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Anxious lives: Tracing the life course of a medical diagnosis through illness narratives

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ANXIOUS LIVES: TRACING THE LIFE COURSE OF A MEDICAL DIAGNOSIS
THROUGH ILLNESS NARRATIVES

BY

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DISSERTATION

Submitted to the University of New Hampshire
in Partial Fulfillment of
the Requirements for the Degree of

Doctor of Philosophy
in
Sociology

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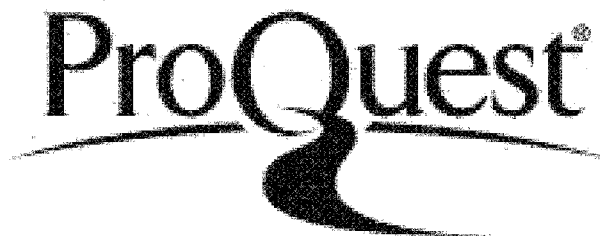


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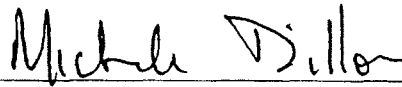
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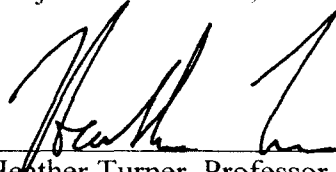
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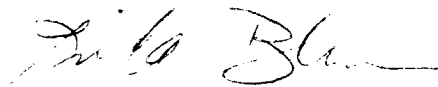
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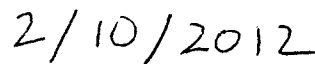
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ABSTRACT

ANXIOUS LIVES: TRACING THE LIFE COURSE OF A MEDICAL DIAGNOSIS THROUGH ILLNESS NARRATIVES

by

Jennifer J. Esala

University of New Hampshire, May 2012

This dissertation is a study of medical diagnosis, specifically anxiety disorder diagnosis, from the perspective and through the narratives of people who have been diagnosed. In this study, I address two core research questions. First, how does social materiality (e.g., bodies and objects) contribute to, shape, and lend empirical understanding to the experience of an anxiety disorder and the experience of illness in general? Second, how does medical diagnosis translate from the medical institution into the lives of people who have been diagnosed, and how do those diagnoses transform in and through the social lives of people? To address these questions, I conducted in-depth interviews with forty people who had been diagnosed with three specific forms of an anxiety disorder: generalized anxiety disorder, panic disorder with agoraphobia, and panic disorder without agoraphobia. I also conducted eight months of participant observation at anxiety disorder support groups. Through these illness narratives, I traced the co-construction of illness experience and medical diagnosis from the perspectives of

people who have been diagnosed. These narratives were loosely divided into three parts: before, during, and after diagnosis, which mirror the structure of the dissertation.

Accordingly, I first describe how people came to decide to seek medical care and diagnosis. Then, I turn to how gendered bodies and the gendering of anxiety/ fear in general and the gendering of the diagnosis of anxiety disorders in particular complicated the diagnostic process itself. And, finally, I explore how the medical diagnoses evolved in and through everyday social interactions and experiences, often well beyond the purview of medical institutions. These narratives suggest that physical bodies, everyday objects, and medical diagnoses figure prominently in the life course of an anxiety disorder.

CHAPTER ONE

REVIEW OF THE LITERATURE

Medical sociology examines the social underpinnings of health and illness. This dissertation is a study of the social life of the most prevalent set of mental health diagnoses: anxiety disorders. Nearly a third of the U.S. population at some point will meet the criteria for an anxiety disorder and about 18% of the population has met the criteria in the previous twelve months (Kessler, Berglund et al. 2005; Kessler, Chiu et al. 2005). Not only is anxiety quite common in the United States, it also has significant personal and social consequences. For instance, anxiety disorders have been linked to an inability to carry out daily tasks (e.g., grocery shopping and caring for children) and to decreases in work productivity (Allgulander 2006:104). Likewise, anxiety disorders are correlated with high rates of unemployment, lower levels of educational achievement, higher rates of marital strife, and impaired social skills (Shearer 2007). People diagnosed with anxiety disorders also have higher rates of medical utilization (even compared to people with other mental health disorders) and are more likely to be diagnosed with depression and to attempt suicide (Shearer 2007).

While anxiety disorders are both common and consequential, there has been surprisingly little study on the topic in medical sociology. An informal search of scholarly social science articles on anxiety disorders and, as a comparison, on mood

disorders (which have lower a lifetime prevalence of about 20%) reveals a deeply skewed body of literature: toward the study of mood disorders and away from the study of anxiety (see appendix A). There are, however, two important exceptions to this trend. Jackie Orr's book *Panic Diaries* provides a, theoretically rich, historical account of panic and panic disorders, while drawing on her own experiences of panic, and Allan Horwitz and Jerome Wakefield, in their forthcoming book *All we have to Fear*, provide critical reflections on the modern medical diagnosis of anxiety disorders (Horwitz and Wakefield 2012; Orr 2006). With the limited amount of sociological literature currently on the topic, there remains much to be gained from the continued sociological study of anxiety disorders. Specifically, there is still no empirical sociological account of the experience of anxiety and anxiety disorder diagnoses from the perspective of people who have been diagnosed.

The nature and objective of this task, however, is not obvious. Despite the common and fundamental objective of medical sociology—to explore the sociality of health and illness—the theoretical and methodological approaches in the field are diverse. As such, I open this chapter by locating the approach of my dissertation in this varied intellectual landscape. I employ a phenomenological and constructionist approach to health and illness that empirically engages social materiality. The foregoing sentence demands substantial unpacking, and, to that end, the following pages are dedicated to describing this particular approach to health and illness while placing it in the diversity of work within the sociology of medicine.

Objectivists and Constructionists

Medical sociology can be loosely divided into two approaches to theory and research: objectivist and constructionist. While I will outline sharp distinctions between objectivist and constructionist research, the field in practice is far more complex. That is, there is often substantial overlap between these theoretical and empirical approaches to the study of health and illness. There are, however, core distinctions in the field that—when plainly articulated—help clarify the assumptions, objectives, strengths, and weaknesses of any given approach. Moreover, I make these firm distinctions to clarify the purpose and the theoretical and empirical approach of this particular inquiry. Since I take a constructionist approach in this dissertation, this review is primarily focused on constructionist work, but I will take a few paragraphs to discuss each and delineate between the two.

Objectivist research is primarily interested in the social origins of disease and health inequalities, is marked by a positivistic approach to research, and largely employs quantitative methods. Constructionist work in medical sociology, in contrast, seeks to understand the socially constructed nature of health and illness and generally employs qualitative research methods. Another way of looking at the difference between objectivist and constructionist work in medical sociology begins by delineating between “disease” and “illness.” Disease is the physiological and biomedical phenomenon, while illness is the subjective and social experience of disease (Phil Brown 1995:39; Jutel 2009:286). Objectivist researchers in medical sociology study how social factors contribute to disease, while constructionists study the social development and experience of illness, as a social category.

