-broken and I was heart-broken and that was a very depressing thing, but I've been far more depressed over absolutely nothing, you know, just in this place. I can't explain what it is. (2)

Peter and Victoria highlighted the personal challenge ensuing from this confusion:

That's part of the reason that the depression hit me so hard. I would always say to myself "I'm a smart guy, why can't I control this?" You know, "I'm an intelligent person"--I had good morals and I take care of myself; "why can't I handle this? I should be able to handle this!" (10)

You have a brain, you have a body, you know what needs to be done around the house, you know what needs to be done . . . to take care of your family and it's just like, there's no reason on earth you shouldn't be able to do it. . . . I just kind of felt like someone had put a hundred pounds on my shoulders. I . . . couldn't see any reason why I felt this way." (5)

Others expressed similar frustration with the discrepancy between normal desires and expectations for life and one's ability to reach them. After commenting on her lack of "backbone" to do anything during her depression, Elaine went on to describe how she felt like a "failure as a human being--because I had just really been knocked off my feet and I just couldn't do anything. . . . I just had to be the most worthless person; I had been so active and strong for a long time (2)." Kellie said "I just lay there feeling terrible about yourself and wondering, "what is my problem?" You know, "why can't I just make myself shape up and do something?" She spoke of forcing herself to get out of bed, "I got to the point where I'd just have to get angry with myself. It was the only way to get something accomplished." (16).

In addition to not being able to feel normal sorrow, Elaine went on to highlight the perplexing contrast with positive life experiences as well. "And I have a wonderful life too. I mean I have what most people would consider the ideal, perfect kids and you know perfect (*laughs*) what most people would consider a really great life so that's what's so stupid. Everybody's, "what in the world could you be depressed about?" (2). Others pointed to the contrast between their dark feelings and a positive ambience--"Even though the flowers were out and . . . the warm sunshine it was . . .doom and gloom" (4); "[it] doesn't matter how many lights I turn on in the house . . . I still feel like it is so dark" (5). Elaine further commented on her previous joy of Christmas and Disneyland as a grandmother--"if it was something that I used to

find fun, there was just no fun in it and I just would feel so bad that I really couldn't enjoy those things that normally you just (*laugh/cry*) are supposed to enjoy so much."

Beyond the individual confusion, the puzzlement of surrounding family and friends also appears to have a significant impact in "ramping up" the urgency for an explanation. As Kellie said, "It's hard for family and friends to understand that you really, really, *really* are not doing this intentionally" (16). Elaine recounted, "[My mother] feels like [depression is] something that, you know, you wouldn't have if you've really been living right . . . but I really have tried pretty hard (*laughs*)" (2).

While many friends and family provide helpful support, their behavior was often described as complicating things, ranging from being resistant, questioning, and challenging one to exercise more will-power, to being annoyed, angry, exasperated and believing treatment is evil. When asked, "Has your current understanding of depression ever been challenged?" Camille said, "Yes by people who've never . . . who don't understand, who think that you can just decide to be happy and snap out of it. . . . I tell (*laughs*) them, 'do you think anybody would choose to live this way? Don't you think if I could just snap out of it and decide to be happy I would have done that a long time ago?'" (3). Elaine related wishing there was some kind of video tape she could show her husband designed to "teach families that it's not this huge character flaw (*laughs*) that it's not just laziness and um . . . orneriness . . . that you could bring home and just ask your family to sit down for thirty minutes and say, you know, this is normal to expect" (2).

After describing her own struggle with misunderstanding of others and her initial fear that she was "going to lose it," Lucy noted, "you need a place to point your finger to where, who's making it happen or what situations made you get to that point . . . because, at first, you just need someone—it needs to go somewhere" (6). Referring to her own period of "overwhelming, slogging . . . tiredness," Jill recollected wondering, "what's wrong, something must be wrong with my body for me to feel like this? (7). Sarah spoke of her initial desire for answers so great that even the possibility of a serious physical deficiency felt like a relief, "Why am I crying all the time? Um, you know, just the confusion of what's going on with me. . . . I mean, I even thought maybe I have a *tumor* . . . if I have a *tumor* then they can put a name to it and I can get it fixed" (4).

Theme 3. Answers offered: "Let me help you . . ."

A third salient theme across accounts was the prevalence of early moment of influence from friends or family, with 6 of 14 participants recounting some kind of initial moment of influential counsel by a friend or family member in their early stages of decision-making about

how to respond. For others, messages came from a medical professional or through television or books. Sarah offered the most vivid example in recounting the following experience after her negative feelings first arose:

I had a very dear girlfriend that lived up the street that saw the warning signs in me. And Emily came to me and explained her story of depression which started for her when she was a teenager. . . She said, “let me help you. I really feel like you are exhibiting the symptoms that I suffer. . . I’ve been down this road; let me help you.”. . . She said, you know, “let’s get you in to see a good psychiatrist, get you e-valued and start you on medicine.”

While resisting this suggestion, Sarah described the pain getting worse and becoming more confused. Her neighbor offered further assistance:

And Emily [said] to me, “Sarah (*sighs*), it’s the lack of serotonin in your brain” and I go “serotonin what in the heck [is that]?” And so she described it in a really simple way that our brain has neurons that will fire up each morning. So on this side, one says “Okay, Sarah time to wake up [and] get the kids off to school” and it will swim across the serotonin bridge to a receptor, a connector and when it gets there that enables you to get up and, you know, go on with your day. Well when that serotonin bridge is broken, there’s no, I mean, it can’t get to that connector. So they’re swimming around and so the confusion in my brain was like “Wahhaha,” you know, and I thought, “okay that makes sense. I can understand that.” And then she said, “and no matter how hard I tried to think positive it was only negative and, I mean, that’s the only door that was open”. . . And I loved it because she had been there and she could put it in simple words to me, you know, to make it click.

A later experience helped reassure Sarah even more about the serotonin imbalance theory of depression:

So a friend of mine who knew I had really been suffering sent me a book. . . and it had pictures in each chapter and there was this picture of this Mom and she was sitting at the kitchen table and she was frazzled. There were dishes on the table; there were piles of laundry behind her; her kids are throwing the laundry, and I went “that’s me” and that was my first connection, like “oh my gosh. That is what I’m feeling.” So, boy did I read. I was hungry you know. . . it was actually the picture in the book that I saw of that woman. You know, I was reading through and I was going “yea . . that sounds like . . yea, okay!” and [it] has really simple pictures of the sero- . . the neurons, and the serotonin bridge and just and I’m going “ooh, that’s what Emily was trying to say to me.”. . So then, when I saw the picture of that woman I went “ah ha . . . yup, that’s what I have.” Then, I read on to the part about medications and it showed that same mom. Now her hair is done; she’s pushing her little daughter and it’s saying people can lead, you know, go back to their normal everyday life. So that gave me, you know, more concrete hope . . . it was like, “okay, I wanna look like her. I mean, I wanna look like me again and I wanna be able to do those things.

Other accounts reflected similar moments of influential counsel. Camille related, “It was actually my mother who put things together . . . long before doctors were actually recognizing it, my mother had already pretty much diagnosed it (*laughs*) in me and. . . Yes she read me the

article and we're going, 'ok yeah. That's me; that's me; that's me.'" (3). Victoria described a dinner party with a friend in the days following a crisis experience involving suicidal thoughts:

It was just about 3 or 4 days after that, in which some friends had invited us to dinner. . . . She and I were sitting in the kitchen and I just felt, just kept feeling like [I should] tell her about this, you know, tell her about what happened. It was persistent, I mean, I just, I couldn't hardly think of anything else. And so I just said, "Anne, you know, could I talk to you about something?" And she says, "sure." I told her about this experience and umm (*sniff*), she's a psychologist. She said, "Victoria, you need to get in and see the doctor since you got depression," you know. "You gotta go, and you gotta see him right away." And umm she said, "the two things you need to do is you need to get on some medication and you need to get into some counseling." And umm I said, "well I umm . . ." you know, I brushed it off but I did promise her I would go to the doctor. So I made an appointment for the next day, went in, saw him and he says "Oh yeah your depressed" and they start me on Prozac. (5)

Kellie spoke at length about the efforts of her brother, who was enrolled in medical school, to first educate her about the nature of the problem she faced:

My sweet brother, he realized that I was--I don't know if you want to call it stubborn . . . that I wasn't taking action--and he was worried about me, so he talked to me once and took me aside, and tried to help explain to me what different drugs were available to help me . . . said he was concerned about me and he wanted me to maybe think about trying some medication. He said "Kellie, You've been depressed almost your whole life!"

When she resisted, he sought to detail the medical school rationale for the treatment:

One time he took me aside and wrote on the white board and explained things, like you know, what goes on in the brain with serotonin, you know, taking the different tracks. . . . He was just trying to help me, explain to me, what happens chemically in the brain when, see, I don't even know enough about it to explain it now. But at the time he explained it, and I understood. But, um, yeah, he just explained what happens when there is a, I don't know if it's a chemical that's not present, I'm not exactly sure how it works, but he showed me what medication would do, and how it would help, um you know, persons who are depressed; it would help reverse that, that process, so. (16)

In addition to the influence of friends and family reviewed previously, participants mentioned doctors' advice as meaningful. Jill related, "Well my family practice doctor's the one who put me on [medication] in the first place, and so he was quick to . . . he was the one who picked up that it was depression right off the bat" (7). Media messages were also referenced. Sarah said:

You know, I remember, you know actually it was the *Zoloft* commercial . . . it's the little blobs, you know . . . and it's sad and it was raining on him and it was gray and then he went [and became happy] . . . I went "Ahh that's the first commercial". . . I remember saying, "that's the first commercial I've seen . . . on anything that addresses depression." (4)

Debbie spoke of a news report on an athlete who killed himself, and added:

You hear radio ads, you know, always doing the sampling for research studies, medications, commercial on the TV that say, “okay, do you have this and this--all these symptoms?” and you think, “well, I’ve got (laughs) ten out of the fifteen so I must have something,” so whatever. (8)

Jill spoke of her relief to hear of media figures sharing about their experience with depression: “There have been celebrities that have written about their own depression. I remember when Rosie O’Donnell wrote in her magazine came out that she had depression. Um, there’s been, like Patty Duke and uh, what’s the gal that played prince- Carrie Fisher are bipolar, both of them.” She reflected, “I think that helps ‘cause you start to feel like, “well, now everybody else will understand it more because this celebrity person has come out about.” There was actually . . . a news anchor . . . that recently has written about his depression and Brooke Shields just wrote her big book on post-partum depression.” She continued, “In 2001, a book came out called ‘The bipolar child’ which I think opened up a lot of [us]--especially for those of us that had kids. You read in that going ‘Wow,’ you know, ‘that’s my son’” (7).

Theme 4. Formal Diagnosis: “I was kind of relieved. . .”

A fourth theme in all accounts was how the experience of formal biomedical diagnosis was variously interpreted. Although true “objective diagnosis” was not a main question of interest, a rough attempt was made to verify the general “objective” conditions faced among the participant sample (whether from formal diagnoses received by participants or from what formal diagnostic criteria individuals appeared to most closely resemble based on their accounts). Based on this analysis, across fourteen participants, seven either reported or appeared to have faced some kind of major depressive disorder, three individuals bipolar depression, three post-partum type depression, two seasonal-type depression and three low-level depression (dysthymia). Six other participants expressed simultaneously facing severe anxiety (OCD, Anxiety Disorder, Panic Attacks), two serious attention problems and two, hallucinations. It was contrasting ways of responding to and evaluating the experience of being labeled with one of these conditions, however, that revealed the patterns of interest. While some had difficulty recalling diagnosis experiences and three were largely neutral with little to say, most participants made some kind of evaluative comments about diagnosis (including those who generally avoided doctors and diagnoses altogether). Of these twelve, responses to diagnosis varied widely—from reports of intense relief, to persisting ambivalence, to deep reservations.

The largest subset of participants spoke of diagnosis as being a relief, ranging from intensely positive evaluations (Elaine, Camille, Sarah, Jill and Robert), to a mostly positive

response (Victoria), to a mixed evaluation including both positive and pained feelings (Lucy). Several spoke of the satisfaction and comfort of having a “name and explanation for something you know is going wrong” (Robert/9): “just to have a name to call it was almost comforting, you know . . . in the idea that enough people have it that they bothered to give it a name . . . so that was actually quite helpful to me” (Peter/10). Elaine, who expressed a burden of significant confusion previously, related:

I remember when the doctor told me that she felt like I was bipolar . . . I actually felt like, you know, it explained . . . um, I don’t know, like she was telling me that it this is something that was treatable--that it was an illness; that it was something that had to do with my brain not working the way it was supposed to work.

Although “not pleased with the idea that I was mentally ill,” Elaine spoke of feeling encouraged with the idea she was facing “something that was treatable” via medication to “stabilize my moods and hopefully clear up my thinking.” She added, “so I was pretty scared in one way but I was also kind of relieved in another,” grateful that her doctor “was encouraging that I could live a fairly normal life if I could stick with my medications and stay on them.” In the face of her mild ambivalence, Elaine told of later encounters that helped her emotionally accept the diagnosis further, starting with a religious leader comparing depression to being hit by a car—“if your arm had been cut off, we wouldn’t tell you to go read your scriptures and pray more (*laughs*); you [would] need to get to a doctor and get the help you need (*laughs*).” She added:

I’ll just never forget when I read a book that said telling someone with depression to pull themselves up by their bootstraps and “just do it,” is like telling somebody who’s had a heart attack to run to the top of a mountain. You know, there’s really no difference. There’s something physically wrong and . . . something wrong with your brain and it’s not working and you can’t force your brain to do something it can’t do anymore than you can force yourself to run to the top of the mountain just after you’ve had a heart attack.

She concluded emphasizing how reading this made her feel “a little bit better about myself” since she had an explanation for not being able to make herself do something while depressed. Others who felt similar to relief with diagnosis expressed similar interest in seeking further validation. Debbie said:

I know I’ve read things on how they can actually see [the brain] and I’ve often thought, “now why can’t I get into this or why does it cost so much?”--where they can look at the brain and see how things are formed and different areas and then be able to prescribe medication. Is that true or have you heard? I’m thinking I’ve seen Dr. Phil or you know different shows that they’ve had specials on that and, or I just wish there were a blood test. (8)

Camille recounted the following experience:

I went to California and saw a Dr. Daniel Ayeman who does what’s called a SPECT scan and mostly it’s done to diagnose patients with ADHD and when we got the scans back, it

showed um there was an area that was just totally grey meaning that there wasn't . . . that part of the brain had kinda shut down. And he explained to us that that part of the brain was the part that managed time--not only being able to get places on time, but organizing your time and accomplishing things, managing money, and all those kinds of things were controlled by that part of the brain that was not functioning (*laughs*). It was great for me to have a picture of my brain that showed, "Hey look! This isn't working." (3)

In addition to offering relief for one's personal confusion, biomedical explanation and diagnosis thus helped legitimize the struggle before individual's friends and family as well. Jill reflected:

For the most part, people know that it's a real thing now. . . . One thing that was nice is I found a booklet--I think I got it from the *NIMH (National Institute for Mental Health)*. It was a little booklet for children about "why is mommy so sad," and I loved that because it helped me sort of explain to my older kids at the time why I was so sad all the time and crying and tired and I liked that. (7)

Not everyone, however, experienced such thorough relief with a biomedical diagnosis. In spite of her relief to be diagnosed and "know that I wasn't alone," she added, "I just didn't like what she was telling me, that I'd have to take medicine and I'd have to stay on it for the rest of my life. You know, it was a relief to go "oh, okay, I can grasp that but don't tell me I'm going to have to stay on meds" (*laughs*). You know what I'm saying?" (4). For Lucy, the conflict was striking:

Two really combative emotions came up when I was diagnosed—one was "God, thank you!" . . . you know, "I'm not insane—this is a real thing. It's in a book somewhere . . . we can start working on it." There was a relief that I wasn't alone, totally, anymore. And . . . it didn't feel so stuck anymore." But then . . . in a way, it made me feel more alone too, cause I was like "oh, it's not a cold that's just going to go away or I can't take some penicillin and look back and go, 'oh, that was crappy'"—so it . . . makes you realize that this is something that's going to be with me for [good].

She continued:

It might be crappy, but at least I know everything. But then on the other hand, it was so defeating, you know, "it's not going away--this is me," you know—and that's sad. You feel like you lose yourself, almost. Like a part of you dies when you're diagnosed. . . .

*J: It's a relief, but a part of you dies?

It's almost like a grieving period realizing that the person that was faking it for so long--she wasn't real. And she kind of did die and that we had to reinvent and restructure this new being, almost. That we didn't have any information on what would make it better . . . it was almost like we were constructing a new being, you know? Giving her the tools and the revenues, making sure she had insurance all the time, you know? I mean, it's hard . . . [you] *do* feel a detachment from everything you thought you were when this becomes where you're at, because this is *not* who I was suppose to be.

Two individuals referred to diagnostic explanation as demeaning and misguided in various ways—expressing hostility to their experiences. Esther, a younger single woman, said:

I've had a multitude of labels . . . and most of them I didn't pay much attention to . . . because only once . . . did my psychiatrist actually sit down and actually *do* the *whole* interview you're suppose to do. Every other time I got labeled it was just guesswork—and I was . . . a couple of times labeled by professionals when they went back and got my medical records and I had never met them and they had never met me. (14)

Kyle, who had once been diagnosed with manic depression at one point, said:

It's too easy to say, "You're bipolar. Take either Depacote, Zyprexa, Lithium, Geodon, Topomax" (*laughs*), you know, it's too easy. But the way health care is now, you know, maybe a doctor doesn't have time to check to see if you maybe have an underlying Lyme disease, maybe you have an allergen, maybe you have, you know, thyroid condition, um. That's my, that's the problem I see, it's too easy to, to put a label on someone without digging deeper.

He later added, "To be fair with the doctors, how can they have time in 10 minutes to figure this stuff out?" He related the following experience during a meeting of the *Depression, Manic Depression Association (DMDA)* support group:

They had a special night where they had a psychiatrist come in and, and, and it was "ask him anything you want." . . . And one woman said. . . . "My son was just diagnosed with ADHD last week and, this was her first appointment with him and it was only a fifteen minute appointment and he was diagnosed with ADHD and prescribed . . . *Ritalin*," and she goes, "can you really diagnose ADHD in fifteen minutes?" And he goes, "Well it is possible in fifteen minutes. It maybe takes longer, but yes, it is possible." And I raise my hand and go "Excuse me." I go, "You're willing to say that in fifteen minutes you can stigmatize this kid for life and give him a schedule two drug, um, and you didn't even check his thyroid? You didn't check for allergy, you did nothing but, but, but write in your little prescription pad . . . You're willing to do that to a kid?" And he goes, "Well maybe it would be okay to take a thyroid test." But, I mean, this crap is happening all over! Um, so that's frustrating to me.

Kyle concluded, "Any kind of diagnosis like that is not liberating. . . .at all. . . . *Just* putting a *label* on a, on a *behavior*, um it doesn't do any *good*, it's not gonna help find root causes, not gonna, you know . . . 'take your meds, you know . . . for life' and some people do that and that's fine, um, it's not the way I want to live life. He further added "once someone is diagnosed they say "it's a lifetime illness. *Lifetime*. Never get better" (12).

As here reflected, concerns about biomedical diagnosis naturally extend to biomedical treatment as well. Once again, some did not reflect any initial resistance to suggestions of treatment. After being told by her doctor about a depression medication study, Debbie related thinking, "well, okay. I'll give it a try and if it does anything . . . we'll just see" (8). At least initially, however, most participants reported experiencing some degree of resistance to the thought of beginning psychiatric treatment. Robert, for instance, who was grateful for a diagnosis said, "Medication, that's for babies. That's ridiculous. . . . I don't want that." Fern said, "I have always been a person who dislikes taking medication. . . I just have never taken drugs at all on a

regular basis. I even have arthritis now and it's difficult to decide to take some *Tylenol* even when it hurts a lot" (11). Kellie, the one participant who never accepted medication, mentioned past experiences underlying her hesitation—specifically, an extremely negative encounter with hormone medication that wreaked “havoc” on her body:

There are a lot of good medicines out there, but there are some that basically just mask symptoms and do not actually heal the body, and because I have had to deal with such issues myself from, you know from taking those hormone pills, I think it was kind of like, “Nope!” It was like, “No way! Before I ever take anything like that again, no matter what it's for, I'm going to be very cautious and find out everything I can about it.”

Kellie went on to mention the expense of medication as an additional factor, as well as concern with “that mentality, too, of ‘I don't want to be tied to a drug to keep me going’” (16).

While reflecting varied degrees of reluctance with medical treatment, it is worth pointing out that interviews did *not* confirm the broad stereotype of people “looking for easy answers” with medication. On the contrary, participants showed great care and caution in their exploration of this option and evidence that this is a difficult decision to make. After being encouraged to start Prozac, Fern recollected thinking, “okay [is] this is just going to be a *crutch*? What's going to happen to me? Am I going to be *dependent* on this forever?” (11). Jill and Peter spoke of their own similar initial concerns:

I saw my grandmother, you know, for years and years and years tied to her pills and I dreaded that. I really dreaded having to (*sigh*) think that for the rest of my life, I've got my pharmaceutical cocktail that I take every day, you know (*laugh*). (7)
Well that's originally the reason that I put off going to uh a doctor for so long, you know . . . I don't want to be dependent on something (pause), you know, I want to be independent and I want to be, you know, “I can take care of this myself,” you know. That was my outward stance and my inward frustration you know that I couldn't . . . I really, really didn't want to take medication. . . . I told him, “I'd like to avoid drugs if at all possible.” (10)

Theme 5. Moments of climax: “I've got to get some help”

A final theme documents some early moments of significant drama that appear to have a notable impact on individuals' course of action (and associated interpretations). Seven of fourteen participants spoke of some kind of early traumatic moment as reinforcing the seriousness of the problem and stimulating their interest in seeking medical treatment. These included difficult break-ups (Camille, Sarah, Robert & Kellie), betrayals from intimate partners (Fern), major stressful changes (Robert, Elaine), thoughts of suicide (Victoria, Jill), actual suicide attempts (Lucy, Michelle) and panic attacks (Peter).

It was in the middle of raising seven children, going back to school and working as a nurse while running several businesses, that Elaine eventually had a “complete mental physical emotional breakdown.” During this time, she spoke to her brother, who was a medical doctor:

[I told him] that I found myself trying to figure out a way to get into a car accident that would be just bad enough to put me in the hospital for a few weeks so I could get some rest, you know, without hurting anyone else . . . and so he immediately hooked me up with a psychiatrist and said, “you know this isn’t funny. You know, this isn’t something you can play around with any longer.” (2)

For Jill, a tragedy in the local community heightened her own urgency:

When I got really bad in 1993, I just, I was afraid. About the same time this lady in [our city]—they found her body, she had had depression and she had taken her life and they didn’t find her for six months. So I was afraid that this would happen to me and I knew that I wouldn’t want to do that, but it’s like the depression takes over; and I was afraid it would do that and I didn’t want that to happen. I reached out for help. (7)

In addition to possible violence towards self, others are pressured by the possibility of harming others. Peter faced regular, lengthy panic attacks associated with his depression; after another one hit him on the way home from teaching school, he decided he was putting children in his classroom in danger by not seeking help: “So that moment that I made that choice (pause) was a huge turning point. . . . I called my mother and my father I called them both and I said uh “guys I’m coming home” . . . At that point I decided to seek help” (10).

Others are impacted by their own actual (surprising) outbursts towards others. Jill described a distressing moment of kicking her child (7). In addition to the conversation with her brother, Elaine said, “the things that sent me into the doctor was I hauled off and smacked one of my kids. I’d never done anything like that before in my life. . . . I’d had a little bit of experience of that with my own mom . . . and I just wasn’t gonna do that, so I ran right to the doctor and said ‘okay now. I can’t be like this’” (*laughs*) (2). Finally, Sarah related two crises events that impacted her powerfully: .

[My husband] was out of town and I thought, “okay, I can make pancakes”—but it was like . . . indescribable effort to force myself to do anything. . . . So I gathered the kids up to the kitchen bar and I’m whipping up pancakes. . . . and I started making them and they were just chit chatting among each other—Not fighting or bickering or anything, but it was so loud to me. It just, I was frustrated and I took a *Corelware* . . . and uh I slammed it on the counter and . . . it went into . . . slivery thousands of [pieces] and I just screamed; and I was not a screamer or a yellor and I yelled, “will you kids just shut up!” And . . . they all just sat there and I started bawling and Lisa said, “what is wrong with you Mom?”

She later related a second experience of giving her baby a bath and wanting her to be quiet, when she started crying—“I just, you know, I just needed her to, I mean, to be quiet. . . . and at that point I knew a little bit of what some of these moms feel who, for one reason or another

drown their babies.” That thought “scared her to death” and prompted her own crying; she called her neighbor immediately and said “Come get my baby. I can’t take care of ‘em; I can’t take care of my family” (4).

Among other things, these rock-bottom/climactic moments seem to “ramp up” even further both personal and collective urgency towards some kind of decisive action. After his panic attack after school, Peter related:

Things had gotten so bad for me that I said, “I’ll do anything . . . I will do anything if you tell me that it will make me feel better.” . . . you know. If you told me the problem lived in my finger and I had to cut it off, I would really, I would have done anything to make that go away and so . . . I said, you know, “let’s try some medication.” . . . The physician said, “well . . . it’s generally well-tolerated--no side effects . . . low side effects”--whatever, I mean, I didn’t know the . . . you know, I just knew I wanted to feel better. (10)

While such experiences lead many to a readiness for medical treatment, Lucy described hurting “so bad” that she initially used illegal drugs and cutting to stop it—since there was “No other way to hurt less” (6). Robert, who described contemplating killing himself, related the impact of this event on both him and his family:

Well, I think that from the first big episode . . . it scared me. I think it really, really, really scared me because here I was at a point where I could have killed myself, I could have done it. . . . And at that point my mom decided, she’s like, “We have *got* to do something about this. We’ve *got to*. And it’s just . . . it’s hanging on too long, and you’re just, you’re gonna . . . you’re having trouble with this. And we just, we just *have* to do something.” And so she . . . um, took me to a doctor. (9)

The combination of painful experiences and surrounding family encouragement lead many to reach a point of willingness to try medications—including some who were deeply resistant. Fern, who was quoted above as not being a medicine person, said that her own painful crises lead her to “succumb to breaking down my own personal code and taking something for it” (11). A handful of participants, however, continued to resist. After describing her medical school brother’s continued encouragement to start treatment, Kellie said, “I was to the point where I was going to take something, even if it was just to take for a few months to see how I feel. It doesn’t mean I have to stay on it forever.” She continued:

But I didn’t. I just felt like in time, usually your wounds heal. So I just figured “I’ll wait.” . . . I think it was because I really felt that I wanted to do everything in my power first to help myself . . . to try everything to exhaust all possibilities before I went ahead and took the medication. . . . [and] feeling like I would eventually find answers. . . . I just thought that everything would somehow work out, and I’d get through it. . . . I just had this feeling that everything was going to be okay. . . . I didn’t know how or when, but I knew that somehow it would. (16)

For some who remained resistant to medications, they encountered threats and attempts at forced treatment from surrounding friends or family. After refusing treatment from his psychiatrist, Kyle was forcibly admitted to a hospital by his wife (12), while Esther described doctors attempting to bypass her resistance and apply pressure via her family (14). In contrast, Kellie's situation was unique in the way her family's response:

[My parents] knew I was struggling with knowing what to do as far as having to take some form of medication, or just to get through it somehow. They didn't want to be forceful and I don't know, take my agency away and say "We're going to take you to see a doctor, and you're going to do this, and take this so that you can have a normal life again," but still [were] very supportive in me and trusted me that I would be able to find a remedy, whatever that remedy was, to be able to heal eventually.

Kellie elaborated, "Some people might look at the situation and say, 'when you are depressed you are mentally sick and you can't think reasonably for yourself.' And so, some people would say it would be appropriate for . . . a parent to even say, 'I love you, I care about you, I'm going to you know, I'm going to take you in; I'm going to get you this appointment with the doctor and get you some help.'" She reflected, "but I think my parents and my family, my parents . . . when we go to them for counsel, they have tried to listen, and, if we ask for their advice, or what they think, they will tell us, and, but, they have tried to let us make our own decisions and figure things out for ourselves. And so I think, that probably played a big role in them not just coming to my rescue and saying, 'You need some help, and we think you need to do this, so we're going to go do it.'" She concluded, "you know, it's that rescuing syndrome. . . . Their attitude was just, 'You know, Kellie, we trust you, we know that you need to find a method that you feel good about that you've prayed about.' . . . They were just praying for me that I would be able to be inspired to know what was the very best for me and my situation" (16).

In summary, the themes reviewed in this chapter help the reader understand some of the nuances associated with a decision to begin medical treatment for depression. Rather than reflect either an easy acceptance of medical advice or a hasty grasp for a "quick fix," these accounts reveal subtle and intense interpretive struggles often accompanying the decision to accept antidepressant medication. Initially, individuals frequently report a personal confusion with the nature of depression that appears to constitute heightened urgency for a tangible explanation. This becomes a meaningful backdrop to understanding the significance and impact of surrounding friends and family in their frequent role to introduce possible explanations. Although some are eager to embrace biomedical explanations, others remain ambivalent or flatly resistant—in part, for the associated implications for treatment. For some of these, the additional

influence of especially traumatic events may augment the urgency of finding relief to a point they are willing to try an anti-depressant. Not everyone reaches this level of desperation, of course, nor do all feel as driven or confused. For those who eventually start taking medication, however, the preceding confusion, wrestling and crisis constitute a literal journey to a decision.

Chapter 5

Interpreting Solutions: Fighting the Monster

This chapter centers on salient excerpts or moments across individual accounts standing out as especially relevant to the adoption, constitution and maintenance of particular depression interpretations. Whereas the last chapter centered on varied interpretations of the *problem of depression* itself, this one explores key events associated with participant interpretations of *possible solutions for depression*. This chapter includes the following “solution interpretation” themes: 1) *Starting medical treatment* 2) *Encountering ambiguous & evolving treatment effects*; 3) *Interpreting states concurrent with medical treatment*; 4) *Encountering additional influence*; 5) *Refusing treatment*; 6) *Previewing life without antidepressants*; 7) *Attempting to taper off medication*; 8) *Evaluating alternatives* & 9) *Considering prognosis and recovery*. We begin with attention to the well-recognized diversity of initial responses to medication: the good, the bad and the ambiguous.

Theme 1. Starting medical treatment: “Miracles” and “carbuncles”

In spite of aforementioned wide-ranging resistance, 13 of 14 interview participants ended up taking medication at some point. Several had difficulty remembering the names, including one woman with memory impairments from electroshock. All participants, though, listed whatever meds they could remember. 12/13 spoke of taking Prozac, most typically as the first anti-depressant they tried. 8/13 took Wellbutrin, 4/13 took Zoloft, 4/13 took Paxil, and 2/13 each took Effexor, Celexa and Lexapro—alongside several “mood-stabilizers” [Neurontin (2 people); Topomax (2), Lithium (1) Depakote (1), Lamictal (1)], several other anti-anxiety drugs [Xanax (2), Valium (1), Clonazepam (1)], anti-psychotic meds in a few cases (Seroquel) and sleeping pills frequently.

Obviously, the actual physiological/metabolic responses to these medications varied across both participants and time. Partially¹¹ linked to this diversity of biological response, personal/interpretive response to medication also varied, sometimes in dramatic ways, from dramatically positive accounts, to mildly uncomfortable/mixed reports, to those claiming little or no effects at all, to dramatically negative accounts. Considering the initial experience of taking a particular medication: How did participants respond to and frame these events? While acknowledging the diversity of a) individual types of depression, b) medications prescribed and c)

¹¹ See introduction for a full discussion of why I view the diversity of personal/interpretive responses to medication only *partially* ensuing from the diversity of actual biological response to these medications.

metabolic responses to these medications, some meaningful patterns of general interpretation emerged across accounts. In describing initial experiences with anti-depressant treatment, some individuals spoke of dramatically positive results. Elaine said:

I felt like it was a miracle . . . like I was in control of some kind of (*sigh*) . . . some kind of demon that just.. uh, I'd been possessed by. . . . It was an absolute miracle because . . . I was calm enough to handle the situation and to cope with everything and then I was able to get some sleep, and I hadn't gotten sleep for years. (2)

Debbie recollected similarly:

You know, the magic part of my life was taking that Prozac. It just seemed to do everything. I had the energy, I was losing weight I could stay up (*laughs*) until 3 a.m. cleaning and everything was organized and it was just wonderful. It was like the superwoman I wanted to be . . . it helped me with my energy--it was just the magic pill that . . there's (*chuckle*) no such thing as a magic pill but that [it] was for me. (8)

After relating a similar “huge difference” of her son starting Lithium, Jill similarly described Prozac as initially giving her more energy and helping her feel active and not tired all the time (7). In relating her “personal definition that a medication is working” Victoria said, “I just, I feel good. I mean, you know, I get things done. I have energy.” In spite of some accompanying sleep difficulties, she concluded, “but I just wake up and I’m ready to go, you know. Plus I’m running around getting things done. You know, just feeling good, feeling happy, just content, you know, very much in control--just that kind of thing” (5). Robert spoke of intermittently “really, really have a lot of energy or really, really tired” on Effexor. In spite of this vacillation, he added “but... as a general rule, I felt more outgoing when I was on Effexor, like I didn't mind talking to people. And usually I'm kind of a reserved-type person, um, at least in a lot of social situations... and, uh... So I – that that worked” (9).

Beyond the sheer physical energy, then, others spoke of a heightened sense of confidence and capability, with Elaine noting being able to “remember things and feeling more capable” (2). After starting Prozac, Debbie said that after a few weeks, “I started liking myself, I didn't have the feeling of ‘I hate the world’, and I felt I had some control of my outbursts. Therefore I didn't resist taking medication because I liked this new person.” She later added, “I like me better on the Prozac—felt better about myself, had confidence” (8).

For some, this “feeling better” had more to do with enhanced calm, than increased energy. Elaine, who spoke of feeling “SO MUCH better” with the “blessing of medication” had previously described “nerves as raw as they could be.” With psychiatric medication, she described an “invaluable” new “ability to deal with kids in a calm manner. . . I couldn't believe the difference the Xanax made in my ability to cope.” Referring to her current anti-depressant medication, Elaine concluded it “seems to handle me really well” and effectively “steadies” her

(2). In these kinds of ways, several saw meds as “maintaining a level of being able to function”

(11). Sarah recollected finally being able to rest:

I remember the first good night sleep I got. When the Paxil, had kicked in, I can't remember if it was a month or you know four weeks or whatever when I had let's see...started on the medicine I can't remember, Jacob, if it was . . . but it was just like I could lay my head down and relax my body knowing that I wasn't fearful to get up the next morning. That sounds so weird, but it was like it was a relaxed, sleep finally. You know it was like “Ooh.” (4)

For some, this calming effect was related to particular ways the medication seemed to prevent negative thoughts from running amok. Fern described Prozac as helping her “not think about so many of the things that were going on”: “if my brain was starting to focus on a negative thought that [Prozac] would divert me from that thought. That's my basic understanding of what happened” (11). Robert and Peter both mentioned less background noise and out of control (“spinning”) thoughts. On an emotional level, others spoke of less emotional static, “downs” not as long, “ups and down” not as intense, and more hope overall. After initially speaking of rapidly shifting mood swings from “one afternoon of bliss” to “*bam*, right back into the dumps. . . my emotions were still just going out of control,” Peter shared one of the more dramatic accounts of starting medical treatment:

I could *feel it* starting to get into my system . . . and for the first time in my life (*pause*), once the medication started to kick in I would wake up calm. . . and for the first time in my life, I was able to use logic and say “you know what? It's gonna be all right.” . . . and then I could move on with life. . . After the medication came through it leveled me out.

He continued with descriptions of changes in his treatment:

When I initially started the medication I started on a lower dose (*pause*) and all it produced was the sense of calmness just the sense that “okay, my mind is not spinning anymore. Now anything could still set me off” . . but I wasn't already going (*pause*). As we upped my medication, um, I began to get that sense of confidence... that sense of uh “it'll be all right,” that sense of control over my emotions.”

Peter continued, “it didn't dull my emotions in any way it just controlled them you know it's not as if I'm never sad it's just you know I'm not always sad you know so for me it's been a very positive experience.” As reviewed earlier, he came to see increased control and confidence as directly proportional to the amount of medication, reaching the following climax:

We finally brought me up to--there was actually a little while there, where I was taking more than the suggested amount. We got our wires crossed--the doctor and I--and I ended up taking (the suggested max is 225mgs), I ended up taking 300 mgs a day and I felt invincible, I felt like a million bucks... I'm on the maximum (safe) dose right now and I have to say my life has never been better.

As individuals talk of feeling better, they also often mention how medications have helped them feel more normal or “myself” again. Peter, who had initially emphasized the pain of feeling out of control, further explained how medication helped “clear away” the “emotional static” in a way that “made that person [his ideal self] accessible to me . . . and now I feel like I am that person or at least I’m close” (10). Sarah said, “[I] found me again” (4), with Camille testifying that “I finally feel like me again and even though I still experience the seasonal depression to some degree, it wasn’t as bad as before” (3). From only a small sample of thirteen participants who took medications, obviously the reported initial effects are dramatic and compelling.

Not everyone, however, saw initial benefits from their experience with medication—with a range of negative reports as well. Victoria, who eventually had better experiences on medications, said that medication initially “weird[ed] me out something awful.” Although she had been recently promoted at work for her skill in improving a friendly atmosphere, she described her feelings after taking Prozac:

I just felt angry all the time. I just thought, “I can’t do this . . . I’m not an angry person, you know.” . . . This was, “I want to throw something. I want to break something. I want to, you know, just scream, just, just blah (*laugh*). . . . this crazy . . . weirded-out feeling. . . . It was really hard. It was hard to control umm when I was at work and not snap at people you know. . . . You just want to chew somebody’s head off, you know (*laugh*). And that wasn’t like me. (5)

Fern, who had a positive initial experience with Prozac, reported the following account with Paxil:

I began to feel distanced from myself. I felt like I was above my body looking at myself. . . . like I was viewing myself and I was not acting for myself. . . . like I was out of body observing myself. . . . And that just made me frightened. . . it really frightened me. I felt like I was out of control with myself . . . and I didn’t want that feeling at all. (11)

Kyle also experienced difficulties on medication:

My regular GP gave me Celexa and *achhh!* Just, just I *hated it*, it just um, not only was I still depressed but now I felt like I had cotton balls in my head, you know. And I’m, [in my profession] I depend on being on the ball and thinking fast and this just was like cotton candy or cotton balls in my head, and just numb.

Referring to a second medication, Lithium, he later related:

I gained fifty pounds in six months, I had *boils* and *carbuncles* that, I swear . . . they were, you know, the size of a golf ball on my legs and even the doctor said “you know, modern day, we don’t see this. This is what they saw in the, you know, middle ages,” you know. And I said “Do you think it’s the *Lithium*?” “Oh *no, no, no*.” . . . my eczema was horrible. Well it was making the eczema go bad and these boils and carbuncles, it was horri . . . it was gross. . . . See I don’t think . . . psychotropic medication has worked for me; it’s only made things worse. (12)

Others interviewed noted a lack of motivation, inability to feel deeply, and other physical effects that included dry mouth, severe bloody nose, “hands shaking really bad,” “gaining a lot of weight” and sexual side effects (6, 7, 9). For some who spoke of being energized by an anti-depressant, it could also reportedly keep people up late and interfere with rest (9).

In sum, the reported initial experience of a particular psychiatric medication can range widely, from dramatically positive to negative—as well as more mixed in effect. As described in the next theme, these experiences often vary *over time* as well—with initially positive or negative experiences changing substantially over the course of months or years.

Theme 2. Encountering ambiguous & evolving treatment effects: “We’ll see how I feel tomorrow.”

While these kinds of dramatically positive or negative accounts can often draw great attention, it was more nuanced and complex evaluations of medication that proved most commonplace in this sample, with most stories reflecting the well-known mixture of risks and benefits. While 10 of 13 participants reported some medical experiences that were either dramatically positive or negative, that same number spoke of more mixed experiences eventually. In what follows, I explore details of the common-place ambiguity of medical treatment for depression that arguably receives less attention than the more dramatic accounts reviewed above. I focus on the “brute” experience of treatment, highlighting the day-to-day experience of treatment, followed by reports on changing effects of anti-depressant treatment over time.