Among the most prominent and influential objectivist research is in social epidemiology and stress process research, broadly defined. These sociologists are interested in exploring what social factors contribute to health or disease. For instance, in an important social epidemiological study, Gregory Pappas and colleagues draw on two sets of nationally representative survey data to assess the relationship between socioeconomic status (SES) and mortality (Pappas et al. 1993). They find that there is an inverse relationship between SES and mortality; in other words, higher levels of income and social status are strongly associated with lower rates of death. Research in this field has linked social factors, such as race, gender, marital status, employment, and geographical location to a wide variety of health outcomes (Latkin and Curry 2003; Link and Jo Phelan 1995; Ross 2000; Schieman, Pearlin et al. 1981; Turner, Wheaton, and Lloyd 1995; Whitestone, and Van Gundy 2006). This body of research has revealed how social inequality contributes to the unequal distribution of morbidity and mortality, which brings into question medical models that rely solely on genetics, biology, and risk behavior to explain disease.

Constructionists and Medicalization

Constructionists, in contrast, focus on how illness is defined or constructed, and among constructionists in medical sociology, their topic of study is predominantly medicalization. “Medicalization” literally means “to make medical” (Conrad 1992). Accordingly, medicalization research addresses how phenomena come under the purview of medicine. In the following paragraphs, I outline three core contributions of research on medicalization to the sociology of health and illness, including: the individualization

of social problems, the organizational and structural foundations of medical diagnosis, and the study of *overmedicalization*.

One key critical insight offered by medicalization research is that medicine individualizes social problems. Peter Conrad observes that, as a society, “We tend to look for causes and solutions to complex social problems in the individual rather than in the social system” (Conrad 1975:19). That is, social problems are “medicalized” (or made medical) and, in turn, treated as patient problems. While many of these medical conditions have been firmly linked to social inequality and oppression (e.g. Pearlin et al. 1981; Turner and Lloyd 1999; Turner and Turner 2005), medicine still largely locates the problem at the individual level, in the patient’s biology and genetics. Conrad continues, “Rather than seeing certain behavior as symptomatic of problems in the social system, the medical perspective focuses on the individual diagnosing and treating the illness, generally ignoring the social situation” (Conrad 1975:19). Similarly, Nancy Scheper-Hughes explains that illness obfuscates important social arrangements and power relations; more specifically, illness excuses the powerful from their role in the suffering of the less powerful. She writes, “A sick body implicates no one. Such is the special privilege of sickness as a neutral social role, its exceptive status. In sickness there is (ideally) no blame, no guilt, no responsibility... society and its ‘sickening’ social relations are gotten off the hook” (Scheper-Hughes 1993:174).

Medicalization research has also thoroughly investigated the organizational and capitalistic foundations of illness. Researchers have shown how seemingly “natural” illnesses are often the creations of corporations. For instance, researchers have linked the contemporary surge in medical diagnoses to the advent of new medications. In a now

classic piece on medicalization, Peter Conrad linked the “discovery” of hyperkinesia (contemporarily, “Attention Deficit Disorder”) to the development of a biomedical treatment (Conrad 1975). Specifically, researchers were surprised to find that amphetamines helped calm a subset of rowdy and disobedient school children, which prompted medical research that identified a set of behavioral problems among children that could be treated with a family of synthetic medications, including Ritalin. Hyperkinesia quickly became among the most prevalent childhood psychiatric diagnosis, which Conrad linked to relentless promotion from the pharmaceutical industry and support from the government. This “discovery” and then expansion of disorder represents an institutionally derived, “putting the cart before the horse”; in other words, the “disorder” was identified by its unexpected (and, then, profitable) treatment. Medicalization researchers are often critical of this approach to developing diagnostic categories, demonstrating that this process creates illness where there was once none.

Medicalization research also offers another, related, critique: that social institutions contribute to the *overmedicalization* of normal experience (Lane 2007; Szasz 1974) and deviant behavior (Conrad and Schneider 1980; Scheff 1999). This strain of research reveals how medicine serves as a “boundary manager” (Rosenberg 2006:416) that is able to redefine “normal” behavior and experience as “abnormal” (Brown 1995:39; Chiong 2001:89; Jutel 2009), and suggests that this degree of definitional control bestows unacceptable amounts of power on medical institutions and industries.

All three of these contributions of medicalization research have indubitably advanced constructionist work in medical sociology. They additionally have two core orientations in common: they address power and take a critical perspective. In the early

1970s, Eliot Freidson (1970) and Irving Zola (1972) were influential in the development of a critical sociological perspective on medicine as an institution of social control, which was in sharp contrast to the prevailing functionalist approach at that time, exemplified by Talcott Parsons (1951). This critical perspective remains core to most constructionist work in the sociology of medicine, and medicalization research most clearly carries on this intellectual tradition. Medicalization research searches for sources of power (most often in corporations and professionals) that press medicalization ever-further (Conrad 2005) and takes an either explicitly or implicitly critical stance on what should or should not be treated as a medical condition.

Constructionism and Ontological Gerrymandering

In this section, I address the critical stance taken by many constructionists in medical sociology, and, then, I return to the issue of power later in this chapter. The popular constructionist position in medical sociology takes a critical stance on illness, which, I argue, lends itself to “ontological gerrymandering”, which is

making problematic the truth status of certain states of affairs selected for analysis and explanation, while backgrounding or minimizing the possibility that the same problems apply to assumptions upon which the analysis depends.... This “boundary work” creates and sustains the differential susceptibility of phenomena to ontological uncertainty. Some areas are portrayed as ripe for ontological doubt and others portrayed as (at least temporarily) immune to doubt. (Woolgar and Pawluch 1985:216)

While Woolgar and Pawluch are specifically discussing how constructionists often treat one aspect of a phenomenon as constructed (e.g., “heroin epidemics”) but, at the same time, treat other aspects of the phenomenon as objective (e.g., people have *always* used mind altering substances). This same basic inconsistency is present in constructionist research in medical sociology as a whole. That is, constructionist medical sociology, on the aggregate, tends to treat some illnesses as constructed and others as objective (as “diseases”).

Certain illnesses are ripe for being treated as “constructed”, while other illness are treated as objective realities. For instance, the biological foundations of disorders like attention deficit disorder, depression, premenstrual syndrome, and bipolar disorder are continually contested in studies of medicalization (Maturro 2010; Malacrida 2004; Pugliesi 1992; Searight and McLaren 1998; Shaw and Kauppinen-Toropainen 2004). Conversely, constructionists researchers treat more firmly established illnesses—like cancer and AIDS—as *diseases* and, instead of questioning their biologic foundations, discuss medicalization *around* the disease. For instance, research on AIDS often addresses the medicalization of sexuality (Albert 1999) and research on cancer addresses things like the medicalization of the diagnostic process (Griffiths et al. 2010). To be entirely clear, the problem here is not that AIDS and cancer are not real. Indeed, they have very, all-too-real, consequences for people. The problem, instead, is that constructionist researchers are making objectivist claims, which I argue, weakens their unique contribution to the study of health and illness. At the most basic level, this approach represents an inconsistent theoretical treatment of health and illness that demands attention.

At the root of this ontological gerrymandering is a critical or “reformist”/ “rebellious” approach to research (Hacking 1999:19). In other words, constructionists of this type seek to reveal that a construction of a certain illness is a “bad thing” and argue that “the world would be a better place without it” (Hacking 1999:19). While it is a valuable and important endeavor to seek to improve the lot of people diagnosed with these illnesses, this attempt at improvement, however, is hindered by this core contradiction in analysis (Woolgar and Pawluch 1985:224).

While this particular approach to constructionism has been debated and critiqued in broader constructionist work (Holstein and Miller 2006; Kitsuse and Spector 1973; Spector and Kitsuse 2001; Woolgar and Pawluch 1985), it remains largely unaddressed among constructionists in medical sociology. There are, however, several reasons to engage in this debate. For one, when researchers treat some entities as constructed and others as real, this brings another level of (hidden) bias to their work. Specifically, this approach assumes that the researcher can gain a perspective from outside of his or her specific local socio-historical context, that he or she can somehow see reality more clearly or more objectively than those whom he or she studies. From a constructionist perspective, however, researchers also see the world, including illness, from a specific socio-historical location and have no special insight about *which* illnesses are constructed. As such, critical constructionists risk riding the cusp of objectivist and constructionist approaches, picking and choosing when something is real or not, and defining “reality” in the process. When a researcher, with all of the authority of an author and an expert, asserts that one illness is constructed while another is real, that real-reality is given disproportionate privilege. Accordingly, the author becomes a powerful actor in

the social reification or deconstruction of illnesses. Certainly, this is precisely the type of power that constructionists strive to reveal and are critical of among pharmaceutical companies, insurance companies, and physicians. And, undoubtedly, this is not the type of power we want to assume.

Ian Hacking observes that this is especially problematic since this critical approach, however liberating it may appear, does little more than liberate ideas that are already on their “way to being liberated” (Ian Hacking 1999:2). For instance, there is a strong tendency in medical sociology to treat psychological illnesses as constructed and physical illnesses as real. This interpretation of physical and mental illnesses, indeed, (1) is *already* a prevailing sentiment in the modern United States and (2) is a distinction made from a particular social position (that of the researcher, not the patient). Likewise, this uneven treatment of illnesses reifies the social recognition and rejection of particular states and is especially limited in that these distinctions are made from a single vantage, often by people who have not experienced the illness. Indeed, this hybrid constructionist/objectivist treatment of illness has real, and not always positive, consequences for people who suffer with them.

Moreover, this hybrid constructionist/ objectivist approach undermines constructionist work at the most basic level. That is, when some illnesses are treated as real and others as constructed, it leaves social constructionist work weak. In this rendering, “objective” diseases become real and problematic, while all other “illnesses” are at risk of becoming—a phrase uttered all-too-often—*just* socially constructed. Social construction becomes obvious, predictable, and fleeting in the long shadow of “real” “disease,” which is simply not the case.

A Phenomenological Solution to Ontological Gerrymandering

Phenomenology, symbolic interaction, and narrative analysis offer strong alternatives to this contemporary trend in constructionist medical sociology. A phenomenological perspective takes the “reality” of the objective world as neither “confirmed nor denied,” but, rather, it is bracketed in an act of “phenomenological reduction” (Schütz and Wagner 1970:6). Instead, “phenomenology is concerned with the cognitive reality which is embodied in the processes of subjective human experiences” (Schütz 1970:13). In other words, phenomenology purposefully sets aside presuppositions about what reality is and, instead, examines how social reality is experienced and, thus, constructed. Symbolic interaction, likewise, addresses meaning-making (Blumer 1970) and leaves “what reality is... to other students” (Goffman 1959:66; see also Turner 1992:105). Instead of asserting that a certain state or condition *is not medical* and has been *overmedicalized*, phenomenological and symbolic interactionist approaches are concerned with how a certain state or condition is, respectively, experienced and interpreted within a particular social context. This approach better avoids ontological gerrymandering by treating intersubjective realities as equally real.

In the *Social Construction of Reality*, Berger and Luckmann define reality as “a quality appertaining to phenomena that we recognize as having a being independent of our volition” and knowledge as “certainty that phenomena are real and that they possess specific characteristics” (Berger and Luckmann 1967:1). These definitions assert the subjective and contingent nature of reality and knowledge, which holds not only for those whom we research but also the researcher herself. In other words, within this theoretical

framework, the researcher does not have a privileged position in apprehending the real reality of things. Instead, Berger and Luckmann assert that a sociology of knowledge (grounded in phenomenology) must address what people know in their everyday realities (Berger and Luckmann 1967:15; see also Smith 1989).

A great strength of medicalization research is its careful study of macro-political and macro-social forces in defining illness, which is paralleled by a general weakness: a propensity for the voiced researcher to speak for the “medicalized” person from a primarily macro-political/ macro-social perspective. There are, however, two contemporary approaches in the sociology of health and illness that provide empirical counterbalances; these approaches address the everyday realities of people who are ill and are particularly amenable to a phenomenological analysis of health and illness. The first is the study of illness narratives, which take as their “object of investigation the story itself ... the purpose [of which] is to see how respondents in interviews impose order on the flow of experience to make sense of events and actions in their lives” (Riessman 1994:1 – 2; see also Frank 2010). Studies of illness narratives, however, are not homogenous in their approach. Some treat stories as representations of reality; some address how power is inscribed in narratives; and others treat narratives as constitutive of reality (Riessman 1994:22). A phenomenological approach is most clearly suited to the treatment of narratives as constitutive of reality (Frank 1997; Kleinman 1988). That is, storytelling is an important way that people can make sense of and structure a chaotic illness experiences (Frank 1997).

These stories, however, are not made in isolation; stories are social. Arthur Frank (1997) observes that illness narratives “have two sides, one personal and the other social.

The *personal* issue of telling stories about illness is to give voice to a body, so that the body can become once again familiar” (pg. 2). That is, illness narratives externalize the experiences of illness that are housed in the physical body. This telling, at once, re-organizes experience, reflects previous efforts at organization, and articulates a personal history of bodily experience. Frank continues, “The less evident social aspect of stories is that people do not make up stories by themselves” (Frank 1997:3). That is, narratives are made in collaboration with others and within a specific social context. Narratives represent one way that individuals are decisively linked to the social world. Thus, narrative analysis can be approached as both a micro and as a cultural project.

The other methodological focus in medical sociology that can contribute to a phenomenological approach to illness is the study of illness experiences. In a word, this is a study of the experiences of illness from the perspectives of people who are ill. This type of research often draws on illness narratives and treats them as representative of experience (Riessman 1994). An exemplar of this approach is David Karp’s *Speaking of Sadness*. Karp interviewed people who had been diagnosed with depression and their family members in order to “understand the phenomenology of the depression experience” (Karp 1997:19). While Karp takes a symbolic interactionist perspective that privileges the illness experiences of people, he still struggled with the disciplinary inclination to view depression and its medical treatment from a predominantly critical perspective (Karp 1997:9). However, as someone who experienced depression, Karp had another vantage on this illness that complicated the default view of *overmedicalization* as a blanket explanation for illness. Accordingly, Karp asserted that there was something

crucial missing in the study of health and illness: research “from the subjective point of view of the person undergoing it” (Karp 1997:11).

Likewise, Jean Elson’s *Am I still a Woman* exemplifies research that addresses the illness experience by focusing “on subjective understanding of what it is like to have a medical condition” (Elson 2004:13), from a distinctly constructionist position. She addresses the lived experiences of women who have undergone hysterectomies to explore the social construction of gender identity. The study of illness narratives/ experiences from a symbolic interactionist or phenomenological perspective (like those of David Karp and Jean Elson), while still the minority in the sociology of health and illness, are emerging.