Day-to-day experience of treatment. To begin, Jill’s account offers a rich vignette of some of the complexities of receiving medical treatment for depression:

The second time [starting treatment] I was trying to find a different medication that didn’t have the sexual side effects, and that’s when I hit rock bottom ‘cause I wasn’t even at a therapeutic level on anything at that point, ‘cause [the doctor] was trying me on this for six weeks to see how I did . . . I was kind of doing the “guinea pig thing” and that’s when I hit rock bottom. And then when my dad died that year, then he upped me a little bit to get me through that. And then a couple of years later is when I tried to go down, couldn’t seem to do it, waited a year, went down another 20 mg, and I’ve been fine since then. But lately, like I said, I haven’t been, don’t feel like I’m feeling . . . and I want to try again. (7)

Victoria spoke of facing difficulties with her doctor’s help:

I guess, umm, partly the medication helps me think straight, helps me think straight because uh, in those times when I haven’t had my medication it’s almost as if life doesn’t make sense. You know, I can’t . . . and this has been times when they’ve upped the medication. And this is times when I have gone in and I said, “I can’t seem to find a direction I can’t seem to prioritize and figure out what I need to do during the day, you

know. And umm that has usually been a symbol that we need to up the medication a little bit or there is some or like I have said before some of the life changes that I'm not aware of. (5)

As reflected in these accounts, exchange with doctors can occur over years—playing an intimate role in both enabling and responding to life events. After acknowledging her ongoing desire to taper, the Jill continued, “I don't know what my doctor will recommend at this time of year, though, as we're going into fall...but I don't feel . . .” I asked, to clarify, “So there's one, like Cipro and then there's another...Wellbutrin. And that is supposed to help you sleep?” She responded:

No, Wellbutrin is just a second one he put me on to help me and then the one for sleeping is Pamilor. It tends to make you drowsy and he said it would also boost the effects of the other two. And he wanted to put me, add another ten, you know a second one of Pamilor at night to make me sleep all through the night, and I just, I don't want to be on that many. In fact, I'd like to. . . he bumped me up to--five years ago my father died and then my grandmother who I was really close to--so then he bumped me . . . I think I was on Paxil at that point, he bumped me up to like 75 on that, which is a pretty high dose. And then I tried a couple of years later to come down and I couldn't, so I waited another year and I was able to go back down to like . . . 50-40, and then I tried to go from 40 down and I couldn't do that. But I did get down from 60 to 40. And you have to try that, like, in the spring and summer. They don't like you to try that during the winter months just because winter's depressing anyway. (7)

Elaine described some of her medical journey following the dramatically positive beginning:

First I was on Zoloft. It aggravated my..um..manic thing. Then I went on to Wellbutrin. It aggravated it, so I just, I'm not on an antidepressant at all. I'm just on the mood stabilizer. Uh so um and that seems to work the best for me. . . . I did a lot better on the Topamax but then um... had a.. an experience where I had a.. kind of exciting thing happen that kind of got me a little bit manic and then found that the Topamax wasn't really holding me there so they.. put me on another mood stabilizer to . . . just keep me from being too manic, but not be as sedating as the Depacote had been. And the Wellbutrin, I found, I felt like it aggravated--I just could not sleep.

She continued, “I've thought a million times my family . . . with the \$500 insurance premium which I feel horribly guilty about (and that's every month). . . . I just feel like such a drain on my family” (2). Michelle, who had been especially faithful in complying with treatment gave the following explanation of “how her current drugs work together”:

Really well. I've just recently got off of, I had been on Seraquil 100milligrams three times a day and I noticed that taking it twice a day I'm a lot bubblier, you know, more energetic. The Seraquil in particular kinda has a sedative effect . . . you know, you kinda get that drowsiness mid morning with it and um you really have to kinda consciously . . . work through that, you know. Um, it's real easy in the early stages of recovery to just kinda give into it and go back to bed (*laughs*). (13)

Robert and Victoria related the mixture of increased energy and challenged sleep:

Effexor especially seemed to... just it either made me really, really have a lot of energy or really, really tired. But it wasn't really predictable as far as what I was gonna get. And so but... as a general rule, I felt more outgoing when I was on Effexor. . . and sometimes I noticed like extreme things, like it would keep me up... really late. . . . And... uh... I dunno, that's just kind of the way it was. It was kind of erratic and unpredictable but definitely potent, definitely noticed differences. (9)

When the medication is working umm I just, I feel good. I mean, I ummm, you know, I get things done. Umm I have energy, I'm and . . . I've had to sort this out because we recently figured out that (*laugh*) that what I lovingly refer to [as] my "pharmaceutical cocktail" is preventing me from sleeping well. I sleep for about two hours and then I am awake. I sleep for another two hours. And so I have to I have to separate that, you know. But umm, I just wake up and I'm ready to go, you know. Plus I'm running around getting things done. You know just feeling good feeling happy. Just content you know umm very much in control you know. (5)

Something of the complexity associated with changing medications, dosages and side-effects are evident in these comments. Jill commented that finding the right dosage and keeping her medication regimen stable had become a dominant theme of her experience, even an overriding goal:

I guess a theme [of my story] would kind of be just . . . the constant struggle to find a balance. . . . so that you can be happy, so that you can have feelings, so that you can... have the energy that you need to engage in life and do things with your family and to be a productive member of society. To be medicated enough so that you're not a weirdo and embarrassing your kids, but to not be medicated so much that you can't engage in life. I think that's the whole thing; that's my whole goal. Just to find out where that medication line is. Where it is that I can be and still feel protected from the disease, but still be a little bit of myself at the same time. (7)

Lucy spoke with some exasperation about her "cocktail of drugs that I needed to take everyday just to maintain a *kind of* a balance"—"It's very hard to get to, and it doesn't always remain, you know? Sometimes it stops *working*, so you have to change them again. So . . . sometimes you're just like it—'it worth it? (*whisper*)'" (6).

Individuals were asked at the time of the interview how many years they had faced (serious) depression and how many of those years they received medical treatment. Responses can be organized into three general categories. Seven participants spoke of facing depression for a number of years and receiving medication that same amount of time (18/18 years; 16/16; 14/14; 13/13; 12/12 & 10/10 years). Three participants spoke of medical treatment over different ratios of their total years facing depression (14/16 years; 4/9 & 2/4 years) and a final group of four participants spoke of only briefly taking medications—from several months to a year and a half. Of the average experience of facing depression for 9 years (range: 6 months to 18 years), 8 years was the average time that participants had been treated with medication (range: 3 months to 18

years). Across all 15 participants, this reflects an average coverage of 66% of depression years including some kind of medication use. An intense weariness of long years of facing depression and navigating these kinds of treatment decisions was evident across interviews. Kellie related, “I think it got to a point where I was just so tired of not knowing what to do . . . so frustrated” (16). Robert said, “The only lesson I can think of is just keep trying, just, just keep, keep trying You just have to keep going. You don’t have any other choice. You can kill yourself or you can keep going. I mean, which one do you wanna choose?” (9). Jill added:

Things are going well enough in my life right now that I feel like I want to lower it again. I’m always wanting to do that, I don’t. . . it’s kind of . . . you know, I’m sitting on the fence, cause it’s like “yes I have to have meds” and I’ve accepted that, but “yes I’d still like to get down off of them,” you know, if I can (*sigh*). . . . It’s a roller coaster, sometimes you feel like, “okay good, I’m on meds, I’m glad [that] I’m on em,” other times it’s like, I look at my pill case (*laughs*) and feel like a grandma--“I got this big old pill case! I take all these meds” (*laughs*)! And you wish you didn’t have to and you think “oh man, what am I gonna do when there’s this big earthquake someday and I don’t have access to my meds, am I just, just going to disintegrate?” (7)

Changing medication effects over time. Beyond the common ambiguity of day-to-day experience, there was also a pattern of treatment effects changing over time. For some, like Robert, positive effects started occurring after experimenting with several medications (9). More often, it appeared the reverse was occurring, with initial positive effects eventually ceasing. Debbie, who spoke of experiencing Prozac initially as “the magic part of life [that] seemed to do everything” went on to say, “for a while--like maybe two or three years—[Prozac] seemed to work, and then all of a sudden, it just gradually did not work. . . . and I kept trying all these others.” She related her long search over the years for another medication or combination of meds “to make me feel like I did when I first started taking Prozac” (8). Camille also described Prozac “working great for a year and then it just quit working”:

I started becoming depressed and they, my doctor increased the Prozac and it just didn’t do anything, I continued to become more and more depressed and so I finally just--“this is not working.” And that’s when I started to see the psychiatrist. . . . There was no explanation. . . . [I] said, “I’ve been taking Prozac for . . . a little over a year and it worked great, but it’s not working anymore. I’m just getting more and more depressed.” And we tried increasing the dosage and it didn’t help, and he said, “sometimes that just happens to people.” He said, “we don’t know why it happens; it just isn’t effective anymore” (3).

Elaine, who also had good initial experiences on anti-depressant medication noted a number of side-effects becoming troublesome, noting “I thought [it] was a wonder drug when I went on it. But, after I’d been on it for quite awhile,” she related emerging side-effects such as emotional “jitters” and a “hard time putting sense together” that forced her to give up writing

poetry (2). Robert, who spoke of Effexor helping him feel more energetic and social, later related:

There was one point I just noticed that, um. . . I started to feel really nervous, even when I was taking my medication--it was just a different feeling. . . . And so I wondered, "Well, you know, maybe my medication's not working." So I went and saw the doctor and he thought, "Well, this is just anxiety," so he gave me uh, I think it was Buspar, the uh anti-anxiety drug and then he also gave me a small of Atavan. . . He just said, "Those are for the bad days." (9)

To summarize, individual response to medication can evolve in different directions over time. For four participants, this meant that initial dramatically positive effects ceased or wore off, transitioning to a more mixed/positive response. For two other participants, medication effects went from a good to mediocre/bad response. On the other hand, two participants spoke of initial negative experiences eventually becoming positive, with a third describing no effect of the drug initially, followed by eventually noticing a difference. Laying aside reported effects, the more interesting question was how individuals came to think about their worth and meaning.

Theme 3. Interpreting states concurrent with medical treatment: "What is going on now?"

The foregoing themes depict variation in largely the actual reported medical effects over time. While such variation is interesting and has received insufficient attention in the research literature, this study proposes that such brute patterns cannot be fully appreciated when considered on their own. Accompanying this variation in effects is evidence of striking variation in how such effects are interpreted and narrated across participants. This theme takes up some of the more nuanced, subtle differences in interpretation evident in participants' continued experience with medication—ranging from ascertaining the source of particular good or bad states concurrent with treatment, to evaluating these same states, to making sense of states associated with an end to treatment.

Ascertaining the source of a state concurrent with treatment: "Where are these feelings coming from?" In speaking of uncomfortable states arising concurrent with medical treatment, participants revealed some interesting deliberations about their source. These states range from mild feeling of numbness and lack of motivation, to more dramatic and painful conditions. Jill said, "I don't feel like I'm feeling. . . . I do have emotions but, it's just hard to explain. . . I don't *feel* you know, like I don't *feel* what everybody else feels (*sigh*)." She also said, "I want to feel deeper. . . . those deep, you know, chest feelings that you get. I don't want just the superficial happy, you know, "I'm happy today or that was fun to do or I'm excited to read this," I want to *feel it inside*" (7).

Jill attributed the absence of feeling to medication, parallel to Elaine's explanation for her lack of motivation (2). Debbie, however, who also complained of a similar lack of motivation, wondered about the possibility of another hidden condition that hadn't yet been diagnosed. She was then asked, "When you're going through something hard, do you ever struggle with whether it comes from depression or whether it's like a side effect from the drug?" She replied, "I usually just think it's the depression" (8). Sarah's early experience with Zoloft illustrates this same issue in a more dramatic way:

One of the negatives of the Zoloft was I still was suffering quite a bit of anxiety and panic attack and I remember . . . (*nervous laugh*) you ever had a panic attack? I mean it truly feels like your heart is just jumping out of your chest . . . and that, your breathing you know you start hyper-ventilating but you think you are having a heart attack. . .

*J: Was that something you had experienced [before]?

Yea. Well before I had even gone on my med, you know, any meds. Well actually, now that I think about it, I had anxiety but I had never really experienced a panic attack, I think, until I went on the Zoloft and I remember calling Emily saying "this is making me have panic attacks!" . . . and she says Sarah "it's not the medication, it's your anxiety that you want this to work so bad" and I kept saying "are you sure? Are you sure, Emily!?" I said, "because, if I can't . . . so the Zoloft it it it . . ." (4)

Sarah wondered aloud whether, in fact, the Zoloft came before her panic attacks or not. Sarah related her doctor's conclusion that Zoloft didn't have enough anti-anxiety effect to pull her out of her own struggle with severe anxiety. After being prescribed a replacement prescription of Paxil, she reported feeling calm again.

This account illustrates a particularly tricky challenge with medications. When negative states are experienced concurrent with medical treatment, how are they to be interpreted? Continuing the pattern in Sarah's account, three other participants likewise commented on fairly serious conditions, while questioning or minimizing their connection to medication. While mentioning some serious memory loss concurrent with treatment, Camille wondered briefly whether it was "a result of medication or simply the way my mind works," before emphasizing the memory loss as inevitable: "You just deal with it. What else can you do? And I've just figured well maybe those are parts of my life that I just don't wanna remember anyway, so it's okay" (3).

Robert, who was happy with the energy boost he felt with Effexor was then asked about "side effects?" After saying initially, "You know, not really any... not really any that were too, too bad," he added:

I will say, you know, on Effexor, I almost think that it was maybe too much for when I would have the increases in energy or whatever. *Sometimes* I felt like my heart raced a little bit, and I've *noticed* ever since then . . . kind of um... I get pains in my chest. I

mean, I don't know if that has anything to do with it. It could be something *totally* different, but I *have noticed that*. So, I don't know...(9)

Robert described confusion about other strange effects, "It seemed like, and I and they never really... knew for sure, but I started breaking out in hives, um, just all over my body for no reason... It wasn't, you know. I wasn't eating anything different, no... uh... No changes other than, you know, possibly stress" (9). Along the same lines, Victoria related the story of waking up nearly paralyzed, "I woke up one morning and could not move. I mean literally I was just paralyzed. It scared me to death" (5). She attributed this experience to a random physical reaction, "What it was, was that it was just some kind of freak thing where the nerve endings just, for some reason, just kind of locked everything up and so it was really muscle relaxants and pain killers you know and it took an couple of days for everything to improve (*laugh*), you know, and I was fine." When she raised the concern with her doctor, he reassured her, "it's so rare you know that I really doubt that it will ever happen again" (5).

Evaluating states concurrent with treatment: "Is this what I want?" In cases where a particular emotional state (whether positive and negative) is clearly linked to medication, a second question becomes relevant: how exactly should that state be evaluated? This constitutes a second subtlety in the process of interpreting medication effects. In some cases, the emotional state associated with medication is judged as clearly positive or negative (see above, *Theme 1*). Even when this happens, there is not necessarily a one-to-one correspondence between challenging effects and negative evaluations—with many instances of difficulties concurrent with medication narrated positively (see Ch. 8).

More typically, the worth of a particular effect itself, however, remains especially challenging to judge and interpret. For instance, just as a state of numbness presented difficulty in ascertaining *its source*, numbness may also entail particular challenge in evaluating *its worth*. Jill hinted that her personal evaluation of a numb-like state varied depending on how well she was feeling overall:

When I was really bad and I knew I needed help, I wanted to be on it . . . and now maybe I'm doing better--and that's why I'm feeling like it's giving me the "flat line." 'Cause when you really need it, I don't think you feel that [concern with side-effects] as much. You just feel good, you know, because you're not depressed anymore. But I think when, like right now [when feeling concerned with side-effects], maybe I'm emotionally doing alright and maybe it's keeping me too "flatline": I'm not feeling much of anything. (7)

More frequently, difficulty judging the worth of medication effects appeared to reflect more general questions about how to think about side-effects alongside the other effects of the drugs—i.e., deliberating the overall question of the worth of medication in their lives. As with

initially starting medication, some reported no resistance to remaining on meds. Camille said, “I’m fine taking medications; if I have to be on medications the rest of my life [then] fine, [it] doesn’t bother me” (3). Debbie added, “I didn’t resist taking medication because I liked this new person. I learned about chemical imbalances in my brain and the comparison to diabetics needing insulin. I looked at taking meds as a must” (8).

Others who had experienced initial resistance described how positive experiences later lead them to abandon former concerns about medication. Peter, who had agreed to take medication after hitting “rock bottom” said, “I tried that medication and found out that it . . . didn’t dull my emotions in any way it just controlled them . . . I got used to the idea of taking medication and I saw how much good it did me um then I lost all my reservations about medication” (10).

Still others spoke of lingering or continuing reluctance to remain on medications—with a range of responses that resulted. In the face of some difficult side-effects, some decided to quit, such as Fern’s reflections on experiencing out-of-body feelings on the drug: “I’m a very cautious person, and when I had that feeling it just frightened me and I just said, ‘this was enough’ . . . when the *Paxil* started doing these funny things with me, I just said ‘no, I need to have control’” (11).

Most other accounts reflect less decisiveness and more intense vacillation. For Lucy, questions about particular side effects prompted some intense wondering about whether depression or the drugs effects themselves were to blame for her earlier dark moods. Reflecting on a period of gaining weight on the medications during high school, she said:

You don’t know why at all, like—and it’s not that you’re eating a ton—a lot of the time you really didn’t know the source anymore because you’d be 200 pounds and you’d want to kill yourself because you didn’t want anyone to see you. You wouldn’t go to school, cause you *hated* yourself so bad, and I looked back and go “was I depressed?” or was it just—“my doctor made me [a] frickin’ 200 pounds?”

Jill, who previously spoke of “dreading” being tied to pills and disliking their numbing effect, described further of the rollercoaster of emotions involved in her treatment—between acceptance at “having to have medication” and “always wanting” to decrease the amount of treatment:

But still, you know, you don’t want to be put on, be put on a med and have to stay on it and you want to go off of it, but it felt good to be on it. When I did go on Prozac I had more energy and I liked that about it. . . . You know, like sometimes you’re just okay with it, other times you’re thinking “no I’ve got to, you know, I’ve got to, I don’t want to be on them.”

She added, “my only two complaints right now are the sexual side effect that is severe and the fact that, you know, I don’t feel like I want to feel.” After being recommended an

additional drug, Jill noted, “I’ve been *so reluctant to do it*. And, and see, I’m, I’m, what’s the word . . . not a hypocrite, but I mean, I say, I need the meds, I’m okay with taking the meds, but I *don’t want to be on the meds (laughs)*.” Speaking of her own eventual reconciliation, she commented, “It took a mind change for me to finally get to where I could say ‘I’m grateful that I was born in this day and age where I could get the medication that I need.’ . . . it took me a while to come to that.” Jill continued:

You go through that, “well I don’t want to have to take a medication,” you know, yea, you go through that whole process in your mind of “Oh I, you know, I don’t want to take medication . . . every day of my life”, and then you take it and start to feel a little better and then you think “okay, you only need to be on it a few months” and that didn’t work.

She concluded, “I wish I didn’t have, you know . . . to have meds. . . . I had to just tell myself, you know, ‘It’s okay. You’ll just be on these meds and it’s okay to be on these.’ You have to talk yourself into it, basically, you just have to talk yourself into it” (7). Similar reconciliations over time were evident in other accounts. Robert said, “The idea that you can’t live without these little pills is somewhat upsetting, I think. But . . . or *was* somewhat upsetting. To me, it’s normal now” (9). For some, this reconciliation included accepting difficult side effects as necessary.

Not all who continue their treatment reach such a personal reconciliation. Debbie, who spoke of medication ceasing to work after initially feeling like “superwoman,” later commented:

I hate taking pills daily. . . I keep thinking, what if I forget or what if I double take it? . . . I just hate it. I hate remembering to have to bring [my pill box] wherever I go and . . . to worry about it, the schedule of it, you know, in the morning, “do I take it with *food*?--do I have to not take it with *milk* or take a full glass of water with *this one*?” or whatever . . . all those little things.

She was then asked, “do you see yourself accepting it more in the future?”: “Hopefully or I’m in big trouble--(*laughs*). Oh everyday. I’ve got to convince myself. I can convince others but accepting it myself, I just . . . I struggle with that . . . it’s easier for me to tell somebody else, ‘oh yeah you need, you need it, you need to accept it’. . . even though they say it’s just like diabetics. I can tell that to somebody else but for me to accept it, I don’t.” Debbie later said, “I have to keep telling myself it’s a *chemical imbalance*” (8).

Ultimately, participants ranged in their general opinion of medication at the time of interview — from 3 unconditionally in-favor, to 8 ambivalent, but generally in favor, to 2 ambivalent, but generally opposed, to 2 unconditionally opposed. In a rough split, there was one group largely favorable (Elaine, Camille, Sarah, Victoria, Lucy, Jill, Debbie, Robert, Peter, Michelle) and a second largely unfavorable (Fern, Kyle, Esther & Kellie) to traditional biomedical treatment.

More interesting than overall participant disposition towards medication, of course, was evidence of how they arrived at that point. While Chapter 6 examines this question in detail based on key narrative resources, here we can trace characteristic “trajectories” of personal interpretations and evaluations of medication evident over time (only those nine participants who spoke of changing perceptions are included here). Four participants reported miraculous initial effects, and held onto a belief in the potential of medication even when these positive effects had lessened or ceased (Elaine, Sarah, Jill & Peter). Two participants who had reported good initial effects, in contrast, began questioning the potential of medication when the effects had become mediocre or bad (Fern & Jill). Among those who reported initial negative or neutral effects, two eventually came to embrace the potential of meds when their effects had improved (Victoria & Robert) and two rejected them outright when their effects remained ambiguous (Kyle & Esther).

By emphasizing patterns of resistance, these trajectories may be framed in a slightly different way. Attitudes of resistance over time may be organized in a continuum of five groupings, as follows: On one end, two individuals were seemingly never resistant to medication and remained openly accepting of their current medication at the time of interview (Robert & Michelle). A second group was initially resistant to medication, but had changed their feelings after starting to embrace medication they were taking at the time of the interview (Elaine, Sarah, Victoria & Peter). A third group (of one person), was likewise initially resistant, and while remaining on medication at the time of the interview, remained deeply hesitant (Jill). A fourth group, likewise reflected enduring resistance and had followed it to cease medication by the time of the interview (Fern, Kyle & Esther). A final group (of one) had experienced enduring resistance and never started medication (Kellie).

Interpreting states associated with a cessation of medication: “What is going on now?” Here, I focus on diverging interpretations of states associated with a *temporary cessation of medical treatment*. Previously, a tendency was reviewed among some participants to attribute negative states concurrent with medical treatment to depression itself. A similar pattern is reflected in the manner that negative effects arising concurrent with a *decrease in medical treatment* are typically judged. This interpretation, which also arguably plays a significant role in participants’ eventual treatment decisions, is reviewed in two parts: the interpretation of temporary, accidental cessations examined here and the interpretation of deliberate, planned tapering reviewed in Theme 7 below.

Some participants report getting to a point where they mostly experience no side-effects as medication regimens are constant, but notice considerable turbulence when it changes. For instance, as reviewed earlier, Jill described hitting “rock bottom” during a transition between

medications, “‘cause I wasn’t even at a therapeutic level on anything at that point” (7). Victoria spoke of “those times when I haven’t had my medication”:

It’s almost as if life doesn’t make sense. You know, I can’t . . . and this has been times when they’ve upped the medication. And this is times when I have gone in and I said, “I can’t seem to find a direction I can’t seem to prioritize and figure out what I need to do during the day, you know. And umm that has usually been a symbol that we need to up the medication a little bit or there is some or like I have said before some of the life changes that I’m not aware of.. (5)

Similarly, an increased dosage was the natural response when the Jill faced her own difficult period—“And then when my dad died that year, then [my doctor] upped me a little bit to get me through that” (7).

Two additional accounts further illustrate both the nature and implications of interpretations in the accidental/temporary cessation of medication. When asked, “Have you ever had any uncomfortable side effects on the medication?” Peter answered, “I’m trying to think (*sigh*) no not really, I mean only when I don’t take it.” He went on, however, to speak of negative emotions from the absence of medication:

Well, I know that (*pause*), I can tell when I haven’t taken a medication . . . there are physical and personality aspects that come out when I haven’t taken my medication . . . um I get a lot more moody, and by that I mean I’ll tend to take something very personally. Someone will say something, and I’ll say, you know, “boy that really” and, you know, it will make me very angry. You know, I’m generally a very even tempered person but [without medication], I’ll get angry really quickly . . . I don’t feel in control of myself, you know, I, you know, I just, I’ll snap and I’ll say just about anything, to just about anybody (*pause*) you know (*pause*) and, you know, I hate that—I don’t like it, you know, I like being in control.

Peter related the following explanation of uncharacteristic behavior:

A couple weeks ago I was at home and uh (*pause*) my mom and I started talking about something, and it was, I hadn’t taken my medication. I didn’t remember um (*pause*), and without even thinking I just mouthed off to her. And I don’t do that, like that’s not, I just, I just mouthed off I said, “you don’t know what you’re talking about so you better just be quiet” you know. And, you know, that’s not me, like I don’t do that. I mean our relationship is such that I don’t have to do that. We can speak honestly one another . . . and as soon as I said that I sort of reflected on it, and I knew I said, “oh yeah I haven’t taken my meds today.” (10)

Others mentioned noticing greater physical repercussions of not taking medications—dizziness, upset stomach, light headed. Robert commented:

As far as Wellbutrin is concerned . . . I noticed, I guess I noticed that it was working when I *didn’t* take it. If I would miss doses, and I’m bad – I’m horrible with consistency, um . . . then I’d start to just feel . . . kind of jittery and on edge . . . And so . . . that’s really how I’ve noticed that. . .

*J: So, when you don't it, you notice you're jittery or on edge, and when you take it again, and that goes away?
Yeah...

Robert shared further thoughts about the jittery and “on edge” feeling “kind of the way that I felt in my earlier years when I was knew something was wrong, didn't know exactly what it was, you know, as far as having racing thoughts and stuff that would end up, you know, pulling me down into a cycle of depression” (9). As will be reviewed in the later tapering theme, how exactly individuals come to interpret negative emotional states during an accidental cessation or deliberate tapering of medication may have significant practical consequences for ultimate decisions about treatment.

Theme 4. Encountering additional influence: “As my doctor explained to me. . .”

In navigating different treatment issues reviewed above, individuals clearly do not deliberate alone. In the case of difficult emotional states concurrent with medication, participants appear to be significantly influenced by surrounding relationships (similar to initial treatment decisions described earlier). These range from additional encounters with family and friends, to doctors and other health professionals. Similar to the earlier theme exploring surrounding community influence on *initial problem definition*, this theme examines and reflects the same influence relative to *interpreting treatment*. 4 of 12 participants who had received medical treatment spoke of some kind of significant influence from surrounding relationships in their continued decisions about that treatment. Once again, this influence ranges from informal helpers (family and friends), to that encountered with medical professionals. Since this influence plays an obvious role in the formation of positive convictions about medication, this theme ends with a brief review of some of these favorable treatment conclusions reached by participants.

To begin, friends and family appear to play an influential role in helping individuals think through and process difficulties and ultimately maintain compliance. After being helped by her friend and doctor to resolve fears about drug-induced panic attacks, Sarah later referred to the general influence of her surrounding community:

It's the people around you that . . . they can tell you're not you; it was the people at work. . . I was teary again and finally . . . [my coworker] said, "I am calling your doctor right now something, your medicine is not right" and I go "I haven't changed." . . . it's the people around you that see it more than you really do, actually see your mood change, your appearance change. (4)

Similarly, Victoria recollected:

And so, you know, [my friend] would check up with the medication, “how are you feeling?” She is kinda the one that, umm she got me through this because, you know, she would be the one that said “umm Victoria, your fuse is really short; tell me how you are

feeling,” you know. “It’s the Prozac...go get something else,” you know. And then she would say “how is this [medication] doing?” and [I would say] “well, I feel this way; I feel that way.” And then, that’s when she said, you know, “I want you to try this Zoloft go ask your doctor if they will give you some.” (5)

Debbie related that “another way [that] you know medication’s not working, is people around you tell you. ‘Have you taken your medication today?’ (*laughs*) or whatever so, people around you notice things” (8).

Jill, whose “daily life” account of medication was reviewed earlier, later spoke of her efforts to help two sons who faced emotional struggles. After petitioning her psychiatrist to diagnose and treat her first son, she spoke of her efforts to educate him:

I’ve had to teach that to my, my son that’s bipolar; I’ve had to teach him that it’s just like anybody else that has to take medication. It’s like someone with, you know, diabetes or someone with a cardiac problem, your body needs this medication to function. You have to take it. . . . From the beginning when he was diagnosed, I said “this is something for life, you’ll have to be on these medications for the rest of your life.”

Jill continued, “My husband’s become the alarm clock basically, ‘Did you take your meds today? Did you take your afternoons? Did you take your night pills?’” Relating the experience of her other son, she said, “They tried him on Ritalin. It was too strong for him; he just had that glazed- over look, you know. But it would calm his temper down. And the summer before eighth grade he just begged me, ‘can I just not be on it?’” This son eventually stopped medication and managed the problem himself. Jill’s other son, however, continued treatment in the face of similar resistance, “He would just never want to take ‘em. And even in the early stages of taking the mood stabilizers, he, you know, would sometimes throw out ‘I’m never going to take my meds again!’ you know. He got mad at us, but as he’s matured, he’s accepted it and he forgets. He has a hard time remembering” (7).

In addition to the influence of friends and family in reinforcing a course of treatment, interviews consistently illustrated an important role for doctors in guiding people through the resolution of complex evaluations, a theme evident in earlier vignettes as well. Indeed, while friends and family seem to play the greater role initially, once individuals are in the system, doctors seem to play an increasing role. As always, these experiences varied across participants. While four individuals spoke of resisting encouragement from medical professionals (see *Theme 5 below*), three participants spoke of encounters with doctors as making a significant impact on their decisions to continue treatment—the focus of this part of the theme. After mentioning her co-worker insisting on calling her doctor, Sarah continued:

So anyway, I was able to go in right then. I talked to Dr. Maxwell and she said “you come in, Sarah, I want to see you today.” And she said, you know, “I’m going to add

some Wellbutrin to your Paxil” and I said, “well I don’t want any more meds.” And she explained to me, she said, “Sarah. . .” I said, “how come it’s not working?” and she said “there are other little neurons that need a reboot from time to time” and I said (*sigh*), you know, again, I didn’t want to take more meds. And she said “let’s just try it and see.” And so she added 100 in the morning and 100 at night. (4)

In the face of patient concerns about being on many medications, doctors can play a major role in shaping people’s decisions and often prompting individuals to move forward. Elaine spoke of feeling hesitant to start Xanax, not seeing how it would help since she could not get out of bed as it was. In visiting with her doctor, however, he convinced her “this stuff will help you be able to function.” She went on to confess, “I thought I knew more than the doctor did” and described a critical process of “learning to not be smarter” (2).

Victoria recounted a time she began to feel better, prompting hopes of being able to get off the medication:

Once I was doing well--the business and work was going along fine—I decided, “okay, (*laugh*) you know, I can get off this medication,” you know. And I tried and tried and tired. And my doctor very wisely sat me down and scolded me and said, you know, you will probably be on this medication for the rest of your life. And you have to come to terms with that. And he said, “I don’t think you’re looking at this the right way. He said you should be the way . . .he put it thanking god that he has brought this medicine that you can live a good life and have a way to accomplish that.” (5)

She called that encounter a “major shift” for her—recollecting again, later: “I had that conversation with my doctor where I said ‘I’ll never be off this medication’—him just saying, ‘you now what? Be grateful. This is out of your control. But you know it’s all alright’” (5). Ultimately, such reinforcement from family, friends and doctors appears to contribute in many cases to a loss of hesitations about medication. After her own evolution, Sarah reached a conviction that medication was necessary to have a clear mind, for its help towards her “serotonin and chemistry being balanced” (4). Several other participants shared similar convictions. As Victoria noted, “The medication really helps me have a life. . . . I mean . . . if life is sailing along smoothly and I didn’t have my medication, the days would just be gloomy and gray just lack luster.” Speaking of therapy, she continued, “they definitely have to work together because I can’t do it without the medication” (5).

Jill, who spoke of previous resistance to meds in her interview, similarly concluded, “I’m a firm believer in medication for me it’s pretty dramatic, with and without meds.” She later added, “like I said, I don’t, you can’t get better without medication. You can talk and talk and talk but you can’t get better without if your chemicals are messed up” (7). Michelle, whose story reflected impressive faithfulness to medical treatment, was asked, “other people have struggled to be compliant in treatment and instead, go on and off of medication. How have you been able to

stick with it?": "Because I see the difference in the quality of my life, my ability to function. . . You know if this is what it takes in order to have the life I do today I think that's a small price to pay, so . . . But a lot of people don't see it that way" (13).

Theme 5. Refusing treatment. "It's only made things worse. . .

As reflected below, not everyone reaches such conclusions--nor are all individuals responsive to professional assurances to continue treatment. Some participants had less positive experiences with drugs and medical professionals, in particular. While participants commonly spoke of an uncomfortable exchange with a doctor, two individuals, specifically, spoke of extreme dissonance during interactions with medical professionals. Kyle and Esther's narratives provide especially vivid illustrations.

Esther had initially entered treatment for depression with openness to medical treatment, but also with many personal questions. Her first difficulty came from the general professional response to these concerns:

When I initially went into the system . . . I was kind of frustrated--*confused* would be the best word, because I was sitting there saying "these are the kind of services and support that I want" and the system was saying "no, no, no you're going to take whatever we're giving you."

Esther said, "I just felt like . . . they didn't really care if I had any questions or concerns."

She continued, "Just so many times that I was sitting there saying, you know, 'here are the things in my life that are bothering me' and having a majority of the people that I dealt with in the system saying, 'well, that's great—but I really don't care now. . . . take the drugs.'" While initially showing a willingness to try the medications, she added:

A lot of times I wasn't getting a lot of information—they would, you know, give me list of like four or five side effects and then I'd go on the web and I'd find that there were like sixteen and I would ask why they hadn't mentioned the other twelve?

Esther continued:

What I was always told when I was in the system was . . . "well, you know you have this chemical imbalance in your brain and if you just take this medication it would fix it." . . . They had a really narrow way of defining the problem. . . "we can fix it; just take this and you'll be fine" . . . and I wouldn't do that. . . . I was this *thing* that they felt I had to fix and the way that they could fix me was to force me to take medication which I wasn't really interested in doing.

During this time, she also researched alternative resources on her own and brought them to the attention of doctors:

I found generally across the system that when someone's first idea didn't work they didn't have a lot of interest in researching what else might be out there. . . . When I would find resources . . . I found the system was fairly closed to even looking at any of the other alternatives. . . [I found] some article about alternative treatments and I remember bringing it to one of the practitioners I was working with, and him just basically handing

it back to me and telling me that he didn't even want to look at it because he was certain he already knew what was. He didn't want to look at it—gave it right back.

Ultimately, she spoke of “realiz[ing] that I had the strength to stand up and say no.”

Esther describes the doctors' response to her resistance:

They didn't know what to do. . . . They saw the person who they had labeled with any number of things . . . and, then they saw this [same] person who was sitting there saying “no, I don't want to take these drugs you're giving me.” . . . They didn't want to deal with it—and you know, it was the old, kind of, “shut up and take your drugs” you know, they're expecting you're not going to get by if you don't get the drugs (*laugh*).

As she persisted in her refusal to take medication, Esther recounted other doctors' responses:

It would vary—some would just flat out tell me, “It can't be. You don't know what you're talking about. Of course, you're mentally ill and you're in denial that you're mentally ill”. . . . And a lot of times they would just start bypassing me and go right to my family, sort of like, “we don't really agree what you're saying, so we don't want to deal with you. We're just going to talk with your family who understands what we're saying.”

Since her family was willing to force her to get treatment, she agreed to see a psychiatrist to “keep them off my back.” For a short time, she tried medication at their request: “I was initially forced to—it wasn't very much, very long. . . They were just pushing it and pushing it.” Referring to family concerns when she quit, she added, “Luckily, it was a time when laws were not favoring forced compliance . . . compared to current laws making it easier for family members to forcibly commit family members” (14).

Kyle's story reflected similar discomfort with medical advice. In spite of uncomfortable side effects, reviewed earlier, he initially tried to work with his doctor, “I stayed with it and then he said ‘well now *double it* and then back off and then double it again’ or something like that. So I tried that.” After experiencing weight gain, blunted emotion, boils and carbuncles, he concluded “it just, uh . . . it wasn't working” and asked his doctor, “Do you think it's the Lithium?” “Oh *no, no, no.*” It was at this point the doctor suggested adding another medication:

He goes “well, we're going to add Wellbutrin to the mix.” And I said, “you know what? I don't want to take that rollercoaster ride with you. It's making me nervous, I have problems with my sleep anyway, I've heard Wellbutrin is, you know, can cause insomnia.” He goes “well then we can add something for that.” And I go “I'm not going to be a poly-pharmacy experiment. It just . . . that just doesn't work for me.” And he raised his eyebrows and he goes “I'm, giving you the script, you know, talk to me next week.”

Kyle went on to research medication profiles for himself and conclude that the drugs had become a part of the problem. At the end of his interview, Kyle raised concerns that as new

problems arise, doctors were inclined to simply adding more medications in a “rollercoaster of *med after med after med.*”

Other treatment accounts also reflected a similar response to worsening symptoms: either increasing dosages or adding new and different medications (poly-pharmaceuticals). Of the 13 participants who had tried medication, 77% (10/13), were administered more than one psychiatric medication—ranging from four individuals who spoke of taking a combination of three drugs (e.g., anti-anxiety, anti-depressant and anti-psychotic), to six taking two medications at a time. In addition to the 2-3 psychiatric/psychotropic medications, participants also spoke of concurrently taking other medication to address side-effects (e.g., sleep aids) and medications for other independent physical conditions. Of the other three individuals who never experienced poly-pharmaceutical treatment, two took medication for only a short time, while the third (Kyle) was encouraged to add an additional medication, but refused.

Other accounts reflected similar poly-pharmaceutical concerns. Referring to a period of taking several medications including Depacote and Xanax, Elaine described problems with weight gain, muddled thinking, fatigue and diabetes. After her internist asked her to bring in all her medications so he could review them, he said “how in the world . . . you walk through that door I will never know” (2). In contrast, other individuals’ response to similar poly-pharmaceutics was often quite positive. Jill spoke favorably about her doctor saying, “well, it wouldn’t hurt to just try it and see if anything happens” as he added another medication to “boost the effects” of other medications (7). Camille said:

My psychiatrist has been absolutely fabulous. He’s willing to try combinations of medications that probably wouldn’t normally be put together or um, you know, dosages that that my regular doctor never would’ve even thought to prescribe. Not dangerous dosages by any means but he’s been practicing for quite a long time and is very respected. (3)

We have examined accounts of participants both strongly resistant and strongly in favor of medical treatment. As mentioned previously, however, the bulk of participants lie in between these extremes: with some satisfied with treatment, alongside some with real concerns. In the next two sections, some additional aspects of more ambivalent experiences are detailed. These individuals typically are neither willing to reject treatment nor embrace it entirely. To begin, we listen in to how these individuals think about life without medication.

Theme 6. Previewing life without antidepressants: “The person off meds is scary. . .”

When participants spoke of times of considering tapering off medication, they expressed poignant emotions, ranging from aching fears at its potential dangers, to an adamant belief in its

possibilities. Several individuals expressed fear at the possible consequences of tapering off medications. Victoria said, “I really dreaded having to (*sigh*) think that for the rest of my life I’ve got my pharmaceutical cocktail that I take every day, you know (*laugh*). But umm, it’s better than the alternative, you know . . .”(5)

What is the “alternative” to being on medication? Unsurprisingly, many report expecting a return of difficulty in the absence of medication—from a lack of basic cognitive capacity, to more frightening prospects. Jill reflected, “I’m grateful that I was born in this day and age where I could get the medication that I need so that I wouldn’t be locked up in the attic somewhere, or indisposed all the time (*laughs*)” (7). Elaine similarly commented, “I’d really like to be off the meds, but the person off the meds is *scary*.” She went on to elaborate her fears as specifically linked to her family:

I don’t know, I’ve thought a few times I wish I could see a window of time where--and I’d wanna talk to my doctor about this--where I could play around with my medications and see how I did going off of them, but my grandchildren (*shaky, crying*) I don’t want my grandchildren to see me as this bitter, angry (*laughs*) . . . you know, ‘cause all it takes is the screaming . . . and that’s how they’ll remember you for the rest of their life--so it’s just not worth risking the relationships. . . . You know, it’s not at all fun and games to take the stuff but it’s, the alternative is really unpleasant . . . it’s the difference between me and a normal person (or fairly normal person) and being the weird lady, you know, so I feel like the medications are worth it.

Although the fear of others’ appraisal of her actions while off medication reflected her primary concern, Elaine spoke further of another more basic fear:

There’s just nothing scarier . . . really deep depression is about the scariest thing I’ve ever experienced. And I just don’t wanna be there. Um... and...so. . . it’s something that I’m scared to death of now. I’m scared to death of going into a depression. (2)

Others spoke of the influence of their fear of depression and a real dread of its return. One woman spoke of the fear that comes when a worsening mood “doesn’t stop—when it doesn’t just become a bad day” (6). Speaking of the same potential return of depression, Kellie noted, “Every once and a while, I will feel that feeling. It may be a particular day where those feelings come back, and it’s scary. And I think, “Oh no!” (16). Robert similarly commented, “I mean, you just know what’s coming. . . in the back of your mind since you’ve been through the cycles a bunch of times, you know what’s coming. . . . When things start to go wrong, I’m just like, ‘Don’t get depressed, don’t get depressed’ (9).

Naturally, such fears of depression may lead individuals to avoid tapering off medication—with the fears of life without meds more broadly, playing a critical role in keeping individuals compliant. Even Kyle, whose tapering was successful, said of it, “I did feel nervous.

I knew if I didn't succeed and ended up wacko again I would lose a lot of freedom in how I lead my life” (12).

Explaining her own commitment to stay on the medication, Sarah recounted, “I just said there’s, I’m not gonna (sighs), I can’t go back to what I was. . . . I can’t because it scared me so bad” (4).

Once medication is embraced as central to fighting depression, the fear of depression may lead individuals to an intense attachment to this treatment, with Elaine summarizing her “whole goal” as finding the right dosage level for her to be able to function (2) and Jill asking hypothetically, “what am I gonna do when there’s this big earthquake someday and I don’t have access to my meds, am I just, just going to disintegrate (laughs)?” (7). This attachment was also reflected in another vignette from Sarah’s account:

I was on a low dose of Zoloft and, it needed to be bumped up a lot faster than it was. . . I remember calling Emily going, “it’s not gonna work for me, I know it’s not gonna work for me” (very upset). And she’d go, “Sarah, honey, you know, it will; you know it will. Just give it a little time.” I’d get the panic and the anxiety and fearful that I’m gonna be in this state forever--this, this despair. (4)

In spite of such fears, a desire to taper may persist for years. Of 11 participants who took medication for an extended period of time, 5 spoke at some point of either tapering or having a desire to taper off meds. As cited earlier, for instance, Elaine spoke of wishing for a “window of time” where she could “play around” with her medications and see how she did going off of them (2). Jill also spoke of her long-standing hope of tapering off medication:

And [my doctor] wanted to put me, add another ten, you know a second one of Pamilor at night to make me sleep all through the night, and I just, I don’t want to be on that many. . . . he bumped me up to, five years ago my father died, and then my grandmother who I was really close to, so then he bumped me up to like 75 on that which is a pretty high dose, and then I tried a couple of years later to come down and I couldn’t so I waited another year and I was able to go back down to like whatever it was, maybe it was 50-40, and then I tried to go from 40 down and I couldn’t do that. But I did get down from 60 to 40.

Reflecting on her experience, she summarized:

When I was really bad and I knew I needed help, I wanted to be on it. And then, I was such a high dose, I wanted to go down off of it . . . And once I was doing well the business and work was going along fine I decided, “okay (laugh) you know, I can get off this medication.”

Jill described her doctor’s response:

And my doctor very wisely sat me down and scolded me and said, “You know, you will probably be on this medication for the rest of your life. And you have to come to terms with that.” And he said, “I don’t think your looking at this the right way.” He said, “you should be thanking God that he has brought this medicine that you can live a good life

and have a way to accomplish that.” And I thought, “well, I guess so,” you know (chuckle). (7)

Against the counsel of relatives, doctors and their own frightening narratives of the future, some make the decision to try leaving medication anyway.

Theme 7. Attempting to taper off medication: “Damn the torpedoes--I’m going to do it . . .”

The following theme examines participant comments about actual efforts to taper off medications. Of the 13 participants who started medication, 9 spoke of having a desire to taper or cease meds at some point (Elaine, Sarah, Victoria, Jill, Debbie, Peter, Fern, Kyle & Esther), with four never mentioning any interest (Camille, Lucy, Robert & Michelle). This interest appeared to evolve and vacillate for many, with Debbie, for instance, moving from satisfaction in ongoing medical treatment to a growing desire to taper, and Peter the reverse—with a gradually decreasing desire to taper over time until he was content with ongoing treatment. Among the nine participants who considered tapering, all but one tried it. The following illustrates both outcomes and some of the difficulties encountered—including both emotional turbulence associated with tapering and particular *interpretations* of this emotional turbulence. While the sub-theme’s title implies boldness involved in decisions to taper, more often than not, accounts reflect a haltering nervousness accompanying this step.

The necessity of a gradual taper was not always something of which people had been aware. Lucy said, “I never . . . no one told me that when you started taking them that you had to kind of withdraw from them—like you had to slowly go off of them” (6).

For others, it was difficult for some to find a professional willing to supervise tapering off of medication. Debbie spoke of being “unable to find help to taper; nobody seemed to want to take me off Effexor” (8). With previously reported significant positive and negative treatment experiences, she eventually spoke of her own attempts to taper off medication:

The couple times I *tried* to get off, it’s just not gonna happen. And you see the side effects of getting off and nobody likes me and I myself don’t like me when I get off the medication. . . . I don’t remember which one it would have been with. I would say Prozac or Paxil. . . . You feel good, you know, you’re feeling so good and you just think “this is wonderful I don’t need this.” I mean, now I know but at the time you think I’m just feeling so good everything’s running nicely, you know, let’s just try to get this so I’m not dependent upon this medication. . . . But um usually about three to four weeks I notice that, okay, I’m getting very nervous, very tense I can feel myself getting tense. And then just, the wanting to stay in my little cage . . . and not wanting to go out to see people. . . .

*J: This is what you felt like with trying to wean yourself off, that’s what you’re talking about?

Right.

*J: After you reach this point, then what happens?

Right. I think I stop myself completely, but then I start taking it and within like a week or two I'm okay. (8)

Others report similar experiences. Elaine recounted:

Every couple of years--I got to the point that I thought, "I felt really good" and I did; I just cut down on the Topamax and actually ended up not taking it at all for awhile. But then, I just felt everything coming back. And so I had to get back on something . . . and then [doctors] tried these other things. (2)

Jill described hoping to taper in the previous section had actually "tried I tried and tried and tried" to decrease her medications:

I've seen when I've tried to go off of them how hard it's been. . . . Like if I try to lower the dose I can see it starting to happen again, the symptoms, and I don't want that either so it's like I had to just tell myself, you know, "It's okay. You'll just be on these meds and it's okay to be on these"; you have to talk yourself into it, basically.

Even after being discouraged by her doctor's "scolding," she added:

Lately . . . I haven't been, don't feel like I'm feeling . . . and I want to try again. . . . I think things are going well enough in my life right now that I feel like I want to lower it again. I'm always wanting to do that, I don't. . . it's kind of . . . you know I'm sitting on the fence 'cause like, "yes I have to have meds" and I've accepted that but "yes, I'd still like to get down off of them," you know, if I can (*sigh*). (7)

In previous themes, the difficulty of interpreting negative states coinciding with a *stable regimen of medication* was evident. Here, the added challenge of understanding turbulence with a *changing dosage* is evident. As reflected in the aforementioned fears of participants, as these individuals began to encounter painful feelings concurrent with a decrease in meds, we see both reach the same conclusion: *the depression has returned*. Debbie concluded, "I'm pretty sure it's a chemical imbalance though because I've tried to wean myself off the medication and it's just not a good idea--I don't like me." She also said, "So I have to keep telling myself it's a *chemical imbalance*--it's not gonna go away with . . . you know, I can't, I'm not one of those that could take it for a couple of years and then be good for five years. It's . . . I'm stuck. I'm always going to have to have medication" (8).

Similar to interpretations of active treatment, here we see evidence of consequences associated with the particular ways individuals interpret treatment cessation. In both cases, how to interpret negative emotional states concurrent with treatment is the critical issue. As noted earlier, among the nine participants who considered tapering, all but one tried it. Of those who tried it, however, only three of eight individuals actually got off medications (Fern, Kyle &

Esther). The rest were either dissuaded from trying again (Jill) or continuing to experiment, with some trying and failing multiple times (Elaine).

Even after tapering, however, tension and struggle as to the appropriateness of treatment may continue. Kellie recounted the experience of an acquaintance who had stopped taking medication, “She is off of it now, but she is struggling and she is wondering if it is something that she needs, that she should have kept doing or that she needs to get back on. It’s that struggle . . . wanting to take it but not wanting to be tied to it” (16).

Theme 8. Evaluating alternatives: “What else could be done?”

Since interpretations of medical interventions for depression are the primary focus of inquiry, attention to views of alternative treatments has been limited. The following theme captures comments about general openness to alternatives, followed by accounts of the recovery process and the role of family, friends and professional counselors. While the focus here is on instances of support from friends/family, Chapter 7 breaks down patterns in difficulties during a depressive period for these same relationships.

Kyle began searching for alternative support when medical side-effects were becoming burdensome, but initially remained unaware of any other viable ways of addressing his depression. After learning of some alternative interventions, he started considering the possibility of tapering off meds—an idea adamantly opposed by family members. In spite of personal fears and the concern of his family, Kyle gradually tapered over several months and found eventual relief in major changes to his diet and sleeping habits, as well as his overall stress level. Reflecting on this experience, Kyle spoke at length about alternatives and articulated various perspectives more than other participants. First, he noted that in some cases where medication is emphasized, “There’s very little talk of alternative treatment. Reflecting on his wife’s decision to forcibly hospitalize him, he asked:

What else could she have done? What else?” You know, I don’t know and that’s the problem. . . . I think if something works for someone . . . that’s great, but there’s got to be alternatives . . . for people when medication doesn’t work and right now it’s just not there. And there has to be more than “take meds and if that med doesn’t work, well then try this med and then we’ll try this med.” Well, there’s got to be more. (12)

Referring to the major impact that better management of her blood sugar levels had on her depression, Michelle remarked:

No psychiatrist ever suggested to me in all this time . . . “check this out” or “maybe if you took this seriously you would improve over here,” you know. . . I don’t know how much research they’ve done about that correlation between diabetes and depression. (13)

Kyle recounted a conversation with an acquaintance having difficulties on medication:

She was not happy with what meds were doing and she was on this rollercoaster of *med* after *med* after *med*; she was having problems with her liver from Depacote, um, so she was asking me about going off meds . . . I said “What else have you tried? . . . Have you tried this, have you Omega-3’s, have you tried exercising, have you tried therapy? . . . I wrote to her, “. . . I do advocate exploring other alternatives *IF* you feel your meds are doing more harm than good.”

Kyle, Fern & Kellie all commented on wishing individuals would try other things before medication (11, 12, 16). Kyle went on to suggest that such alternative interventions could potentially duplicate any positive effects associated with the drug: “[Medication] did work to bring me down [from mania]. I think if I had been weaned off the Benzo and put in a nurturing environment, I know I would have done the same thing.” He subsequently called for research on viable environmental interventions:

When they study twins, when one of them has been diagnosed with bipolar, the odds are 60% that the other one will be diagnosed. Well, that means four out of ten--even though they have the same exact genetic makeup--they’re not ever going to be diagnosed. *That’s what we should be studying*, not the 60%. Study the 40%, what they do different. Was it something they weren’t eating, something nurture [or] nature? What was it?

Kyle paused to clarify:

I’m not anti-meds and anti-psychiatry either because it *works* for some people and some people, some people need it . . . I guess. I think it should be a last resort though. I think unless, unless, there is a *true crisis*, someone’s suicidal, someone’s homicidal, someone’s just trying to kill themselves. Unless there’s a true crisis like that .. why not try some alternative like . . . exercise and therapy, rather than *right away* going into the psychotropic drugs . . . Unless a person is in a crisis situation, I personally think Omega 3’s, diet, exercise and *some* kind of therapy should be first line treatment.

In spite of believing Omega-3 fish oil had helped him, Kyle discussed the typical response of doctors:

I have been taking the stuff for five years now, my regular GP poo pood it, you know, he said “What is this stuff? Omega-3 fish oil?” . . . No doctor is gonna say, “you know what? Go to Sam’s club and get a bottle of this and start taking six capsules a day..” It’s the equivalent of having an eight once salmon filet a day. . . . and see what happens.” [or] “Start getting some exercise,” that’s not going to happen. Maybe it happens with some doctors, but the majority, it’s not gonna happen. They can get us a prescription for, you know, Prozac, Paxil and Celexa, Effexor, one of those.

Esther similarly noted, “I found the system was fairly closed to even looking at any of the other alternatives” (14). Even when doctors are open to alternatives, Kyle pointed to a resistance regarding the notion that medication can be replaced:

I've always seen [psychiatry] as being "more meds, more meds, more meds, take your meds, take your meds, take your meds." There's very little talk of alternative treatment and if they talk about alternative treatment, it's an *added* treatment *on top* of your meds. Never *instead of*. (12)

Exploring alternative recovery pathways. While not all participants had achieved a significant degree of recovery, there were some accounts of genuine progress and recovery. In addition to comments about medication, participants also emphasized other components to recovery. A number of people spoke of shifts in other physical conditions (beyond brain chemistry) playing a role in lifting the depression—including better treatment for hormonal problems (16), diabetes (13), losing weight (11), nutritional and sleep changes (12) and exercise (2). Laying aside physical shifts, three individuals, in particular, spoke at length of life-lessons that had a significant impact on their recovery.

Peter, who loved his teaching job, spoke of feeling perpetually dissatisfied with his performance. He then related this defining moment in therapy:

I told [the counselor] one day in session, "you know my goal is to be 100%--be the best teacher I can be every single day of every single year." He said, "you can't do that." I said, "what? What do you mean I can't do that?" He said, "you can't do that. You're not always going to be your best." He said, "there are days when I am the best psychologist I can be. And there are days when I just stink for whatever reason. Maybe I didn't get enough sleep. Maybe I had a bad day at home. Maybe I didn't eat breakfast or have my cup of coffee; there are days when I am just no good." He said, "you can't always be 100% all the time." And that stuck with me and it allowed me (pause) to have those failures and say, "well I'll do better next time." (10)

In further emphasizing an intense learning process associated with recovery, Peter linked much of it to a changed relationship with God:

In many, many ways I feel like I've been *reborn*. I feel like I've started *a new life*--like I've started life over . . . I've had to relearn all the things I thought I knew [like] socialization skills I had to *completely relearn*, you know. I had to change my assumptions about the people around me. . . and so I would, even rather than recovery, I might even call it rebirth . . . I have established a new and strong relationship with Christ in that time, you know, which has been (pause) there are no words for what that has done for me . . . so many things have changed I mean I grew more in that year than the 10 years previous and it's really (pause) I'm in a place where I find it exciting.

Associated with this process, he attributed his recovery to addressing aspects of his life preventing him from being his true self—letting go of false aspects of himself:

In my particular case, depression was about *confronting* these issues that had haunted me my whole life (pause) and *figuring out a way to live with them* so that I *could be* the person *I wanted to be*. . .because one of the things that was fueling my depression was I had this image in my head of a successful person. . .you know this is a picture of this

successful [me]... and I was so angry and frustrated that I couldn't get there... ultimately, I think (pause) if you if you want to look for a cure or a positive treatment for depression it needs to be about letting go of (pause), letting go of the idea (pause) I mean, you know, maybe what you thought is for you, isn't for you. Maybe you're depressed because you are in the wrong place or you are doing the wrong thing (10).

As a second major example of lessons learned on the way to recovery, Fern spoke of the emotional reprieve associated with being able to forgive her husband who had abandoned her:

My religious foundation enabled me to turn over some of my grief and some of my depression to the Lord, because . . . I had to exercise forgiveness with my husband. . . I felt like I had to let the atonement work and it took a long time and I was mad at God for a long time when this happened . . . I had to come to a point in my life where I could get rid of that anger. . . . I had to forgive entirely and it took me awhile. I am a very passionate person and I was still deeply in love with my husband in spite of all that he did. It was difficult for me to get to that point where I could just let go and forgive him. . . . So I suppose that reading the scriptures, reading church books and different things like that had helped me to put a different perspective on my life so I could get beyond the depression.

Referring to her darker periods, Michelle added:

I have, again, used my religious faith to get through and turn things over to God and . . . talk things over with Him . . . I feel like my faith has gotten me through everything that I've gone through and only because I have an understanding of what life is and why we're here . . . Because I'm *sure* that if I didn't have that understanding I certainly could have considered suicide on many occasions just because my circumstances were so bleak. (11)

It was Kellie, however, that said the most about learning lessons as central to her recovery. In light of her decision to not take medication, Kellie reflected on her persisting belief that her recovery would eventually come—"I just thought that everything would somehow work out . . . that's what kept me going I'll get better, it just takes time, you know" (16). She went on to describe emotional issues that "kind of just worked themselves out" as she improved her overall physical health and came to "see [herself] differently" and have a "different outlook on my future, my life and my potential":

Gradually, I started coming . . . out of it. . . . the symptoms started just kind of wearing off gradually (and so at that point, I didn't even think anymore about taking the medication). . . . I can't really explain how things happened. Things just started . . . I really believe it was a combination of things: probably just time, and learning more about myself (which, when you can do that, that brings a freedom, I think).

In continuing, Kellie focused on details of the change over time:

It has been a long process, a long time, probably over 15 years . . . gradual, you know . . . something will happen and I'll realize something and it's like, it's kind of like, little by

little, you know. It's kind of like you're carrying this heavy burden or heavy weight on your back that weighs you down physically and mentally and just in every aspect. It seems like it's just this burden, and then little by little I find, you know, I receive knowledge about myself, or, I gain more experience, time passes, my wounds heal, or whatever it is. It's like little by little there's just a little more lightness to my step. A little more weight is lifted . . . it's a feeling of there being a sunshine back in your life, and um, probably the best way to describe it is probably, and also to say it's a feeling of freedom. . . . It was a little piece of knowledge and freedom . . . like a burst of I don't know, a burst of . . . power, that's another word for it. It's power that I gained.

She went on to describe learning “truth” about her life situation as key to a freedom to move forward:

It's a great feeling when you know the truth about something. You know you could have been involved in something terrible, you know, an accident, or you could have been abused, or any number of things and it doesn't change. You're still going to be someone who's scarred in some way. But having truth about the whole issue does bring a freedom, and it gives you, I think, the courage and the strength to move forward, and to just progress where you are, even though you feel like you've lost years in your life with that depression. You know, “Aw, I've wasted my whole life, it's a waste because I've been depressed and haven't lived up to my potential, and all these things,” but, you know, somehow it's okay. You just start where you're at. You know, we have to start over again, probably at many points in our life. . . . starting over fresh every time. So yeah, I'd say there's a freedom, there's sunshine again in your heart, and it's little by little there's just this heavy weight that's being taken off you.

At this point, I clarified, “So it kind of just like it went away?”

Uh-huh. . . . Yeah, I think for me there were so many little issues that were causing it that I, I'd find something and something would make sense, and it would click and I'd say “ah-ha!” cool, you know, this is it.” . . . Basically it was just, it was a process. . . . you know, like if the depression was just because of this broken up relationship, then with time and understanding and more experience, then you know, your heart would heal. I could have gotten over it that much quicker, but because there were a lot of issues, it took a long time. . . . it's taken me this long, but I'm getting to the point where I'm understanding--I'm learning a lot about myself, and reasons for why I feel the way I do, why certain situations scare me, why I react, why I do things, and so I'm understanding me more, and so that has helped me more, I guess in a way, come out of the depression. (16)

Understanding the specific “alternative” of family and friends. As reviewed below, participants spoke of several variants of community support that had a significant impact—from people who “knew just what to do,” to others who were “just there” or perhaps just “acted normally.” Sometimes helpful support was especially directive, while other times it was primarily trusting of the individual. After reviewing how others' support benefited individual recovery, we turn to the reverse: ways that a chance to *help others* reportedly benefited an

individual facing depression. Finally, we briefly review ways that severe emotional problems may “drain” and exhaust one’s family support.

To begin, Debbie spoke of a family member with the special touch to “to calm me down. . . Um but she just, I don’t know what she does; she just has the magic of cheering me up (8). Victoria related the following experience on a dark occasion following her mother’s funeral when she was looking through old family heirlooms:

I remember . . . just umm feeling so overwhelmed about it and [my neighbor] came. And she just sat there with me and she (weeping) asked me to tell her about these things, what they were, and what they meant, and what part they had in my family. And then she asked me, “what would your mamma do to make you feel better?” Oh that one is easy “she would brush my hair” and . . . and she sent my daughter after my brush and just sat there and brushed my hair and helped me work through that particular day. (5)

Jill mentioned the influence of one neighbor’s support, in spite of her lack of knowledge regarding depression: “I [had] one person say to me ‘I don’t, you know, I don’t understand depression, I don’t know what it’s like, but I can see that you’re having a hard time.’ So even though she didn’t get it, she was still sympathetic about it and that was nice” (7). Peter similarly described the response of friends:

When the time came that I needed them (pause), they were supportive at a distance. They were like many people I’m sure would be: they were unsure of how to help. They didn’t know what to say, what to do; they were uncomfortable, but they were helpful. I mean . . . they would do what I asked, you know, and if I said, “look don’t be offended . . . I just need to be alone for a while,” they would say, “okay” . . . And we all came through it, you know.

He continued:

The best thing they ever did for me was just act normal around me, you know, I would go through all this intense stuff on my own and then I would come out and say “hey lets go get a beer,” you know or something. And they’d say “okay” and, you know, they would sit and talk about baseball or football or you know politics you know or whatever it is we talked about but they didn’t treat me like I was diseased or different they still gave me that respect and that was what made all the difference, you know. My parents were there in the trenches with me (pause) and my friends were there when I needed to get out of the trenches (laughs).

Speaking of his family, Peter remarked:

Oh man, my family has been just unbelievable, just unbelievable. They just stood behind me so much, uh just 100% and I know that it had to be very traumatic for them to watch me go through what I went through. My parents . . . we were very tight and for them to watch me go through what I went through, um the feelings must have been . . . awful for them, but nonetheless they stood by me [and] backed me up. They said anything you need, we’ll get it. I don’t care how much it costs. I don’t care where we have to go . . . If you gotta fly to India to see the best doctor in the world, we’ll go, you know. And they

backed me up 100%. They said, “you know, whatever you gotta do to take care of this, we’ll be there right there with you.

He concluded, “I just thank God for that and I really pray and I hope that other people out there who have depression can have a similar support system people who will be there for them because really they’re the only reason I made it through all this” (10).

Lucy similarly spoke of particular relationships as life-saving—“Two teachers . . . they kept me alive . . . some days they were the reason I was there the next day and they’ll never know that . . . Two people that never knew—they made or broke some of my days, you know.”

Referring to her mother, she added:

My drugs cost, even with insurance, 600 bucks a month—and my Mom’s got part time jobs, I mean two jobs . . . and she’s still there to try to help me out. I mean, if that’s not love, you know. . . . In one sense, it’s amazing, knowing that that person will do anything to make your situation the best they can.

About these relationships, Lucy concluded that she could look at them and say, “‘I’m okay.’ Because sometimes that’s all you need—like during a humongous panic attack when you feel like it’s all going to end. If you can think just for one second, ‘I’m okay because this person loves me. And they’re there all the time.’ You don’t have to believe it . . . ever. But sometimes it keeps you around” (6).

Sarah similarly spoke of her community as “24-7 counseling any time I needed it.” She added, “I don’t know . . . that I would have made it honestly. . . . It was truly my mom and dad and sister and my friends that kept me, you know, got me to the point I needed to be (4).

Victoria recounted a particularly poignant account of her husband’s impact on her recovery—starting with a moment of crisis:

I just got home and I thought, “oh I just don’t want to be here anymore.” I picked up that bottle of Valium and thought, “I could just take all of these right now. That would be that and I wouldn’t have to live like this.” And I could remember sitting in the kitchen just bawling [and] just thinking, what do I do. And the thought came to me to call Paul [my husband] and I did I called him. I said, “I need you right now.” And . . . I don’t know, he must have flown home a hundred miles an hour because he was there within minutes. And I just said, “I’m going to take my life.” And he said, “let me give you a blessing first” and he did he gave me a priesthood blessing.¹² And I will never forget that blessing because he just pleaded with Heavenly Father. And he didn’t plead that I wouldn’t leave him. He pleaded that Heavenly Father would have mercy on me so that I would not suffer, you know. And (*sniff*) I remember think that it occurred to me that he loved me enough that my suffering was more important than my being here. And it’s kind of a weird thing but after that there was a real peace that came.

¹² This is a common occurrence in Mormon families, where an individual receives a blessing after being anointed with oil.

Two additional vignettes depict the impact of Victoria's husband:

I woke up one morning and could not move. I mean, literally I was just paralyzed. It scared me to death. And Paul said 'we have to go to the doctor, we *have* to go to the doctor.' . . . And you know, I don't want a doctor. . . . And so this morning was just so horrible. And Paul just rubbed me and rubbed me; I could barely move, but I was in just such pain. And he said. . . 'I'm just going to call this other doctor and we're gonna go.' We messed up the credit card buying medicine, but it's worth it. . . . and Paul has never, I mean he has been so supportive in that, you know, we will find a way even if we have to borrow the money. . . . Even when I say we can't afford it or go without (laughs) but, you know, he just laughs and he makes it happen, you know. (5)

In some cases, it appears that especially directive help is critical, as reflected in this vignette from Jill's narrative:

When I had my [depression] episode a year ago, a friend of mine . . . she was persistent to get me to get help. And that's what you need, is someone that will not let you just . . . "you can stay in bed today, but you're going to call the therapist," is what she said to me that day. "I'm going to let you stay in bed today, but you must promise me that you'll call the therapist and set up an appointment." And that's what you need, someone who will just take the reigns and tell you, "you've got to . . .", you know, and she's the only one who's ever done that. And that may have been why I did so well last year coming out of it. (7)

In other cases, less direction and more trust appeared especially powerful. As detailed in Chapter 4, Kellie emphasized the space and trust received from her parents as critical—alongside their willingness to be present: "Even just to bounce ideas off of them. You know, and get their ideas, it's definitely helpful. It's definitely helpful just to talk . . . Just get it out so you have this assurance that you're not crazy you know?" She continued:

They knew I was struggling with knowing what to do as far as having to take some form of medication. . . . They didn't want to be forceful and, I don't know, take my agency away and say "We're going to take you to see a doctor, and you're going to do this" Their attitude was just, "You know, Kellie, we trust you, we know that you need to find a method that you feel good about." . . . They were just praying for me that I would . . . be inspired to know what was the very best for me and my situation. (16)

In addition to the impact of others' help, some mentioned the opportunity to help others as beneficial in their recovery. Sometimes, this was a passing reference to others' as a kind of distraction, such as Fern, who spoke of life after her divorce--"I didn't have time to be depressed because I just had to function for my children" (11). In other instances, the chance to care for a child seems to have a particular emotional impact. Speaking of her baby girl, Jill remarked:

She . . . I don't know if she knows it but she has been like my little lifesaver, my little life preserver. Uh, I know that the year my mom died when she was born that year. Had I

not had her I probably wouldn't have gotten out of bed and gone through the days, you know, I had to get up and take care of that baby (7)

Victoria similarly said about her young daughter:

She is a cute girl; she is my joy. She keeps me going, you know. Anyway, when talking about depression there are days when I feel like, you know, I could just run away. . . . But to have her here you know keeps. . . . Love can do that. You gotta stay here, you know, even though [there are] those occasional dark days when I feel like, "ugh, it's not even worth living anymore," you know, she's right there. . . She makes it worth living. (5)

Lucy, still fighting the effects of severe abuse, similarly spoke of the impact of her own baby girl—"For the first time, I mattered" (6).

Finally, two individuals mentioned consequences of the unfortunate drain that severe emotional problems can be on a family unit. Reflecting on the duration of her battle with depression, Elaine summarized her family's emotional response, "Well, uh, I've tried; it's been eight years and . . . I mean, it just gets old. They just don't wanna hear about it anymore (laughs)" (2). Michelle told of being called by her family in the hospital and told that "I couldn't come home again." She explained:

And what they meant--what I understand now. . . I think one of the things with mental illness is that we do not do a good job of supporting families of the person whose mentally ill. My, uh I didn't realize the toll, the responsibility I put on my sister and her family when I would be so suicidal and my sister drove me to ECT treatments. . . It takes . . . a toll on your relationship with your family. It takes a toll on your relationship with your friends too. You just I mean, *how many times* can they listen to you re-hash the same thing. Um, I can remember during one hospitalization . . . calling this friend of mine and asking him if he would give the eulogy at my funeral and would he be able to forgive me if I ended my suffering. You know, that's *a lot* for a friendship with withstand and, you know, this friend did. He still was there, um but it's really hard.

In light of this, Michelle spoke of the positive impact of professional assistance via a supported apartment program on her family relationships:

That gave me the support of this agency and the support of a case manager and . . . what that did was that has allowed my relationships with my family to heal. Now my sister only has to be my sister. And my daughter and my son just have to be my kids. And they know and I know that if I have a problem, that I have a doctor. . . So, that's been important in the healing process. (13)

While participant accounts confirm a powerful reported benefit from positive relationships with friends and family, it appears there are times when talking with someone external to one's natural support system can be critical.

Considering the specific alternative of psychotherapy. As an important member of their support system and community, psychotherapists were also highlighted as a helpful alternative.

Comments ranged from an assortment of barriers and difficulties with counseling, to its potential when it goes well. Robert reflected a classic resistance to counseling:

I didn't talk to anybody; I think my mom had mentioned a couple times though, "I think you need to go talk to a therapist" but I was not going to (laughs) go and talk to anybody because only crazy [people] went and talked to them. . . . I thought that my problem was not that major. (9)

Others spoke of more pragmatic concerns. Camille described going to a counselor after "resisting for a long time" because "number one because of finances and second because I thought it was mostly a chemical thing, and what was a counselor going to do?" (3). Similarly, Elaine initially felt encouraged to seek counseling, but arrived to find the counselor asking for \$150 up front that she didn't have (2). Peter related the following experience with his first therapist:

Well the reason it wasn't helpful is because I very easily could have replaced him with a *dead fish* and gotten the same kind of response. He would sit there and he would say, "well how are you feeling today?" "Well, you know, doctor I don't feel very good and the reason I don't feel good is this, that and the other." And he'd say "really well how does it make you feel?" "I'm not here because I'm cheery; I'm here because I am something is wrong" and, you know, we went through five or six session like that where it was just you know "uh huh, uh huh" and he's writing furiously on this clipboard (pause) and he's not *talking to me* and he's not offering me . .

He continued:

I needed help; I needed *tools*; I needed something...and uh and he was offering me *nothing*. You know, he never, he never asked me you know "what do you want to do about this?" he never said . . he just sat there and listened. . . And the first session, I said "well, you know, well he's getting a feel for the problem." And the second session I said "well, you know, maybe he's still trying to see how deep it goes." And the third session I said "boy, you know, he ought to be saying something" and by the fifth session I said "I've *had it*. I've absolutely *had it*. I can't *handle this anymore*. You know, I'm reaching out for help and I'm *trying* to be patient I'm *trying* to be understanding and he just he's *not helping me*." (10)

Robert, whose resistance to counseling began this section, eventually acquiesced to see a therapist and related this experience:

Counseling was okay, but for some reason – I don't know why – and maybe it's just because I'm bull-headed and stubborn and I don't know... um. I didn't like counseling because it seemed like every time I would go and talk to the counselor, it would bring back memories of things that made me depressed. So, a lot of times I would walk out of there more depressed than I was when I walked [in]. (9)

When counseling went well, it was often reported to be impactful. Peter himself reported eventually finding another therapist that "made a *huge* difference in my life":

All I ever wanted was a chance to try and dig myself out, but I know I needed help I needed *tools* I needed something... [the second counselor] was able to zero in on what was causing me to feel this way and what *I could do* to help myself... As soon as he knew what we were dealing with he started giving me tools right away . . . And *immediately*, I felt, even after the first session . . . I had made some progress. “Okay, I’m not cured. I’m not, you know, whatever, but I have a couple of tools now. I have some tools in my pocket that whenever something starts to go wrong. . . I have something I can use.”

As reviewed in the earlier section, Peter spoke of specific lessons as critical to recovery:

I got some *tools*. I got some *help*. I got some *direction*, you know, he . . . set me right on a lot of premises that I had wrong. For example, he let me know that, “no the whole world doesn’t lose the ability to sleep before a big event, you know, and the whole world doesn’t . . . feel this way about themselves when they don’t get something right, and you don’t always have to be perfect all the time.”

He concluded:

The other thing is he never claimed to have a cure all. That was really good for me. He didn’t say “this is *the answer* you *do this* and you’ll be fine” he said “you know this works for some people and uh give it a try and if it doesn’t work we’ll come back and try something else” . . . um and that that to me was terrific . . . what was helpful was the fact that I was taking steps to alleviate my own pain. . . (pause) I mean, all I wanted . . . from the first moment I knew I had a problem . . . was to (pause) to *get in there* and *start working on it* you know I wanted to be able to *get in there* and . . . to be able to *battle it* . . . to *stand my ground* against it so I could you know (pause) so I could *take back my life*. (10)

Fern spoke of being “able to articulate what I was feeling to a counselor”—to have “an audience for my feelings” since she didn’t “have a spouse that you are use to unloading your feelings onto” (11). Kyle specifically highlighted the potential impact of “some kind of therapy”—“I don’t necessarily mean a paid Ph.D. It could come from a book, a friend, a group . . . The thought process needs to change somehow” (12). Lucy described being touched by a psychologist who gave her his home phone:

I don’t even see him every week now, but if it’s getting bad in my life, he will call me every day, or he will call me once a week. And he just says, hold on till that next phone call, and that’s all he asks me. But he realizes, he doesn’t take it further than that, or look at me differently, but he’s available, he’s made himself approachable, and not on a different level than me, which has made me open so much more of myself to him, and in doing so benefited myself so much more. (6)

While the potential of therapy was well acknowledged, views on its relation to medication differed widely. Even therapy advocates often emphasized its secondary place in relation to medication. Jill noted:

I'm a firm believer in medication, because I don't think, I mean, I think therapy is good, but it doesn't help if you're not calmed down. It doesn't, I mean . . . *You can't talk it out; it's chemical (emphasized)*. Talking it out or going for a jog isn't going to help the chemical imbalance that's going on, and for me it's pretty dramatic, with and without meds. (7)

In a similar spirit, Victoria added:

The medication really helps me have a life. The therapy helps me not crash and burn. Not crawl up in a ball and cry every two hours you know what I mean. Or feel like I want to give up on life. . . I mean . . . if life is sailing along smoothly and I didn't have my medication, the days would just be gloomy and gray just lack luster. And that's not a bad thing but it's not the way I want to live my life. So I need them both. Medication always *(laughs)*. (5)

Theme 9. Considering prognosis and recovery: "Can I get better?"

To conclude, we zoom out to examine participant interpretations of the broader horizon of prognosis and recovery. In Chapter 7, attention is given to variation in participants' actual definitions of recovery. Here, the focus is on a related question asked to all participants: "do you believe permanent improvement with depression is possible?" Elaine related, "[My doctor] was encouraging that I could live a fairly normal life if I could stick with my medications and stay on them" (2). Victoria reflected:

Well, I resolved that it will never be better, okay? My own definition of better would mean that I wouldn't have to take anymore pills—okay, that's not going to happen. I mean unless some brilliant person comes up with a pill that just fixes it permanently.

She suggested that the best recovery she could aspire toward was having more self-control in a changing environment. Even while acknowledging some improvement, Victoria went on to similarly conclude:

But, you know, there will always be life changes. That's just part of living on this earth, you know. There are always gonna be things that are going to change and you know maybe from that perspective I will never be better that way, you know, but one can hope. (5)

As Jill mentioned earlier said of her son, "from the beginning when he was diagnosed, I said "this is something for life, you'll have to be on these medications for the rest of your life."

In extension of an earlier quote, this same woman remarked:

I'm permanently going to have depression and I'll be on meds my whole life and I had to take, it took a mind change for me to finally get to where I could say "I'm grateful that I was born in this day and age where I could get the medication that I need so that I wouldn't be locked up in the attic somewhere, or indisposed all the time" *(laughs)*.

Jill also noted, “I just, like I said, I don’t . . . you can’t get better without medication. You can talk and talk and talk but you can’t get better without, if your chemicals are messed up (*emphatic*)” (7).

Debbie, who spoke of being “stuck” with a “chemical imbalance,” responded similarly when asked, “Do you ever talk about getting better from depression?”: “I don’t think that’s possible. I just . . . I *want it to* but I don’t think that I . . . I think, just a couple years ago, I just faced it that I’m just always gonna have to have something” (8).

For others, a similar narrative of permanence is tied to long years of struggle. To the same question of “Do you ever talk about getting better completely—like a permanent improvement with depression?” Robert answered, “No, not really. I mean, I, uh . . . I just don’t know. . . . I [have] fought with it so long that I just don’t know that that’ll ever happen” (9).

From long experience, many simply conclude they are not getting better. Kyle described speaking to his friend about recovery, “I go ‘You *are gonna get better.*’ And . . . she said ‘Am I?’ I go ‘well *of course* you’re gonna get better.’ She goes ‘I don’t think I am, Kyle’” (12).

In spite of such despair, one striking feature of many accounts was a common impulse to *want to believe they could get better*¹³. Robert, who had mentioned that he didn’t “know that recovery would ever happen,” later added:

But I, I hope, I keep a . . . a thought in my mind that, you know, life goes [on], you gain more experience, who knows what’s . . . out there? But I . . . there’s also a part of me that says, “You know, you may deal with this the rest of your life.” (9)

Even with those currently seeing their condition as permanent, this impulse prompted a hope against hope. Knowing of my exposure to “latest findings” as a graduate student, Elaine asked me during the close of the interview:

What are you learning? Is there a getting better from this or not? I mean, they told me in the beginning there wasn’t . . . [but] I’m hoping that I can make improvements that are permanent and that I will. I am getting better than I was certainly. I don’t know how much better, you know, I don’t know if I can ever be what . . . I probably can’t be what I was when I was twenty but I think I can certainly get better than I was eight years ago, yeah.

*J: Who told you that you don’t get better?

Well my initial diagnosis--they said this is something permanent. This isn’t something that you’ll ever not have (2).

¹³ Different recovery views seemed comforting for different participants. Some were relieved in accepting depression as a lifetime challenge, other felt comfort in the hope of full recovery.

Two participants spoke of the actual *moment* they heard about such an alternative view. As described in the other chapter, Kyle spoke of discovering the *National Empowerment Center*, a website run by a psychiatrist recovered from schizophrenia:

The site is all about recovery--that recovery *is real*. . . . Until I got to that site, all you heard was drilled into people "Lifetime, Lifetime, it's a lifetime illness, you're forever going to need meds; you got to stay on your meds." Um . . . there's no hope there for recovery. (12)

Michelle, who had faced both schizophrenic and depressive symptoms, spoke of participating in a recovery-oriented treatment program (Mary Ellen Copeland's *Wellness Recovery Action Plan*—mentioned by two participants in the study as helpful) during one of her many stays in a psychiatric hospital. In one of the sessions, she heard the story of a woman who had faces similar difficult circumstances.

Kate had been hospitalized in the late 50s out east in a state hospital. The family was told that there was no hope for her recovery that they should just go and forget about her. And after eight years Kate started to get well, and the staff realized that she was having conversations with getting little groups of people together for conversation and she'd help the staff with little things. And they realized that Kate was well enough to go home. Kate went home she worked for 22 years as a school dietician in a kinda of inner-city type school. She helped her son raise 7 children as a single parent and was never hospitalized again.

Michelle continued:

[This] was the first seed of hope. . . . I thought, "if Kate could get well after 8 years maybe I could get well after 2 or 3." . . . I remember a conversation with the psychiatrist out there saying "I have faith the size of a mustard seed to begin rebuilding my life and if you can work with that little, I will try living one more time." (13)

Camille remarked similarly, "The important thing is that I know that it won't last forever. Before I had no hope. I couldn't see a light at the end of the tunnel" (3). After recounting gradually successful efforts to regain the capacity to take care of herself, Michelle spoke of a second turning point involving a seminar on tape (Pat Egan's *Inside Outside Program*):

This particular video is finally what counteracted "you'll never live independently again." It was that first conclusive evidence that people really do . . . [there] really is something beyond "you can never live independently." . . . There's a lot of people that don't understand that you can recover.

This woman, who had first received a "seed of hope," reflected on an earlier treatment experience:

This doctor told my family that I would never be able to live independently again. . . . Even though I have made progress over the last 4 or 5 years, there's still *always* that seed

of doubt that was planted . . . you know, “can I really take care of myself?”. . . That’s a *long time* to have one remark. . . but it was said by the doctor so it had so much *power* and so much influence. And you know if you went back and asked him, he probably wouldn’t even remember having *said that* and yet it’s had all these ripples for the last several years.

*J: You said a seed of doubt in your family?
In my family and in myself too. Um hmm.

Michelle concluded about her experience, “One of the things that I’ve learned since then is that you can *never predict* the recovery of another individual” (13).

Before concluding this section, one qualification is important to mention. While the hope of recovery seemed beneficial to some, for others this expectation could be almost offensive and stifling in its seeming naiveté. Lucy, who had suffered perhaps the most intense depression suffering of any participant (over an extended period), said:

Everybody makes that promise, “it’ll get better.” And when it’s not getting better, you know, and . . . you’ve been hurting alone for so long, that promise really . . . holds no weight. You know what I mean? Because you’re like “no, I’ve been dealing this for, you know, ten years by myself, and hurting that long for that bad, you think you can turn it around in a few months?” (6)

Robert also claimed, “one of the ideas that pushed me to be more depressed was the thought that I had to beat this problem. And, uh . . . and that, that was [during a certain period], that was a motivating factor for the depression (9). He went on to speak of gaining more realistic expectations in terms of his own recovery.

In summary, this chapter helps the reader understand some of the nuances associated with the continued navigation of medical treatment. Rather than reflect an easy acceptance of treatment compliance, these accounts reveal subtle interpretive aspects often accompanying the decision to continue (or cease) receiving treatment. Overall, the above analysis highlights the degree to which individuals evolve in their self-understanding over time to a point where they fully embrace treatment or eventually give it up.

Initially, many individuals report a dramatic experience with medical treatment, whether positive or negative, that appears to galvanize a particular way of thinking about medication generally. Even while the bulk of other reported experiences tend to be more ambivalent, these initial experiences seem to have a lasting effect in the way individuals subsequently endure changing effects and other difficulties concurrent with the medication. Interpreting these complex emotional/physiological changes and difficulties seems to be a particular challenge for individuals. As was the case with the initial problem definition of depression, confusion

generated by these treatment questions becomes a helpful backdrop to understand the significance of friend, family and doctor in shaping the ultimate interpretations adopted. Although some gain a resolve and conviction to continue treatment, others flatly reject medication—while still (most) others remain ambivalent, wrestling with their opinion about treatment. In spite of significant doubts about life without anti-depressants, a good number of individuals eventually attempt to taper off medication. As was observed during treatment itself, the interpretations of states associated with tapering are diverging and wide-ranging, with obvious consequences for what an individual eventually decides. In addition, depending on differences in how overall treatment experiences are interpreted, views of both alternative interventions and recovery itself may likewise differ. Once again, for all who have endured depression and experienced its dominant treatment, the associated confusion, hesitations and conflicted treatment advice ensures, as with problem definitions, a veritable “journey to an answer.”

Chapter 6

Adopting Distinct Interpretations of Depression and its Treatment: What Resources are Leveraged in Narrative Formation?

In the foregoing chapters, general themes across individual stories have been reviewed. Taken together, these themes inform the three empirical questions in an implicit way: 1) how do diverse narratives of depression and its treatment arise, 2) what constitutes meaningful differences between narratives and 3) how are they maintained over time? In the following three chapters, insights and results relevant to each question are made more explicit, with evidence for each issue summarized and elaborated upon more directly. Starting in this chapter, these findings are presented alongside insights from the broader literature on depression interpretations.