As I have suggested, medicalization research and the study of illness experiences/ narratives are not mutually exclusive. Indeed, much of medicalization research, in some way, addresses the narratives and experiences of people. The choice to talk with individuals about illness, however, in no way guarantees a particular epistemological and analytic approach; instead, I argue that studies of illness experiences/narratives have the *potential* to address the phenomenology of illness from a constructionist perspective without ontological gerrymandering. From this phenomenological perspective, reality is located in intersubjectivity, and the study of illness narratives/experiences allows for a vantage on that constructed reality, privileging the lived realities of people who experience illness.

Phenomenology and the Study of Social Materiality

In addition to avoiding ontological gerrymandering, the phenomenological study of illness experiences/narratives opens up the study of bodies and the material world, which have been historically neglected in the social sciences and, more surprisingly, in the study of health and illness. There has, however, been a contemporary surge in research on the body, evidenced by the establishment of the Section on the Body and Embodiment in the American Sociological Association and the development of sociological journals on the body, especially the influential *Body & Society* (established in 1995). Nonetheless, the sociological study of the body has been relatively newly and has remained largely peripheral to the core of the discipline as a whole and in medical sociology.

In the following, I describe two intellectual trends in sociology on the empirical treatment or, rather, lack of treatment of the physical body and of objects. Together bodies and objects constitute a social materiality, that substance of everyday reality, and a topic carefully avoided by the strong majority of sociologists. In recalling these intellectual trends, I intend to draw attention to the possibility and the importance of productively continuing to bring materiality back into sociological study, especially in the study of health and illness and in the study of gender.

The Body in Sociology

Sociology has historically reflected the Cartesian rift between the mind and the body and has implicitly agreed that these two entities can be studied separately, perhaps even should be studied separately. The body has been relegated to the physical sciences, whereas the mind belongs to the humanities and the social sciences (Turner 1992:32).

The study of the body has been neglected in sociology in large part because there is an “implicit anxiety about ‘essentialism,’ that is against the Aristotelian doctrine that some objects, however described, have essences” (Turner 1992: 107). Seriously addressing the body has often been interpreted as giving credence to the essentialist position. With a cultural history steeped in notions of innate and biological differences that have reified inequality as legitimate (Gould 1996), the body became a contested site for social scientists, especially among race theorists and feminist scholars (Sydie 1994). Indeed, “feminist theory in the West has been preoccupied with shifting attention away from biology as an explanation for inequalities between the sexes to the social and cultural conditions that produce masculinity and femininity” (Davis 2007:126; Fausto-Sterling 2008; Spelman 1988).

Many of the efforts of social scientists to deal with essentialism have unintentionally ceded the body to scientific inquiry, to those who are, assumedly, uninterested in the social bases of materiality. For instance, Anne Fausto-Sterling locates the distinction between sex and gender, made by second wave feminists, as the “Achilles’ heel” of feminism. While this distinction initially allowed feminists to reclaim the social “gender”, it simultaneously ceded the biological “sex” to putatively non-feminist scientists. As a consequence, “biologists and medical scientists have spent the past thirty years expanding it [sex] into arenas we firmly believed to belong to our ally gender” (Fausto-Sterling 2008:1493). Fausto-Sterling asks, “Can we find a way to talk about the body without ceding it to those who would fix it as a naturally determined object existing outside of politics, culture, and social change?” Indeed, she suggests that the distinction between sex and gender, nature and nurture, materialist and sociality are

counterproductive and should be better theorized and re-integrated to remedy this medical and scientific cooptation of the physical body. Not just people, but also their physical bodies are gendered, literally shaped by gender ideology and gendered practices.

One way that postmodern feminists have attempted to reclaim the body is by conceptualizing bodies as culturally inscribed (Bordo 2003; Butler 1993; Haraway 1991). Treating the body as inscribed reclaims it as an object of study for social scientists by demonstrating how the body is configured by social forces and cultural ideas. From this perspective, the body is more than organic; it is cultural text. Some feminists, however, suggest that this approach, instead of bringing the body back in, further disembodies the social agent (Davis 2007:127). Postmodern feminist theory that deals with the body has become “so ethereal, so divorced from women’s everyday experiences with their bodies” (Davis 2007:121) that the physical body has all but lost its place in understanding the experience of women. They argue that postmodern feminists have largely rejected the feminist standpoint epistemologists’ claim that new and essential knowledge can be developed by addressing the experiences of women, arguing that the body is so deeply inscribed that experience will never get at the “truth.” Davis argues against this movement in thought, explaining that although the lived-experience of the body is complex and deeply inscribed by social and cultural entities, this is no excuse to ignore the body and reduce it to the sole status of text, to, in effect, remove the body from the physical world (Davis 2007:133). Davis argues that instead of rejecting the physical body as too complicated or difficult to measure, which weakens theories of gender and action, feminist theorists should be devoting time to “finding ways to *theorize* it” (Davis 2007:133; see also Connell and Messerschmidt 2005; Epstein 1990).

Despite this movement in gender theory to incorporate the body—specifically the gendered body—into our thinking about the social world, the bulk of sociological literature has and generally continues to frame the social actor as a largely disembodied and rational agent strategically interpreting the social world. In addition to gender theory, social science research on the topics of emotion and violence provide two other good exceptions to this trend of disembodiment (Collins 2008). Nonetheless, the “rationalistic bias in sociology” continues to mute important non-rational sources of action, specifically the body (Turner 1992:23). This division has led to a blind spot in sociology. Sociology has privileged rational action based on reflective thinking, but neglects the importance of the body in action (Swidler 1986; Vaisey 2009). The empirical and analytic inclusion of the body invites the irrationality or non-rationality of physicality, emotions, and so forth into our sociological discussion (Vaisey 2009). It is surprising that sociology has, for so long, successfully maintained distance from the body, which exists at the center of many of the core human experiences, such as “social processes . . . related to the conception, gestation, birth, development, death and disintegration of the human body” (Turner 1989: 35). This avoidance is doubly surprising among researchers in health and illness.

A Phenomenological Approach to the Body

The body poses significant challenges for the social sciences, while simultaneously offering much, if done carefully, in the way of analytic development. I argue that a phenomenological approach to the body is a powerful way to deal with many of the challenges involved in theorizing the body, while exposing the utility of including the body in social science research. In particular, phenomenological theorists have outlined three highly productive ways of understanding bodies, the last of which most

clearly advances contemporary theorizing on the body. For one, every person *is* a body, which indicates that the body is a part of the self. In other words, the physical body is a core and essential component of lived experience and selfhood. Also, every person *has* a body, which means that the body is also experienced as an object or an instrument that the subject (the person) can reflect on, act on, and act with. Lastly, the body is an actor, which suggests that the body, as an organic entity, can act on the person and in the social world. While the last two forms of the body suggest a mind-body dualism, the three forms of body, however, occur in tandem, which give way to a unified bodily experience. At any given moment, we are our bodies, we manage our bodies, and our bodies move us to action. Importantly, embodiment varies widely across cultures, over time, and between types of people. This particular scheme and interpretation of bodily experience is specific to contemporary “western” culture and, as such, serves the purposes of studies—like this one—that address physicality in the United States today.

As I have suggested, the body as a *social actor* is missing in most constructionist work in medical sociology, which can be traced back to legitimate concerns about essentialism. This, nonetheless, remains a glaring omission. Connell, likewise, asserts that “bodies are involved more actively, more intimately, and more intricately in social processes than theory has usually allowed. Bodies participate in social action by delineating courses of social conduct—the body is a participant in generating social practice.... We need to understand that bodies are both objects of social practice and agents in social practice” (Connell and Messerschmidt 2005:851). Indeed, it is not just that we manage our bodies and that our bodies are socialized, our bodies too act in the world, act on us, and move us to action.

Indeed, the body in distress is a primary mover in social life. A sharp and unrelenting pain in one's chest presses one to action. More modestly, hunger pangs press one to the refrigerator (Schütz and Wagner 1970:43). Of course, these bodily sensations are guided and transformed by the cultural context in which they emerge (Martin 2001). For instance, responses to chest pain may differ between men and women, young and old, and the insured and uninsured, and responses to hunger are shaped by diet, income, geographic location, and, perhaps, gender. Nonetheless, the body plays a vital role in action, whatever that action may be or how widely it may vary. As such, silencing the body, treating it as passive, represents an ineffective solution to the specter of essentialist research. Instead, there is theoretical and empirical space to view the *physical* body as a culturally inscribed social actor. Bodies should not be erased from the study of social action; instead, they should be carefully integrated back into it, with attentiveness to how to accomplish this without falling into essentialist tropes.

*Objects in Sociology*¹

The treatment of social materiality in sociological research is uneven. While sociological literature on the body is limited, it absolutely dwarfs the literature on objects (Cerulo 2009). This empirical omission cannot be explained by the newness of the topic. Indeed, the role of the material world in social life has been addressed by classical theorists Karl Marx and Emile Durkheim. Marx located material conditions as the sole premises from which the study of society can begin (Marx and Engels 1970:42), and Durkheim observed that the material world takes on social meaning (e.g., “totemism”) and becomes central to the development of social life (Durkheim 2008:180). There is

¹ A parallel and more extensive discussion of objects in sociological study can be found in “Emerging Objects, Developing Practices” (Esala and Del Rosso 2011).

little question that the material world had secured an important place in the writings of some of sociology's earliest and most influential classical theorists. Contemporary sociologists, however, have only recently begun purposefully studying the material world (e.g., Csikszentmihályi and Rochberg-Halton 1981), and this endeavor to include objects in sociological analysis remains a rarity.

The removal of the material world, and specifically objects, from sociological study has been traced back to Max Weber and then Talcott Parsons (Cerulo 2009; Owens 2007). Weber asserts that overt action is non-social if it is oriented solely to the behavior of inanimate objects (Weber 1978:22). That is, action in relation to the material world is not social and, as such, does not fall under the purview of sociological study (Cerulo 2009). Talcott Parsons similarly relegates the material world to the status of “nonsocial” (Parsons and Shils 2001:5). While there was an initial movement in social theory toward the inclusion of objects in the study of society, there was—apparently—a more influential movement away from the material world.

Symbolic interaction, however, did much to bring the material world, in the form of objects, into sociological study. Mead located objects, human and otherwise, as critical to social existence and selfhood (Mead 1938:428). Then, Herbert Blumer (1969)—in the process of systematically defining symbolic interaction—developed three categories of objects: physical objects (e.g., trains and cars), social objects (e.g., conductors and drivers) and abstract objects (e.g., the laws of physics and symbolic interaction). He further clarified the interactionist approach to objects by theorizing that “the nature of an object—of any and every object—consists of the meaning it has for the person for whom it is an object” (Blumer 1969:11). In short, intersubjective meaning-making imbues

objects with sociality. Blumer's discussion provided clear theoretical space in symbolic interaction for the inclusion of a wide range of objects in the study of social life.

Even more recently, in the sociology of science literature, there has been much concern about how knowledge is communicated across boundaries (Star and Griesemer 1989), and, as such, the material world/objects have become central to their intellectual project. Latour, for example, developed the concept of "immutable mobiles" to describe the transformation of information into material things, such as maps, that are both durable and mobile (Latour 1987:227, 2005:227; see also Smith 1989). Sociology's turn toward "things" (Komter 2001), "objects" (J. Cohen 1989), and "actants" (Latour 2005) has brought technologies, laboratory objects, animals, everyday objects, and bodies into the purview of sociological analysis. This inclusion of the material world in sociological study has also occurred despite long-standing traditions, specifically Weberian and Parsonian ones, which actively avoid such inclusions. This dissertation builds on these contemporary trends that take seriously the importance of the material world in social life.

Social Materiality, including bodies and objects, are again emerging as critical in the study of social life. The significance of materiality is especially salient in the study of health and illness. Nonetheless, the hesitation of sociologists to address social materiality is not without reason, especially within the prevailing epistemologies in constructionist medical sociology. For instance, one of the risks of critical constructionist research on social materiality, which treats some entities as constructed and others as "real" ("ontological gerrymandering"), is that it runs the risk of not only reifying *social* phenomenon—from their particular socio-historical location—but also essentializing

bodies and rendering material conditions deterministic. The combination of the dominant critical constructivist approach and the study of materiality are likely to produce the very problems of essentialism that sociologists have sought to avoid.

Conversely, a constructionist and phenomenological study of illness narratives/experiences situate reality in intersubjectivity, where it is theorized that all experience is contingent, constructed, and social. The seat of reality for phenomenologists, much like symbolic interactionists, is in the ever-shifting intersubjective landscape of social actors. Accordingly, this approach is amenable to the study of social materiality because it refuses to speculate about the objective (non-subjective) grounds of reality and, as such, locates the material world as both malleable (never reified) while still absolutely vital to the study of social life. This dissertation, then, takes on the task of studying illness narratives/experience from a phenomenological/ symbolic interactionist perspective while taking into consideration the role social materiality in illness.

Social Construction, Power, and Diagnosis

This phenomenological perspective and approach, admittedly, lacks of an extensive discussion of power that is typical in constructionist medical sociology. The study of intersubjectivity is predominantly a local and micro analysis, which closes off many opportunities for critical reflections on the role of power (at the macro/ institutional level) in illness experience. While this approach may be lacking a critical edge that constructionist medical sociologists are accustomed to, it is lacking for a reason. That is, this approach privileges the lived experiences of ill people—as constructed through their

illness narratives—and resists discussing power and macro institutions until observable traces of those social institutions emerge the illness narratives.

In this dissertation, medical diagnosis served as one such observable trace of power and as a vital link between the lived experience of illness and macro/institutional medical power. In other words, I address power through a concerted focus on how medical diagnosis—as an institutional construct—operates in the lives of people. In the following, I review literature on the sociology of diagnosis in order to elucidate how the study of lived experience and diagnosis has the potential to extend current medicalization research on medical power and authority.

A Sociology of Diagnosis

Diagnosis represents an empirical moment when the individual/ micro experience undeniably meets the institutional/ macro construct (see appendix B on the historical development of the diagnosis of mental illness). Medical diagnosis represents the critical juncture when an individual becomes a patient, when experience becomes disorder. Through diagnosis, the institution of medicine decisively enters the life world of the person diagnosed. From there, diagnosis acts in the lives of the patient, structuring the illness experiences of patients, linking individuals to broader medical institutions, and defining and delineating between normal suffering and treatable disease.