While attending to a variety of aspects in the adoption of particular interpretations and stories, the focus in this chapter is on the narrative “resources” that participants draw and rely upon in the creation of their particular story. While a “resource” is customarily seen as some kind of physical, concrete object, the word is used here more broadly to also refer to common mental and emotional states associated with facing depression (confusion, urgency, resistance). Resources may thus include physical objects (e.g., books, data, videos), programs, people, particular states associated with treatment and the treatment itself. In each case, these entities may be engaged in experiences that are ultimately leveraged in the adoption/creation of a particular story. This smorgasbord of narrative “resources” is proposed to scaffold the formation of unique stories of depression and its treatment. To begin, we set the stage by considering the role of pain and confusion itself as a fundamental narrative resource for the way it appears to *heighten* individuals’ need for adopting some kind of concrete explanation for depression in the first place. This urgency-for-explanation is proposed as a key state ultimately leveraged and ‘drawn upon’ in the creation of particular narratives.

1. The Pain of Confusion: “I couldn’t figure out why I felt that way. . .”

Half of participants spoke of some kind of confusion early in their depression narrative, often centered on desires/expectations for life and their inability to reach them; for example, wanting to sleep but *not being able to*; wanting to enjoy life, but *not being able to*; wanting to experience relationships but *not being able to*. For some, this entailed a battle between competing desires, such as wanting to participate in common activities, but also *wanting to avoid them* or yearning for people to be with, alongside an *impulse to avoid them*. In addition to confusing clashes between internal desires, expectations and abilities, others spoke of the

perplexing contrast between their depressing feelings and external realities, including a happy, positive childhood, an otherwise happy family life or surrounding positive physical conditions like a sunny day. Contrast with other surrounding individuals also became a source of confusion—both in comparisons with others’ happiness and their more normal levels of sorrow.

Confusion thus stems from the perplexing discrepancy between intensely negative feelings and surrounding signs they should be feeling differently (i.e., good weather, loving family, other people staying happy or experiencing normal sorrow in their own tough times)—prompting questions such as, *Where is this coming from? Why does this hurt so bad? Why can’t I control or overcome this? Why does it come out of the blue?* Confusion has been noted as a common aspect of chronic pain narratives generally (Hydén, 1997). Polkinghorne (1996) cites May’s belief that “major life events . . . often tear apart previously meaning-giving stories” and leave the person to face “profound insecurity, self-doubt and inner conflict.” May highlights the role of mental pain, in particular, in the “decomposition of a person’s previously developed . . . life design (p. 302). In her exposition of narrative analysis, Riessman (1993) similarly identifies “biographic disruption” often associated with chronic illness as prompting efforts to “reconstruct a coherent self in narratives” (p. 219).

In the case of depression, it appears that the intense pain can literally “ramp up” individuals’ already inherent need to interpret and explain what is going on. Compared to when life is going well (when one arguably has less of a need to make sense), it appears this pain, when combined with striking confusion about its source, can lead some participants to even a desperation for answers.¹⁴ Other studies specific to depression have highlighted uncertainty as a tangible source of additional pain for both distressed individuals and their dear ones (Garfield et al., 2003; Lewis, 1995). One survivor in another study noted, for instance, “not knowing what it was making it twice as bad” (Badger & Nolan, 2007, p. 29). In all these ways, confusion itself becomes an initial resource on which individuals may draw in the adoption of particular interpretations.

Beyond the personal pain, individual accounts clearly reflected a burden in the confusion experienced by surrounding family—i.e., “It’s hard for family and friends to understand that you really, really, *really* are not doing this intentionally” (16). Associated with others’ concerns, participants spoke of grappling with the debilitating pain stems primarily from their own *messed up self*. This, in turn, appeared to further heighten the urgency for other explanations—further “ramping up” individuals’ own need for answers. As Lucy said about her early experience with

¹⁴ The notable exceptions were those attempting to simply numb themselves or zone out to the pain or individuals with obvious reasons for the depression (abuse victims).

depression, “You need a place to point your finger to . . . it needs to go somewhere” (6). This second level of confusion appears to have a significant influence—especially when family or friends are critical or blaming. This helps explain further how an individual’s desire for answers could become so great that even the possibility of a serious physical deficiency like a tumor can feel like a relief (4).

2. *Friends and Family Offering Answers: “Let me help you . . .”*

Grasping the role of confusion becomes an important backdrop to analyzing a second narrative resource identified in the study: advice and suggestions from friends and family. As noted previously, Rappaport (1998) has argued in his work on community narratives that individuals do not create their own personal story “whole cloth” out of nothing, but instead draw on narratives available in the broader collective. McAdams (1999) similarly notes “a sense in which a life story is jointly authored, both by the person whose story it is and the culture within which the story is embedded” (p. 488-489). As reflected in Sarah, Victoria, Kellie & Camille’s accounts, surrounding friends and family often play an active role in sharing and instructing distressed individuals on potential explanations for their pain. These kinds of instances of exchange constituted the most abundant category in the coding process, with 53 references across interviews. Such exchanges appear often to be meaningful galvanizing moments in the adoption of a particular narrative of depression and its treatment.

The overall degree to which individuals gave credence to counsel from family/friends varied widely. On one side, some like Victoria and Sarah took a helpful friend or family member as a major guide—casting them as literal heroes in their story. On the other side, individuals like Kyle and Esther saw family’s intentions to help as intrusive and over-bearing, with Kyle describing having to learn to forgive their aggressive attempts at influencing his treatment decisions.

As evident across accounts, “community influence” is no monolithic entity—often representing competing, even contradictory advice. Response to community influence subsequently also varied according to what specific advice was given. Some who were encouraged towards medical treatment, for instance, responded favorably (Sarah), while others resisted and resented the pressure (Kyle). Others who were encouraged *away from medical treatment* rejected this pressure and embraced medication even more (Elaine), while others were persuaded by such opposition (Kellie).

Among other things, this analysis has implications for understanding the larger interplay between personal and cultural narratives. On one level, encounters with friends, family and medical professionals may be understood as moments for the potential transmission of prevailing

narratives. Since participants varied in the degree to which they accepted surrounding views, however, it would be incorrect to portray this as some kind of linear effect. Instead, as different possible narratives are voiced different friends or family members, individuals are presented with the interpretive raw material out of which they craft their own personal stories. In this way, while some appeared to adopt a conventional biomedical narrative wholesale, others embraced only a part (e.g., liking diagnosis, but not medical treatment), while still others seemed to reject the same narrative entirely.

While moments of actual verbal conversation were the most common influences identified, observing others also appeared to exert an influence. In a reference not shared previously, Jill said:

When you have a friend or two or three . . . on Prozac too . . . you can feel like, “Okay, I’m not so bad,” you know. If they’re on it, I can be on it. . . . The biggest thing for me accepting it was knowing other people were on meds too that I knew. . . that made me more accepting of it. (7)

While personal acquaintances (talking or observing) seemed to exert the most palpable influence on individual interpretations, different kinds of media were referenced as well.

3. Biomedical Diagnosis and Explanation: “It was such a relief. . .”

In addition to comments from family/friends, participants also mentioned interaction with medical professionals as significant in the formative understanding of their problem. Against the backdrop of pain and confusion, the formal experience of receiving a diagnosis, in particular, is proposed as a third key narrative resource on which participants draw in the creation of their own understanding and overall story.

In their own interviewing study of women’s use of the biomedical explanatory model, Schreiber and Hartrick (2002) found that all participants received understanding of the model initially from a physician. In earlier chapters, this study examined variation in individual evaluations of biomedical diagnosis—from easy embrace, to ambivalence, to sharp rejection. As noted in the literature review, ambivalence has been documented in other qualitative depression studies, with individuals varying in the degree to which medical diagnosis is experienced as implying more or less control over depression and more or less hope for recovery (Gammell & Stoppard, 1999; Karp, 1997; Lewis, 1995). Here, we turn to consider implications of these diverging stances toward diagnosis for how participants’ come to see and narrate their experience of depression overall.

First, it is worth highlighting one evident reason that biomedical explanation seems to be readily embraced as a part of individuals’ narrative. Simply put, the biomedical narrative

addresses and answers the very questions reviewed earlier as particularly confusing and painful (i.e., *Why does this hurt so bad? Why can't I overcome this? Why does it come out of the blue?*). Drew and colleagues (1999) document an association between the spontaneity, unpredictability and intransigence of symptom onset with the adoption of a biological narrative. As reflected in the accounts of Camille, Jill, Elaine Kellie & Peter, participants expressed excitement at a concrete, *physical* explanation, as well as the promise of a tangible, *physical* solution. More than simply offering an intellectual explanation, biological theories appear to address the *emotional pain* that results from thinking that the pain stems from one's own weakness. Since a "medical/biological illness" has a currency as a concrete and material entity, it appears to legitimize the struggle with depression as a "real thing." Such explanations may thus provide crucial credibility to address others' confusion and establish a language for depression that communities can deal with. This may explain the relief documented in other interviewing studies when individuals receive a depression diagnosis (Stoppard & Gammell, 2003) and specifically, when they come to see depression as primarily biological (Badger & Nolan, 2007; Ridge & Ziebland, 2006; Schreiber & Hartrick, 2002).

In addition to addressing personal confusion in a powerful way, formal medical diagnosis has been shown to often mark a significant change in how people come to talk about depression and see themselves overall (Gammell & Stoppard, 1999; Rogers, May & Oliver, 2001). In their exploration of the depression experience of 43 women, Schreiber and Hartrick (2002) remark on the "profoundly influential" occasion of individuals first hearing about the biomedical explanation for depression. They describe how this encounter leads participants to question previous knowledge, and engage in "ongoing process of revision to accommodate new information," ultimately "reformulating a new explanatory model," which, at times "completely substitutes" for their previous understanding (pp. 96-97).

As reflected across interviews, these revisions can descend to the very level of identity. For some, diagnosis clearly provided some kind of reassurance for a stable new identity by explaining where their pain was coming from and outlining a course of action. For others, however, the reverse effect was striking. As reviewed in an earlier chapter, Lucy reflected, "You feel like you lose yourself, almost. Like a part of you dies when you're diagnosed. . . . like a grieving period realizing that the person that was faking it for so long--she wasn't real." She continued, "and she kind of did die and that we had to reinvent and restructure this new being, almost. . . . Giving her the tools and the revenues, making sure she had insurance all the time . . . it's hard." Lucy concluded, "[you] *do* feel a detachment from everything you thought you were when this becomes where you're at" (6).

Biomedical explanation and abuse. It was Lucy's story that also illustrated one of the most vivid consequences of biomedical explanation for individual narratives—an excerpt not reviewed to this point:

When I was six, [my step-mother] locked me in the closet for three days, without food. . . I was scared of the dark when I was little. And I remember screaming at first . . . and after a few hours, I was like *so* embarrassed because I had to go to the bathroom. And my Dad was there, but he never opened the door. And after three days, she let me out. . . When the screaming went on longer than she would have liked, she, she taped my mouth and taped my hands behind my back and she hog-tied me . . . like weird stuff. And I was just like so embarrassed that I had gone to the bathroom in this closet. . . embarrassed they were going to open the door . . . I still see her in the corner of the closet just shaking and I look at her and I cry. . .

As reflected in the quote opening the introduction, Lucy described during this time, “very bad beatings to the point of unconsciousness, ripped, broken and arms taken out of socket.” In the wake of these experiences, Lucy described starting to “pull away at eight” and being taken by her real mother, who was unaware of the abuse happening with her father and step-mother, to an internal medicine doctor. While still fearing to disclose the abuse, Lucy hoped her doctor would recognize what was happening: “I hoped that was how it would just eventually, just *stop*, you know--that they would just keep guessing . . . I don't know . . . I just kept hoping that maybe my doctor would see through my lies . . . of me going, ‘I'm fine.’” Although Lucy recalled “there was always this feeling that something bad was going wrong with me,” she said, “but they just never could figured it out.” Eventually the doctor put her on Prozac for depression.

Although expressing anger at doctors “for allowing for so much . . . to go underneath the radar,” this event appeared to powerfully influence Lucy's narrative at a young age in fairly surprising ways. Namely, Lucy began from this time to emphasize biological deficiency as the primary cause of her emotional struggles, including depression (6).

Shreiber and Hartrick (2002) propose one of the “unintended consequences” of a biomedical narrative as “shift[ing] attention away from the meaningful psychological, relational, or situational dynamics that women talked about within the context of their depression.” They suggest that prevailing biological explanations seem to often effectively drive out or “render the situational factors” in a depression story “irrelevant” in even severe cases (pp. 100-102). Speaking of the biochemical theory, Esther likewise said, “a lot of times it drives out other things that might be going on” (14).

Interestingly enough, although medical discourse has been shown to be adopted more frequently when life stressors do not seem to be relevant (Gammel, 2004), the insight here is that

conventional medical discourse *itself* may deemphasize and minimize the seriousness of life stressors. Chapter 8 explores the same inclination as a strategy for maintaining one's narrative.

Prevailing psychological models have been criticized for similar tendencies. While proponents of the *biopsychosocial model* celebrate it as a framework that addresses all factors (Zuckerman, 1999), for instance, some have raised concern that it minimizes environmental factors in actual practice (McLaren, 1998). Referring to the *diathesis-stress model*, as well, Drew and colleagues (1999), suggest that the importance of traumatic external event may be “downplayed since it is seen not as a cause, but as a trigger for depression (i.e., any one of hundreds of such events could serve as the trigger” (p. 192).

In this section, we have considered implications of a biomedical diagnosis for individuals' views of their own pain, their identity and their surrounding life circumstances. Laying aside these personal consequences, we turn now to the implication most of interest to this study: how individuals facing depression think of solutions. As we continue exploration of resources relevant to particular narratives of depression and its treatment, the following discussion reveals dynamics especially connected with medication itself. Since problem and solution definitions are intimately connected, once individuals settle on a certain explanation of the problem, certain solutions also become more or less amenable and agreeable. Obviously, the embrace of a conventional biomedical explanation typically corresponds to embracing medical intervention as well—with biological explanation providing an initial and critical impetus for moving forward in treatment. On the way to analyzing the embrace of solutions as another resource for narratives, it is first important to squarely examine an intervening state commonly mentioned by participants.

4. Personal Reluctance: “I’m just not sure about this. . .”

While a number of individuals embraced biomedical interventions readily, a greater number spoke of significant hesitancy both initially and throughout treatment. *Reluctance* or *resistance* here refers to a reported hesitancy to receive medical diagnosis or its associated treatment. Chapter 5 detailed the many aspects and nuances associated with this resistance among depression survivors—including changing resistance over time and distinct ways it was interpreted. Depending on the participant, it varied in duration and intensity. In multiple ways, resistance is here reviewed as another resource relevant to the adoption of particular narratives.

Across accounts, participants discussed multiple reasons underlying treatment resistance—from dulled creativity, to constraining one's sense of personal strength, to a desire to avoid dependency, to a dislike of drugs in general. In his own research across fifty depression

narratives, Karp¹⁵ (2006) identified the response to treatment heard most often as “ambivalence toward medications, of reluctance to rely on them, of movement from one drug or dose to another, and of uncertainty about the treatment’s efficacy” (p. 21). He goes on to highlight an assortment of queries evident in his interviewees:

Must I take drugs for my pain? . . . How well are the drugs working? Are the side-effects bearable? Might other drugs or other doses work better? Will drugs ever solve my problem? How much do medical experts really know? Should I stop taking my medication? Who am I when I take mind-altering medications? (p. 18).

Two recent surveys of patient concerns corroborated such findings on a larger scale, documenting medication concerns that included dislike of adverse/side effects, feeling the drugs were not useful or effective, worries about addiction potential and long-term dependency in order to function and feeling like they were better (Manber, et al., 2003; other study cited in Holmes & Hudson, 2003).

While such studies confirm hesitations surrounding psychiatric medication, in particular, it is worth noting that such concerns are fairly common to any medication. For 324 patients taking medication for four chronic illnesses (asthma, renal, cardiac, and oncology), Horne and Weinman (1999) note “over a third (36%) reported strong *concerns* about the potential adverse effects of using their medication based on beliefs about the dangers of dependence or long-term effects” (p. 555). Even so, compared with cardiac drugs, Benkert and colleagues (1997) document a particular level of distrust among the general public regarding psychotropic medications. According to their study, psychiatric drugs were believed to involve significantly more severe side effects and prompted more fear of losing control.

It is also worth noting that medication concerns vary according to certain individual characteristics. Based on a questionnaire survey among 895 adult patients attending 20 general practices in England, significantly more men (67.4%) than women (54%) believed antidepressants to be “addictive” (Churchhill et al., 2000). A recent telephone survey of 829 ethnically diverse patients meeting criteria for clinical depression in the prior year found that African Americans and Hispanics are both less likely than Caucasian individuals to embrace antidepressant medication (Cooper et al., 2003). Most recently, a large-scale Internet survey measuring treatment preference, stigma and attitudes toward depression across 78,753 persons

¹⁵ I discovered David Karp’s work while in the middle of my own and have found in his insights and illustrations, in particular, both a counterpoint and corroborating voice in the analysis of depression narratives. Because his sample of fifty individuals is so large and his questions so similar, I draw on his conclusions and examples extensively in what follows. (As a long-time anti-depressant user in his own fight against depression, his fairness in examining both positive and negative aspects of the experience is also something I value).

with significant depressive symptoms confirmed the same pattern. Compared to whites, African Americans, Asians/Pacific Islanders and Hispanics were all more likely to prefer other things like counseling and prayer to medications; ethnic minorities were also less likely to believe in the efficacy of medication overall, and more likely hold beliefs that antidepressants were addictive (Givens et al., 2007).

Younger patients also report slightly more resistance than older individuals (Griffith, 1990; Lorenc & Branthwaite, 1993). Moses and Kirk (2005) note a consistent ambivalence towards medication in youth, with large numbers embracing medication and other large numbers resisting it for its side effects. While resistance to medical treatment is fairly prevalent across demographics, it is thus disproportionately manifest in communities historically disenfranchised and oppressed: women, children and ethnic minorities.

Laying aside the source and demographics of resistance, we turn back to the primary issue of how resistance functions as a resource for individual narratives—that is, how those facing depression navigate such resistance and what it means for the formation of their overall story of depression and its treatment. At a minimum, such resistance appears to function within a narrative like oppositional friction or turbulence, leading some to turn back and others to seek additional assurance. Where it exists, resistance thus has to be overcome before individuals accepted initial treatment and/or its continuation.

At first glance, whether the “friction” of resistance is overcome appears to involve a simple cost/benefit decision based on actual effects. Based on a survey of 81 primary care patients given maintenance antidepressant medications, however, Horne (2003) explored adherence to psychiatric treatment for depression in the context of medication beliefs—suggesting that decisions about treatment depend on two main belief categories--“perceived need for the medication (necessity)” and the “perceived potential for the medication to cause problems (concerns).” Logically, they hypothesized adherence would be greater among those whose beliefs about necessity outweighed beliefs about concerns related to medication (and vice versa). In an earlier study, Horne and Weinman (1999) note that psychiatric patients were significantly less adherent than asthma and cardiac patients—a distinction partially explained by the fact their *concerns* about medication tended to outweigh their beliefs in its *necessity*. They go on to suggest that patients facing asthma and cardiac disease, for instance, may see a stronger link between their medical treatment and the increase or reduction of symptoms than those receiving medical treatment for severe emotional problems.

Of significance to Horne’s work is the evidence that resistance is a complex state involving more than simply whether treatment “works” or not. Indeed, they emphasized

medication beliefs as the strongest predictors of treatment adherence—exerting an influence beyond demographic factors (age, gender, and educational experience) and clinical factors (type of illness and number of prescribed medicines). In other words, the degree to which treatment is *interpreted* as necessary and not, harmful or not, is the primary factor in whether individuals overcome hesitations and resistance to persist in medical treatment for depression.

If anything, my own findings suggest that participant response to resistance is even more complex than Horne surmises. In addition to the contributions of varied objective factors and personal characteristics, my interviews reflected evidence that judgments of levels of necessity and concern regarding treatment vary dramatically over time according to distinct experience, encounters and events. Depending on how individuals respond to diverse prompts in the face of such reluctance, overall narratives of treatment appear to evolve considerably. The remainder of this chapter explores nuances in this continuing process of narrative adoption. In cases of such lingering reluctance, the following two additional narrative resources seem to be especially influential in individuals' ongoing movement to embrace biomedical treatment and narration.

5. *Moments of Crisis: "We've just got to do something. . ."*

As described in Chapter 4, individuals often recounted early moments of extreme pain or challenge in their early narrative of depression as influential in their decision process of what to do. Beyond the intense need-to-explain associated with depression reviewed earlier, these rock-bottom/climactic moments seem to “ramp up” personal and collective urgency even further—constituting an effective preface to some kind of decisive action. In relation to the adoption of a particular narrative, these moments specifically appear in some cases to provide a concrete and compelling rationale needed to overcome personal resistance to some kind of formal treatment. This was most vividly reflected in Peter and Robert's reflections on crisis moments: “Things had gotten so bad for me that I said, ‘I'll do anything . . . I will do anything if you tell me that it will make me feel better’ (10); “And at that point my mom decided, she's like, ‘We have *got* to do something about this. We've *got to*’” (9). Jill and Elaine both commented on a similar urgency flowing from times of particular intensity and stress.

Karp (1997) describes similar moments among participants of “not being able to live like this,” noting that even while resistance to medication often remains, “the depth and persistence of their misery proves great enough” that influenced by others, individuals decide to move forward in treatment: “anything if you're depressed is better than being depressed. I knew I had to do something” (p. 90-91).

Similar to community influence noted earlier, it is important to neither overstate nor oversimplify this narrative resource. Rather than automatically causing this kind of readiness, crisis moments appear to significantly increase the thrust towards treatment--adding another influential factor to the complex process of simultaneously crafting one's narrative and making a decision about treatment. If resistance functions like "friction," crisis moments may be seen as strong wind pushing and pulling in a certain direction. Part of the thrust and pull of the moment, of course, are influential friends and family stepping into the crisis to again offer advice and counsel. In the absence of these messages, it is unlikely that such crises would have such an impact on individual narratives.

Against this backdrop, one specific message from surrounding relationships appears to be particularly influential. As Kellie recounted, her brother emphasized medical treatment as a temporary attempt, "[He said] 'just try them for a certain amount of time,' just to see if it would help me while I was getting through that time. It didn't mean I had to continue taking it for the rest of my life, but just for a time so I could get through whatever I needed to get through." In another instance, he told Kellie, "You can enjoy life now, even if you just take the medication for 6 months, it would be worth it" (16).

During Peter's crisis moment, he drew on the same narrative notion—"maybe I'll take it for six months and then I'll stop, you know--just something to get me over the hump" (10). Even when the storm of crisis hits, some individuals appear to consent to medical treatment only with an understanding that it will be used in the short-term to "kick-start" their recovery—accepting its use on this condition (see Badger & Nolan, 2007; Grime & Pollock 2003). Karp (2006) notes, "whatever the particular route that leads people to medication, when drugs are first prescribed for them, they rarely foresee a permanent relationship. . . . At this early point . . . they may view their connection with medication as . . . an association that will help them get past a difficult time in their lives (p. 73).

While some are able to rely on medication for only a short-term, many of my participants spoke of being unable to get off like they had hoped (see Ch. 8). Referring to the discrepancy between initial expectations and this eventual reality for many, Karp writes that an individual's first slow and ginger steps into a "new world" of treatment is "the beginning of a process of commitment that has far more wide-ranging implications than people can possibly see at the moment when they swallow the first pill prescribed for them" (p. 75). To conclude this analysis of narrative resources, into this "new world" we now go.

6. *Taking Medication: “I felt like superwoman” // “I lost a part of myself. . .”*

As reviewed above and in earlier chapters, arriving at a willingness to take medication is a journey for many, if not all. For those who choose to accept medical treatment for depression, their subsequent experiences with drugs constitute a sixth and final narrative resource in the initial adoption and formation of their own particular narrative of what they are facing and what should be done about it.

In Chapter 5, wide differences between reported effects across interviews were reviewed. While the range of these positive and negative experiences are real and worth exploration on their own right, the initial focus in this section goes beyond the effects per se, to how the effects appear to be framed and interpreted. After examining how these interpretations are relevant to narrative adoption, this section concludes by reviewing a number of shifts to narratives that findings confirm as ensuing from initial medical treatment for depression.

While some report little or no initially effect at all, the contrast between reports reviewed earlier was striking--“I can think clearly now” vs. “I’ve got cotton balls in my head”; “I feel like superwoman!” vs. “I feel weirded out!”; “My life has never been better” vs. “the eczema has never been worse.”

In his study of life-story biographies, McAdams has identified two especially common patterns evident across accounts: “redemptive and contamination narrative sequences.” *Redemptive sequences* are defined as accounts where “an affectively negative or bad life-narrative scene is followed by an affectively positive or good outcome” with “the good ultimately redeem[ing] or salvag[ing] the bad that precedes it.” These would include experiences of sacrifice, recovery, growth, learning, and improvement such as illness followed by a cure, and an estrangement followed by a reunion with a dear one. *Contamination sequences* on the other hand, were defined as accounts where “extremely good life narrative scenes suddenly, and sometimes dramatically, turn bad” (McAdams & Bowman, 2001). Examples include victimization, betrayal, loss, or return of depression following a previous good period.

These patterns seem to map on to many initial accounts of medication—both positive and negative. On one hand, a salvation or redemptive narrative frames the encounter with medication almost like an evangelical speaks of conversion—i.e., life was bad, until *that day* I got on *Prozac*. In Elaine, Sarah, Debbie & Peter’s reports of positive initial effects of medications, in particular, they framed the experience using terms of an “absolute miracle” (2), a “magic pill” creating a “superwoman” (8) and feeling like “a million bucks” with a life that had “never been better” (10); in each case, the initial impact of medication was portrayed as a dramatic redemption.

On the other hand, a contamination narrative packages the encounter with medication as a “horror story” (Karp, 1997, p. 94)—with doctors framed as literal villains and pharmaceutical companies something of an evil empire. Correspondingly, Kyle portrayed the effects of medication as “carbuncles and boils” that haven’t been seen since the “middle ages.” He went on to portray psychiatry as disinterested in true healing and affirmed, “I am grateful to have found stability and to be free of psychiatry for the time being” (12). Esther similarly described doctors from her previous experience as demeaning and even abusive in attempting to force her to take medication, as well as claiming they lied to her in minimizing side-effects (14).

These diverging frames are also reflective of the broader rhetoric evident in societal discourse, discussed in the introduction—i.e., pharmaceutical companies and treatment advocates framing research and treatment progress as essentially a redemptive, ‘glory story’ (Kramer, 1997), while anti-psychiatry groups portray the effort as a conspiracy leading to great harm (Breggin, 1991).

While the specific way treatment effects are framed appears to be important for narratives across the duration of individuals’ experiences (see Ch. 8), this initial “first impression” of medication appears to leave an especially lasting impact. Like the traumatic events that often galvanize a narrative justifying medical treatment, an initial effect that is received to be either dramatically wonderful or horrific appears to likewise cement the formation of a particular narrative relative to treatment. Indeed, as examined in Chapter 8, references back to this initial encounter are a common feature of narratives. When narrated positively, these initial treatment experiences seem to become a touchstone to which individuals return to reaffirm and reinforce their convictions when difficulties arise. These kinds of positive frames for experiences subsequently reassure individuals about treatment and decrease fears—as Robert said that taking medication “opened my eyes and made me realize that, ‘you know, this may be the right thing for you’” (9).

Not only do such experiences provide memories of positive emotion, they also appear to introduce particular new ideas. Those with initially positive treatment encounters, for instance, are introduced to the idea that it is possible to effectively dissipate depression with the right medication. In addition to taking heart in medical treatment, multiple participants confirmed that such an experience may likewise galvanize beliefs in depression’s biological nature—a pattern reviewed extensively elsewhere. Karp (1997) similarly related the account of a man whose “taste of drug success solidified his commitment to a biomedical view of his illness” (p. 39).

In addition to influencing views of treatment and depression, the taking of medication has evident influence on one’s narration of self and identity. Peter spoke of the medication as making

his ideal self “accessible,” with Sarah and Camille testifying to having “found me” (4) and “feeling like me” (3) again. Such effects parallel Moses and Kirk’s (2005) “psychosocial side effects” in consumers of medication reviewed earlier—i.e., increased self-confidence and the alleviation of guilt (pp. 392-393). In his influential 1993 book, *Listening to Prozac: The landmark book about antidepressants and the remaking of the self*, psychiatrist Peter Kramer recounts experiences of medication “catapult[ing] people into new ways of behaving,” with transformative powers that “went beyond treating illness to changing personality . . . outlook and self-image in quite fundamental ways” (xv, xviii). Kramer goes on to document cases of individuals having dramatic and positive “makeovers” after starting treatment and essentially rediscovering who they really were.

In contrast to treatment effects that appear to positively impact individuals narratives, other accounts reflected a more ambiguous dynamic. For some like Lucy and Jill, for instance, treatment prompted significant confusion about who they were. This was corroborated particularly in several comments from Karp’s (2006) study. One woman said, “I know I’m better on medication . . . [but] there’s been a persistent confusion about the real me since I started taking Prozac.” After expressing appreciation for vividly positive effects of medication in her life, a second interviewee reflected “Would I be a completely different person? And will I ever know that? And can I ever say, ‘This is who I am’ as long as I’m on these? That’s my issue with drugs.” A third individual recounted:

My therapist told me that the pills would make me “more like me” . . . I go back to her and I say, “It’s not happening.” You know, the pills take me away from me, they do something else. The Lithium sort of organizes me, the Wellbutrin lifts me up, the Benadryl, puts me down. But it’s not me (pp. 19, 112- 113).

Finally, reflecting the sentiment in Lucy’s account of feeling “like a part of you dies” when accepting biomedical explanation and treatment (6), the taking of medication can be experienced by some as deeply disruptive of one’s sense of self. Another Karp participant similarly reflected on his feelings upon starting medication for depression: “you’re losing part of yourself . . . It was the fact of being altered. Now I’m no longer going to be who I was.” Karp identifies two key identity issues: “What it means to feel like oneself” and “whether one’s ‘true’ self is revealed or obscured by the pills one takes”—noting that “virtually everyone in my sample continued to question how psychotropic medications affect who they are at their core” (pp. 98, 100, 107). Based on interviews with 32 social work students and practitioners taking psychiatric medication, Davis-Berman and Pestello (2005a/b), explored the impact of taking medication on one’s sense of self. While documenting the development of a medicated self as complex and

varied, they found a “small number of those who feel that medication led to an improved self, and the majority who felt damaged by their experience with medication, and expressed varying degrees of ambivalence about its use” (p. 283).

For better or worse, the experience of taking medication itself thus appears to be another major narrative resource on which participants draw in the initial adoption and creation of a particular story and narrative of their experience. For those who adopt a positive narrative of treatment--through friction, wind or whatever the details--this narrative subsequently appears to carry a force of momentum that literally propels individuals forward through additional turbulence that arises (see *Ch. 8*).

In summary, multiple resources upon which individual narrators may draw have been reviewed above. Depending on the individual, varying contributors appear to be more or less salient in adopting a narrative. Some individuals seem primarily influenced by a neighbor or friend--others by a doctor--in the adoption of their own narrative of the problem and solution. Others resist all persons and traumatic experiences in fidelity to a non-medical narrative. Still others resist community influence, but when their own trauma hits, acquiesce to fully embrace a conventional medical narrative of both treatment and the problem itself.

Overall, tangible resources such as interpersonal interactions and taking medication itself are argued to interrelate in important ways with resources that include states such as confusion, resistance and urgency. Interpretive decisions thus occur against a backdrop of intense emotional states and regular influence from family and friends--ultimately galvanized for some by dramatic experiences with life crises or medical treatment itself. Over time, this complex mixture of states and experiences fore-structures individuals' ongoing and evolving interpretations, decisions and further experiences in the crafting of their own unique narrative.

Chapter 7
Breaking Down Stories:
How Do Narratives Meaningfully Converge & Differ?

This chapter focuses on the question: How do narratives meaningfully converge and differ? In Chapter 3, basic structural comparisons between story content were made involving overall plot, protagonists, etc. Building upon previous chapters, this chapter summarizes similarities and differences between stories in specific reference to key content issues. In addition to further examining narratives in terms of medical treatment, this exploration also zooms out to consider several non-medical related aspects of depression narratives.

Any two depression narratives may obviously vary in an enormous number of ways. Prior to interviews, several issues were selected as questions of particular interest for any depression narrative. These included how individuals saw 1) the role of the body in depression; 2) the role of personal agency in both depression and its recovery; 3) the role of medical treatment in recovery; 4) the precise nature of recovery from depression and 5) the role of friends/family in recovery. Taken as a whole, a review of narratives along these five distinctions provides a good backdrop to understand what is going on content-wise across stories—i.e., similarities and differences. For each issue, themes from this study will be examined against findings, arguments and text from other similar studies in the literature.

1. Narrating the Body: How is Biology Involved?

Varied participant responses to biomedical diagnosis were detailed in previous chapters. Related to and accompanying this experience, all but one participant spoke of a meaningful role for biology in their depression—albeit in different ways. Indeed, even more interesting than *whether* they saw depression as biological, was *how* participants variously saw depression as biological.

On one hand, a number of participants spoke of depression as linked to a chemical imbalance. Jill spoke of “a brain chemical . . .that is not letting those neurons connect [like] you need, and so you don’t function” (7); Victoria referred to “a chemical in your brain that says you can’t be happy and content” (5); Sarah shared her understanding of a “chemical that says ‘okay . . . time to wake up get the kids off to school’ and it will swim across the serotonin bridge . . . and when it gets there that enables you to get up” (4).

It is the *neurochemistry* of the brain, more than the body or even the brain as a whole, that receives the primary emphasis here. As noted by other depression narrative researchers, the

chemical imbalance theory has become dominant across individual accounts (e.g. Schreiber & Hartrick, 2002; Stoppard & Gammell, 2003; Ridge & Ziebland, 2006; Karp, 2006). When a particular narrative is shared by many people and institutionalized in policies and procedures, it may be called a “dominant cultural narrative” (Rappaport, 1998).

Although not necessarily linked to a biochemical explanation, the degree to which the chemicals are here depicted as *instrumentally*¹⁶ related to emotions is striking—i.e., causing emotions in a unilateral way, independent of any other factor. This same instrumental characteristic was evident in mentions of genetics as well (less frequent than brain chemistry, but also common): “Depression does have roots in genetics . . . the same way people are born with physical limitations, sometimes they may be born with, uh, a physical limitation that affects them mentally” (9); “I realize . . . that it probably is genetic most likely it ran in my family. It wasn’t *caused* by anything other than me being born to my particular parents” (10). Such an instrumental frame of the brain and body generally may logically predispose an instrumental portrayal of external chemicals inserted into the brain as well.

A second characteristic salient to these accounts was the degree to which these biological deficits were depicted as largely permanent. Victoria was later asked to elaborate on how she “defined depression?” “Hmmm. . . it’s that little glitch in my brain that’s not producing the chemical that lets me be happy and content. I mean that’s at least that’s the way I look at it now” (5). Jill said, “You can’t talk it out; *it’s chemical*. Talking it out or going for a jog isn’t going to help the chemical imbalance that’s going on” (7) [her emphasis]. Debbie similar recounted, “it’s a *chemical* imbalance--it’s not gonna go away with . . . you know; I can’t--I’m not one of those that could take [medication] for a couple of years and then be good for five years. It’s . . . I’m stuck” (8).

A chemical imbalance is here portrayed as also a permanent condition—impervious to enduring change through therapy or exercise. As Jill later elaborated:

I’m a firm believer in medication because I don’t think, I mean, I think therapy is good, but it doesn’t help if you’re not calmed down, it doesn’t, I mean . . . *You can’t talk it out; it’s chemical!* . . . I just, like I said, I don’t . . . you can’t get better without medication. You can talk and talk and talk but you can’t get better without, if your chemicals are messed up (*emphatic*) (7).

The presumed permanency of this deficit is likely responsible for some of the tension seen at diagnosis. Like this study, Stoppard and McMullen (2003) summarize the nature of relief

¹⁶ Reflected in its noun form of “instrument,” instrumental here refers to how tools are typically applied unilaterally to passive objects—i.e., “indicat[ing] the inanimate, nonvolitional, immediate cause of the action expressed by a verb, as *the rock broke the window*” (*Dictionary.com*, 2008).

accompanying the experience of depression diagnosis for women interviewed: “Her feelings of distress and ill health are not her fault, she is not to blame (“there really is something wrong with me/”It is not just in my head”)—she has an illness called depression, which involves a chemical imbalance in her brain.” They go on to note, however, that “this view of depression can also go hand-in-hand with the idea that one is flawed in some way or otherwise weak” (p. 3).

To be clear, this prevailing biological portrayal certainly does not rule out other contributors. Indeed, these same participants referenced above mentioned a significant role for surrounding life conditions in their depression. Interestingly enough, these environmental conditions also appeared to be frequently portrayed in a unilateral, instrumental way, with environmental stressors portrayed as something of a “trigger” to activate or aggravate underlying physiological deficiencies (in turn, causing the negative mood). After describing his conviction about genetics as the root of depression, Robert added, “I don’t think [however] that that’s the whole deal as far as what causes it . . . certain events take place in one’s life that, you know, kind of make those weaknesses express themselves” (9). Echoes of the “diathesis-stress” portrayal of illness were reflected in the way multiple participants spoke of the role of situational factors in their depression.

In terms of the biology, however, the chemical imbalance theory was the dominant explanation in this sample. Some, however, expressed concerns at what they saw as an over-focus on chemical imbalance in explaining depression, such as Kyle: “So you know, there’s so many things . . . that can cause someone to be loopy, I mean the brain is such an amazing organ and it does . . . get messed up sometimes. But we kept on being fed these “well. . . it’s a lack of serotonin.” Citing his review of the research, he added, “Well now we’re finding that we’re not finding a lack of serotonin in the brains of the depressed. . . yet, the public still believes that” (12). Speaking of the biochemical hypothesis, Esther remarked, “I went in knowing that it just couldn’t be *that*; it wasn’t *only* that. It couldn’t be the whole . . . only a chemical imbalance; it had to be more than that.” She added, “I think a lot of the evidence. . . is pretty lacking—people just seem to buy into it” (14). In recent years, the primacy of biochemical explanation has indeed been questioned by a number of scientists, with many deciding that in terms of brain function, it must be more complex than a simple chemical imbalance (Valenstein, 1998; Lacasee & Leo, 2005).

Other participants subsequently spoke of depression as linked to the body in another way. Rather than emphasize neurochemicals only, other participants emphasized relevant processes in the whole body. After acknowledging the role of some kind of genetic predisposition, Kyle said, “There are hundreds of reasons why an individual or for that matter generations of individuals

from the family may have susceptibilities to . . . depression.” He went on to say, “they might be genetic, they might be susceptibilities, they might be allergens, abuse issues, there’re so many issues it’s not *one thing*--it’s not like diabetes.” As noted in Chapter 5, participants spoke of a number of other physical conditions playing a role in depression, including hormonal problems (16), diabetes (13), obesity (11), surrounding toxic chemicals (12), nutritional deficiencies (12), disrupted circadian rhythms (2, 12) and exercise (2).

This broader emphasis is reflective of increasing attention to more complex portrayals of the neural underpinnings of depression. Specific to the brain itself, the broader discourse reveals multiple processes of interest beyond neurochemistry. Investigations into neural networks over recent decades, for instance, are pointing to their potential role in depression and other emotional problems (e.g., Siegle, 1999) and showing them to be remarkably plastic and changeable (Arbib & Amari, 2003).

Notably, this view contrasts with both characteristics of the first portrayal above: the instrumental relation between brain and emotions and its presumed permanency. Rather than chemical deficits *inevitably* impairing functioning until/unless corrected, alternative portrayals highlight the changeability of the brain by more than pharmacological interventions. After commenting on finding Lithium to initially be helpful in “working to bring me down,” Kyle added, “I think if I had been weaned off the Benzo and put in a nurturing environment . . . it would have done the same thing” (12). For this view, then, environmental stressors become something more than a static trigger. For instance, Kyle went on to say about his depression:

If I, you know, if I go without sleep and start partying a lot and get over extended and stressed, yea . . . I’ll hit depression.” . . . I know the recipe for madness, I know I could bring myself another depression . . . I know that recipe. I lose my sleep; I drink too much, um, . . . I get, I get involved in too many things, that’s the recipe for madness for me. (12)

Elaine reflected on her past care for her body in relation to depression:

You’re not gonna be able to let yourself get sleep deprived your whole life. You know you can’t. You’ve gotta kinda watch this and not think that you can go without sleep just because it feels like you could . . . (*laughs*) you can’t do that to your brain for years on end. You can’t not feed yourself. . . . You’ve got to take care of your body because your body takes care of your brain. (2)¹⁷

Well-worn neural networks, of course, cannot simply be “zapped” like tumors with chemotherapy—nor does this imply a solution of simply “choosing to be happy.” Yet this

¹⁷ Since much of the text reflecting these distinctions was not reviewed in previous chapters, more new verbatim is included here than in Chapter 6. The same is true of the following Chapter 8.

portrayal does appear to open up greater optimism about recovery. Indeed, as maladaptive pathways are allowed to atrophy and individuals exercise new neural pathways, significant levels of recovery may be possible (see Rosenzweig & Bennett, 1996). After learning about brain plasticity, my own sister Mary said, “wow, that kind of makes me more hopeful I can do something that will help this change!” This portrayal also resonates with more sophisticated views of personal agency ebbing and flowing on a continuum, as reviewed later in this chapter.

2. *Narrating Agency: Is Personal Choice Relevant to Any of This?*

A second distinction of interest relative to depression narrative content is the question of human agency. The degree to which individual choice is seen as involved in depression (and its treatment) has significant implications for the ensuing experience of depression. This is most evident in participants’ recollection of comments from friends/family suggesting that the coming or going of depression (or happiness) is largely a free choice for each person to make. Camille described challenges from people “who think that you can just decide to be happy and snap out of it.” She added, “I tell them, ‘do you think anybody would choose to live this way? Don’t you think if I could just snap out of it and decide to be happy I would have done that a long time ago?’” (3). Lucy similarly remarked, “If I were to choose this as my illness—if anyone really truly believes this is the one I would have picked, you’ve got to be kidding, honestly” (6).

Unfortunately, this portrayal, here called “radical agency,” appears fairly prevalent among the general public. Based on the same survey of 984 adult surgery clients in England (91% response rate), just over one-third (35.7%) agreed with the statement that “if you are depressed you have to pull yourself together” (Churchhill, et al., 2000). Problematic implications of this particular narrative are obvious: self-blame, discouragement, etc. As described in Chapter 4, this portrayal may heighten the actual burden of depression, as Kellie said, “It’s hard for family and friends to understand that you really, really, *really* are not doing this intentionally” (16).

Kyle admitted to similar attitudes prior to his depression:

You don’t know what depression is until you have it. And, uh, before I had my first depression, I believed that depression was a bunch of crap, you know, “pull yourself up by the boot straps, quit feeling sorry for yourself, go into a damn cancer ward for kids and you’ll see something to be depressed about, you know, what the *hell* do you have to be depressed about?” . . . I didn’t believe in it until it happened to me. (12)

Clearly, those who voice this portrayal of agency may actually aggravate the paralysis of depression and potentially distance victims from critical community ties to a greater degree as individuals feel unsupported, harshly judged and misunderstood.

Surely the greatest flaw of “radical agency,” however, is how at odds it is with the reality of depression. In nearly every narrative of depression, participants comment on real constraints and limitations on one’s own agency. From the beginning, participants spoke of coming clearly against their will and beyond their control—including one woman who spoke of “getting it” during a stressful period like she had got a cold. Peter recounted “slipping” into a depression that eventually “took hold” (10). And Jill recollected her fear that depression would cause her to hurt herself, “I always said ‘it takes over.’ It takes over your personality, that’s why I was afraid that I would take my own life . . . the depression might do it for me, and that scared me, scared me a lot” (7). Kyle used images of violence to depict his depression: “it just really started to hit me hard . . . I got smacked with my first depression . . . it threw me up high and, you know, I fell down, uh, and it was horrible depression” (12).

As a final vivid illustration of these constraints, I turn to an outside account that had a significant impact on me in early graduate school—this, from the therapist and author, A. B. Curtis (2001):

It had snowed a rare eighteen inches in Washington, D.C., and I love the snow. The first few flakes of any snowstorm fall directly into my heart. My husband and I are spending the weekend with another couple, our best friends. Between us we have a gaggle of preteens who are busy building a snow fort outside, while we four adults are toasting our toes in front of a cheery fire, chatting cozily.

The snow is still sifting down from a billowy gray sky that looks like it was painted long ago on Chinese silk. A beautiful day. A perfect day. My husband throws back his head and laughs at his buddy’s joke. I too am smiling broadly. Then the smile slides off my face as I feel my inner self suddenly give that downward jerk. In a nanosecond everything good is gone. I am submerging into that empty pain, sinking helplessly into myself, going further and further away from everybody. Faster and faster I am sucked into that alternate universe of agonizing, utter loneliness called depression. They don’t notice. They are laughing and passing me the cheese and crackers and they don’t know I am no longer here. I have gone to misery (pp. 40-41).

In contrast to the previous portrayal, an admission of real constraints to agency can be a relief to those facing depression. Where a community accepts these constraints, victims may feel supported, understood and judged fairly. Given the human implications of competing portrayals, investigations of agency and severe emotional problems are becoming a subject of systematic study in recent years. One of the sub-scales of the *Perception of Depression Questionnaire (PDIQ)* is “Self-Efficacy, which reflects perceived controllability of the illness” (Manbera et al., 2003). Likewise, one of the five components of “illness representations” identified by Leventhal and colleagues (1980) is “controllability/cure (beliefs about the degree to which the disease is amenable to control or cure)” (as cited in Churchill, et al., 2001, p. 905). And in a discourse analysis of ways of talking about mental health based on mental health service users in Ireland,

Speed (2006) identified “intrinsically different ways of talking about mental illness” across the discourse, each alluding to “different conceptions of agency on the part of the service user” (p. 28).

When taken to an extreme, agency may be de-emphasized completely. Kellie spoke of her brother trying to help her realize that depression “didn’t have anything to do” with her efforts and that recovery didn’t rely on her making any changes—telling her, “I know you don’t think you’re doing all that you can but you really are!” (16). Sarah spoke of her previous attempts to do anything to resist the onset of depression as naïve (4) and Victoria expressed gratitude for knowing that “nothing could have been done”:

I guess the ...it’s the best shift in my thinking is knowing that this . . . wasn’t something that I could have controlled. I mean, the fact that I got depression . . . there was nothing I could have done to keep me from getting it, you know? I mean, it’s not like if you don’t smoke you won’t get lung cancer, you know? I mean, it’s not that kind of a thing; you can’t say, “well it’s because I ate the wrong thing or, you know, I got exposed to radiation or some, you know, some crazy thing like that; it couldn’t be helped, you know. (5)

In speaking of her seasonal depression, Camille similarly remarked on its inevitability in that “every winter I would become depressed.” She continued, “but then in the spring I’d come out of it and one year I just didn’t come out of it . . . it just had always gone away before and this time it didn’t. I couldn’t live that way” (3). This prompted her to seek treatment—“And so I called my regular doctor and he put me on Prozac and that worked great for a year and then it just quit working” (3).

In this vignette, notably, both the coming and going of depression were experienced largely as happenings beyond any personal control—from depression that “comes” and “goes” to treatment that “works” or “quits working.” Similar to the discussion of brain chemicals and genes, both depression and its treatment may thus come to be framed overall as unilateral/instrumental experiences. As a result, individuals may see themselves as having little potential of meaningfully impacting the going or coming of depression, except in relation to treatment itself—which, in turn, may be framed as largely a technical choice with unilateral consequences as well. In their discourse analysis of representations of mental illness in Serbian newspapers, Bilic and Georgaca (2007) document one of the characteristics of the “discourse of bio-medicalization” being “people with mental health problems as passive sufferers of their condition” (p. 167).

Some of this decreased sense of control may simply be related to the unpredictability of medical treatment. Said one woman, “Before that, every day I woke up I knew what I was going

to feel. Once I started taking that drug, I didn't know. I didn't know if I was going to wake up happy or if I was going to wake up sad, [or if] I was going to wake up angry. I didn't know" (Karp, 2006, p. 29).

After reviewing the literature examining learned helplessness within depression treatment, Moses and Kirk (2005) note a consistent link between psychiatric treatment and an external locus of control and decreased autonomy. Feminist researchers such as Stoppard and Gamell (2003) have raised concerns with the impact of medical treatment and its implicit narrative on women's sense of empowerment—highlighting the minimal attention to social context, the strong deference to others' judgment, and the emphasis on elements outside of individual control. Another individual admitted, "There was a sort of deterioration of that resolve in me to get through anything when I started taking drugs. I sort of felt like, 'Well, gee, now that I'm sick, . . . [it's] something that I don't have to fight through anymore. There's a reason and it's not that I can't do something or I'm too lazy or whatever'. But there was something in me that gave up the fight (Karp, 1997, p. 89).

Regardless of the cause, this overall shift towards this disempowered state recalls Bruner's distinctions between "agentic" and "victimic" life plots. Whereas agentic plots center around self-determination, confidence, active striving, and responsibility, victimic plots reflect a life depicted as "as out of their control":

In victimic life stories, the protagonist is shaped by conditions beyond his or her control. . . . the accomplishment or failure to achieve life goals depends on factors that are unable to be changed . . . The protagonist is oriented more toward avoiding negative possibilities than to actualizing positive possibilities. Success in life is measured by what negative happenings did not occur or what one was able to prevent from occurring (cited in Polkinghorne, 1996, p. 302).

Unfortunately, the attention this issue receives typically posits a debate or competition between "choice" or "no choice," as if these were mutually exclusive options. Among other things, this debate between extremes may prompt a further polarization in portrayals. For instance, as illustrated in Chapter 4, one reason a biomedical diagnosis comes to be so relieving for some, is a context of having to defend against the idea that one has "brought depression on yourself" (and need to simply "pull yourself out of it"). Thus, the insistence on "*nothing I can do*" may, in part, be prompted by the prevalence of "*it's your fault*" blaming messages among friends or family. Ultimately, this highlights the need for further research regarding a more moderate and sophisticated (alternative) articulation of agency avoiding the excesses of both preceding portrayals.

One possibility suggests that neither of these narratives is completely satisfactory, delineating the actual role of personal agency as something that ebbs and flows on a continuum (see Williams, 1992 on a “human context for agency” and Charles Taylor on “embodied agency” in Abbey, 2004, p. 3). This allows discussion of a meaningful role for agency in the experience of depression and its treatment without lapsing into the problematic notion of depression being entirely a product of choice—either its coming or going. Indeed, the same individuals who emphasized the overpowering experience of depression, emphasized choice in relation to behaviors that could indirectly impact depression. Referring to health-related behaviors, Camille spoke of realizing, “I could change even if nobody else did--that I had choices...and really that’s like a shift from being a victim of the disease to saying, “No more. There are things that I can do to change it” (3). Sarah spoke of learning she had choice relative to her thinking:

Before I went to counseling and *Recovery inc*, I just thought that whatever I thought was true, I didn’t realize I had choices to make different thoughts go into my brain, so in learning that I now understand that I control everything within my own skin and this is recovery terms and that’s called “inner environment.” And everything outside of my own skin is called “outer environment.” I can’t control what *you think*, what happens with the person that . . . cuts in front of me [driving]. But I can control how I react to that. (4)

In describing his recovery from depression, Peter emphasized the centrality of realizing his own personal power and agency in life generally—“I get to kind of shape myself in whatever image I see fit and it’s great (laugh).” As key to his recovery, he went on to emphasize “*confronting* issues that had haunted me my whole life . . . so that I *could be* the person *I wanted to be*.” He added: “For me depression was a way of life, and now it’s not anymore . . . so now when I look at things in my life, I realize . . . I see many more possibilities, you know. Depression was one possibility of many...it wasn’t just ‘the way things were’” (10). Two of the most severe cases of depression reflected similar emphases on discovering agency. Michelle spoke of a “turning point” in her recovery as admission to a unique in-patient treatment center during a suicidal period: “What I noticed was when you’re in a psychiatric unit somebody unlocks the door, you step over the threshold and they lock the door behind you.” She continued, “In [this center] they brought me down to this dorm like building where I would be staying and *nobody locked the door*. And what that meant to me was that every minute that I was there, I was making a decision to participate in my recovery and I had the choice whether I wanted to stay or I wanted to go” (13).

In a second account, Lucy, who had also related severe physical and sexual abuse as a child, reported the following key realization, “You start learning ‘what is my part in this?’ and ‘how can I make my life better despite all the things I’m going to have to overcome every day?’”

She continued, “We all need to be held accountable. The time that I started getting better, I feel, is when I sat down with myself and looked at *every minute* of my life and I took my part in it and I held myself accountable for what *was mine*.” Lucy clarified:

And that can be tricky, you know, because you don’t want to take everything, right? But until you hold yourself accountable for what *was* your part in it . . . only then and *then only* can you become in charge of changing the future. . . . the minute you realize that you *were* an active part of your life .. is the minute that you realize “I’m still an active part in the progress that I can make in the future.”. . . No one can define your quality of life. (6)

She concluded, “So, I think that . . . always hold people accountable .. but don’t let them out of sights with it, you know—don’t let them go into a dark hole, you know” (6).

From reacting to living situations, to general life orientations, to making personal changes, to approaching depression specifically, these individuals highlight new ways of acting in response to their situations *as important in their recovery*. After detailing the shift from agentic to victimic plots following traumatic events, Polkinghorne (1996) goes on to detail the reverse: a renewed sense of self-determination and agency accompanying the restoration of an agentic plot.

Some may justifiably feel uncomfortable with this portrayal—seeing in the allowance of *any agency* the tempting impulse to hold depression victims entirely responsible for a) their own pain and b) their recovery. It is precisely for this reason that the foregoing analysis has juxtaposed portrayals of *all, none, and some* personal agency in relation to depression and its treatment—suggesting an implicit continuum on which agency can ebb or flow. Without falling into either blaming or victimizing those facing depression, this third alternative seeks to clarify a meaningful and moderate place for personal choice and initiative. In a context of violence or abuse, for instance, the truth that individuals do not “bring on themselves the abuse” is not the same as saying “there is nothing we can do to fight or prevent it.” Rather than “making it go away” by simple choice, this role for agency entails doing what is necessary so the depression will dissipate over time. As Kellie concluded, “Well, things are just going to work out for me in time and I just have to try to do my part in the meantime” (16).

3. Narrating Medication: Is This Stuff Helping Me or Not?

Among the general populace, it is commonly assumed that treatment either “works” or “doesn’t work”—with results based on varied physiological effects. That outcomes and biological changes can be interpreted or narrated in fundamentally different ways may still be a new idea for many. Indeed, among my own sample, participants naturally took for granted their own current interpretations as reality.

Attention to diverging interpretations of the body, then, is unique in itself. As Kleinman (1988), one of the early pioneers of this research area asserted, illness narratives “tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation” (p. xiii).

One of the greatest challenges for those facing depression is knowing when to attribute a particular state to medication versus some other condition. For instance, while Sarah interpreted panic attacks as primarily coming from her own anxiety, Kyle attributed carbuncles and boils as primarily coming from the medication (see details in Chapter 5). This confusion applies to positive instances as well. Grime and Pollock (2003) cite one person as saying, “I don’t really know if they [medications] are working. I just know I’m getting better and I’m wondering what’s causing it” (p. 517). Garfield and colleagues (2003) report one patient reflecting, “Yes the medication has helped, but it’s difficult to determine quite how much it’s helped when you’ve had a circumstance change as well” (p. 525).

This difficulty of discerning the source of a particular state varies from situation to situation. As Karp (2006) writes, “Sometimes the connections between drug use and emotional changes are unclear. In other cases, however, alterations in moods, feelings, and emotions are sufficiently intense after taking a medication that there is no mistaking cause (p. 111).

This question has implications for identity as well. Jill said of her confusion about the true effect medication treatment, “I still wonder ‘who am I really? What’s my real personality?’” (7). Moses and Kirk (2005) quote a patient as saying, “I need to know what is my personality and what is caused by the pill. I don’t know whether my feelings are what I feel or what the pill causes me to feel” (p. 391). Naturally, whether a positive feeling hails from one’s resolve or from Prozac may have much to say about one’s self-image.

Laying aside interpretations of the source of a particular state concurrent with medication, a second major question deserves further attention: how to evaluate *the worth* of a particular state? This question often occurs when the source of a particulate state is settled, while the worth of that state remains in question. This may appear counter-intuitive, given the general inclination to speak of medication as either “working or not.” Yet like other substances such as alcohol, whether its effect is experienced as “positive” or “negative” depends on more than merely metabolic differences or blood alcohol levels. In the case of alcohol, obviously differing cultural interpretations of an inebriated state may differentiate between whether an individual is experienced (by others or oneself) as *more or less* “exciting, fun and dynamic” when under the influence.

In like manner, the precise worth of an effect across a variety of substances is no obvious interpretative decision. As reflected in earlier chapters, family may naturally disagree on how well a medication is working. In Kyle's case, his mother and father differed sharply in their evaluations of medicine's impact on their son's bipolar symptoms. Kyle went on to reflect on "who decides" when someone is feeling better or worse:

You know, you can take that back to the lobotomy when Freeman was made man of the year for *Time* magazine, you know, by running around the country giving people lobotomies with an ice pick, I mean he performed these things in hotel rooms sometimes. And, you know, no one asked the patient if his life became better. Often times, life became better for the people surrounding him, his family, her family, and the Kennedy's lobotomized their mildly retarded daughter because, uh, she was becoming sexually promiscuous. . . . So was life better for the people around me? Well [when] I was on the medication compared to when I was, you know, hypomanic, "yea" [better for my family]. But it wasn't better for me. (12)

The answer to "who decides," of course, is ultimately and most typically thought to be professionals—both doctors and researchers. In the popular view, science is often seen as reflecting monolithic agreement on solid and conclusive answers—with clear "findings" establishing reality when it comes to medication effects. On closer view, however, as noted in the introduction, there is a striking degree of general variation in conclusions regarding medication effects in the research community. Where some argue medications are largely effective to alleviate emotional problems (Kramer, 1997), others conclude they are mostly ineffective or "placebos" (Kirsch, Moore, Scoboria & Nicholls, 2002), while still others claim there are significant negative/iatrogenic effects being overlooked (Breggin & Cohen, 1999). In cases of agreement on a particular negative state associated with medication, whether to call it a "side effect" (implying overall necessity and tolerability) or "adverse effect" (implying the reverse), also varies across researchers (see Breggin & Cohen, 1999). Depending on the general view, there are associated differences on whether populations are seen as *over- or under-medicated* (Moses & Kirk, 2005).

A final narrative distinction regarding medication worth mentioning is the scope of time in which effects are evaluated—short term vs. long term effects. Participant comments about medications primarily centered on immediate emotional states, with only two individuals raised any concern with long-term effects. While acknowledging some benefits of his anti-depressant medication, Kyle emphasized concerns with long-term impacts of other sleeping medication used in his treatment: "In the short run, I *loved* those sleeping pills [tranquilizers], I loved them. . . . a tranquilizer to cool someone out for *just on short term*, um, would be okay, but in the *long run*, I think there's always going to be a price to pay" (12). Alternatively, Ridge and Ziebland (2006)

note an individual remarking, “When people say to me, ‘Oh, I’d be worried about the long term effects’? Well all right, let’s say Seroxat is more likely to . . . take 5 years off the end of my life. I’d say, ‘Well it’s better than feeling f*ing awful now’” (p. 1043).

In the current research and professional discourse, there is clearly insufficient attention to longer-term outcomes for medication. Given the limited number of formal studies of long-term outcomes (e.g., Ziere, et al., 2008; Williams, et al., 2008), additional research in these questions appears to be justified, including the application of qualitative studies as a formal part of the outcome research for psychiatric treatment (Crawford, et al., 2002).

4. Narrating Recovery: What Does it Mean to “Get Better” Anyway?

Closely associated with distinct evaluations of how and whether a medication is working and the nature of a good treatment outcome is the question of “what does it mean to get better anyway?” Participant views on this question were reviewed, ranging from emphasis on recovery as managing the depression and being able to function, to an emphasis on feeling joy again in life. Camille said:

To me, knowing when you’ve gotten better is when you’re able to really laugh--and not only laugh on the outside but on the inside too--when you’re able to find pleasure and joy. And you know that that you can’t be happy all the time and you’re okay with that (3).

In contrast, Daniel Fisher, President of the *National Empowerment Center* (2006/2007), writes of a “rehabilitation” portrayal of recovery as “recovery of function despite still having the permanent impairment of mental illness.” The metaphor here is a spinal chord injury, where with support, a person can once again function in society. The impairment, however, remains permanent. In a similar way, this view of recovery says that “people can regain some social functioning, despite having symptoms, limitations, medication, and remaining mentally ill” (no page number). Consistent with this view, several participants essentially saw recovery as essentially a matter of regaining basic functioning in life. Other studies have documented a similar range of patient thoughts about recovery (see Ridge & Ziebland, 2006).

As with treatment effects, it is worth mentioning at this point that the way recovery is defined may have significant influence on those facing depression. In the case of the two individuals reporting a lack of deep feelings, for instance, personal definitions of what it *means* to get better may determine whether this state is accepted to be “as good as we can expect to manage for my condition” versus “not good enough.” In their study of doctor and patient treatment

narratives for depression, Rogers, May and Oliver (2001) suggest that reports of client satisfaction may be linked, in part, to generally low expectations of treatment.

Obviously many other questions remain. Combined with previous reviews of recovery accounts and interpretations of prognosis, at a minimum, the foregoing analyses call for greater care in drawing rigid conclusions about whether recovery is possible and what recovery means—even more so in offering them to others. More directly, however, it might be proposed that different meanings of recovery deserve more attention than they have received in the research and popular literatures. Presuming and asserting one universal definition (of recovery or a “good outcome”), while well-intentioned, may arguably constrain thoughtful deliberation on the topic. And while it certainly seems important to assert the reality and potential of recovery, it would be problematic if such a zealous proclamation obscured significant differences in “*what exactly recovery means?*”

5. Narrating Community: How Can Friends/Family Really Help?

Another key issue in participant accounts of depression is the uncertainty among friends and family as to how to support individuals facing it. As a community psychologist, I find myself interested in all aspects of community support and connection (or lack thereof) for those facing depression. Holding this sense may be both especially important and especially difficult for those facing depression. Hurst (1996) documents the “profound betrayals” from close figures that often prompt a depressive spiral. Regardless of its cause, those facing depression also often disconnect and isolate, even when social connection is earnestly desired (Karp, 1997)—hiding ill feelings and putting on a mask. Reinforcing this silence and isolation are families not wanting to talk about the problem or simply not acknowledging it at all. At the outset of the project, I aimed to understand how participants narrate their sense of community over the course of the depression—including feelings of belonging, identity and emotional connection.

For those facing depression, it seems clear that friends and family are often experienced in very different ways. On one hand, they are portrayed as primarily buffering against and fighting depression (the problem narrated as coming *in spite* of these relationships); these include examples of family and friends extending love, trust and unconditional support reviewed previously. On the other hand, friends or family are portrayed as primarily contributing to the depression (the problem narrated as coming partially *because of* these relationships); these include examples of family and friends showing skepticism, being harshly judgmental and blaming, as well as being overly-forceful in recommendations--also reviewed previously. In most accounts, participants spoke of a mixture of positive and negative instances. Past chapters review

the role of friends and family to introduce particular depression explanations and associated interventions (Ch. 4), as well as positive support for individuals in the recovery process overall (Ch. 5). In this section, we look specifically at the relationship difficulties during a depressive period for family, friends and individuals themselves. Where previous chapters largely review bounded moments of interaction with family, this section elaborates and traces three broader patterns identified across narratives as barriers to authentic support—each especially relevant to circumstances when a family member has endured depression for a long period of time. These include isolation/avoidance, over-involvement and ambivalence.

A well-known pattern is the distance in relationships that may ensue from depression: You begin to feel (pause) just completely disconnected from your own life and from the people around you... I felt like I was in a place that no one else could reach...you know *they don't know how I feel*. . . they can't possibly understand (Peter/10)
I think depression for me .. the word that always comes to mind is “detachment,” when you become alone—it’s the sad, the dark place. But the biggest word, I think, is “alone”: how cut off from everything you either make yourself or they make themselves .. *so* alone, yeah—frightfully alone. (Lucy/6)

Disconnection has been identified as a theme in both adolescent and adult narratives of depression (Hetherington & Stoppard, 2002). While the isolation appears at time intrinsic to the depression itself, individuals also spoke of observing their actions pushing away loved ones:

When you're dealing with depression, it is all about you. I've spent so many years trying to . . . get well, physically and emotionally, that it *has* been all about me . . . in the midst of your illness, the world is *only as big as you*. The only thing that you can understand is what you need or what you want and you have *no comprehension* that your episode has made somebody else late to work or caused them to have to take time off from work to drive you to a treatment or go pick you up. (Michelle/13)
They [friends and family] stay away. Um, I've discovered . . . I became a very needy friend, which drives people away. . . you lose friends--not that they're not your friends anymore--they just don't . . . you know, you're just closed in. (Jill/7)

Beyond the sadness of isolation, others spoke of another pain involved in having to rely on others—an intense desire that others not worry about them. Lucy said, “where there were people around that I could have gotten help from. . . I just started learning at how to become better at hiding what I was going through”:

I just learned how to read the people that wanted to help me, and how I could be what they [expected] . . . how I could spend as little time as possible with them. . . . You learn how, with everybody around you just how to make it go away for their sake more . . . than to ever get better . . . completely, like to start working on it.

Lucy then explained her rationale for hiding the pain:

The thing is, that when you love people, and they love you, and you know that, I mean . . . you come to them at first, and you're like, "this is where I'm at and I can't do anything, please help." And you see them working trying to do what they can, but you're not feeling better, you know, and you might even be getting worse. And you just see that look of frustration, or, like, they don't know what else to do, and it's not they're mad at you. It's just, you just see that look like "god, I've done everything," you know, "We've worked on this for so long, why isn't it changing?" I mean, you just start feeling so awful and you don't want them to feel that, you know? So instead of both of you feeling that. . . eventually [I was]. . . like, "no, I'm fine". . . so, at least one of us isn't hurting, you know. And a lot of people are doing that.

In contrast, she reflected on her hope during her previous abuse that people would see through her attempt to be isolated: "I just kept hoping that maybe my doctor...would see through my lies, you know, of me going, "I'm fine." When finally disclosing the abuse to her therapist, however, Lucy similarly recounted her deep ambivalence:

When I finally opened up with the therapist, I was almost like, "was it worth it?" Like . . . for so long, I have been able to suppress it and pretend it never happened. . . . was that worth it to not just let everyone else . . . just go on without knowing and I'd be the only one hurting, you know? Because I hate knowing now that I worry people, you know? . . . I almost think I should have just shut my mouth and kept going . . . because even though it hurt, it wasn't hurting everybody else. (6)

Kellie spoke similarly of her avoidance of conversation:

I didn't really choose to talk about it a lot with friends because I know it's a depressing . . . depression is a depressing subject, and I didn't want to, I don't know, I didn't want to subject them to that. I didn't want them to feel sorry for me and not know what to do. So, I can be a really good faker when I want to.

She added, "people can sense when they're around you something is wrong, and I didn't want that, so I stopped going to you know . . . sport activities and things like that" (16). Peter spoke of similar tactics, "The first skill I acquired was how to keep people from asking questions. . . . just little misdirection: 'Oh, I'm sick today, uh I got a cold today, oh man I didn't sleep at all last night.' Just give somebody an excuse to ride it off" (10). He further described walking around "with my sweatshirt on and my hood pulled down. . . . you'd be amazed how easily a person can disappear if they want to . . . the right combination of clothing . . . colors and keeping your head down, you can become a ghost and I did and I got very, very good at it" (10).

In addition to the personal pain of individual isolation, there is also pain reflected in surrounding loved ones. This pattern is evident in accounts of other emotional problems as well. In the context of eating disorders, Tierney (2005) reports a parent's grief witnessing a child "just deteriorating before our eyes" and their pain of uncertainty: "you sort of think, 'what on earth is going to happen next with this?'—[it's hard] not being able to plan anything" (p. 376). In the

case of eating disorders, there is growing knowledge of ways that families and friends may support victims (Honey & Halse, 2005; Hall & Cohn, 1999; Sharkey-Orgnero, 1999; Vandereycken, 2005, Whitney et al., 2005). Even so, this remains a difficult challenge. Families may feel helpless in their efforts, perceiving “any attempt to help on their part as unproductive,” as noted by parents who say, “I try to do what I think is right at the time but it always seems so wrong” and “Nothing you do or say makes a difference” (Whitney et al., 2005, p. 445). Even with sincere desires to help, well-intentioned efforts can aggravate the situation (Rorty et al., 1993).

Returning to depression, the first way that communities appear to aggravate a problem is becoming over-involved: checking in too frequently and encouraging treatment to a degree that is overbearing—a theme reflected in some accounts described in previous chapters. The general literature around family therapy confirms that in crisis situations, family members often become involved in ways that are literally debilitating and defeating to the individual in crisis—including over-eager attempts to “fix” a problem (Coyne, Wortman & Lehman, 1988). This kind of “support” may obviously provoke difficulties even further, with documented linkages between the nature of family response and treatment outcomes (Whitney et al., 2005).

This is clearly a challenging issue for caregivers—who can feel as if walking on eggshells, negotiating contradictory messages such as “Treat me normal and don’t worry, but *don’t pretend nothing is happening*” // “I don’t want to be around people . . . but don’t leave me alone.” Lucy went on to give counsel to caregivers about being sensitive, but not too sensitive:

Don’t take anything personal that they say to you . . . I’ve learned that they’re at the point that they’re just as scared and frustrated and they don’t know what the hell is going on. . . . But on the other hand, don’t take anything as trivial--*everything* they say you need to think about it. . . . especially if it looks like they want to die. . . . On the other hand, you know, I’m saying don’t take it personally if they’re attacking you—it’s just, they’re scared just like you.

She acknowledged, “And I know, it seems like you can’t do both. . . . It’s a very hard place to find” (6). Although the challenge of finding the right way of helping is real, when families reach that point, there is evident power involved. In contrast to entertaining, distracting, ignoring, pressuring, or trying to “make things all better,” Chapter 5 recounted multiple instances of families *being available, being interested, being concerned, being loving and being constant*. In the context of eating disorders, Sharkey-Orgnero (1999) specifically describes family willingness to approach individuals with compassion, honesty and firmness as a turning point in individual progress. More than simply “hanging out,” *being there* calls for surrounding loved

ones to remain proactive in honestly inquiring and gently encouraging in a way respectful of personal agency.

Unfortunately, rather than seeking out this balanced way of helping, some families can simply grow weary of helping. Elaine reflected:

Well . . . it's been eight years and . . . I mean, it just gets old. They just don't wanna hear about it anymore (laughs) so I have tried to talk to them about it . . . I got my husband a book on, you know, living with somebody [who was depressed]. I had to read him everything that he's read out of it. He hasn't read it. He reads every night for an hour (laughs). (2)

Coyne and colleagues (1988) detail how family may react with hostility and distance to an individual who appears to be refusing counsel, prompting a similar outcome of “giving up” on a person in frustration. Sarah reported that her husband “didn't want me taking that time” to go to support group meetings and when she asked him to come with her said, “oh that stuff isn't for him.” After being admitted to the hospital, she called to ask why he wasn't there: “How come you're not here and he says, ‘well Sarah, I talked with the doctors and they said there was nothing I could do’” (4). Camille said of her husband: “His solution was to not deal with it and so he'd find excuses to be out of the home and which of course was just a vicious cycle” (3).

Another kind of resignation can also occur after long years of struggle, when surrounding friends and family simply “get used” to an individual living in pain, accepting that the person will *always be that way*. Whether from fatigue, disinterest, or strategy, lack of involvement can obviously also impact the person facing depression. Whereas over-involvement can fuel a worsening of the problem directly, this approach may intensify it by sheer inattention. Such community distance may reinforce the inclination of victims to be isolated to an even to a greater degree.

Chapter 8

Sustaining Interpretations of Depression and its Medical Treatment: How are Narratives Maintained Over Time?

Given the formation or adoption of a particular narrative regarding depression and its treatment, how is that narrative maintained over time? This chapter extends the previous exploration in Chapter 6 of how narratives arise and Chapter 7 of how they diverge in key interpretations and structure to examine how narratives are perpetuated over time. Alongside the significant research attention currently being paid in compliance/adherence studies to the maintenance of *treatment* for depression, here we attend to the maintenance of *treatment narratives* associated with depression.

While this analysis could justifiably consider a host of potential contributors, from the power of large institutions to the continuing role of particular narrative resources, the primary focus is to better understand what participants are *doing and saying* that appears to be contributing to the continuation of their particular narrative. While narrators arguably continue drawing on resources for the maintenance of their story just as much as its initial adoption, once the narrative is formed, the real action seems to shift beyond these resources to what individuals actively do in relation to the narrative they have adopted.

The umbrella term used to refer to these activities is *narrative strategies*. Unlike the typical use of this term, “strategy” does not here imply a conscious, deliberate process, nor does it suggest one that is largely cognitive. Since humans typically embrace their own story as “reality,” in literally no case did participants appear to be aware of the potential role of these activities in the perpetuation and maintenance of their own “narrative.” Regardless of limited awareness, activities identified below will be argued to have clear and evident implications for the continuation of particular narratives.

A theoretical basis for attention to “strategies” in the analysis of narratives is evident in the literature highlighting the purposive, functional characteristic of language. As articulated by Drew and colleagues (1999) in their discourse analysis, this study also assumes that language is more than a “neutral transmitter for relaying dispassionate descriptions of something that has occurred or was experienced.” “Rather,” they continue, “people organize their talk rhetorically; that is, they argue for a particular description of events or phenomena and struggle against other possible competing descriptions (e.g., one’s constructions are constrained by how they are, or by anticipations about how they may be received by others).” Drew goes on to highlight the “social actions being performed” in any unit of language (p. 193). In Clark’s (2008) compilation of

depression narrative analysis, there is emphasis on “the work these stories do,” including “bringing meaning to sufferers, explaining depression, justifying therapies and treatments, and reducing the burden of shame.” She concludes, “Thus, depression narratives have their work cut out for them.”

As reflected in this latter comment, a second way to understand the significance of strategies for narrative maintenance is to examine their related implications for eventual action. Although strategies are being primarily analyzed here for their *consequences for actual narratives*, in most cases there are logical associations with or consequences for a particular behavior as well. As Coffey and Atkinson (1996) note, “Individual social actors recall and retell events or describe past experiences . . . in certain sorts of ways that account for, justify, excuse, or legitimate action or behavior (p. 100). Correspondingly, while emphasizing the maintenance of treatment narratives associated with particular strategies, discussion below will naturally touch on related implications for treatment as well.

To review, maintaining narratives is thus understood to rely on particular strategies reinforcing the way one ‘sees’ oneself and is comfortable narrating oneself, as well as to resist other ways of ‘seeing’ and narrating. These include 1) *Seeking reassurance from friends, family and doctors*; 2) *Affirming the evidence for a particular explanation*; 3) *Reframing past experiences to fit current conditions and convictions*; 4) *Looking to help others by sharing one’s experience of treatment*; 5) *Persisting in medical treatment*; 6) *Reconciling difficulties concurrent with treatment*; 7) *Narrating life without medication*; and 8) *Defending one’s narrative when it becomes challenged*. We first lay out a starting-point for this examination by recapitulating one critical emotional state that appears to frequently undergird a need to “maintain” one’s story in the first place.

Resistance reprise: “I still don’t know how I feel about this all . . .” In Chapter 6, the function of treatment resistance as a resource for many participant narratives was likened to “friction” that raised dissonance in the receipt of medical help and thus required additional external “force” to be overcome. Surrounding encouragement, moments of crisis and positive initial effects of medication were all subsequently reviewed as narrative resources that helped individuals discount this resistance and gain conviction to move forward with treatment.

Laying aside its role in the formation of narratives, we here consider its relevance as a backdrop to the emphasis of this chapter, narrative maintenance. As reviewed in Chapter 5, while such resistance and tension was relevant to many accounts, it obviously did not “play out” consistently across stories. Some followed this kind of resistance away from treatment,

decreasing dosages or stopping medication entirely. In spite of having to move through and overcome fears of life without medication, these individuals (four in this study) ultimately concluded that they feel better pursuing a recovery without medications.

The rest of participants, however, (ten in this study) pushed through their resistance and hesitations to persist in treatment. For six of these participants (Camille, Sarah, Victoria, Robert, Peter & Robert), the momentum of early positive treatment experiences was great enough that no further mention of major resistance was made. For the other four who likewise continued medical treatment, however, resistance appeared to continue and even increase (Elaine, Lucy, Jill & Debbie). Rather than be carried forward in their narrative by the “interpretive inertia” of experiences similar to the others, these four individuals recounted multiple ways in which they seemed to be working hard at persisting in both their treatment and the corresponding narrative that justified it. It is in the context of this kind of continuing resistance that the question of narrative maintenance becomes especially interesting. In the face of such lingering reluctance or hesitance about treatment, how do individuals hold on to their conviction and belief about moving forward? As will be evident below, this question is relevant to more than just this vacillating subset of participants.

1. Accepting Monitoring: “Have you taken your medication today?”

As with the adoption of narratives initially, the maintenance of a particular story seems often to draw and rely on the ongoing encouragement of the surrounding community. *Accepting monitoring* refers to a willingness to allow friends and family to reassure and help one ‘stay the course,’ as it were. A third of participants who had received medical treatment spoke of some kind of significant influence from surrounding relationships in their continued decisions about that treatment.

As detailed in Chapter 5, doctors and other medical professionals appeared to play an especially significant role at this point in encouraging continued forward movement in a particular treatment (and its corresponding narrative). Although there was significant variance in the amount of credibility and trust given to doctors, their influence across accounts was striking. As reviewed previously, Victoria had started considering tapering when, “my doctor very wisely sat me down and scolded me and said, ‘You know, you will probably be on this medication for the rest of your life. And you have to come to terms with that . . . I don’t think you’re looking at this the right way.’” The doctor went on to encourage her to be grateful that god brought medical treatment into her life so that she could have support to live a good life. Victoria spoke of this as

a turning point as she took the advice to heart (7). Sarah, Elaine & Debbie spoke of similar moments of influence.

Especially for those facing continued personal treatment resistance, the role of these kinds of interactions appears critical. In such cases, the surrounding community seem to become almost an extension of the treatment system in its monitoring and ensuring of compliance: “People keep telling me, . . . ‘Have you taken your medication today?’ (*laughs*) . . . People around you notice things” (8). With a few exceptions (Kyle’s mother, Sarah’s husband), most friends and family mentioned across accounts voiced encouragement to continue medical treatment. Sarah’s neighbor and co-workers, for instance, encouraged her to continue trying medication and discouraged her from the temptation to attribute negative emotional states such as panic attacks and worsening mood to the medication itself.

While some like Sarah and Victoria *responded favorably* to these efforts from friends and family, others like Kyle and Joan *resisted* their efforts and grew more concerned about medical treatment. Alternatively, Kyle *responded favorably* to his mother’s attempts to raise alternatives, while Sarah *resisted* these same efforts by her husband. While most attention here examines the way community can reinforce a dominant biomedical narrative, similar dynamics thus appear to be at play in bolstering and maintaining a counter narrative.

Since most family and friends appear unsurprisingly oriented to the “dominant narrative” of treatment, for those with concerns about treatment, overall community encouragement can be experienced as *critical and threatening*. With the exception of his mother, surrounding people confronted Kyle with significant concern and a message that he was being dangerously naïve. He and Esther were subsequently both threatened with forced treatment when they resisted the counsel given them. In both cases, this kind of interaction seemed to reinforce counter narratives deeply critical of psychiatry. Across circumstances then, both assurances and hostility in surrounding interactions appear significant for the maintenance of (distinct) individual stories.

2. *Affirming the Evidence: “It was great for me to have a picture of my brain . . .”*

While the foregoing interactions with others appeared critical, more often than not it appeared that participants were finding their own narrative momentum primarily independent of others. Some of the most evident manifestations of this were the multiple ways that individuals reaffirmed the validity of their overall treatment narrative. This second cluster of strategies included pursuing additional evidence for one’s story and highlighting evidence of divine favor.

Pursuing additional scientific evidence. Some narratives reflected ongoing efforts to learn and gather additional evidence supporting a particular story. After recounting mental health classes she had taken, Debbie related, “Once the internet came out, I just seemed to read everything and almost . . .overly learn about it.” She reported hearing about how “they can look at the brain and see how things are formed and different areas and then be able to prescribe medication . . . I’ve seen Dr. Phil or, you know, different shows that they’ve had specials on that.” She asked me, the interviewer, “Is that true or have you heard?” She then continued:

I’ve often thought, ‘now why can’t I get into this? or why does it cost so much?’ . . . I just wish there were a blood test, you know. Maybe sometime down the road, they’ll have genetics figured out of what exactly causes it. It’s really hard to know . . . I don’t know, I’d like to donate my brain if they can learn (*laughs*) anything about it. (8)

Sarah concurred, saying, “we need a blood test, like a diabetic that says ‘this is how much exactly you should be taking’ . . . these are dreams, you know” (4). After fighting with her husband about family finances during her depression bout, Camille recounted a trip out of state to secure a SPECT scan. As reviewed in Chapter 4, she spoke of her excitement in getting the scan results back—“it showed . . . there was an area that was just totally grey, meaning that there wasn’t that . . . that part of the brain had kind of shut down; and he explained to us that that part of the brain was the part that managed time . . .[and] money.” She continued, “all those kinds of things were controlled by that part of the brain that was not functioning (*laughs*). It was great for me to have a picture of my brain that showed, “hey look! This isn’t working” (3).

This kind of an initiative to seek and reach for additional evidence may thus function as a strategy to bolster one’s narrative. More than simply providing any explanation, the kind of evidence sought appears to reinforce a story that is personally comfortable to individuals. In their analysis of depression discourse, Drew and colleagues (1999) note that individuals “constructed themselves as blameless, competent and worthy,” actively seeking to exculpate themselves for having experienced depression. They go on to highlight, “energetic work done by participants to promote a positive self-view in their narratives” (pp. 201-202).

The use of this strategy in maintaining a biomedical narrative may thus be additionally understood as a function of its continued resolution of added painful confusion about the fundamental nature of depression in the first place. This seems especially true in the face of challenging side-effects, where a conventional biomedical narrative continues to offer compelling answers to hard questions about the depression itself.

Since all participants spoke of times of seeking out and embracing certain studies, books or insights, it is important to clarify that the seeking of evidence is not unique to those adopting

the prevailing treatment narrative alone. Kyle and Esther, for instance, both spoke of doing personal research on alternative perspectives and interventions. In fact, a French study of psychotropic users found that “looking for additional information” via doctors, media and exchanges with others was “an act of autonomy” that among their sample was typically associated with non-compliant medical behavior: “Talking to other people and reading the information leaflets are more often done by non-observers [i.e., non-compliant patients]” (Baumann & Trincard, 2002, p. 389). As elaborated later in this chapter, individuals from diverse views come to emphatically claim science as being ‘on their side.’

Although seeking additional evidence is thus a strategy common to the maintenance of diverse narratives of treatment, there is one unique characteristic that appears to differentiate some cases. Beyond simply affirming the evidence, some participants appeared to have a habit of re-affirming the validity of their narrative repeatedly. Jill and Debbie both commented on patterns of self-affirmation regarding their beliefs: “I wish I didn’t have, you know . . . to have meds. . . . I had to just tell myself, you know, ‘It’s okay. You’ll just be on these meds and it’s okay to be on these.’ You have to talk yourself into it, basically, you just have to talk yourself into it” (Jill/7). Debbie added, “I’ve got to convince myself. I can convince others but accepting it myself, I just . . . I struggle with that.” She then added, “I have to keep telling myself it’s a *chemical imbalance*” (8).