While diagnosis is arguably one of the essential features of modern medicine, its study in the social sciences has been subsumed in broader studies of health and illness. About two decades have passed since Phil Brown first called for a sociology of diagnosis (Brown 1990, 1995). There is, however, still no cohesive body of literature that directly examines medical diagnosis (Jutel 2009:278). In this section, I draw together the

disparate literature on medical diagnosis in order to (1) highlight the empirical differences in taking a macro versus a micro constructionist approach to the study of health and illness and (2) to demonstrate how a micro/ phenomenological study can effectively address power.

The study of diagnosis further elucidates the implications of studying illness from a macro/ critical perspective and from a local/ phenomenological perspective. The study of the institutional creation of diagnoses and the lived experience of diagnoses reveals diagnosis as “multiple” in sociological research (Mol 2002); that is, diagnosis becomes a different thing for different people (researchers) from different perspectives. From the macro/ institutional perspective diagnosis is predominantly an alienating construct, while the study of the local illness experience indicates something altogether different. For instance, individuals who suffer with distressing symptoms—without an explanation for them—long for the explanatory power of a diagnosis (Nettleton et al. 2004). From this perspective, within this particular socio-historical moment, there is something quite functional and desirable about medical diagnoses. The study of diagnosis from this local perspective reveals an increasingly complex picture of medicalization. That is, diagnosis—and, thus, medicalization—is Janus-faced: while it renders distress comprehensible, meaningful, and shared, it also indicates a difference and signals abnormality.

Medicalization as a positive and productive process is often neglected in critical constructionist sociological research. Diagnosis, however, often “works” in the lives of people. At the most fundamental level diagnosis does what any category does: it organizes and sorts disparate phenomena into (relatively) agreed upon entities. Diagnosis

● represents “the initial social discovery of the condition” (Brown 1995:34) and serves as a critical organizing tool (Jutel 2009:279). That is, diagnosis allows the suffering person to know “what is wrong” and helps them make sense of their experiences.

Diagnosis also allows the patient (and the physician) to move “between the idiosyncratic and the generalizable ... between the subjective and the formally objective” (Rosenberg 2002:241). Accordingly, diagnosis serves as a vital link between the individual and the social. What appear to be individual experiences, such as fear and anxiety, become inextricably linked through diagnosis to cultural expectations, organizational structures, and codified documents. Simply put, diagnoses (1) organize experience and (2) bridge individual and social worlds (Bowker and Susan Leigh Star 2000:7 – 8). Neither of these processes is inherently productive or harmful, but, rather, must be studied as they are experienced by people.

For instance, while the distinctions made through diagnosis organize social life, they can also complicate it. One key problem posed by medical diagnosis is that generalizable categories, like diagnoses, never fully capture the local experiences of distress. For instance, “diseases are conceptualized as distinct, objective entities that are common to afflicted patients” (Chiong 2001:90; Rosenberg 2002) even though physicians are often confronted with “unclear, unconnected, and mysterious” symptoms (Phil Brown 1995:39). Physicians are expected to organize those disparate symptoms into a discrete entity. This paradigm of “disease specificity” (Rosenberg 2006:412) “structures the expectations of patients and physicians” (Chiong 2001:90). That is, doctors expect to find (and define) discrete diseases, while patients expect to receive clear and fitting diagnoses. But, of course, diagnosis does not always fully capture the lived experience of the patient.

At the intersection of people's lived experience and of diagnosis as a category/process, reside the idiosyncratic individual and the general institutional narratives, which are navigated by the medical practitioner, the patients, and his or her friends and family. Indeed, "diagnosis remains a ritual of disclosure: a curtain is pulled aside, and uncertainty is replaced—for better or worse—by a structured narrative." (Rosenberg 2002:255, *emphasis mine*). That is, diagnosis attempts to replace individual narratives with an institutional narrative. Diagnosis represents the lowest common denominator in shared physical, emotional, and mental distress. This reductionism is a cost of linking individual distress to social experience. In the process, diagnosis re-orders and segments "corporeal states, valorizing some, disregarding others, and in any case, exerting an important *material force*" (Jutel 2009:278, *emphasis mine*). Accordingly, diagnostic categories have the potential to significantly alter the experience, even the physical experience, of distress.

Diagnosis is, thus, necessarily reductionist; it takes the complexity of social experience and physical, mental and emotional distress and reduces it to a standardized set of criteria. It is incredibly difficult to fit "idiosyncratic human beings into constructed and constricting ideal-typical patterns, patterns necessarily abstract yet, in individual terms, paradoxically concrete" (Rosenberg 2002:251). The idiosyncrasy of lived experience—that so often fails to conform to diagnostic categories—suggests that people will often need to alter and modify either the meanings of their diagnoses or the meanings of their experiences. The friction between social categories and individual experiences suggest that the relationship between the two will be contested "in countless clinical, bureaucratic, and administrative contexts" (Rosenberg 2006:409). This tension

and negotiation is the core object of study in this dissertation. In short, I explore how it is that people and diagnoses accommodate one another.

Diagnoses appear as institutional, professional, abstract, and formulaic, but they—more importantly—also “have real world consequences for particular men and women” (Rosenberg 2003:504). Diagnoses take on meaning in the lives of people who are diagnosed, and, as such, absorb the nuance and texture of the social lives of individuals (see Karp 1997). While diagnosis certainly reduces a wide range of experience—in many regards—to a set of diagnostic criteria (Kleinman 1988:6), components of the illness experience continue to evolve in relation to “broader social perceptions and interactions such as interpersonal crises, perceived interference with social or personal relations, social support from friends or family, sanctioning on the part of another family member, perceived interference with work or physical activity” (Phil Brown 1995:45). In short, while a diagnosis is an objectified set of criteria, it is also manifests over time in a relationship with specific people and within specific social contexts (Pickering 1993).

Following Charles Rosenberg, I argue that an important oversight in the study of medicine in general and diagnosis in particular is that, “even though contemporary diagnosis is ordinarily a collective, cumulative, and contingent process, it is significant that most of us think of it as a discrete act taking place at a particular moment in time” (Rosenberg 2002:256). Contrary to this image, people spend much time and effort formulating their own interpretations (and categories) for their experiences before official diagnosis and continue to spend time and energy making sense of the medical diagnosis in the context of their local experiences afterwards (Kleinman, Eisenberg, and Good

1978). A sociology of diagnosis can provide a more complete and detailed map of the diagnostic experience, taking into account the life experiences that lead to diagnosis and the consequences of diagnosis for people afterward.

The extent to which medical diagnosis continues to evolve “beyond the clinical doors” (Chiong 2001:89), arguably, represents a relatively new phenomenon. While researchers argue that there has never been a “more skeptical or reflexive period” (Rosenberg 2006:418; see also Giddens 1991), Rosenberg observes that this skepticism and reflexivity stands in stark contrast to the reductionism that abounds in modernity, which is especially evident in medical diagnosis. The meeting of a skeptical/ reflexive culture and reductionist medical categories strongly suggests that there will be tension between the two. This is further complicated by the fact that patients have more medical choice and informational resources, and, as such, they are more likely to take the interpretation of their illness into their own hands (Jutel 2009:294). The autonomy, access to information, and reflexivity of modern patients illustrate how diagnosis is becoming an increasingly complicated and dynamic social process.