In a study of Huntington disease narratives, Cox (2003) observed a similar phenomenon associated with a certain controversial procedure--“there is a continual need to renew and justify, if only to oneself, the ongoing commitment to a decision” (p. 274). An especially intense need for more evidence thus seems to reflect battling against inclinations to the contrary. For these individuals, a continued “maintenance dose” of a justifying narrative appears to be required to move forward in conviction regarding their decision.

Attesting to divine guidance. Some participants also pointed to spiritual experiences as another kind of evidence for their account. In several instances, these references were about general support and comfort in facing and overcoming the problem. Kellie and Peter, for instance, both spoke of recovery as stemming from God’s intervention and love (10, 16). Victoria and Sarah both recounted touching experiences at their lowest points of darkness—Victoria’s through an inspired blessing (5) and Sarah’s after pleading for help and feeling “Heavenly Father’s arms just wrap around me” (4). Even Lucy, who expressed some hostility towards religion generally, recounted what she believed to be a miraculous instance of an individual being prompted to return home right after she had slit her wrists (6).

Clearly, faith is a powerful narrative resource for many individuals, with reference to it

a powerful strategy to maintain one's course and overall convictions, as in other instances. In a few cases, however, participants went beyond general convictions of support to claims of God's specific guidance in relation to treatment decisions. Victoria, for instance, went on to recount recurring promptings to speak with the woman who first referred her to a psychiatrist. It was after her doctor encouraged her to discard her hesitations—"you should be thanking god that he has brought this medicine [so] that you can live a good life"—that she embraced treatment enthusiastically.

One morning, however, Victoria woke up paralyzed and completely unable to move. As reviewed elsewhere, she attributed the terrifying state to random causes, rather than anything related to her treatment. On this occasion, Victoria emphasized the blessing of encountering another doctor through this experience that turned out to be especially helpful to her. In reflecting on that episode, she said, "I just think that . . . [god put me in a place where I had no choice, and I would go where He wanted me to go to meet this just wonderful [man] . . . I feel so blessed. . . . And I can't help but seeing all the way along, the Lord's hand in getting me through" (5).

Both Sarah and Victoria went on to share a sense of calling and mission to educate others regarding treatment. Victoria spoke of her amazement at the frequency of phone calls "out of the blue" where an individual says, "I know this is really weird, but you know, my doctor just said that I have depression and I just feel like something told me I should call and tell you that." She added, "when people . . . ask me about it, I feel like I always know what to say." Like Sarah, Victoria emphasized her excitement at her sense of being used to help others.

3. *Reframing the Past: "I was a little naïve back then . . ."*

In addition to emphasizing and affirming *past events and experiences* as supportive of one's current narrative, several individuals commented critically regarding their *past views* in light of their current views and perspective. In particular, when individuals embraced biomedical explanation/treatment, their interviews often reflected a criticizing and reframing of beliefs prior to their change of mind. *Reframing the past* here refers to a reconsideration of earlier events and perspectives regarding treatment, depression itself and its purported causes.

Revising views of past depression experience. Recollecting his views from an earlier period of facing depression, Peter said, "I learned to live with it and . . . assumed that most people felt the way I did." From his current vantage point of seeing depression as a primarily biomedical condition, he added, "I didn't really understand what it was that I was dealing with" (10).

Accompanying this change in views over time, Peter also reported seeing his past experience with depression differently as well:

I didn't realize until after I had gotten help how far back the depression went...like, I can remember it all the way back into childhood you know four five six years old...and until (pause) you know, that point in time, I didn't realize how far back it went. (10)

Kellie's medical student brother encouraged her thinking in the same direction:

He said he was concerned about me and he wanted me to maybe think about trying some medication. He said "Kellie, You've been depressed almost your whole life!" And, you know, he said, "I remember you always, you know being in your room, and just always wanting to be by yourself."

These comments impacted Kellie's own thoughts about her past views:

I guess it took talking to him to make me look back and really look at . . . that depression. . . all during my, um, teenage years, I guess. I didn't realize this before, but talking with my brothers . . . has helped me realize some things. Um, when I was younger I remember feeling depressed a lot. You know, feeling sad a lot, but I didn't really ever take it as anything serious because you know it was during that time where your hormones are crazy and you know you're changing, and I just figured, and I think my parents probably did too, that it was just all a part of growing up. But as I look back on it . . . it really made me think; it made me look back . . . when I was younger and, "yeah he's right, you know?" I didn't realize. . . I just assumed that . . . I was just maybe a little bit more sad than most people and it was just something that I needed to learn to overcome . . . So, he helped me open my eyes in that respect . . . "maybe there was an issue there." (16)

"I didn't realize this before, but . . . talking with them has helped me realize some things." "As I look back on it . . . he's right, you know? . . . He helped me open my eyes . . ." Kellie's quote was represented here in its entirety for its rich evidence of a significant amount of reframing going on. Sarah similarly commented on misguided early beliefs about her pain as something other than chemical depression: "I just remember saying, 'oh, Sarah you're just having a rough week, you know; it'll get better . . . next week.' That was my way to make it through the week, you know, like, 'Sarah, you know this will get better'" (4).

In each case, original views of depression were narrated as naïve and misleading compared to current views. As stories evolve from initial emphases of "it's just growing up/puberty/a rough week/a little bit more sad" to something biomedical and concrete, the contrast between the two stories thus appears to be leveraged as a strategy to reinforce and maintain the latter narrative.

Minimizing trauma and abuse. In Chapter 6, particular interpretations of severe trauma and abuse were reviewed in relation to the adoption of a biomedical narrative. Here, similar interpretations are reviewed as relevant to strategies upholding individuals' narratives.

First, however, on a more general level participants often mentioned a wide variety of challenging environmental conditions and events that may have contributed to their emotional pain—from job loss and the stress of raising a family, to other health problems and actual abuse. Elaine, for example, described a time preceding her depression that included: raising five children (all under the age of six), reversals in her husband's business and financial difficulty, having to move on three-days notice, having to start working outside of the home, having another baby and going back to school to take graduate level classes. Accompanying this “incredible, incredible, incredible amount of stress,” she described, “I didn't sleep for a period of about 5 years, more than three or four hours at a time.” It was during this period, that Elaine visited a doctor: “He went through a stress survey on it and told me that it was anxiety and depression that I was experiencing . . . [and] suggested Valium.” After resisting this suggestion, some additional stress lead Elaine to seek advice from a second doctor: “He explained that what I was experiencing was probably paralyzing anxiety and prescribed Xanax, [then] gave me a depression assessment . . . and . . . started me on Prozac” (2). Reflective of her physician's response to her pain, Elaine's subsequent narrative literally centered around attaining the correct medication types and dosage levels.

Elaine's account thus reflects the same basic pattern of abuse minimized in Lucy's account (see Ch. 7). Indeed, while several others spoke of abuse as relevant to their depression, in each case its contribution was vague and inchoate—with an explicit focus on biological deficiency as the primary cause (Lucy, Jill & Debbie).

Obviously, individuals and doctors look to biomedical explanation when it appears that emotional pain being experienced goes clearly beyond what seems merited by surrounding (even crazy) life circumstances. As Chapter 6 detailed, this seems to be the basic reason that in many cases, an (internal) biological explanation takes priority over external explanations. Furthermore, it seems important to point out that the basic relevance of both environmental and biological contributors is also commonly understood across participants. In fact, most participants seemed to express a sophisticated understanding of the interplay between the body and external situations. Having said all this, these accounts corroborate other accounts of abuse victims to reflect a striking and unmistakable pattern of de-emphasizing surrounding life experiences.

In Lucy's case, she became so passionate about psychiatric treatment that she volunteered to share her story to educate others about mental illness. When doing so, Lucy

recounted avoiding mention of the past violence from her father: “Especially in my lectures, I don’t go too much into my past, because, um . . . some people look at it and go, ‘well she was abused—that’s all that’s wrong with her.’” She continued, “No, [depression] might have come to the surface faster because of what happened to me, but this is something that can happen even if [abuse] doesn’t” (6). Notably, Lucy’s quote reflects a desire to defend a conventional narrative of depression (i.e., emphasis on underlying diathesis, only brought to the “surface” by varying levels of external trauma) as the explicit reason for which she, herself, minimized past abuse in her volunteer speeches.

After describing another woman with a history of tragic accidents and abuse, Schreiber and Hartrick (2002) note how she explained away any connection to her depression during the interview:

There was no consideration of the possibility that the past life trauma that she spontaneously related in her depression story may have contributed to her current depression. It seemed that the woman consciously turned away from exploring the complex web of depression that was revealed through her story and toward the more concise and concrete BEM [biomedical explanatory model] (pp. 100-102).

It thus appears as if the active minimization of past abuse can, in some instances, be important to reinforcing and sustaining one’s overarching narrative—i.e., keeping the focus on biomedical explanation.

Alleging treatment concerns as having been naïve. In addition to casting previous views of depression as times of relative ignorance, individuals also criticized previous views of treatment as reflecting similar naiveté. Sarah went on to recollect prior worries about medical treatment: “[I thought] ‘No, no that can’t be me, you know. No, I’m not a medicine taker.’” She continued, “I resisted and just [wanted to] be independent . . . you know, ‘I’ve done this before and I can do it on my own.’” She went on to emphasize this period of refusing medication as corresponding with greater grief and pain, “And it got worse and worse and worse. . . . My brain felt it was scrambled eggs . . . for me to make simple decisions, it overwhelmed me.” Ultimately, Sarah emphasized “a wall of denial” relative to both biomedical diagnosis and treatment as largely responsible for her early pain (4).

Referring to his own prior worries about potential negative effects of medical treatment, Peter suggested they were possibly related to the illness itself: “That’s what I had in my mind, now again under the affects of the depression I was not thinking clearly, but that was what I had in my mind and so it really put me off for a long time” (10).

Others like Kyle and Esther were similarly encouraged to see their concerns about treatment as reflecting denial and even manifesting the effects of sickness itself—an insinuation

that both rejected firmly. Across cases, past treatment concerns were thus narrated as either valid or ignorant, depending on the current narrative espoused, in turn, I would argue, effectively *bolstering* that same narrative that seemed to direct the re-framing in the first place.

4. *Looking to Help Others: “I think he probably has some kind of disorder . . .”*

Alongside instances of being supported and upheld by others in treatment, multiple participants spoke of their own interest in doing the same thing for others. This striving to help educate and support others in treatment is reviewed as another strategy in maintaining narratives. Efforts range from noticing and cataloguing symptoms in others, to sharing one’s own story, to actually encouraging treatment in others.

Speculating about others’ symptoms. At the mildest level of outreach, individuals reported frequent reflection regarding potential signs and symptoms of depression in others. Debbie said, “I think my daughter probably has..something” and added, “for a long time we used to think it was in the water here. There are so many women in this neighborhood that are suffering different depressions . . . and those are the ones I know about. I’m sure there’s other’s that haven’t said” (8). Sarah noted similarly, “Having been through my depression I pick up on . . . signs of people, you know, girlfriends or whoever” (4). After describing his mother’s panic attacks and agoraphobia, Peter said:

My father--although he’s never been he’s never gone to any kind of psychologist--I think if he were to go he would probably have some sort of anxiety disorder...you know, he’ll stay up late at night worrying about something he’ll pace the floor uh you know...he may only sleep a few hours a night if there’s a problem going on and it’ll consume him. . . . and it goes on down the line I mean my grandfather was the same way. (10)

As evident here, the highlighting of others’ possible symptoms sometimes stretched back into one’s own family history. After mentioning an aunt with depression, Fern similarly speculated that it has “probably runs in our family”: “I remember my grandfather saying his mother was a person who was the most insecure person he had ever met. I can see she probably experienced depression sometimes in her life” (11). Jill reflected the most vivid illustration, highlighting potential evidence of many disorders in multiple branches of her family:

Once I learn more about bipolar and how genetic it is, I look to my family and I think it’s on my paternal side. Um, like I said, my mom was neurotic and irrational and I don’t know if that was a mental health problem or the result of her surgery, but my, my brother would have been diagnosed ADHD in this day and age. . . . After I got to know my father, he was very obsessive compulsive, (*laughs*) . . . and a little bit hyperactive, too: kind of a frenetic type of person, just always, you know, couldn’t sit still, could not sit still. . . . And then his father, all I know about my grandfather--‘cause he died when I was about four--was that he was an alcoholic, which they say is a red flag. Whether he was,

had some kind of mood disorder and it was self medicating or just had the addictive personality, I don't know. . . . (7)

Beyond such speculation regarding others' symptoms—past and present--some spoke much about helping others in more direct ways, first, by calling for more education and second, by actively seeking to facilitate diagnosis and treatment. Each is highlighted below.

Calling for more public education. While participants differed in what they viewed as the needed content of public education, most were insistent on the need for more extensive and frequent educational campaigns about depression. Among participants, there were actually varied degrees of comfort in talking about depression—from some who were worried about being identified while sharing, to others who were regularly on the speaking circuit sharing their stories. At least five participants from diverse views (Sarah, Victoria, Lucy, Kyle & Esther) had been actively involved in sharing their stories as part of formal treatment advocacy efforts. Debbie spoke of her excitement at wanting everyone to learn what she had learned: “I want to be an advocate. I've taken classes on . . . talking to others. . . I want everybody to understand it now.” She continued, “I tried to share my story with the people that I meet. . . My sisters. . .I've talked to them and they've gone in to get help (8).

Kyle and Sarah each ended their accounts expressing interest in what they could do to help and reach out to others and mentioning their own advocacy work. Once again, in spite of both claiming the banner of “education,” their respective organizational affiliations reflect contradictory messages in respect to psychiatric medication (see websites for *MindFreedom Support Coalition International* and the *National Alliance of the Mentally Ill*).

In addition to reflecting an impulse to helping others, these calls for education and efforts to share and retell one's own story, once again, indicate another way individual narratives are strengthened and maintained (also reflecting well the previous strategy of “affirming evidence”). Indeed, the retelling of dramatic treatment experiences throughout communities and by institutions may be a major way that knowledge of narratives spread and becomes dominant.

Facilitating others' diagnosis and treatment. In addition to educating others, several people emphasized desires for facilitating treatment, including preventative screening efforts to get people on medication earlier. Along these lines, several spoke of their efforts to facilitate the diagnosis and treatment of their own children, with three participants mentioning kids who were also taking medication. Speaking of her daughter, Camille further related:

My experience enabled me to recognize signs in her at a very young age and to seek help for her. She was diagnosed when she was eight years old, which from everything that I have read and heard is almost unheard of to catch it that early.

*J: So you just saw signs of it and got to a doctor; is that how it happened?

Mmmhmm and at first he thought we were simply dealing with, uh, depression . . . Um I also took her to California to have a SPECT scan and there they told me . . . what is going on in her brain was bipolar, but it took her psychiatrist quite a bit longer to make that formal diagnosis. (3)

It was Jill's account of seeking to help her sons, however, that was the most vivid reflection of the potential role of both educating others and facilitating their treatment in the maintenance of one's own narrative—especially when she asked her son to come in the room and verify details during the interview itself. Before this happened, she had been recounting her sons' initial diagnoses and medical treatment. After one son started to act violently on the medication, she related:

They still hadn't properly diagnosed him. One psychiatrist on the panel had mentioned in his notes "possible bipolar" and that's when I grabbed that ball and ran with it. And that's what it was. But it took me a while to come to that. . . . It was me that had to go after 'em, and after 'em, and after 'em, you know. I had researched it and, you know, I must have suggested to a psychiatrist several times "Do you think he could be bipolar? . . . and finally several months down the road, she says "well, it wouldn't hurt to just try [the mood-stabilizer] and see if anything happens." (7)

After her son began treatment, she subsequently began educating her son about his bipolar depression, as reviewed earlier: "I've had to teach him that it's just like anybody else that has to take medication. . . . 'your body needs this medication to function. You have to take it' . . . From the beginning when he was diagnosed, I said 'this is something for life; you'll have to be on these medications for the rest of your life.'" Jill's son did not initially respond well: "He would just never want to take 'em . . . you know, he got mad at us, but as he's matured he's accepted it and he forgets, he has a hard time remembering."

A second son was also placed on medication, but disliked it and eventually quit: They tried him on Ritalin . . . he just had that glazed over look, you know. But it would calm his temper down. And the summer before eighth grade he just begged me, "can I just not be on it?" And I said "well, we'll try it." And he was strong willed enough that he could just tamp it down, get it under control of himself. They say that *can* happen; it's *rare*. . . . He morphed around the age twelve to thirteen. Like I said, we don't know how he did it, it's just that he's so strong willed and focused.

When I asked, "So, those struggles with your oldest son have passed?" she responded, "I know that before he [left home] he told a friend of mine that he still gets those feelings, he just

has to. . . I mean we could ask him-“Terry, come here!” At this point, she called in her second son who had quit medication years ago:

Do you still have any of the feelings you had when you would lose control, when you were younger? Do you ever feel like you have to get a hold of yourself..or you’ll lose it?
*Terry: No, actually, quite the opposite. I, like, ever since they took me off the Ritalin, . . . it’s rare that I ever actually ever get mad. . . like I get frustrated with things but I’ve never ever like gotten to the point of actually being mad at something.

Jill interjected, “It’s not a normal thing that you were able to get a hold of yourself like that. We were just saying that year in seventh grade, you sort of morphed from someone with, you know, the anger all the time to what he is now. . .”

Terry responded to his mother with some disagreement, “Quite the opposite again.” I asked him, “How would you explain the change?”

He acknowledged, “Yea, I used to get mad a lot.” Terry then emphasized again how the struggle ended after learning some new things, “But, I don’t know, things stopped really bothering me . . I guess I just realized that like everything’s not, like earth-shakingly important so there’s no reason to really, just like, to get so mad and out of control.

Jill interjected again, “Well, it had to have been a real internal struggle that year; you may not remember how hard, I mean, for you to, to get a grip on it.” Terry again disagreed:

I don’t think so, ‘cause by the time you took me off [medication] I was asking you to take me off ‘cause I didn’t like it anyway and I knew I’d be able to take care of it myself. So when you took me off, it wasn’t...I don’t remember it ever being a struggle. I think the struggle was, like, with the medication because I didn’t like it. I was struggling with the side effects of it more than I was trying to control my own self.

Jill spoke somewhat defensively, “Well it was the wrong medication for you. They just didn’t have anything else; they didn’t know what else to do.” She then challenged Terry a little, “[our neighbor] said you told her once that once in a while you still get those feelings that you’re just able to...kind of push ‘em down and be alright.” Terry responded, “I can’t remember a time when I’ve ever like, got to the point of like, being extremely mad at something. Getting frustrated, but I don’t ever remember getting, like, angry at things. Nothings come up.”

Jill hastened to add, “He couldn’t even remember a lot. . . I remember sitting down with him and saying ‘this is what you were like when it was so difficult’ and he didn’t even remember a lot of it.” Terry responded, “I just found that being positive is a much more, it’s a happier way to live; I’d just rather be positive, than be mad at something so I just don’t let it bother me. . . . I found out that that’s something you can do to control yourself.

“Well . . . not if you have a chemical imbalance” Jill retorted. “Yea, well maybe I did it natural,” said Terry. Unable to let it go, Jill returned to emphasize improper diagnosis and medication types:

They never were able to properly diagnose you. You didn’t fit any of the molds. You didn’t fit the ADHD mold, although he was kind of hyper. . . . it was first grade when his teacher said “I think that he needs some kind of medication.” . . . and Ritalin was really the only thing that they had at the time to even treat anything with and that was the wrong medication for him.

“It has really bad side effects . . .” Terry said. “It does,” Jill agreed (7).

This exchange is reproduced at length for how vividly it reflects this strategy of helping-others-to-help-confirm-my-own-narrative in action. In it, we see not only the mother’s attempts to educate and help her sons—but the personal importance of doing so to suit her personal narrative. Specifically, it was striking to see the extent to which this mother insisted on a particular way of interpreting her son’s recovery. After seeking confirmation from Terry that he still wrestled with severe emotions under the surface, her son denied this and attributed his improvement, in part, to getting off medication. At this point, she interjected and insisted on his emotional improvement as some kind of random “morphing” perhaps reflecting a unique level of willpower able to somehow manage severe emotional struggles without medication. When Jill emphasized how hard it must have been for him to “get a hold of himself” without medication, he again disagreed and asserted it was easy once he learned he had a choice. He then suggested that the side-effects of the medication were a bigger challenge than struggling to control his behavior. After suggesting that he had been on the wrong medication, Jill insisted a third time that he had difficult feelings under the surface. When he denied this once again, Jill insisted on his lack of clear memory of the true situation.

In microcosm, this mother-son interaction illustrates and confirms the degree to which individual sharing can be connected to and reinforcing towards one’s own individual narrative. In it, we see the personal importance *for the mother* to believe that the emotional struggle had continued at some level after stopping the medication. Seemingly, the reports of her recovered son reflected enough of a contradiction of her own experience (and that of her unrecovered son), that it became necessary to narrate it as a “rare case” of exceptionally strong willpower. In the face of repeated denials and challenges by her son, Jill insisted on holding to her own story. As further evidence of Jill’s need to narrate others’ according to her own story, the interview was later interrupted by her husband. She introduced him and after complimenting him on his loving support to her during rough times, she said:

They actually thought that he was depressed for awhile.

[Husband] *No . . . you* thought I was depressed for awhile.
They put you on an anti-depressant for a couple . . .
[Husband] Because you *made them* for a month and then I quit taking them and said “this is *stupid*” and I never took it again (*they both laugh*) (7).

Speculating about others’ symptoms, re-telling one’s story to others, and assisting them to receive a diagnosis and begin treatment are proposed as other related ways that individuals reinforce and affirm the validity of their own narrative of depression.

5. *Persisting in Treatment: “I’m a firm believer in medication. . .”*

Alongside its influence on the *formation of narratives*, an individual’s actual experience of treatment is proposed as having an equal or greater impact on how these narratives are *maintained over time*. The decision to persist and adhere to medical treatment, in particular, is highlighted as another strategy in maintaining a conventional biomedical narrative. (Alternatively, the decision to cease treatment would disrupt the same narrative and contribute to forming another).

On the most basic level, the ongoing presence of medication itself may function as continuing evidence that the biomedical explanation is accurate. Just as early positive medication effects appeared to increase many participants’ confidence in biological explanation overall, the continuing awareness of one’s decision to take medications for emotional pain seems to act as a subtle and enduring reinforcement of the same justifying explanation. For instance, several participants who expressed serious reservations about treatment nevertheless spoke at length about things such as recent doctor visits, the importance of finding the right dosage and their schedule for taking medication. For these participants, the ongoing presence and taking of medication seemed to reinforce and spur the continued adherence to its treatment narrative, in a way not dissimilar to the reminders of surrounding friends and family.

The role of treatment adherence as a maintenance strategy for narratives arguably goes deeper than external reminders, however, to its direct impact on interpretation itself. Most basically, when a behavior (like medication taking) that corresponds to a particular narrative is perceived to be rewarded, it naturally reinforces not only the behavior, but the interpretation behind the behavior (like biomedical explanation). A treatment experience evaluated positively will thus reinforce the justifying explanation for that treatment, in turn, making it more likely that an individual turns to both medication and its justifying biomedical etiology again. In this way, once individuals gain an initial conviction regarding treatment, it may also color and shape subsequent judgments—acting as a backdrop out of which other treatment experiences, for better

or worse, are evaluated. For instance, individuals who chose to medicate first symptoms seemed naturally more inclined to do the same with future difficulties (i.e., medicate the side-effects). Alternatively, individuals who resisted medicating first symptoms or ceased treatment seemed naturally inclined to do the same with future difficulties.

As a final, most vivid example of interpretation being galvanized by treatment, once individuals initially attribute positive emotional change to the effects of medication, subsequent changes in emotional condition may be more readily and consistently credited to medication. This was evident in narratives where the effects of medication had come to be closely intertwined with major emotional issues generally. In Jill's account, for instance, the taking of medication came to be seen as a natural response to a loved one's death—"And then when my dad died that year, then [my doctor] upped me a little bit to get me through that" (7). In a similar vein, Victoria spoke of times when "life doesn't make sense" as corresponding to times when she hadn't been faithful with the medication. After so many years of taking medication, her interpretations reflected an imprint that extended even to deep issues of meaning, direction and purpose. She continued, "this has been times when they've upped the medication . . . when I have gone in and I said, 'I can't seem to find a direction I can't seem to prioritize and figure out what I need to do during the day,' you know. And umm that has usually been a symbol that we need to up the medication a little bit" (5).

On multiple levels, then, persisting in medical treatment itself can bolster and reinforce both *treatment maintenance* and *treatment-narrative maintenance*. Joining this strategy are two more medication-related dynamics described below. It is when dramatic initial effects subside and difficult side-effects emerge that some of the most subtle and fascinating strategies for narrative maintenance can be observed. The following sections take up two more related clusters of strategies—starting with the framing of difficult states *concurrent with medical treatment*, and moving to consider diverging frames for *one's life without medication*.

6. *Reconciling Difficulties Concurrent with Treatment*. "You just have to deal with it, you know?"

Earlier in this chapter, the telling of one's story of depression and its treatment was reviewed as an example of "educating others" as a maintenance strategy. Whether told or lived out, individual treatment narratives are here and in the remainder of the chapter dissected at closer view to consider constituent interpretations and affirmations that appear to be playing a role in their overall maintenance. Like interpretation and narrative itself, these are held to be more than merely passive "*beliefs*"—instead reflecting key constituents of *practices* that are "lived and continuously accomplished" by those facing depression.

In this section, one of the primary impediments to treatment (and narrative) maintenance is examined: difficult effects. Alongside more common studies of how side-effects or adverse-effects are directly addressed by professionals or patients, this section examines how they are variously *interpreted* or *narrated*—in particular, how they are framed in ways that permits individual narratives to be perpetuated over time. These specific ways include: *Holding to the memory of initial positive effects*; *Seeing mixed medical effects as acceptable*; *Narrating difficult medical effects as inevitable and necessary*; *Seeing difficulties as reflecting individual diversity or randomness*; *Seeing difficulties as coming from wrong medication types or dosage levels* & *Believing there is a right medication*. To conclude this section, a brief discussion will review apparent implications of these assumptions for how individuals subsequently respond to and endure difficult effects.

Holding to the memory of initial positive effects. In Chapter 6, it was proposed that dramatic initial evaluations of medication may play a role in the adoption of a particular narrative. When difficult states arise concurrent with medication, this same resource may be referenced as part of a larger strategy to emphasize early memories of positive treatment impact for reassurance during tough periods. Both Elaine and Debbie, for instance, although experiencing difficult side-effects at the time of interview, referred back warmly to earlier experiences. Debbie recounted, “You know, the magic part of my life was taking that Prozac. It just seemed to do everything. I had the energy; I was losing weight I could stay up (*laughs*) until 3 a.m. cleaning and everything was organized and it was just wonderful. It was like the superwoman I wanted to be.” After expressing some angst “because I’ve tried so many different medications” since that period, she almost wistfully acknowledged still wishing there would be another “magic pill” like Prozac (8).

Debbie’s story is reflective of several others in relating years of searching for the right medication(s) to help her feel well after initial effects subside. This kind of persistence arguably would not be possible without a positive initial memory that individuals could hold onto. In this sense, the memory of dramatic initial effects may literally “buffer” against future challenge. Like a conversion or *redemptive story*, it may take on a remarkable personal staying or sticking power—helping people “hold on” through turbulence and withstand rough times (see below, *Cumulative implications of reconciling treatment difficulties*).

If memories of initial positive medication effects appear to frequently reinforce ongoing hope when treatment effects subside, this outcome does not necessarily seem to be the case. A failure of treatment after early positive effects, for instance, might alternatively prompt *worse hopelessness* in one facing depression. In Camille and Debbie’s narratives, for instance, after each reporting initial treatment effects that were dramatically positive, they expressed particular

distress when these effects faded and attempts to duplicate them with higher dosages and additional drugs were unsuccessful. After relating a similar story from one of his interviewees, Karp (2006) summarized the pattern, “No doubt Mike’s later disappointments with a wide array of drugs were deepened by their contrast with this early success.” He later spoke of the “unfathomable disappointment [individuals] feel when a medication that temporarily ‘cured’ them simply stops working,” comparing it to the “shock experienced when a lover suddenly leaves” (pp. 45, 82).

Seeing mixed medical effects as acceptable. Since all individuals dislike side-effects, it is overall judgments of benefits outweighing the downside that generally leads individuals to persist in any course of medication (see Ch. 6; Horne & Weinman, 1999). While some participants strongly asserted the clear need for medication, alongside downsides emphasized as minimal (Sarah, Peter, Michelle), for others, the cost-benefit ratio just barely was enough. In reference to her depression and psychotic symptoms, Lucy said the following about her current medication cocktail:

I am on the right dose that *I’m* okay with right now, but it’s not perfect by any means. I still hear voices a lot of the time, but it’s turned it down a notch. And I’m not *rapidly* cycling . . . but I still do, you know what I mean? So it’s almost just like I’ve *settled*. It’s not things are *great*, it just doesn’t *hurt* as bad as it used to. (6)

Narrating difficult medical effects as inevitable and necessary. Beyond the rough distinction between beliefs of “necessity” and “concerns” described above, this study suggests that some specific nuances of belief and language may also influence treatment and its overarching narrative. For instance, negative effects associated with a medication may be interpreted as “side-effects” or “adverse effects” depending on the original evaluation of medication itself (Breggin & Cohen, 1999). In the former case, the emphasis is on effects that are tolerable and inevitable—i.e. “all drugs having side-effects.” Camille said the following about memory loss she believed was possibly linked to her medical treatment: “You just deal with it. What else can you do? And I’ve just figured well maybe those are parts of my life that I just don’t wanna remember anyway, so it’s okay.” When her family expressed frustration about this side-effect as well, Camille responded similarly, “I just I tell them . . . “Um, I’m sorry this is how it is and we all just have to learn to cope with it” (3). By narrating uncomfortable effects in this way, they come to be experienced as both necessary and less ominous.

Side-effects, of course, are not always narrated to be acceptable. Accounts of Fern & Kyle both reflect decisions at some point that the effects they were experiencing were not okay. Karp recounts a poignant vignette of a man’s experience after visiting his mother’s grave site:

I heard something on the radio and it clearly reminded me of my mother, some early stuff that she would sing to me from the song “Lightly like a Rose”. . . . [it] immediately caught me. And I listened to it. I wanted to cry. I just couldn’t do it. It was clear that the trough had been cut off. And I knew, and I knew that it was the Prozac. . . . And I said, “F* you, Prozac, I want to cry for my mom” (p. 109-110).

Rather than use a frame of “side-effects,” an effect seen as dangerous or intolerable may thus be framed as an “adverse effect” (Breggin & Cohen, 1999). In the latter case, the emphasis is on effects that are neither worth tolerating nor inevitable.

Seeing difficulties as reflecting individual diversity or randomness. Confusion in understanding the source of depression was reviewed previously. When a medication is added to the picture, it naturally increases the complexity of explaining both positive and negative states: Was it the medication? Was it my own biology? Was it something else entirely? A major theme of earlier chapters was the struggle to ascertain the precise source of negative (or positive) states arising concurrent with medical treatment. In some cases, such as Kyle’s negative reports of *Lithium*, negative effects were attributed to the medication itself. In other cases like Sarah and Victoria, participants reach a conviction that certain negative effects were likely ensuing from sources other than the medical treatment for depression. One popular alternative explanation for difficult states is emphasizing the sheer complexity and distinctiveness of individual situations and physiologies—as Kellie articulated, that “everybody’s situation is very unique” (16). After being challenged by a woman who said medication hadn’t helped her, Victoria responded, “I mean, that’s an easy one, because everybody is different. I have a friend who swears by Prozac; she wouldn’t take anything else. Well . . . her make up is different, you know” (5).

While reflecting an undeniable and basic reality, this emphasis on diversity at times appears to function as a catch-all explanation for difficulties. Camille referred to unique differences as justifying the need for doctors to experiment with medication--“And you go to doctors and everything is trial and error because every person is so different” (3).

Alongside diversity and uniqueness, a related narrative emphasis is randomness and/or mystery. After Prozac helped her for a year, Camille recounted when it ceased to work. After the doctor tried increasing the dosage and it didn’t help, he explained, “sometimes that just happens to people. . . we don’t know why it happens; it just isn’t effective anymore” (3). As mentioned earlier, Victoria woke up paralyzed and completely unable to move. Rather than attributing such difficulties to the medication directly, she emphasized it as coming out of the blue: “What it was, was that it was just some kind of freak thing where the nerve endings just, for some reason, just kind of locked everything up.” Her doctor’s response further reassured her: “it’s so rare, you know, that I really doubt that it will ever happen again” (5).

Seeing difficulties as coming from wrong medication types or dosage levels. As reflected in the discussion of side-effects earlier, even when negative state appears connected to treatment, it can be narrated in a way that preserves the centrality of medication (for narratives and practice). With acceptance of some degree of inevitable difficulties solidly rooted, critical attention goes elsewhere—starting with the details and particularities of treatment itself. Rather than medication itself being to blame, it is the wrong amount or kind. As reflected in these interviews, insufficient dosage levels or “wrong medications” frequently receive the blame for discomfort and difficulty. Jill lamented her son’s long-standing emotional difficulties as follows: “He’s done better since he’s been put on the right medications, all those years on the wrong medications” (7). Others spoke of searching for years for the right treatment specifics; Elaine, for instance, summarized her “whole goal” as finding the right dosage level to be able to function better again (2).

In a related interpretation, others assert difficult states as coming from inaccurate diagnosis. Lucy, for instance, emphasized throughout her narrative that long years of painful emotion were principally caused by improper diagnosis (6). And even after acknowledging that medication had been contributing to violent side-effects for her son, Jill remained focused on the misdiagnosed depression itself as her son’s primary problem: “. . . they still hadn’t properly diagnosed him” (7).

Believing there is a right medication. The flip side of the belief that problems come from a wrong medication or inaccurate dosage, of course, is the conviction that another, better medication could change that all. Alongside the touchstone of looking back to positive earlier experiences is the evident influence of looking forward to positive visions of what can still happen with medications—i.e., the conviction that one day, a medication or combination of medications will be found that works (better or for a longer period of time). This conviction was implicit in a number of participant narratives reflecting long journeys to find the right combination of medication types and dosages over the years (Elaine, Sarah, Peter, Michelle).

In their own interviewing sample, Schreiber and Hartrick (2002) recount one woman who reported experiencing multiple childhood traumas prior to facing depression; after starting medical treatment, she subsequently “spent her days researching new antidepressant medication on the Internet.” They conclude, “Even women who described having little success in spite of having taken a variety of antidepressants continued to hold out hope that they would eventually find a medication that would ameliorate their depression (p. 96; 100-102). Karp (2006) suggests that “the search for the ‘right’ drug is analogous to the search for Mr. or Ms. Right”: “Just as people hold out hope of finding the perfect mate despite repeated disappointments, those suffering from depression often remain convinced that there’s an ideal drug for them” (p. 75-76).

Cumulative implications of reconciling treatment difficulties. When individuals interpret difficult effects as necessary side-effects, temporary reflections of wrong prescriptions or random unfortunate occurrences, the single or joint operation of these convictions may arguably have consequences for treatment choices and experience.

One of the most perplexing dynamics I observed across interviews was the degree to which individuals persisted through side-effects that appeared gut-wrenching to me. Jill, for instance, recounted the decision she and her husband felt forced to make between continuing sexual intimacy and continuing treatment:

My husband and I had to sit down and make the decision of “do we want me to be well?” . . . and he decided that he’d rather have me [emotionally] function. . . . and so that’s just something we’ve had to deal with which hasn’t been good; he’s just basically taken an oath of celibacy. (7)

Others spoke of significant weight gain (Lucy), memory loss (Camille), heart pain (Robert) and financial debt from medical payments (Victoria). Jill went on to speak of her first son still facing bipolar depression—recounting a time when his treatment on Risperdal, Adderall and another medication were “working too hard on his heart. His heart was beating so fast and pushing such a large fast velocity through the heart it was causing a murmur” (7). Even so, Jill spoke of this as an inevitable part of his necessary treatment. Individual willingness to continue treatment in the face of tremendous difficulties can be, at times, remarkable.

Such willingness to endure and persist through such difficulties over long periods of time is here proposed to ensue, in part, from the effect of this series of beliefs and convictions described above. When taken together, these interpretations constitute a strategy of systematically minimizing uncomfortable states and difficulties concurrent with medication.

The surprising degree to which individuals, at times, tolerate and overlook painful side effects is reflected in other studies as well. As one example, Karp (2006) interviewed one man who described working with his doctor for forty weeks trying to find the right medication: “I was willing to put up with feeling like nauseated to the point of just about throwing up for about two weeks and staying sick in bed trying to adjust to the Prozac.” After stopping Prozac, he described “working my way through the SSRIs”: “Then I get into Paxil. Paxil has me nauseated . . . I stayed on it for a while . . . the first eight hours after I take a Paxil I am sick, really sick. The second eight hours . . . I’m sick and shaky Then after eight hours of being sick and shaky I start getting a little bit of relief” (p. 41).

Such persistence, of course, relies on more than treatment narratives. Karp goes on to argue that long years of enduring treatment side-effects may not happen without commitment to a

particular narrative of the biological cause itself—noting that the “unflinching commitment to biomedical solutions” is “nearly always the backdrop for years of experimentation with a series of medications”; “To stick with drug experiments virtually requires the belief that your biology is bad” (pp. 39, 77; see Ch. 7).

7. *Narrating Life Without Medication: “What happens if I stop taking these?”*

In addition to particular convictions about difficult effects, participants also reflected on multiple aspects of what life would be like without medication: *How would I face depression alone? Is there anything else that can help? Is improvement without meds even possible? Would depression come back if I taper?* These interpretations and beliefs regarding life after treatment are proposed as likewise relevant to the process of maintaining one’s overall narrative of depression and its treatment. These beliefs include: *Seeing life without medical treatment as equivalent to ‘facing depression alone’; Assuming alternatives are not viable; Narrating complete recovery as unlikely & Narrating tapering difficulties as a ‘return of the depression.’* After reviewing the nature of these specific interpretations, I conclude this section reviewing a strategy overarching many of these assumptions: *Confiding in physicians.*

Seeing life without medical treatment as equivalent to ‘facing depression alone.’

Independent from considerations of treatment, the dread of depression coming back was reflected across multiple accounts (Elaine, Kellie, Robert, Lucy). Since it is to medication that most participants turned for relief, naturally they associate its presence with safety from depression and its absence with a return. For this reason, even when acknowledging problems with psychiatric treatment, many individuals insisted that life would be worse without them. Camille said, “I’d really like to be off the meds, but the person off the meds is *scary*” (2). Reflecting on an imagined future without medications, Jill remarked, “I’m grateful that I was born in this day and age where I could get the medication that I need so that I wouldn’t be locked up in the attic somewhere, or indisposed all the time (*laughs*)” (7). In this way, a fear of depression comes to correspond very closely to a fear of one’s life *without medication*.

Said another way, life without medication may thus come to be narrated as literally equivalent to facing depression alone—a scary proposition, indeed. The role of this kind of fear in treatment compliance has been documented by others as well (Carder, Vuckovic & Green, 2003; Grime & Pollock, 2003). Another interviewing study cited an individual as saying, “you’re afraid everything will go wrong if you don’t take your medicine” (Knudsen et al, 2002, p. 933). In a French study of psychotropic users, Baumann and Trincard (2002) point towards “the feeling

of fear” as functioning to “put taking the medication into perspective” and specifically countering the “guilt from non-observance” (p. 389). The fear associated with not taking medication seems to effectively overwhelm the guilt some may feel in taking them.

Karp (1997) elaborates the point in an interview where he asked a patient, “Can you see yourself getting off this medication?”:

I really don't want to because I'm afraid. I don't really have any side effects other than the upset stomach, the appetite fluctuation, and the sexual dysfunction which I can live with. [Recently] I said [to my psychiatrist], “Well, I can't tell the difference [between] being on it or not being on it.” And she said, “Well, if you stopped taking it . . . you would notice it because you would fall back into the depression.” That's how you'd know that it was working. So I said, “Well I don't want that because there's nothing worse than not being able to sleep, not being able to eat, and not being able to function” (p. 99-100).

Rather than the benefits of treatment, it is here the threat of its discontinuation that functions to reinforce compliance. Although very real to individuals, these combined analyses raise the striking possibility that such fears may be neither natural nor inevitable. Like other heightened feelings among participants of urgency, excitement or accusation reviewed in earlier chapters, fears of a foreboding future may likewise be ensuing largely from a particular narrative or interpretation of experience.

Assuming alternatives are not viable. Implicit to the assertion that life without medication is equivalent to facing depression alone, of course, is the assumption that medical treatment is the one and only legitimate way to address the problem—i.e., that there are no viable alternatives. While alternative treatment options remain a common desire among distressed individuals (Carder, Vuckovic & Green, 2003), other research confirms that they have remained minimized and obscure to those facing depression (Badger & Nolan, 2007; Rogers, May & Oliver, 2001). In Sarah's account, for instance, suggestions to exercise or improve her diet were received as a naïve expression of her husband's misunderstanding of depression:

He didn't understand; there wasn't the education about , you know, depression. He'd thought . . . “you're not eating right. You're not getting enough rest or . . . You need to exercise, Sarah. C'mon get up and go jogging with me.” That was there was no way . . . so I had that turmoil, you know; so I had his lack of . . . understanding depression. (4)

As reflected here, Schreiber and Hartrick (2002) suggest that the dominant biomedical narrative may indirectly discount alternatives. Badger and Nolan (2007) document doctors directly discouraging the same. Other narratives similarly confirm that a conviction of the necessity of medication may underlie a disbelief in alternatives. As Jill said, “You can't get

better without medication. You can talk and talk and talk but you can't get better without, if your chemicals are messed up" (7).

This kind of skepticism regarding improvement without medication arguably undergirds the aforementioned assumption that the alternative to medication is "suffering alone"—positioning "getting medical help" against "going it alone." Schreiber & Hartrick (2002) note that interview participants "seemed to equate the term treatment with medical intervention" (p. 94). As one Kellie's brother counseled, "you can have a good quality life now [with medication], you don't just have to suffer through and wait for time to pass and just think that you can do it all on your own. You can enjoy life now" (16). Once again, as reflected here, accepting medical treatment is positioned against "suffering through" and "doing it all on your own."

That there are implications of these views seems clear—for both individuals and their caregivers. One man, in explaining his continued treatment efforts in spite of side effects, said, "I didn't know of any other way" (Karp, 2006, p. 71). These kinds of assumptions may help explain the force behind individuals' eventual reconciliation with the idea of treatment: "Just a couple years ago, I just faced it that I'm just always gonna have to have something" (8). As a result of this dichotomy, surrounding friends and family may be more inclined to see rejecting medicine as rejecting recovery, thus predisposing family to be more resistant to any change in a course of treatment. This perhaps explains, in part, why Kyle's parents were upset and his wife threatened to leave him when he decided to begin tapering: they saw no alternative way for him to recover.

Narrating complete recovery as unlikely. Independent of both diverging views regarding alternatives and medication are those related to overall recovery itself. Among the interpretations reviewed in previous chapters is a belief that fully overcoming depression may be a naïve goal—a view voiced by multiple participants. Gammell and Stoppard (1999) described women hoping that depression would not re-occur, but generally believing depression was "something they had to live with" (p. 120). Ridge and Ziebland (2006) found that a "language of recovery" was not readily available to patients in the UK national health service—highlighting "anti-recovery" tales of people being "perpetually trapped in mental illness" (p. 1041). For those participants in this study who came to believe recovery was possible, the moment of hearing about this possibility often appeared to be significant turning point in their narratives.

Limited accessibility of recovery language may have subtle, but significant consequences for individual improvement. However, since all professional helpers logically speak of *some kind* of recovery, it may be more accurate to say that it is different ways of talking about recovery, such as reviewed in Chapter 7, that matter more for those facing depression. Depending on the exact portrayal of recovery, individuals may come to be satisfied or not with their current state.

Some may simply come to accept wherever they find themselves as the best possible state given the illness--“I’m not well, but I’m better than I would be without [medications]” (p. 67).

Consequences, however, go deeper than merely acquiescing to treatment. Several participants defined depression as “hopelessness”—such as Kyle, “When you’re depressed, you’re *not going to get better*. You *don’t think you are going to get better*. . . No hope” (12). For individuals already facing the hopelessness of depression, it is more than ironic to consider the personal effect of being told they cannot recover:

My initial diagnosis--they said this is something permanent. This isn’t something that you’ll ever not have. (Elaine/2)

[I was told] “It’s a lifetime illness . . . you got to stay on your meds.” (Kyle/12)

This doctor told my family that I would never be able to live independently again. (Michelle/13)

While there is wide acknowledgment of hopelessness naturally coming from depression itself, there is much less attention to the subtle way that certain treatment narratives may literally and tragically reinforce this message and feeling as well. At the time of final revisions for this thesis, the author was invited to give a public presentation on depression at a local Kiwanis club, where he discussed competing narratives of recovery. Following the presentation, a woman approached him and related with some emotion the long struggle with bipolar depression of one of her best friends, a Mormon mother of several small children. Three months ago, during a visit to her psychiatrist regarding some medication problems, she was told that depression would probably be life-long and that her anti-psychotic treatment would likely be a permanent need. This mother came home, wrote a letter to her family, and killed herself. While any suicide is tragic, what is arguably more disturbing is the likely way her suicide would be narrated by most involved, including the psychiatrist: “isn’t bipolar depression a terrible illness?”

When one can see an endpoint to the pain, it often seems possible to get through almost anything, as Camille said, “The important thing is that I know that it won’t last forever. Before I had no hope. I couldn’t see a light at the end of the tunnel” (3). When the very person offering “help” affirms that one’s condition is life-long, however, the logical consequence is deepened hopelessness. Rather than trapped by the disorder itself, these individuals may arguably be equally confined by the *sheer lack of any alternative way to think* about the future.

Not incidentally, it is worth noting that a “recovery movement” in mental health is becoming increasingly embraced (Fisher, 2007), with growing evidence and documented possibilities of full recovery from severe depression (see Curtis, 2001; Fisher, 2007; Ridge & Ziebland, 2006; Shreiber, 1996).

Narrating tapering difficulties as a 'return of the depression.' For some, the kinds of assumptions detailed above may prevent them from ever considering stopping medication. A recent qualitative study of 16 anti-depressant users was entitled, “Better safe than sorry--why patients prefer to stop using selective serotonin reuptake inhibitor (SSRI) antidepressants but are afraid to do so.” This study explored some of the dilemmas involved in stopping these drugs and specifically “why these dilemmas tend to be solved by continuing rather than stopping.” The authors conclude that “the fear and uncertainty about stopping without sufficient guidance were stronger than the fear and uncertainty about continuing [treatment]”—prompting the choice of being “safe” rather than “sorry” (Verbeek-heida & Mathot, 2006).

While this seems to be the most typical trend, many others still choose to attempt tapering in spite of their fears. Karp notes that “after years of drug-taking, most of those I interviewed longed to know who they would be in the absence of the drugs. Even those who felt well, even cured, on their medications often fiddled with dosage levels and considered stopping their medication altogether” (p. 117).

Three quarters of participants who started medication reported passing through periods of experimenting and tapering, albeit with distinct outcomes. According to Dr. David Fassler, studies illustrate approximately one quarter of those taking anti-depressants stop within three months, with overall compliance less than 50% by six months (as cited in Tanner, 2008). As reflected above, the prevailing fear with tapering is a return of depression—understandably viewed as the major barrier. Less acknowledged, however, is another subtle interpretive strategy that may play an even larger role in the tapering process.

During this process, individuals naturally come to feel emotional shifts. As this occurs, individuals may interpret any turbulence in distinct ways. For instance, Lucy said, “the couple times I tried to get off—‘just not gonna happen.’ And you see the side effects of getting off and nobody likes me and I myself don’t like me when I get off the medication” (8). A recent newspaper article recounted another individual’s attempts to taper associated with her resistance-- “I was so eager to consider myself well and to go off of it.” The article continued: “but each time she stopped, debilitating depression including suicidal thoughts would return”—prompting her to give up the attempt (Tanner, The Associated Press; 2/20/08).

Considering an emergence of emotions during tapering as a return of depression is a natural impulse—and consistent with other strategies reviewed above. Most, including everyone in my sample, seem to take this interpretation for granted. Others seem to struggle with the question. Speaking of his own period to taper off medications, Karp (2006) writes, “throughout this time I vascillated, often within minutes and throughout the days and nights, about the wisdom

of my decision to stop taking medication. I could not distinguish the effects of stopping the drugs from a ferocious return of my mental illness (p. 6).

Beyond the more obvious, physiological barriers to tapering, I would argue that to a large degree it is the particular interpretation laid on top of these concrete challenges that potentially makes the greatest impact on the process and outcome of tapering. A recent study reflecting one of the “most methodologically rigorous pieces of research into people’s experiences of coming off psychiatric drugs,” drew on both quantitative and qualitative data via interviews and questionnaires with 204 individuals who had made efforts to come off psychotropic medications (Read, 2005; cited in Holmes & Hudson, 200X). In addition to finding that “over half of the sample had difficulties in coming off medication,” they noted that “many withdrawal reactions mirrored psychiatric symptoms/disorders” (p. 1). In light of this, Glenmullen (2005), a doctor at Harvard Medical School, recently decried the wide-spread interpretation of difficulties accompanying a tapering of psychiatric medication as automatically meaning the original condition is returning:

Many doctors have not been taught that [negative symptoms experienced] shortly after lowering the dose of an antidepressant are drug-induced withdrawal phenomena. Doctors and patients who are unaware of antidepressant withdrawal can mistake the symptoms for a return of the patient's original psychiatric condition, leading to years of additional unnecessary treatment (p.1).

Glenmullen goes on to explain that with a decrease in *any* medication, there are withdrawal effects in normal humans as the body adjusts to the absence of the chemical. Withdrawal effects came to the attention of researchers in the mid 1990s and have now been observed with all major classes of antidepressants--66% of patients stopping Paxil, 60% stopping Zoloft and 78% stopping Effexor. These effects may be even worse than the original condition, including, “depressed mood, low energy, crying uncontrollably, anxiety, insomnia, irritability, agitation, impulsivity, hallucinations, or suicidal and violent urges. . . . disabling dizziness, imbalance, nausea, vomiting, flu-like aches and pains, sweating, headaches, tremors, burning sensations, or electric shock-like ‘zaps’ in the brain” (p. 7). Awareness of these withdrawal symptoms is crucial, Glenmullen argues, in understanding how they can *mimic the original psychiatric conditions*. From his own practice, Glenmullen recounts a woman’s earlier effort to get off Zoloft as part of making a “fresh start” in life. As difficult emotions returned, the woman rushed to her previous doctor in a panic: “I guess my doctor . . . didn’t know about withdrawal. Instead, he confirmed my worst fear: That I was a hopeless case because I quickly became depressed and anxious again without the drug” (p. 2).

The impact of the experience may be enhanced when individuals subsequently find relief

on medication. Returning to Karp's struggle to taper, he continued "my resolve to complete the experiment was most severely tested" ultimately describing its dissolution during a weekend of particular difficulty: "At that moment I knew my decision to stop the medication had failed, and I took some Klonopin. That night, I slept better than I had in weeks. The relief was enormous" (p. 6-7). For those who endure similar periods of testing and find a return to medication bringing relief, the impact on personal interpretations of treatment is obvious.

A failed tapering effort may thus lead individuals to conclude that their biological deficiency was even *worse* than realized and that medication is needed *even more* than previously assumed. The student in the article above concluded, "If I've learned anything from this journey, it's that medication really works for me" (Tanner, The Associated Press; 2/20/08).

Glenmullen notes:

Being caught in the antidepressant catch-22 needlessly exposes patients—often for years—to the side effects and long-term risks of psychiatric medication. In many instances, not only is the drug restarted, the dose is increased and additional drugs are added to "treat" withdrawal that has been mistaken for depressive relapse. In the process, patients get the false impression that their psychiatric conditions and prognoses are far worse than they actually are (p. 5).

In contrast, when negative states associated with tapering are understood to likely involve withdrawal effects, in many cases people can "ride out" temporary effects and eventually be fine without medication. The remainder of his book details a personalized, gradual tapering program designed to reduce the severity of withdrawal effects. There are growing resources and books with good recommendations about withdrawing safely from medication (Glenmullen, 2005; Breggin & Cohen, 1999; Harper, 2008).

Overarching strategy: Confiding in physicians. The foregoing three clusters of strategies each reflect particular ways of approaching or narrating medical treatment, its difficult effects and its absence. While helpful to parse out distinct assumptions and beliefs in this area relevant to the maintenance of individual narratives, it would be a mistake at this point not to again highlight the relationship context in which these beliefs are maintained. Just as certain beliefs appear to arise largely from the significant influence of surrounding friends, family and medical professionals—these ways of approaching treatment described above appear to be sustained to a significant degree by individuals' trust in others, especially in this case, medical professionals. When difficult effects arise, it is to the doctors that individuals typically go for answers and assurance.

As highlighted in other places, the impact of these interactions with a doctor in a critical moment can be dramatic, with their counsel a turning point in many accounts. Whether or not

such advice is embraced or rejected, however, depends on an individual choice to trust the doctor—proposed here as an overarching strategy in maintaining one’s treatment narrative, perhaps mediated by beliefs reviewed above. Conversely, distrust and wariness is an important factor of disrupting a conventional biomedical narrative and forming another.

In addition to a certain deference often given to any helper in society, that associated with medical doctors appears to be of a particularly powerful kind—perhaps linked with the promise of alleviating quickly our pain. In addition to assurances, I would suggest the certainty of doctors themselves as also influential in eliciting patient confidence. Indeed, if these evaluations about medications were challenging for participants in my study, by and large they didn’t appear to be a struggle for their doctors. The reported certainty and boldness of doctors in trying diverse combinations of psychiatric medications was striking. Even when a person’s reaction to a first medication was very negative, the belief in psycho-tropics appeared, in this sample, to literally never be questioned as the primary solution by doctors, with the next step typically assumed to be trying another dosage or drug type.

This level of professional certainty may prove to be an even larger factor in the maintenance of treatment (narratives) than is now realized—especially in light of the reluctance towards medication depicted earlier. Indeed, one large survey of 403 primary care patients across five practices found that higher percentages of patients trust their doctors than they trust the medication they offer (Brody, Khaliq &Thompson, 1997). In the face of such treatment distrust, it seems obvious that the interpersonal trust in doctors alone may be a significant factor in overcoming fears to press on.

The source of this kind of certainty is important to consider. In one relevant study, for instance, Lacasse & Gomory (2003) examined 71 psychopathology course syllabi from 58 different graduate schools of social work to determine whether contrasting viewpoints on the nature of mental disorder, reliability and validity of diagnosis and drug treatment were evident. The authors concluded there was “little evidence that graduate psychopathology courses cover viewpoints other than the most conventional and institutional--that of biomedical psychiatry,” noting that “a small handful of secondary (textbooks) . . . provide the majority of the mental health content in these courses” (p. 383). In light of its potential importance, more studies are needed on the discourse of medical doctors and other professionals in the context of tremendous trust given them by patients.

Of course, this trust varies individual to individual. Kyle referred to his doctors’ prescription decisions as a “crapshoot” (12), while Esther felt belittled and demeaned by her interactions (14). From Karp’s (2006) study, one man describes his doctor as follows:

I'm saying, "This guy doesn't know what the hell he's doing." I thought he was experimenting with me. And he thought he knew everything. He wasn't listening to me when I told him Prozac worked (p. 56).

For some like Kyle and Esther, medical professionals attempt to force treatment in the face of such resistance—an action that seems to typically reinforce an anger and rejection of a biomedical narrative even more. After recounting being “forced” to take Prozac during the time she was being abused as a child, Lucy expressed anger at this doctor “for allowing for so much . . . to go underneath the radar,” linking that, in part, to his level of confidence—“Doctors who feel that they are god” (6).

It seems clear that the level of trust in medical professionals varies dramatically by region as well. In a 2002 study by Express Scripts, a prescription benefit firm, prescription orders were tabulated across states. Utah ranked 7th in total prescriptions overall and 1st in anti-depressant prescriptions (Walch, 2006). While critics of the *Church of Jesus Christ* pounced on the finding as solid evidence of the psychological oppression of Mormonism,¹⁸ this simple correlation conflicts with other evidence of lower suicide rates and less depression among active Mormons (e.g., Jensen, Jensen & Wiederhold, 1993; Hilton, Fellingham & Lyon, 2002;) and a recent Gallup poll ranking Utah as number one for well-being among the 50 states—a full point ahead of runner-up Hawaii (Arave, 2009).¹⁹ From my own experience as a resident of Utah, I would point to the high level of trust in authorities cultivated among Mormons (similar to conservative religious people generally), as the most compelling explanation for high prescription rates. Just as Latter-day Saints trust their priesthood and auxiliary leaders to guide them in beneficial ways, they are more likely to trust other authorities, in this case doctors, to do the same. Judd (1999) suggests that it is Utah's higher rate of education per capita that leads them

¹⁸ According to a 2004 report to the Utah Office of Planning, Utah is 62% Mormon, with estimates of 42% of those being ‘active’ church-going members.

¹⁹ A more comprehensive explanation would not discount the role of religious faith, but would address it in a more sophisticated and complex way. For instance, Utah consumes less alcohol and illegal drugs than any other state, raising the possibility that non self-medicating residents may have more need for “legal” resource for emotional issues (Judd, 1999). Also, drawing on Allport's distinction between intrinsic and extrinsic religiosity, Bergin and colleagues (1987) have conducted research that confirms religiosity's relationship to mental health depends on the *specific way* individuals are religious, with intrinsically committed/motivated individuals more mentally healthy, on average, and extrinsically committed (means-to-an-end/utilitarian), less mentally healthy. (Harkening back to William James' statement that there health and unhealthy ways of being religious). One recent study that showed active Mormon young men less likely to commit suicide than the national average, corroborated this point in showing that inactive Mormons were *more likely* and at greater risk for suicide (Hilton et al., 2002). Although interpretations of this point might vary dramatically, I take it to be, at a minimum, a third possibility in explaining of the higher anti-depressant rate in Utah—i.e., members who are extrinsically committed or those who have rejected the church entirely are likely to be more depressed than the national average.

towards seek professional help for emotional problems, rather than seek to self-medicate or address it in other ways.

Where a cultural respect for authority exists, this may conceivably even override the kind of lack of trust noted earlier. After her doctor prescribed Valium, Elaine recollected her response, I thought he was crazy because, I thought Valium was something that would calm me down and I said to myself--but not to him because I didn't want to challenge authority—"now I don't need anything to calm me down anymore; I can't [even] get out of bed!" (2)

Speaking of her response to advice from a professional friend to start medications, Kellie recounted similar hesitancy: "I resisted. And maybe I shouldn't have, but I did. I couldn't help it, I just resisted it. . . . I didn't want him to feel that I was rejecting his ideas, you know, because I held his opinions and ideas in very high esteem" (16).

Sarah spoke of her attempts at "trying you know to be my own doctor" as dangerous and naïve--eventually learning to "not be smarter than the doctors" (4). Elaine similarly confessed to previously thinking she "knew more than the doctor did" and also spoke of "learning to not be smarter" (2). As a mirror image opposite, Kyle came to question "just tak[ing] the doctors' word for it and do[ing] whatever they say to do" (12) and emphasized the importance of personally researching possible treatments before starting. Esther reached the same conclusion after finding more side-effects in her internet research that her doctor had conveyed (14).

8. Defending One's Narrative: "They just don't get it! . . ."

Many of the strategies reviewed above--emphasizing, highlighting, elaborating, sharing and testifying of a particular narrative--are proactive, on-the-offense strategies of reinforcing and maintaining one's story. In the opposite direction, individual accounts also reflect more reactive, defensive strategies and postures that address what appears to be threatening to one's own view. In contrast to agreeable input which naturally reinforces one's preferred narrative, disagreeable input may either galvanize or weaken an individual's commitment to the same.

For those who withstand opposition, they may go on to frame challenges as false, mistaken and even dangerous or harmful. Elaine, Jill and Sarah spoke critically of those who challenged their treatment. This kind of a response to challenge may arguably become a critical reinforcement to one's story. For Victoria, to illustrate, being questioned and challenged was evidence of her narrative's validity as she emphasized feeling inspired to know how to respond (5). While opposition appeared to strengthen convictions for many, for others such critique appeared to play a role in their ongoing hesitancy. Elaine noted "I've been challenged plenty,"

and added, “I guess if I didn’t have so many people that I felt like . . . kind of look down on me for taking the medication, I might feel a little different” (2).

Framing opposition as ignorance. As indicated earlier in this chapter, individuals may often re-frame previous doubts and skepticism as having been naïve and ignorant. As reviewed elsewhere, others who retain doubts about treatment often find their concerns eliciting the same response. In attempting non-medical alternatives, for instance, Kyle spoke of a sense from others that “I’m in denial” (12). Esther spoke of doctors’ response to her own treatment concerns: “Some would just flat out tell me . . . ‘You don’t know what you’re talking about. Of course, you’re mentally ill and you’re in denial that you’re mentally ill’” (14).

Overall, such instances reflect a larger strategy at play. Namely, in response to treatment concerns, individuals, friends/family and doctors often appear to insist on their own narrative as certain, obvious and proven—in turn, casting alternative views as naïve and ignorant to some degree. In the context of “narrative asymmetries” where individuals are challenged to make sense of “enigmatic and frustrating situations,” Ochs & Capps (1996) note that “narrators alternate between two fundamental tendencies—either to cultivate a dialogue between diverse understandings or to lay down one coherent, correct solution to the problem” (p. 32).

From the latter standpoint, the truth about one’s own view (and others’) is fairly certain and established—with ambiguities and complexities in the research dismissed as insignificant. Across accounts, a line is effectively drawn between people “getting it” or not; “people who know” or an individual who “just doesn’t get it” (4). Once again, this rhetorical strategy was evident in participants from diverse views—with both proponents and critics of medical treatment in the study speaking of science as “on their side” with the findings “very clearly” justifying their position.

Such distinctions were evident in particular aspects of narratives as well. For instance, Several raised questions about the scientific validity of prevailing biomedical explanations, with Kyle calling them “diagnonsense.” In contrast, others, including Sarah, Victoria and Camille, spoke of the scientific validity of prevailing biomedical explanations as an established fact. For the latter group, the questions were assumed to have largely been settled.

Beyond the interview evidence, one need not look far to discover prominent examples of such certitude. The medical compliance literature, for instance, asserts antidepressant treatment as indubitably effective—attributing patient concerns and reluctance as reflecting basic irrationality or ignorance (Dwight-Johnson, et al., 2000; Löwe et al., 2006). Concerns may be thus downplayed as illusory: “It is of interest that *concerns* about medication arose from (potentially mistaken) beliefs that regular usage could result in long-term adverse effects or

dependence” (Horne & Weinman, 1999, p. 564). Many research teams thus hint at the notion that not wanting treatment reflects an implicit ignorance or lack of knowledge.

Dwight-Johnson and colleagues (2000) raise associated practical questions such as, “should practitioners honor a patient’s autonomy in declining or deferring care for depression, especially when this choice may be associated with poverty or lack of knowledge?” They go on to emphasize “an important role for patient education” in “promoting informed decision making” and call for more research examining the potential of education in “motivating depressed patients to seek active treatment” and “shift[ing] patient preferences” (pp. 532-533).

As mentioned earlier, similar certitude is found in studies critical of medical treatment (Breggin & Cohen, 1999). In both cases, certainty about one conclusion or the other may “trickle-down” to professionals and patients alike, with little difficulty evident until encountering someone with the opposite conclusion, who is similarly *certain*. Ultimately, for all involved, this portrayal reinforces “sharing the truth” as the primary issue—justifying a sense of a cause, mission or crusade associated with education and advocacy, noted earlier. Unsurprisingly, those participants most involved in education (both proponents and critics of psychiatry) were also those who seemed most convicted that the clear and indubitable truth was in their possession.

Seeing questions and concerns as stigmatizing. One way to defend one’s narrative is thus to insist on the certitude of one’s view and suggest that alternative views are ignorant and uneducated. A second associated defensive posture is reflected in suggestions that treatment resistance reflects an unfortunate prejudice or stigma against depression.

While many expressed concern with public stigma, they attributed it to very different sources. For instance, Kyle spoke of stigma as ensuing from the receipt of a questionable diagnostic “label”—emphasizing public fears as an unfortunate byproduct of a misguided psychiatric practice. Sarah, on the other hand, emphasized stigma as ensuing from misguided fears of uneducated citizens. From her perspectives, Kyle’s own criticisms of medication would likely be seen as a reflection of such stigma.

Of course, it is important to recognize a kind of opposition that clearly deserves to be decried for its belligerence. As related elsewhere, participants spoke of being called lazy (3) and blamed (2) for facing depression. Elaine said “I’ve been challenged many times; they wanna know who said it and when and in what book and how many research studies backed it up” (2). Lucy said: “It’s amazing how low you can feel when someone you love keeps saying ‘so when you getting off that medication?’” (6). While overbearing and blaming comments clearly need to be condemned, it appears that this kind of harsh questioning can prompt some to see *any question or critique* of their treatment narrative to be attacking and stigmatizing.

In a op-ed during a recent “Mental Health Month,” a medical doctor lambasted the editor for publishing an article that had explored critiques of medication (May, 2007 “Sensationalist Reporting Fuels Stigmas”; *The Modesto Bee*) and proposing the newspaper would “do well to highlight the many advances in mental illness treatment and real hope of recovery, instead of perpetuating stigma.” After asserting tremendous recovery rates associated with medication, he claimed that any critique of this view reflected distortions from prejudice, rather than valid concerns. He concluded by addressing critics in this way: “unfortunately, the stigma of mental illness extends to its treatment, and side effects of psychiatric drugs tend to be exaggerated in the public's mind compared with other medications” (Lewis, 2007). Accusations of “exaggeration” and “stigma” may thus automatically be made toward those raising questions. An emphasis on stigma may further reinforce calls for conventional public education about mental illness to counter the presumed ignorance shrouding such critique.

A final strategy for maintaining narratives is therefore interpreting any questioning of a biomedical narrative as stigmatizing; this may contribute to the defense of one’s narrative as questions are automatically framed as an “attack.” For instance, Jill criticized Tom Cruise, one well-known challenger to psychiatry, as stigmatizing, “I’d like him to come and live in my shoes for a while. . . . people like him have no business passing judgment like that. That’s what sets it back, that’s what sets us back . . . he doesn’t know what he’s talking about” (7). In contrast, Kyle saw Tom Cruise as raising valid concerns, “They crucified him. But in fact what he said had some basis of *truth*, you know. Um, and he *wasn’t* trying to just knock down Brook Shields. He was saying we need to wake up and look at other alternatives. We need to look at *root causes* . . . you know, what *causes* post-partum depression?” (12).

He then raised specific concern that opposition to medication was automatically interpreted as coming from the scientology religion—and suggested that legitimate scientific critiques were not being given a fair hearing. Speaking of researcher David Healy, who had explored the link between suicide and violence, he noted, “because of that he’s been *banned* from all sorts of universities; you know, he’s lost appointments, so that’s, he’s *honest*, I mean he’s saying it the way it is” (12). Once again, however, the emphasis on resistance as inherently stigmatizing, may lead any critic or challenger to be cast as dangerous and fanatic.

In the same manner, individual reluctance and resistance to treatment may be attributed to external reluctance. Debbie, who spoke of struggling to convince herself to continue treatment explained, “I think if you know . . . if things were different, if people around the universe would accept it more, I think it would be easier to handle and accept” (8). Not everyone attributes personal resistance to external stigma, of course, with some suggesting resistance as reflective of

genuine problems with the medication itself. Overall, however, it is arguably more common for explanations of resistance to be portrayed as reflective of external prejudice against a biomedical view of depression and its treatment.

Chapter 9

Conclusion: “So What?”

This study began with curiosity as to why views of medical treatment for depression varied so sharply and so widely among those facing depression and other stakeholders (researchers, helping professionals): “*Prozac saved my life*” vs. “*Prozac ruined my life.*” From the beginning, the hypothesis has been that there had to be something more than sheer metabolic differences in drug effects or researcher bias in outcome studies at play—something in addition to these other variables that could be contributing to the process by which individuals reach very different conclusions.

As documented in the foregoing chapters, depending on how and what individuals come *to think* about depression and its treatment, they may have distinct experiences arguably leading them to arrive at very different places in terms of treatment and recovery (and their associated conclusions). Like a virtual reality “choose your own adventure novel” or “murder mystery play,” significant shifts in individual journeys are evident moment by moment. Rather than reflecting inevitable destinations, these individual journeys are here proposed to be meaningfully prompted, bolstered and reinforced by distinct interpretations and overall narratives. Indeed, beyond simply a random, free choice of “what to do” or “where to go from here,” these ongoing trajectory adjustments seem to be inescapably mediated by one’s received way of explaining or narrating the problem of depression (Ch. 4) and ensuing way of approaching potential solutions (Ch. 5). Beyond variation in physiology, community and other objective factors, this analysis suggests that narratives may, in fact, be substantial, even “driving” forces behind both the ensuing treatment experience and ultimate conclusions reached by those facing depression.

The process and manner by which this influence was exerted was divided between analyses of the “adoption” and “maintenance” of narratives. First, an array of narrative resources was examined as foregrounding for the initial formation and adoption of unique stories regarding depression and its treatment (Ch. 6). As anticipated, the opportunity to examine diverse “expert” narratives close-up has permitted many insights on how individuals negotiate the complex terrain of conflicting prompts and resources on the surrounding landscape of any depression experience--from intense states of confusion, resistance and urgency to influential moments with surrounding friends, family and the medication itself. Depending on particular interpretations and decisions made along the way, individual trajectories may subsequently diverge sharply over time and reach distinct places in terms of both outcomes and conclusions (interpretations/narratives). In addition to distinctions in general structure (Ch. 3), ensuing stories meaningfully vary across

multiple key issues, including how physiological conditions, personal agency, and medication itself are narrated (Ch. 7).

Although referring to the “choose-your-own-adventure” adolescent novels above, this metaphor is not entirely accurate. Throughout the process of narrative adoption, while individual agency may be implicit, persons clearly do not often seem aware of all their options. In an examination of the relevance of narrative in complex decision-making processes, Cox (2003) notes that decision-making is “seldom a completely conscious, rational . . . process,” with the degree to which choices are consciously experienced as a decision varying widely: “choices are always hedged in by constraints; we are not free to decide upon just any course of action nor are we ever positioned in such way that we can see what the full range of choices might consist of” (pp. 262, 273). It was the surprising limitations on open exploration and choice itself in my home community that prompted this study in the first place.

After arriving at a particular narrative, to be sure, the story isn’t over. Across a wide range of strategies, a great deal of attention and energy appears to be directed toward the ongoing maintenance and perpetuation of individual stories (Ch. 8). In terms of understanding what underlies divergent and passionate perspectives regarding treatment, this process appears to be at least as important as that involved in forming the initial stories.

In spite of some attention to surrounding influence from friends, family and doctors, the lasting impression throughout these chapters may have been that adopting and maintaining a story were intra-psychic, subjective processes occurring largely ‘in the heads’ of those facing depression. If that was the case, logically, ensuing proposals and implications for practice would also primarily center around mental processes. Although this study’s methods naturally directed primary attention to patterns in interpretation and narrative, it is worth mentioning that from the beginning these terms were defined as explicitly linked to practice—i.e., narrative as a kind of “holistic interpretive *practice* that is lived and continuously accomplished moment-by-moment” (see Ch. 1). It is thus how this lived *practice of narrating* comes to be initially set in motion (adopted) and sustained over time (maintained) that this study has focused its examination. Implications of these insights for additional community practices will be reviewed below.

Like any study, this one has limitations in scope and purpose, therefore pointing naturally towards other research that could illuminate beyond the boundaries of its own claims. For instance, how do narratives of anxiety, eating disorders, ADHD and schizophrenia arise and play out in individual experiences? Are the dynamics of creation and maintenance similar or are there meaningful differences? Moving beyond narrative questions, the way the adoption and maintenance of narratives are embedded within particular settings, institutions and communities

would be helpful to better understand. How do individual communities variously reinforce or oppose the adoption of particular narratives of depression and its treatment? How are distinct narratives either sustained or disrupted over time within these same settings? How may the dynamics of each process meaningfully differ across varied communities? Could the differing prescription rates in a given community be related to distinctive trends in narrative adoption and maintenance? More specifically, could the relatively high concentration of mental health advocacy organizations like NAMI and CHADD²⁰ within a particular locale cultivate an atmosphere where the adoption of biomedical narratives is especially prevalent and likely?

Three Proposals:

Laying aside these additional questions, we turn to the ultimate consequences of this study's findings—aka “so what?” If, in fact, the dynamics of these practices are central forces in guiding individual experiences and the conclusions they reach, what is the significance of this for actual lives and practice? More specifically, what are the implications of these findings for other practices, especially for professional and informal care-giving and for the heroic survival efforts of those facing depression themselves? In light of these general conclusions, the following three implications are proposed:

1. Deliberation before education: First, ongoing disagreement across multiple key questions suggests a shift in how stakeholders engage across differences (or not). As noted in Chapter 8, it is currently common for individuals involved in fighting emotional problems to present their own position as certain while portraying alternatives as deeply flawed. Through both advocacy and education, primary energies of competing organizations have been invested in disseminating these messages in broad campaigns to convince others of the established “truth” about depression and other severe emotional problems, in turn “debunking” alternative views as misguided or simply “biased.” When actual exchange occurs, it is more often than not combative and hostile—reflecting the same aggressive tactics, this time turned on each other.

Even researchers who have turned to invest their energies in understanding attitudes of those facing depression have often done so as part of a larger agenda of overcoming obstacles and “barriers to treatment” (e.g., Benkert, et al., 1997; Jorm, et al., 2005). A favorable interpretation of this treatment is thus typically assumed in many studies, and not generally questioned against

²⁰ NAMI (National Alliance of the Mentally Ill) and CHADD (Children and Adults with Attention Deficit/Hyperactivity Disorder) are two of the premiere mental health organizations in the nation. Although active across the nation, they are well-known to have an especially strong presence in the state of Utah.

alternative interpretations in any serious or rigorous fashion. A factor analysis of a national survey of nearly 4,000 Australian adults noted a striking discrepancy between professionals and the general public in views on a wide range of interventions—with psychological and lifestyle interventions favored over the medical ones (Jorm et al., 2005). Rather than discuss how doctors might encourage and facilitate public willingness to make lifestyle and psychological changes as well, however, the researchers highlight the alarming need to help better persuade the public of the importance of medical treatment: “Educational campaigns to improve public knowledge about treatments will need to take account of these pre-existing belief systems” (p. 877). Aikens and colleagues (2005) similarly call for patient “education about symptom course, medication response lag, the rationale of maintenance treatment, and the link between early discontinuation and subsequent decline (p. 28). With a few notable exceptions (Karp, 1996/2006; Stoppard & McMullen, 2003), much of the research focused on perceptions or attitudes about treatment thus presumes one interpretation as obvious reality.

Perhaps the most unfortunate aspect of this scenario is its categorical denial of the existence of more than one thoughtful, viable perspective about emotional problems. On a general level, this frame may arguably stifle open discussion and thereby feed an increasing polarization of views described earlier, as individuals only talk to others who agree with them (Bishop, 2008). In addition, this position may effectively dissuade those facing depression to critically explore different interpretations of their own experience. Instead, the message to distressed individuals becomes to simply “accept the truth” about emotional problems and reject others views as potentially dangerous. As Gattuso and colleagues (2005) note:

Depression literacy strategies tend to adopt rather unsophisticated one way models of communication in which individuals are supposed to “absorb” correct health messages when they circulate within the popular media. . . . People who refuse to take up the expert view of depression as illness can only be seen as non-compliant, ignorant or, in the dominant discourse, illiterate (p. 1640).

To be clear, if or when an indubitable truth becomes apparent on any issue, proclaiming and disseminating it is surely the right and sensible approach. However, as long as ideas remain so tentative and contested across views, it seems necessary to reign in or question the massive educational campaigns underway (from diverse perspectives). Indeed, if there is one thing that can be acknowledged without controversy, it is that there are significantly different perspectives evident on a host of questions and at multiple levels (survivors, caregivers, professionals and researchers). In spite of positive intentions among advocates and educators, the presence of serious unresolved issues suggests that declaring one view as *the view* (“reality”) may only further confuse the situation—especially for those in distress.

In place of such advocacy and educational campaigns, a viable practical alternative is possible. *Deliberation* is a formal practice involving individuals from multiple, conflicting perspectives coming together to compare, weigh and carefully consider different views, interpretations and options. The primary purpose of doing so is not to persuade, but to collaborate on genuinely seeking better collective understanding and potentially a wiser course of ultimate action (Heierbacher, 2007). As illustrated by the foregoing accounts, interpretive differences are deep-set enough that more open, joint exploration of key issues could be extremely productive. Since particular views across these issues have implications for how problems are both experienced and addressed, the well-being of people's actual lives are at stake. (Incidentally, this became my answer to why there was such emotional intensity and resentment in these conversations: *ideas matter for actual lives.*) A discourse shift towards greater deliberation may thus potentially lead to tremendous consequences for good on all sides.

Clearly, a more deliberative practice would require significant change on the part of the many involved in fighting depression. Those researchers, practitioners or patients in the “anti-psychiatry” camp, for instance, would need to take greater care to avoid automatically inscribing malevolent, power-seeking motives to those offering psychiatric treatment. In addition to seeing genuine intentions to help, this camp may take care to not deny the experiences of those reporting significant help from psychiatric medication and consider more carefully the influence of difficult interpretive issues in the process of evaluating treatment. Likewise, for those who feel positively about medication, they might also find opportunities to hear out those who see otherwise—being careful to not automatically write-off negative experiences and critique as “fanatical.” Many thoughtful concerns have been raised in relation to psychiatric treatment that have yet to be adequately addressed (from any party). On this note, it is worth recognizing that greater deliberation across deep difference serves no single agenda; instead, it calls on all involved to slow down educational campaigns and intervention efforts in order to *think more together*. As a result, deeper *collective* knowledge and a more powerful *collaboration* across viewpoints may potentially ensue.

Of course, if such an exchange were merely about semantics or subjectivities, it might matter little. As illustrated in this thesis, however, since distinct narratives contribute to the literal creation or expression of remarkably divergent experiences, the process and product of such a deliberation may matter a great deal—especially for individuals actually facing depression. Indeed, this study indirectly highlights the provocative possibility that particular narratives of depression may contribute tangibly to the problem itself. For instance, individuals may be socialized to be victims of feelings in general and the body specifically; further, individuals may

be led to believe the depression is permanent with no full recovery. In this way, they may be led overall to a passive place of feeling inevitably hijacked by depression and waiting on meds to work: helpless and largely powerless. A prevailing narrative of depression may also predispose distance and deterioration in relationships above and beyond the impact of depression itself. In all these ways, individuals may face bondage not simply to depression alone, but to a particular way of thinking about depression. There are multiple ways we contribute to and reinforce depression unawares by the way we approach and talk about it. Implications of narratives may thus be seen as constituting part of the conglomerate burden of depression, with certain interpretive distinctions literally prolonging the suffering and interfering with the healing process (Schreiber & Hartrick, 2002).

Based on the foregoing, this is no simple matter, since both medical diagnosis and treatment may be experienced as alternatively relieving/liberating and burdening/disempowering depending on the situation. Previous chapters have explored how many have embraced biological explanation as a tangible way of explaining the real constraints on agency for those facing depression (Lewis, 1995). From this view, a portrayal of disease is relieving and disburdening. On the other hand, others have raised concerns with portraying depression as primarily an internal disease (Gammell & Stoppard, 1999), highlighting the way severe external conditions such as poverty or abuse may be minimized by these prevailing problem definitions (Shreiber, 1996; Shreiber & Hartrick, 2002). From this view, a disease portrayal can be pathologizing and disempowering.

The crucial point, once again, is whether those reflecting these kinds of differences can come together to discuss and collaborate. As long as proponents of these diverging views work separately, respective inquiry and interventions are more likely to emphasize their own position as the only feasible option. In contrast, a joint exploration/deliberation between views may lead to innovative insights. For instance, those physiological accounts which acknowledge neural plasticity may explain real constraints on personal agency without denying either the centrality of surrounding circumstances or a meaningful degree of individual choice within these conditions (Curtis, 2001).

From such a vantage point of diverse stakeholders, we may thus come to consider other innovative views of depression itself. Drew (1999), for instance, cites Yardley's notion that psychopathology can be seen as an "intersubjective phenomenon, constantly negotiated and redefined by sufferers and their immediate contacts." Depression experience may subsequently be understood as "continually constructed and reconstructed moment by moment through linguistic and social practices and self-conscious reflection" (p. 194). Greater consideration may

thus be given to eastern narratives of emotional challenges, as well, that depict “mind-weather” or “mental events” that one must pass through, rather than true representations of self or identity (Ridge & Ziebland, 2006; Segal, Williams & Teasdale, 2001; see also Maisel, Epston & Borden, 2005). By opening up the discourse beyond exclusive portrayals of biological vulnerabilities triggered by externals, deliberation may expedite an empowering understanding of body, context and choice that avoids both victimizing and victim-blaming.

Once again, if distinct narratives truly undergird the prolonging of depression to any degree, this would also suggest that recovery from such hopelessness is likewise intimately connected to particular interpretations of both what is happening and what may be expected in the future. After noting the limited availability of a “language of recovery” for patients, Ridge and Ziebland (2006) went on to describe people adopting narratives of lasting and long-term recovery, concluding that the establishment of “hopeful and authentic life narratives” as a key to longer term recovery (p. 1052).

Further insights such as these, to emphasize, are only possible with open exchange and exploration of differing views. In a current climate where many assume that the nature of depression is largely a settled issue, the existence of this kind of a dialogue itself cannot be taken for granted.

The choice is evident. In the face of different views, should individuals fight and minimize each other’s claims on the truth, or learn to listen and explore and talk and consider together? As Ochs and Capps (1996) highlight, narrators in ambiguous situations may choose “either to cultivate a dialogue between diverse understandings or to lay down one coherent, correct solution to the problem” (p. 32).

2. Deliberation for all: While acknowledging its potential, some may assume such deliberation is primarily appropriate for researchers and practitioners. It becomes important to thus emphasize that critical exploration is not a luxury reserved for doctors, psychologists or academics. Given the striking contrast in treatment evaluations, in particular, individuals facing depression deserve to be fully informed of ongoing disagreements and competing viewpoints. Indeed, distressed individuals themselves are arguably most in need of such critical exploration. Once again, this is at odds with popular wisdom that people facing emotional problems simply need to be educated correctly, so as to pursue the appropriate treatment.

Naturally, this also suggests some change in the role of professionals. In addition to offering guidance at times, therapists and doctors may seek more regularly to help individuals think for themselves about different views and options (see implication #3). This may be a

particular challenge for doctors with typically limited time and expectations for “talk” (Rogers, May & Oliver, 2001). Likewise, researchers may seek ways of presenting findings in a way that may better facilitate collective thinking about an issue (Schwandt, 1996).

For some individuals, this proposition may be viewed as concerning. Recently, in discussing my belief in a need to trust individuals to think critically and deliberate about key issues, a medical doctor friend suggested that it could be “dangerous” to get patients thinking about such questions and that the full complexity and multiple perspectives involved issues that “only trained medical professionals” could address adequately. There are undoubtedly important precautions that should be exercised when opening up the ‘universe of alternatives’ to those facing these problems (e.g., not simply offering alternative narratives without ensuring corresponding resources and support). In spite of potential risks, this view would argue that keeping alternative views from these individuals entails a greater risk (e.g., never finding the approach to treatment that is a best fit for that individual). Ultimately, this approach emphasizes the inherent capacity of those facing emotional problems to think for themselves, however embattled or atrophied these capacities may currently be.