Diagnoses are in active dialogue with the everyday lives of people, in which “diagnosis is both framed by and, in turn, frames the social reality of patients” (Jutel 2011:190). Diagnoses become actors through and in the social lives of people and become “real inasmuch as we have believed in them and acted individually and collectively on those beliefs” (Rosenberg 2002:240). Accordingly, one key question for the sociology of diagnosis—addressed in this dissertation—is: how does diagnosis translate into the patients’ everyday worlds? Medicine’s authority has been located in its ability to define what is and is not legitimate “disease” (Jutel 2009:284; Conrad 1992;

Conrad and Joseph W. Schneider 1980b), which is generally identified at the institutional level and in the confines of the doctors' office. This is a critically important and influential thesis of medicalization literature, but this thesis does not capture how that definitional power extends or fails to extend in the lives of people. The very high rates of noncompliance rates for medication alone suggest that institutional protocol and doctors' orders do not explain how and why people accept or reject medical knowledge (Conrad 1994; Kleinman et al. 1978). A study of diagnosis from the perspective of people who have been diagnosed, on the other hand, provides insight into this extension of—or, perhaps, failed extension of—medical authority and allows for a study of how “psychiatry and its concepts bleed constantly and unavoidably into the larger culture” (Rosenberg 2006:422).

Plan of the Dissertation

In this dissertation, address two core research questions. One, how does social materiality contribute to, shape, and lend empirical understanding to the experience of an anxiety disorder and to the experience of illness in general? Two, how does medical diagnosis translate from the medical institution into the lives of people who have been diagnosed? To address these questions, I document the narratives of men and women who have been diagnosed with an anxiety disorder. Through these narratives, I trace the co-construction of the illness experiences and medical diagnoses from the perspectives of people who have been diagnosed. Specifically, I explore how people come to seek and locate an anxiety disorder diagnosis, the gendering of anxiety/ fear in general, the

gendering of the diagnosis of anxiety disorders in particular, and the long-term consequences of diagnosis in the lives of people.

In chapter two, I address how I collected and analyzed the data and provide an overview of the social characteristics of the people I spoke with and observed and the contexts in which our conversations and the observations took place. In short, this chapter provides the specifics of the methodology and methods that I employed in this study, which build on the theoretical framework I have outlined in the foregoing review of the literature.

Chapters three and four address the research participants' experiences of illness before diagnosis. Chapter three, "Bodies, Objects, and Social Interaction", addresses the research participants' first indications that something was wrong, that they might be ill. I find that while distressing physical sensation served as an important sign of pathology, the conclusion that something was wrong was more clearly secured through social interaction. More specifically, the identification of pathology hinged on the rupture of shared definitions of objects. That is, when interviewees realized that their fearful interpretation of objects were not shared by significant others, this strongly suggested to them that "something was wrong." Indeed, objects served as bridges between the individual and the social experience of distress. Overall, pathology was identified in social collaboration, which depended on shared (and then unshared) interpretations of objects. In this way, social materiality figured prominently into the initial phases of the illness experience.

Chapter four, "Fearless Fear", explores what pressed the research participants to seek medical care. Again, objects play a critical role in the illness experience. As the

research participants' distress intensified and their experiences became more physical, interviewees reported that their symptoms were no longer "prompted" by any specific object or situation. As such, it became increasingly difficult to attribute their physical sensation to the emotion "fear." Rather, they often mistook severe anxiety for other, more medically consequential, physical and mental illnesses, which prompted urgent treatment seeking. In a word, the combination of distress, the falling away of explanatory objects, and the subsequent inability to tether sensation to an emotional experience pressed many of the interviewees to actively seek treatment. Additionally, this chapter suggests that diagnosis plays a critical role in stabilizing, ordering, and neutralizing these types of intense, objectless, and very physical experiences.

Chapters five and six address how gender structures anxiety in general and the diagnostic process in particular. In chapter five, I explore the role of gender in the expression and experience of anxiety. As far as the gendered expression of anxiety, I find that men were less likely to talk openly about anxiety, they provided different ("de-centered") narratives about anxiety, and that the specific context of our discussions of anxiety appeared to especially influence how men talked about anxiety. In short, men were less able to freely discuss their own experience of anxiety than were women. As far as the experience of anxiety, I suggest that men and women may—through socialization—come to physically experience anxiety differently. Simply put, through socialization men became less attuned to fear-related physiology. Although this finding is far from conclusive, the evidence in the interview data that suggests that physical sensation is socialized and gendered—which is supported by a range of research from a diverse set of fields. These preliminary findings are provocative and implore for more

research. Moreover, this chapter suggests that two mechanisms (i.e. experience and expression) of “self-labeling”—which is the process by which people come to label *themselves* as disordered—are gendered (Thoits 1985), which may help explain different rates of anxiety disorder diagnosis among men and women.

Chapter six, “Anxiety Disorders as Gendered Diagnoses”, explicitly address the gendering of the diagnostic process within the doctor-patient interaction. Gendered disorders, like an anxiety disorder, can influence how medical practitioners (among others) see, organize, and make sense of a constellation of symptoms differently among men and women. As a consequence, men with anxiety-related symptoms spent longer amounts of time seeking a fitting medical diagnosis, and doctors consistently misdiagnosed and overmedicated men. These data suggest that there is a network of gendered beliefs and ideology, beyond the individual, that hinder the recognition of anxiety among men and hasten it among women. In combination, the gendered experience and expression of anxiety and the gender-bias in diagnosis provide compelling explanations as to why women are twice as likely as men to receive an anxiety disorder diagnosis.

Chapter seven and chapter eight examine the consequences of an anxiety disorder diagnosis for the research participants. In chapter seven, “After Diagnosis”, I find that medical diagnosis played a critical role in significant transformations in the interviewees’ self concepts, social relationships, and perceptions of everyday experience. Diagnosis altered the interviewees’ self concept by confirming for them that they were “irrational” and that their worldview was fundamentally flawed. This change in self-concept prompted changes in their social relationships; specifically, diagnosis preceded an

increased dependence of “disordered” selves on “non-disordered” significant others (like husbands, wives, friends, therapists, and so on). This transformation represents an extension of definitional power—through diagnosis—from the medical practitioner to significant others in the lives of the interviewees. As a consequence, after diagnosis, interviewees came to see a wider and wider range of less intense distressing experiences—that they once defined as “normal”—as components of an anxiety disorder. Put differently, over time an anxiety disorder diagnosis came to explain increasingly more of the interviewees’ everyday reality. These changes, after diagnosis, prompted confusion among the interviewees about how to distinguish between normality and abnormality and the health and pathology of their everyday experiences, perceptions, and behaviors.

Chapter eight, “The Body – Category Dialect”, extends the previous chapter by focusing on changes in how the interviewees interpreted, experienced, and responded to their bodies after diagnosis. I begin by discussing how diagnosis helped the research participants to order experience and manage distressing sensation by providing new meanings for physical sensation and by allowing the interviewees conceptual and practical space to ignore distressing bodily sensation. Then, I discuss a dialectical relationship between the body and the diagnostic category that facilitated an expansion of what physical sensation an “anxiety disorder” could explain. Notably, in some cases, the research participants used the diagnostic category to explain increasingly distressing physical sensation in terms of anxiety. I then describe how the expanding explanatory power of an anxiety disorder diagnosis blurred the boundaries between an “anxiety disorder” and more medically consequential illnesses.