In both cases, this would entail honestly and fairly acknowledging criticisms of one’s own position—as well as viable alternatives. Failure to do so naturally leads to a constrained deliberation. As noted earlier, Grime and Pollock (2003) documented frequent complaints of not being warned about psychological dependency of anti-depressant medication. Rather than understand how anti-depressants could become a constant need, these individuals began with expectations of medication as merely a “kick-start” to recovery. It appears a casual discussion of side effects or “risks and benefits” is not sufficient to make possible authentic critical exploration among patients. In contrast, an open discussion of competing scholarly views on medication (including those who warn medication could make things significantly worse) may ensure that patients are both fully informed of differing views and able to give a genuinely informed consent (or dissent). The same holds true for preserving authentic exploration of other key issues explored earlier—such as the source of positive or negative states coinciding with new medication and competing definitions of recovery. In the case of a negative state arising concurrent with a particular medication, rather than assuming only physical aspects are relevant, this approach may potentially encourage a more comprehensive intervention. Namely, *before* simply prescribing a different dosage or new medications, professionals may essentially help patients “try out” *different interpretive lenses*—i.e., Are we sure we know where these effects are coming from? How are we defining good and bad? Could drugs be the problem here? Likewise,

individuals may be supported in thinking about recovery on their own terms (Grime & Pollock 2003).

Implicit in this point is the understanding that there are multiple ways of intervening on these questions that are equally well intentioned. Rather than assume they need to *deliver solutions* in a confusing situation (i.e., “Here is the answer”), alternatively, they can approach competing solutions as something to *explore together*—helping clients to think through questions for themselves.

If not with the help of medical professionals, individuals may obviously seek support and direction in other settings as well. As hinted by several participants, the internet provides a rich resource from which to gather multiple perspectives on an issue. Beyond mere individual education, however, over recent decades mutual help and support groups have developed from multiple perspectives. While psychiatry advocacy organizations like NAMI offer these kinds of support groups, there are others that provide alternative views—e.g., *Recovery International* (www.recovery-inc.org/) and *Grow* (www.grow.net.au/igrow/index.php). Rather than centering curriculum and support around biomedical causes and treatments, these groups highlight community support and life lessons relevant to severe emotional problems. Indeed, given the ongoing controversies about medication, *Recovery International* has a policy of neutrality on the issue of medication—respecting individuals’ rights to either choose or decline medication. From the author’s own experience, this is not necessarily the case with other support groups.

In a relevant study comparing support offered from distinct groups to those facing severe emotional problems, Kloos (2000) argued that “treatment program ideology, structure, and praxis provide resources for meaning-making in the form of worldviews, social roles, convincing narrative explanations, and expectations for residents that setting members use to create a sense of purpose and identity.” By examining differences in the practice and discourse of a community mental health center and a mutual help group respectively, Kloos highlighted meaningful differences in both the program narratives and the patient behavior they cultivated. From his summary, the traditional mental health support emphasized “addressing residents’ problems, providing the ‘best professional care’ available, taking medication, and assisting them to fit into a community setting.” In contrast, he noted that the other organization emphasized “distributed leadership, mutual support, personal growth, and community building.” He concluded:

These setting differences appear to influence the process and the content of residents’ meaning-making in terms of thematic content (e.g., differential importance of medication, of social roles, and of relationships for rehabilitation), how they view themselves and

others, how they organize their narrative accounts, and their views of the future (p. abstract).

The precise nature of community support offered, then, may play a critical role in whether individuals are able to deliberate on these issues. This, in turn, may have implications for the degree of choice and agency allowed to those facing depression.

3. Maximizing choice for those facing depression: In addition to critical exploration, the existence of widely diverging views points towards another need: authentic choice in treatment.

The importance of preserving individual choice in the course of treatment has been emphasized by a growing chorus of researchers, practitioners and clients (Ridge & Ziebland, 2006; Sangster, 2005; Schreiber, 1996). The degree to which one has been able to exercise personal choice during treatment is seen by some as key to their recovery (Badger & Nolan, 2007). Of course, the degree to which they have personal choice is *closely related to whether individuals are genuinely able to explore different perspectives*. Indeed, in the end, my answer to why deep set convictions came to exist was there was little consideration of *any other viable interpretation*. When a narrative is unchallenged by any other viable narrative, it becomes simply accepted as reality. The impact of such an unquestioned narrative was suggested on multiple occasions. Perhaps the most dramatic example was tapering efforts where concurrent emotional difficulties were seemingly automatically interpreted or narrated as evidence that the biological deficiency was even *worse* than realized. In each case, an alternative interpretation simply was not available.

While authentic choice often depends on doctors and patients sharing information honestly, unfortunately, there is evidence that doctors often emphasize treatment benefits without adequately acknowledging possible harms or risks (Pound et al., 2005). A recent study of physician communication in the *Archive of Internal Medicine* indicated that only 35% of patients reported doctors discussing adverse side effects with them in the context of general treatment (Tarn, et al., 2006).

By surfacing subtle distinctions between competing narratives more clearly, it has been one of my hopes that the extent and strength of collective exploration can expand. As contrasting narratives come to be seen *as narratives*, I ultimately hope the decision-making process can increasingly come to more fully be under individuals' own control. Rather than dragged down certain narrative pathways, individuals may be aware and dictate which direction they want to go. Rather than fear alternative views, individuals may be open to considering all their options.

Rather than presume answers are certain, families and professionals may likewise be open to learning from different perspectives. Whether in conversation with open doctors or exploring on the internet, facilitating a transparent exploration of different perspectives—including regarding the risks and benefits of medication—may thus indirectly contribute to personal empowerment.

In addition to critical exploration, authentic choice also requires the presence of viable options from which to choose. Unfortunately, like contrasting viewpoints, actual alternatives to dominant treatment options have often remained obscure to those facing depression (Badger & Nolan, 2007; Rogers, May & Oliver, 2001). Like deliberation, the capacity to choose goes beyond the theoretical existence of alternative narratives to whether or not tangible resources and community supports *reflecting these alternatives* are actually accessible to individuals and families. Indeed, while alternatives are a common desire among distressed individuals (Carder, Vuckovic & Green, 2003), their consideration can be both indirectly precluded by a dominant biomedical narrative (Schreiber & Hartrick, 2002) and directly discouraged by professionals (Badger & Nolan, 2007). In turn, where no viable alternatives are understood to exist, even extreme detrimental possibilities may be acceptable.

Rather than dismiss alternatives, professionals need to acknowledge the potential of multiple avenues of recovery beyond medication. In this way, individuals may be facilitated to make their own choices. Such an emphasis does not imply that simple agency underlies the ongoing pain of depression nor that individuals ought to “just choose” to feel happy again. Instead, support may be extended for individuals to exercise whatever agency they have within the bounds of current constraints. As individuals wrestle with recovery, this degree of choice may ebb and flow—with a potential of ultimately growing stronger. Even at the lowest points, however, respecting and maximizing the personal choice of individuals regarding treatment is crucial (Sangster, 2005). In cases of treatment non-adherence, Grime and Pollock (2003) argue for moving beyond additional patient education to achieve unilateral “compliance”—to a growing movement towards a more bilateral professional-patient relationship known as “concordance” (see also Garfield et al., 2003). The aim here is to inform and empower individuals to make their own decisions. People deserve to see different perspectives on issues and be aware of alternative narratives so they may choose for themselves.

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Appendix A: Recruitment Protocol and Flyer

- 1) Explanation of the research to the person: “I am beginning my dissertation research this month investigating depression. As you know, depression is a problem increasing in severity in our communities. My research aims to document personal experiences of fighting depression in order to help us understand better how to treat it. I hope to interview 15-20 people to gather their accounts of depression. Interviews will last 60-90 minutes. I am interested in talking with anyone with experience in fighting depression. Do you know anyone that may have a story to share? Would you be willing to contact them for me?”
- 2) Preparation of the person for contacting others: “I would ask you to do two things in contacting this person. First, briefly explain the research aims and methods—what the study is seeking to understand and what involvement would entail [Read flyer out loud to the person]. Next, I would ask you to personally invite them to participate in the study and leave this flyer with them” (see below).
- 3) Follow up with the person: After this preparation, I left several flyers with the individual and asked if I could call them back in a week to follow up.
- 4) Ongoing snowballing recruitment: After individuals are interviewed, I similarly invited them to contact other persons they know who are potential participants.

“Seeking participants: Depression study.

Do you have a story?

Critical issues in fighting depression as communities can be better addressed with further in-depth research. Help to expand knowledge of depression by participating in an interview at a location and time convenient to you. Involvement will be confidential and \$10 will be given to each participant as a small token of appreciation.

If you have experienced depression in any degree now or in your past, please contact: 217-766-2471 or 801-451-6221

(also--jzhess@uiuc.edu)

Thank you!

Jacob Hess, PhD Candidate

University of Illinois, Urbana-Champaign”

Appendix B: Additional Plans in Case of Distress During Interview

First, the interviewer will take steps to actively promote participant well-being throughout the interview--monitoring comfort levels and the pace of the interview, as well as suggesting that a question be skipped if needed.

Second, at the earliest indication of any degree of serious distress, the interview would be terminated by the primary investigator. This will be done in a way sensitive to the participant with the following basic script: "One of my important goals as a researcher is to avoid any significant distress or discomfort during the interview. Because of this, I would recommend we not continue the interview. I can assure you this will in no way hurt the research project and I would still like to offer you a small token of my appreciation for your participation today. Is this okay?" If the participant wants to continue, I would only do so in the absence of serious distress. Otherwise, I would insist on stopping, offer the full amount of 10\$ in appreciation for what they contributed and ensure there is no concern about 'failing' or disappointing the investigation. (Note: While care with initial recruiting protocol will ideally screen out any participant experiencing such significant distress, these steps and plans are in place as a secondary precaution when that initial protocol fails to detect someone not stable enough for inclusion in the research.)

Third, at this point, the interviewer--an advanced graduate student in clinical/community psychology with some education in psychological assessment--would ask the following two questions to assess the seriousness of the distress (at a most basic level):
--Have you been experiencing any increased difficulty with your depression lately?
--Are there any recent experiences that have aggravated your condition?

Fourth, if responses indicate significant challenges in recent experience or increasing level of depression, I will recommend immediate contact with a health care professional or some other support in their community—for additional assessment and assistance. If they have no previous contact or have interest in additional resources, I will provide information on the following resources as well as any additional resources that appear to be relevant:

Utah interviews:

--Davis Behavioral Health, 801-451-7799; Emergency Services available 24-hours/day 7 days a week 801-773-7060.

--NAMI (National Alliance of the Mentally Ill) Support Groups, Crisis Intervention and Mentors:
David County: Rob & Julianna Morrow Rob.morrow@brooks.com (801) 558-7518 (home) 1st & 3rd Wednesday. @ 7:00 p.m. Bountiful, IHC Center Lobby corner of 400 N. & Main St., Bountiful, UT 84010

Ogden/Weber County: Dan Robinson danr@browning.com (801) 544-1194 ext.302 (801) 710-6127 1st and 3rd Thursday @ 7:00 pm South Ogden Sr. Citizens Center, 580 39th St. Ogden, UT 84403

Salt Lake City: Sal Ventura ventura@xmission.com (801) 243-6105 day; (801) 537-6377 evening 2nd & 4th Wednesday @ 7:00 p.m. Alliance House, 1724 S Main St Salt Lake City, UT 84115

Utah County: Grover Jenson Groverjenson@hotmail.com (801) 225-3855 2nd & 4th Tuesday @ 7:00 p.m. Utah State Hospital, Heninger, 1300 E Center St. Provo UT 84606

Illinois interviews:

--Psychological Services Center 505 E. Green St. Champaign, IL 61820 Voice: 217-333-0041 24 hour crisis line—217-359-4141 (The Psychological Services Center offers a variety of psychological services from individual consultation. The Center is equipped to deliver an array of psychological assessments. Services are available through self-referral, physician referral and/or agency referral. Faculty and student-therapists in clinical and counseling psychology staff the Center. Services are provided on a fee basis).

--NAMI (National Alliance of the Mentally Ill) Support Groups, Crisis Intervention and Mentors:
Champaign: Stefanie Griffin (217)352-2064 61824-1514

Bloomington: Faye Townsend (309) 828-0530 61701-5323

Fifth, while the interview will not be allowed to continue in the presence of serious distress, there are plans for the extreme case. If suicide risk becomes apparent, the investigator would follow the basic standards for mandatory reporting of suicide risk across both states. Namely, in the extreme case that this was necessary, the investigator would break confidentiality to inform individuals in the person's community about the suicide risk. This would be done, if possible, with the consent of the person, as well as his/her assistance in identifying a member of their community to contact. As noted in a previous section, while not trained as a clinician, the investigator has received specific training in assessment for suicide risk as part of his graduate training in a clinical/community psychology program. In the case that any interview experiences such challenges, the investigator would immediately consult and report to dissertation chair, Dr. Wendy Heller, a clinical psychologist—as well as reporting the 'adverse event' to the IRB office and to our psychology department executive officer. Any further action for the participant's well-being would be made at the time, as well as modifications and improvements to the recruiting protocol and/or interviewing schedule.

Appendix C: Informed Consent

UNIVERSITY OF ILLINOIS
AT URBANA-CHAMPAIGN



Jacob Hess is a graduate student in the psychology department at the University of Illinois under the supervision of Dr. Wendy Heller. He is beginning this research project aiming to better understand personal experiences of depression in order to improve the way communities may respond to this problem. You were selected as a possible participant because of your experience with depression. Interview participants must be 18 years of age or older. If you decide to participate, you would be one of 15-20 participants in the study. Participation would involve one conversation in person at a location convenient to you. This interview would be tape-recorded and last between 60 to 90 minutes. If any follow-up questions are needed, they would happen over the phone no longer than one month following the first interview. Your participation in this project would be strictly voluntary and you could refuse to participate or discontinue participation at any time during the project without penalty. Doing so will have no effect on your future relations with the University of Illinois. No research risks are anticipated in the study beyond the possible discomfort of talking about events associated with mental and emotional health. For this reason, if you chose to participate, you should feel comfortable skipping any questions you would prefer not to answer. Recordings made during these interviews would be kept confidential and secure in a locked office when not in direct possession of the investigator. Files will be coded numerically, with an identity key kept separately. Any publication, report or presentation of research that may result from this inquiry would not identify you or any other participant. In an instance, however, where there is any indication an individual may harm self or others, it would become necessary to break confidentiality. As a small token of appreciation for your participation, you will be offered \$10. No additional direct benefits are anticipated, although the research is hoped to benefit society more generally. You may request a copy of research reports at a later date.

If you are not comfortable with documentation of these discussions or have any other concerns or questions about this research please contact Jacob Hess directly at 217-766-2471 (jzhess@uiuc.edu) or Wendy Heller (w-heller@uiuc.edu). If you have questions about your rights as a research participant in UIUC-approved research you can contact the Institutional Review Board Office at the University of Illinois by phone (217-333-2670) or email (irb@uiuc.edu). You will be given a copy of this consent form for your records.

I have read and understand this consent document and agree to participate in the procedures as outlined above--including allowing the interview to be audio recorded for use in the research project.

Signed _____ Date _____

Appendix D: Interviewing Schedule

The final schedule of questions used in the interview are listed below:

Main question—open ended experience: The focus of this interview is on understanding your experience of depression. Let me start by asking you to tell me about your experience in general. [General probes about experience—clarification questions, what happened next?]

Formation/adoption of narration probes (depending on what is shared initially, these questions may be used as needed to prompt further elaboration of their narration): To help me better understand your story, I'd like to ask you to say more about some particular events and features.

- What has been your experience with family during this time? How has your family responded through this experience?
- How about your friends?
- What has been your experience with professional help during this time?
- How was your experience with MDs?
- Did you see a psychiatrist? What was your experience like?
- Were you ever prescribed drugs? What was your experience with psychiatric drugs?
- Can you tell me about experience with counselors or psychologists?
- Was your experience ever impacted by something you read?
- Was your experience ever impacted by something you saw on television—news, feature stories, etc?
- Did you ever hear a story from an acquaintance that impacted your experience?
- If you had to pick an event that most impacted how you make sense of your experience, what would it be?

Nature of narration ('content') probes: If we could, I'd like to zoom in some more specifics of how you think about this experience.

- Narrated beginning: How would you say your experience with depression began?
- Narration of the nature of depression: How do you define depression? What is it? Has your understanding of depression changed through this experience? How?
- Narrated attributions of change: In your story, you discussed both times of improvement and deterioration. How do you explain what basically lead to improvements? How do you explain what most basically led to times of worsening in your experience with depression?
- Narrations of the nature of improvement: What is your own definition of "getting better" from depression? How do you talk about a permanent improvement, if at all? How does someone know when this happens?
- Narrated experience with medication: What is your personal definition of when a medication has worked? How did you response to any uncomfortable effects? Did taking medication affect your relationships with friends or family?
- Narrations of community: You talked about your family and friends already. Of any person, whom have you turned to the most for support? Have your relationships changed through this experiences? How?

Nature of narration ("process/structure") probes:

- Life chapters: You've already described much of your experience—thank you. I would like to ask you to return to this experience and help me understand the sequence of your story by framing it like chapters in a book. What would each of the main chapters be? You may have as many or as few chapters as you like, but I would suggest dividing your story into at least 2 or 3 chapters and at most about 7. If you can, give each chapter a name and review briefly the contents and plot summary for each chapter.

--Theme: Looking back over the story of your experience once again can you discern a central theme, message, or idea that runs throughout it all? Please explain.

Maintenance of narration probes:

--You have shared current understandings of this experience. Have your understandings changed over time? (That is, did you used to believe something different about your depression?) How has your thinking changed? [*This question is more relevant to understanding how the narration arises—but, if used, would fit better at this point in the interview]

--We discussed events that may have contributed to your experience. Has your current understanding of depression ever been challenged (for instance, by something you heard or someone you know)?

Other: What else should I know about your experience in order to understand your story?

Table 1: Meaning and frequency count of interviewing nodes. My own sub-organization of nodes is also evident below, with “Arriving” prefacing any node which targeted evidence of a narrative’s creation/arising, “Continuing” prefacing any node which targeted evidence of a narrative’s maintenance and the actual constitution of narratives divided between “Depression” (problem definition”) and “S” (“Solution definition”):

Coding node	Meaning of the node	Coding References (Number of times text was placed in the code)	Sources Coded (Number of separate interviews placed in code)
1) Arriving through community challenge	Any comments on instances of being challenged by others in their view of depression.	28	10
2) Arriving through community wisdom	Any comments on instances of being helped and taught by others about depression.	53	12
3) Arriving through medical events	Comments on important medication experiences or encounters with doctors or other medical professionals.	35	10
4) Arriving through terrifying events	Comments on climactic or dramatic events important in their story of depression.	19	9
5) Continuing in spite of them	Comments that speak to moving forward in one’s understanding in spite of being attacked by others (“Maintaining story via defense”)	6	5
6) Continuing in these ways	Comments that speak to moving forward in one’s understanding independently (“Maintaining story via offense.”)	18	8
7) Depression basic--what is it?	Comments on the definition or nature of depression	32	14
8) Depression-biology involved or not	Comments on the role of biology in their depression (genetics, biochemicals, hormones, other physical conditions, etc.)	34	15
9) Depression-General increase	Comments about the increase in depression	5	5
10) Depression-identity	Comments about one’s identity in relation to depression	8	3
11) Depression relative to other sorrow	Instances of participants comparing their depression with others’ sorrow (or their own previous encounters with a “normal sorrow”)	3	3
12) Depression temporal origin	Comments on how depression initially emerged	12	6
13) Depression-where it came from	Comments on the source or origin of depression	53	15
14) Participation-against my will	Comments on depression indicating it was outside of their control.	25	10
15) Participation-my participation	Comments on depression suggesting their choice was relevant.	12	7
16) S--Change me or not change me	Instances where individuals reflected on whether personal changes were necessary to recovery	4	2
17) S--Counselors	Comments on professional therapists or counselors	45	12
18) S--Depression coming back	Comments on the possibility of depression returning	9	6
19) S—doctors	Comments on encounters with or feelings about medical professionals—primary care doctors, psychiatrists, etc.	11	5
20) S--getting better . . how	Descriptions of how individuals got better	36	11
21) S--getting better . . meaning	Comments on what “getting better” meant to individuals	16	9
22) S--med side-effects	Comments about side-effects associated with medication	39	12
23) S-meds for how long	Comments about the duration of time individuals were on	10	6

	medication		
24) S--meds going off . . what like	Comments on the experience of tapering off of medication	4	2
25) S--meds not working	Comments on instances when meds were not working	13	9
26) S--meds resisting and/or tapering	Comments reflecting resistance or a desire to taper	33	10
27) S--meds working	Comments on instances when meds were working	40	12
28) S--pharmacy practice	Comments on details of their medical management over time	21	10
29) S--what I think of medicine . . what they are doing	Comments on how individuals perceive the medication to be working	13	6
30) Theme	Comments on the overall “theme” of participants’ experience (the final question)	11	10
Average code frequency		22 average	8.5 average
Range of code frequency		(4-53)	(3-15)

Curriculum-Vitae

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EDUCATION

- 2009 Ph.D., Clinical-Community Psychology, University of Illinois Urbana Champaign. “Prozac saved my life vs. Prozac ruined my life: Investigating the Adoption, Constitution and Maintenance of Distinct Interpretations Associated with Depression and its Medical Treatment.” Split minor: Qualitative inquiry and biology
- 2001 - 2006 University of Illinois Urbana-Champaign, Ph.D. Candidate. Doctoral Program in Clinical/Community Psychology. December 2004, Masters equivalency requirements fulfilled. Thesis: “Scientists in the Swamp: Narrowing the Language–Practice Gap in Community Psychology” (2005) American Journal of Community Psychology.
- 1996 - 2001 B.S. Psychology, Brigham Young University.
- April 2001, Valedictorian of Psychology Department.
 - April 2001, Mark Allen award for outstanding Senior Student in Psychology.
 - 2001, Office of Research and Creative Activities (ORCA) Research Scholarship.
 - 2000, ORCA Scholarship, “A Correlation Study of *Y-OQ* and *OS* performance in a youth outpatient setting” with Shelby Ferrin
 - 1996-2001, Trustees Scholarship, Brigham Young University.
- 1993 - 1996 Viewmont High School
- May 1996, National Merit Scholarship.
 - May 1996 Graduation, Valedictorian

RESEARCH

RESEARCH EXPERIENCE

- 2009-Present Researcher *Utah Youth Village*, examining process and outcomes associated with Village programs, including Alpine Academy, public group homes and treatment foster care, as well as an in-home program (“Families First”) unique within the state. Further

application, development and documentation of the full potential of the strength-based “Teaching-Family” approach is also an ongoing Village research emphasis (<http://www.youthvillage.org/>)

Supervisors: Shanna Draper, MA, Program Director
Eric Bjorkland, JD, Executive Director

- 2005 - Present Co-investigator with Nathan Todd, “Investigating liberal/conservative interpretations of difficult social issues.” Study aiming to better understand meaningful similarities and differences in diverse community views of challenging social issues—from well-known problems (domestic violence, sexual assault) to questions of great disagreement (sexually explicit media, sex education in schools and homosexuality); we began with a hypothesis that attention to nuances of citizen perspectives would contrast with simplistic, stereotypical public framings and potentially facilitate a more productive inter-political dialogue and collaboration between diverse citizens.
Supervisor: Nicole Allen, Ph.D.
- 2006 - 2008 Co-investigator with Danielle Rynczak (Co-facilitator) and Joe Minarik, Program of Intergroup Relations (PIR) dialogue trainer. “University level liberal-conservative dialogue as an alternative setting for inter-political exchange.” Study aiming to understand process and outcome of first of a kind, seven-week Liberal-conservative dialogue course
Supervisor: Joycelyn Landrum-Brown, Ph.D. coordinator, *PIR*
- 2005 - 2009 Investigator, Dissertation Research, “Narrating depression: Investigating competing portrayals of the etiology and treatment of emotional problems.” Study aiming to make sense of the conflicting narratives around the experience and treatment of basic psychological problems.
Supervisors: Wendy Heller, Ph.D. & Thomas Schwandt, Ph.D.
- 2004 - 2006 Co-investigator with Sadie Larsen, Teaching Assistant. “Case study: Testing a dialogic teaching structure in a large lecture class.” Study aiming to document and summarize attempts over two years to structure an introductory community psychology course on a more democratic/dialogical teaching model.
Supervisor: Mark Aber, Ph.D.
- 2004 - 2005 Research Supervisor, “Community action research around the development of Champaign-Urbana Family Week.” Study aiming to understand key aspects in the development of a bipartisan community-wide event for families.
Supervisors: Julian Rappaport, Ph.D., Nicole Allen, Ph.D.

- 2002 - 2003 Research Team Participant, “Components of effective interagency collaboration for domestic violence project.” Study aiming to identify key aspects of successful collaborative work in a secondary analysis of dissertation data.
Supervisor: Nicole Allen, Ph.D.
- 2002 - 2003 Research Team Participant, “Understanding varying perspectives of stakeholders in the coordinated community response to domestic violence.” Study aiming to understand contrasting views of the coordinated community efforts to fight domestic violence.
Supervisor: Nicole Allen, Ph.D.
- 2002 - 2003 Investigator, “Motivation and meaning in genealogical inquiry.” Interviews with local genealogical activists to understand what motivates their participation in family history. Results framed in the context of community psychology’s focus on seeking a “sense of community.”
Supervisor: Julian Rappaport, Ph.D.
- 2001 Research Assistant, “Values and psychology.”
Theoretical investigation of values and psychology
Supervisor: Brent Slife, Ph.D. Brigham Young University
- 2001 Project Co-manager, “Yale University’s SAT pilot test among BYU freshman.”
Supervisor: Brent Slife, Ph.D. Brigham Young University
- 2000 - 2001 Research Assistant, “BYU Counseling Center investigation of tracking outcome in outpatient psychotherapy.”
Assisted in administering outcome research program in the center.
Supervisor: Michael Lambert, Ph.D. Brigham Young University
- 1999 - 2001 Research Team Participant, “Psychotherapy Outcome Research.”
Helped with varied projects exploring psychotherapy outcomes—including supervising an outcome study comparing the Youth Outcome Questionnaire with the Ohio Scales in an outpatient setting.
Supervisor: Michael Lambert, Ph.D. Brigham Young University

PUBLICATIONS

- Allen, N. E., Watt, K. & Hess, J. Z. (2008). A qualitative study of the activities and outcomes of domestic violence coordinating councils. American Journal of Community Psychology 41(1-2), 63-73.

- Hess, J. Z. (2005). Scientists in the swamp: Narrowing the language–practice gap in community psychology. Special issue “Community Psychology and Science,” American Journal of Community Psychology 35(3-4), 239 – 252.
- Hess, J. Z. & Larsen, S. (2007). “Is this going to be on the test?!”: Exploring authentic engagement in a large undergraduate course. Australian Community Psychologist 19(2), 92-108.
- Hess, J. Z., Barr, S., & Hunt, G. (2009). The practice of family mentoring and advocacy: A theoretical investigation of key issues. Families in Society: The Journal of Contemporary Social Services, 90(2), 189-195.
- Hess, J. Z., Rynczak, D., Minarik, J. & Landrum-Brown, J. (in press). Alternative settings for liberal-conservative exchange: Examining an undergraduate dialogue course. Journal of Community and Applied Social Psychology.
- Hess, J. Z. & Todd, N. R. (2009). From culture war to difficult dialogue: Exploring distinct frames for citizen exchange about social problems. Journal of Public Deliberation 5(1) Article 3.

OTHER PUBLICATIONS

- Hess, J. Z. & Verona, E. (2007, August). The next casualty of the culture wars: Good science? Jaam-va-Jaan ("people and society"): A journal of the mind, body, and more. [English/Farsi journal aimed at the Iranian community in Los Angeles]. <http://www.jaam-va-jaan.com/>.
- Hess, J. Z. & Verona, E. (2007, April). Editorial: The next casualty of the culture wars: Good science? Inclinations: Clinical/Community Psychology Newsletter University of Illinois Champaign-Urbana 27(1), 9-11.
- Hess, J. Z. (October, 2002). Comments on the Chicago Research Conference, Community Psychology Networker.
- Hess, J. Z. (2000). A Correlation Study of *Y-OQ* and *OS* performance in a youth outpatient setting. BYU-ORCA Undergraduate Research Journal.

MANUSCRIPTS IN PREPARATION

- Hess, J. Z., Allen, N. E., & Todd, N. (in preparation). Framing community accountability: Citizen interpretations of responding to domestic violence (or not)
- Hess, J. Z., Allen, N. E. & Todd, N. (in preparation). Narrating domestic violence: Investigating distinct citizen interpretations of family abuse
- Hess, J. Z., Moore, M. C., Brahm, D., Judd, Y., Petroske, R. E. & Klok, H. (in

preparation). Narrating eating disorders: Investigating online accounts of anorexia and bulimia.

Hess, J. Z. (in preparation). "*Prozac saved my life*" vs. "*Prozac ruined my life*": Investigating distinct narratives of medical treatment for depression. [Article based on preliminary presentation of dissertation results].

Hess, J.Z. & Boren, B. T. (in preparation) Psychological problems among people of faith: Investigating distinct responses to emotional pain within religious communities.

Hess, J. Z., & Levin, R. L. (in preparation). Narrating the brain: Investigating competing portrayals of the embodiment of depression.

REPORTS

Hess, J. Z. (2008, October). Final report of conference participant feedback on challenge #2: Framing dialogue in a way more accessible to a broader audience. Biennial Conference of the National Coalition of Dialogue and Deliberation (NCDD), Austin, TX. [Accessible on <http://www.thataway.org>]

CONFERENCE PRESENTATIONS

Hess, J. Z., Joseph, D. & Todd, N, (under review). "How does talking matter anyway?" Exploring the potential of dialogue as a potent community intervention. Symposium submitted to 2009 Biennial Conference of the Society for Community Research and Action [With Dave Joseph, Public Conversations Project and Nathan Todd, University of Illinois]

Hess, J. Z. & Johnson, G. (2008, October). Attracting conservative citizens to dialogue events: Liberal-conservative campus dialogue & Mormon-Evangelical interfaith initiatives. Workshop presentation for the biennial conference of the National Coalition of Dialogue and Deliberation (NCDD). Austin, Texas.

Hess, J. Z. (2008, October). Introduction and closing "report-out" on key challenge #2: Framing dialogue in a way more accessible to a broader audience. Biennial conference of the National Coalition of Dialogue and Deliberation (NCDD). Austin, Texas.

Todd, N., Hess, J. Z. & Allen, N. (2007, May). Utilizing narrative research to promote dialogue: Citizen interviews on important social issues. 2007 Congress of Qualitative Inquiry. Champaign-Urbana, Illinois.

Hess, J. Z. (2007, March). "Prozac saved my life" vs. "Prozac ruined my life": Empowering clients to face public confusion about psychological problems. Paper presentation for the Semi-annual Conference of AMCAP: the Association of Mormon Counselors and Psychotherapists. Salt Lake City, Utah.

- Larsen, S. & Hess, J. (2006, October). “Is this important to know . . . will it be on the test?”: An experiment with active learning in an oversized undergraduate classroom. Paper presentation at Midwest Eco Conference, Saugatuck, MI.
- Hess, J.Z., Galves, A., & Levin, R. (2005, June). Levels of analysis: Constraints of a community psychology classic. Symposium conducted at the 10th Biennial Conference of the Society for Community Research and Action, Champaign, IL.
- Hess, J.Z. (2005, June). Going beyond individuals: Is this possible? In J. Z. Hess (Chair), Levels of analysis: Constraints of a community psychology classic. Symposium conducted at the 10th Biennial Conference of the Society for Community Research and Action, Champaign, IL.
- Hess, J. Z. (2005, June). C-U family week as a structure for dialogue and collaboration. In M. R. Cruz (Chair), Living praxis: Personal struggles in value-explicit community psychology. Symposium conducted at the 10th Biennial Conference of the Society for Community Research and Action, Champaign, IL.
- Hess, J. Z. (2005, June). Introduction: The case for individual-level attention in community psychology. In J. Lacasse (Chair), What community psychologists should know about biological psychiatry (The case of clinical depression). Symposium conducted at the 10th Biennial Conference of the Society for Community Research and Action, Champaign, IL.
- Hess, J.Z. (2005, April). Understanding the changing views in psychopathology research. Paper presentation for the Semi-annual Conference of AMCAP: the Association of Mormon Counselors and Psychotherapists.
- Hess, J. Z, Kemp, C, Priya, J. & Kaspar-Hannigan, S. (2004, April). Champaign-Urbana Family Week, 2004: A case study in dialogue. Poster presented at the annual meeting of the Midwest Psychological Association, Chicago, IL.
- Allen, N. E., Watt, K. & Hess, J. Z. (2003, June). Collaboration and social change: Does familiarity breed content? Paper presented at the 9th Biennial Conference of the Society for Community Research and Action. Las Vegas, NM.
- Hess, J. Z., Mack, J., Fryer, D., Vernon, F., (2003, June). Exploring community psychological praxis in a value-laden world. Symposium organized for the 9th Biennial Conference of the Society for Community Research and Action. Las Vegas, NM.
- Hess, J. Z. (2003, June). Objectivism versus relativism: Philosophical hermeneutics as a third alternative. Symposium participant at the 9th Biennial Conference of the Society for Community Research and Action. Las Vegas, NM.

- Hess, J. Z. (2002, November). Researching our roots: Motivation and meaning in genealogical inquiry. Poster presented at the 9th Biennial Conference of the Society for Community Research and Action. Las Vegas, NM.
- Hess, J. Z. & Fuller, L. (2002, January). Strengthening families through community collaboration. Roundtable discussion at Brigham Young University Family Life Education Conference, Provo, Utah.
- Hess, J. Z. (2001, October). Tasting the greatest injustice—Hunger banquets as a community tool: Brigham Young University's 2001 Banquet. Midwest Eco-Conference, Pretty Lake, Michigan.
- Slife, B. D., Hess, J. Z. & Williams, D. (2001, February). Management of inescapable values in psychotherapy. Paper presented at the American Association of Behavioral and Social Sciences, Las Vegas.
- Team of authors from BYU Counseling Center—including Hess, J. Z. (2000, November). The Effect of Providing Counselors with Feedback on Client Progress. Presentation at APA.
- Lambert, M., Hess, J. Z. & Goates, M. (April, 2000). Outcome Research. Poster presented at Rocky Mountain Psychological Association.

DEPARTMENT COLLOQUIA

- Hess, J. Z. (2007, April). How to talk to a conservative (if you must). Clinical-Community Psychology Division Diversity Seminar. University of Illinois. [*Playing off Anne Coulter's offensive book, "How to talk to a liberal (if you must)" to introduce liberal-conservative intergroup dialogue*]
- Hess, J. Z. & Levin, R. (2006, November). Narrating the Brain: Investigating Competing Portrayals of the Embodiment of Depression. Clinical-Community Psychology Division Brown Bag. University of Illinois.
- Hess, J. Z. & Diener, C. (2005, January). Mini presentation: Challenging the stereotypical distinctions between clinical and community psychology. Clinical-Community Psychology Division Brown Bag. University of Illinois.
- Hess, J. Z. (2003, October). 'Colonization of the life world by the systems world': A case for value rationality (phronesis) in psychology. Clinical-Community Psychology Division Brown Bag. University of Illinois.

INVITED COMMUNITY PRESENTATIONS

- Hess, J. Z. (2008, May). Overview: Family mentoring and advocacy Proficior Management Group. Salt Lake City, Utah.

- Hess, J. Z. (2008, April). "I'm afraid you'll have to deal with this the rest of your life": Long-term prognoses, neural plasticity and the recovery movement. Centerville 18th Ward Family Home Evening Workshop.
- Hess, J. Z. (2007, August). Hard conversations in His way: A dialogue workshop. Centerville 18th Ward Relief Society Enrichment Meeting.
- Hess, J. Z. (2005). Classroom unstructure. Student Education Conference, School of Education, University of Illinois.
- Hess, J. Z. (2004). Meanings and motivations behind genealogical research. A research report to the Champaign County Genealogical Society.
- Hess, J. Z. & Measom, R. (2002, August). Mentoring presentation. Slate County Mentor Program, Provo, Utah.

TEACHING, SUPERVISION & FACILITATION

- 2006 - 2007 Supervisor, "Eating disorder narratives research team."
Independent student research into online narratives problems (blogs, websites) followed by a collaborative development of and research into a manuscript investigating key interpretations across problems.
- 2006 - 2007 Co-supervisor, "Liberal/conservative narrative research team."
Facilitated undergraduates in reading on qualitative research and liberal/conservative dialogue, transcribing, memoing and participating in collaborative analysis of interview text.
- 2006 - 2007 Co-facilitator, "Liberal-conservative dialogue course," *Program for Intergroup Relations* in the Department of Education, Organization and Leadership, University of Illinois. ("See Community Psychology Experience")
- 2004 - 2006 Instructor, "Introduction to community psychology," University of Illinois: Over four semesters, worked to develop a structure for a more dialogue-focused atmosphere for a large course. In the final semester, received approval for systematic research (see Hess & Larsen, 2008).
- 2006 Co-instructor, "Keys to scripture study," class at the Urbana Institute of the Church of Jesus Christ of Latter-day Saints.
- 2003 - 2004 Supervisor, "Action research undergraduate seminar: Development

of a bipartisan community-wide Champaign-Urbana Family Week” (“See Community Psychology Experience”)

2001 - 2002 Teaching Assistant, “Introduction to community psychology,”
University of Illinois.

PRACTICE

COMMUNITY PSYCHOLOGY EXPERIENCE

2008 Facilitator/Table Moderator, National Student Dialogue Conference II,
Utah Valley University, Orem, Utah.

2004 - 2007 Facilitator, Coordinator, Assistant and Therapist, Pre-doctoral Clinical-
Community Psychology Internship, Division of Clinical-Community
Psychology, Department of Psychology, University of Illinois, Urbana-
Champaign, “Dialogue and collaboration around local family initiatives”:
Initiating, coordinating and facilitating collaborative campus and
community events and inter-group dialogue (2000 hours beyond required
practica—see details of community and clinical initiatives below).
Supervisor: Nicole Allen, Ph.D.

2006 - 2007 Co-facilitator, “Liberal-conservative dialogue course,” Program for
Intergroup Relations, Department of Education, Organization
and Leadership; University of Illinois, Urbana-Champaign.
Supervisors: Joycelyn Landrum Brown, Ph.D. and Joe Minarak

2007 Facilitator, Intergroup dialogue session, Cultural Competence Committee
(C3) of the Mental Health Agencies Council (MHAC), January.

2006 Facilitator, Big-Small-All community visioning project session,
Champaign County, January.

2003 - 2005 Organizer and coordinator, “Champaign Urbana Family Week” (see
www.cufamilyweek.org).
Supervisor: Nicole Allen, Ph.D.

2005 - 2006 Participant and Facilitator, Intergroup dialogue training:
Supervisor: Joycelyn Landrum-Brown, Ph.D.

2005 Coordinator, Champaign-Urbana Community Dialogues for the 10th
Biennial Conference of the Society for Community Research and Action:
Organized and facilitated dialogues on the following two themes: juvenile
justice/youth development and local educational equity.
Supervisor: Mark Aber, Ph.D.

- 2002 - 2003 Participant, “Health Cares Coalition,” A Woman’s Place Shelter:
Attended meetings and contributing on the subcommittee focusing on
expansion of initiative uniting health care providers to address domestic
violence
Supervisor: Nicole Allen, Ph.D.
- 2003 Participant, “Champaign County Coalition to End Domestic Violence.”
Encouraged a local community initiative to unite separate collaborative
bodies into an umbrella coalition.
Supervisor: Nicole Allen, Ph.D.

CLINICAL EXPERIENCE

- 2006 - 2007 Assistant, Psychological Services Center, University of Illinois Training
Clinic
Clinical supervisor: Elaine Shpungin, Ph.D.
- 2004 - 2005 Group Supervisor, Juvenile Detention Center, Urbana Illinois
Clinical supervisor: Carol Diener, Ph.D.
- 1999 - 2000 Human Service Worker, Vantage Point Youth Services, Provo, Utah

SERVICE AND LEADERSHIP EXPERIENCE

- 2005 - Present Ad hoc Reviewer, Preventive Medicine
- 2007 Volunteer Member, Planning committee for the 2008 biennial conference
of the National Coalition of Dialogue and Deliberation, October 3-5, 2008
in Austin, Texas.
- 2003 - 2007 Volunteer, Committee preparing and publishing department newsletter,
“Inclinations”
- 2006 Volunteer, Midwest Eco Conference Planning Committee, Saugatuck,
Michigan
- 2005 Participant, Planning Committee, 10th Biennial Conference of the Society
for Community Research and Action.
- 2001 Chair, Program/Profile Committee for the *Students for International
Development Hunger Banquet* at BYU.
- 1999 - 2000 Mentor, *Slate Canyon Mentor Program* with Robert, chair of recruiting for
the program.
- 1998 - 1999 Big brother, *Access Big Brother/Big Sister Program* with Eric & Emily.

- 1998 - 1999 President, BYU chapter of Psi Chi, the psychology honors society.
Constructed Psi-Chi Website at BYU.
- 1998 Volunteer, *Utah County Crisis Line*.
- 1992 Eagle Scout, *Boy Scouts of America*. Organizing a project to install a bench, paint and clean up a local camping area.

PROFESSIONAL AFFILIATIONS

- 2006 - Present National Coalition for Dialogue and Deliberation, NCDD, Member
[www.thataway.org]
- 2006 - Present American Psychological Association, Student Affiliate
- 2006 - Present Society for Theoretical and Philosophical Psychology (APA Division 24), Student Member
- 2003 - Present Society for Community Research and Action, SCRA (APA Division 27), Student Member