This dissertation follows the life course of anxiety disorder diagnoses through the narratives of people who have been diagnosed: from the initial experiences of anxiety to decades after receiving a medical diagnosis. My intent is to explore how diagnoses emerge and act in the lives of people. This study reveals that diagnoses, bodies, and objects (in addition to patients and physicians) are active, influential, and constitutive parts of the experience of anxiety.

CHAPTER TWO

METHODOLOGY AND METHODS

In this chapter, I address the methodology (“theory and analysis of how research does or should proceed”) and the methods (“techniques for... gathering evidence”) that I employed in this dissertation research (Harding 1987:2 – 3; Naples 2003:3). My methodology is outlined in the first section of this chapter, in which I provide my interpretation of what qualitative research accomplishes and contributes to the study of society. The subsequent sections of this chapter address the methods (specifically, qualitative interviews and participant observation) employed in this study, including a discussion of the sampling strategy, characteristics of the research participants, and analysis.

Methodology

In this section, I compare and contrast “qualitative” and “quantitative” work, reified as such (Oakley 2000), to clarify what qualitative work does well and to broadly introduce the objectives of my own qualitative methods. But, before I do that, to forestall any confusion, I should clearly state my own methodological position. I am a methodological pluralist who views the social world as incredibly complicated and

complex, and I maintain that this overwhelming complexity necessitates a broad range of methods to even begin to approach it (Law 2004). I find quantitative and qualitative methods to be entirely, interdependently, and differently necessary to the study of social life. In the next pages, I discuss the strengths and potentials of *qualitative* methods and, admittedly, give short shrift to the virtues of quantitative methods. I do this because: this dissertation is based on qualitative methods and, as such, is what I set out to discuss; the potential, purpose, and value of quantitative work has been widely discussed in sociology and is well (or at least better) understood; and the contrast between the two brings the value of qualitative work into sharp relief.

One of the most common (and entirely misguided) critiques of qualitative research is that it is “not generalizable.” Some researchers have responded to this critique by trying to show how, indeed, their qualitative work is generalizable. Clifford Geertz reflects on this approach, “The models that [ethnographers] have themselves worked out to justify their moving *from local truths to general visions* have been, in fact, as responsible for undermining their effort as anything their critics have been able to devise against them” (Geertz 1973:21). Like Geertz (and many, many other qualitative researchers), I maintain that qualitative research is, simply put, not generalizable (since it is rarely, almost never, based on a representative sample) and, indeed, should not strive to be generalizable (since this is neither its strength nor its contribution).

Instead, one of the primary strengths of qualitative work is that it is local and concrete. Herbert Blumer charged his contemporaries with writing about topics, events, and groups of people with which and whom they had no real contact (1969:35 – 36), which lent itself to: the top-down development of concepts biased by gender, race, and

class privilege; flawed sampling strategies that missed marginalized and hard-to-reach populations; and over-extended and biased interpretations of findings. Conversely, qualitative research examines the real-world practices and talk of people that can give body and voice to disembodied and generalizable statistics. Moreover, local qualitative research can provide the methodological and analytic leverage necessary to develop more useful concepts, better sampling strategies, and grounded interpretations (derived from direct observation).

Burawoy has articulated an approach called the extended case method. While, in many regards, this approach is distinct from my own—I emphasize a methodology more closely aligned with symbolic interaction and the Chicago school—it offers an “extension” from the local to the extra local that is central to my own research (Burawoy 1998:5). That is, while Burawoy does not seek “representativeness” in through the extended case method, he does seek to extend beyond the local through theory reconstruction. The extended case method, in part, seeks to link the local to the extra local by putting “folk theory or indigenous narratives” in active dialogue with “academic theory” (Burawoy 1998:7). This approach extends by using the local to refute expansive theoretical tenets “that inspire us to deepen that theory” (Burawoy 1998:16). This particular aspect of the extended case method is amenable to my own approach to research. In addition to the value of qualitative work in articulating local experience, I attempt to reconstruct and contribute to theory in the sociology health and illness.

Qualitative methods are also equipped to address meaning, which is core to the study of culture. Geertz eloquently and succinctly summarizes Max Weber’s view of man in culture as “an animal suspended in webs of significance he himself has spun” and

continues, “I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of a law but an interpretative one in search of meaning” (Geertz 1973:5). The flexibility and sensitivity of qualitative methods allow the researcher to empirically trace intersubjective meaning-making and the more subtle shifts in meaning over time. Likewise, Herbert Blumer’s often quoted description of the premises of symbolic interaction suggests the critical importance of qualitative research in sociological inquiry. He writes,

The first premise is that human beings act toward things on the basis of the meaning they have for them.... The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows. The third premise is that these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters (Blumer 1969:2).

For Blumer, and many other sociologists, social life is composed of a complex of meaning making, interaction, and interpretation. Qualitative research lends itself to an iterative and interactional examination of meaning-making that is sensitive to subtle changes (Hoonard 1997:57). For instance, one of the strengths of ethnography is that it allows the researcher to observe, document, and analyze how meaning-making and social interaction develop over time, and qualitative interviewing, in general, allows the researcher to address the complexity of meaning-making by hearing people’s—often complicated—stories in their own words.

One very powerful way that qualitative research captures meaning-making is by giving voice to previously marginalized groups of people. For instance, Patricia Hill Collins in her book *Black Feminist Thought* draws on narratives and writing of black women in order to provide a thick discussion of black women’s history, perspectives, and experiences that have historically been silenced in academia. This work (and works like

it) provides a more textured, nuanced, and inclusive picture of social life. While a slow development, sociology has gradually allowed more and more voices in; this trend is in large part thanks to the qualitative work of feminist and race scholars (Reinharz 1992).

I offer two brief comparisons between qualitative and quantitative methods that highlight *why* qualitative methods are especially well equipped to capture once liminal voices. First, the objectives of the two groups of methods—generalizability and specificity—play a critical role in what the subsequent data have to offer. While large scale survey studies gain valuable generalizability, they, necessarily, lose marginalized voices. Local specificity is (purposefully and productively) erased in unexplained variance and control variables. At the most basic level, very small populations and local trends are missed in generalizable analyses. Qualitative methods, however, allow the researcher to “build in” peculiarities rather than trying to “control” for them (Becker 1998:56). Qualitative work can, has, and should continue to bring in the voices that are too few, too local, and too poorly measured (or not measured at all) to be heard in quantitative studies. In short, while generalizable research shows critically important large-scale *trends* in research, qualitative research can explore the, equally critical, “unexplained variation” of social life. This is no janitorial sweep-up; studying components of social life that remain invisible in aggregate represents an essential practice that pushes sociological research forward.

Second, the data collection protocols (e.g., close-ended survey questions, open-ended interview questions, and observation/field notes) profoundly and differently impact *what* the research participant can communicate. Qualitative methods significantly expand the range of what can be said and how. Survey research certainly allows the “respondent”

to speak but only in the terms defined by the researcher. As anyone who has done any amount data entry can attest to (which I can), respondents often mark multiple boxes (when they were told, “Only choose one!”), cross out words in the questions and responses, and write (sometimes copious) notes in the margins. What happens to those marks in the analysis? Generally speaking: nothing happens. These marks are often discarded as irrelevant or cited as grounds for indicating “missing data.” The qualitative researcher, however, would see these marks as potential data and as signs that there is more that this person wants to say. Qualitative work has the potential to capture a greater range and depth of what *each person* has to say by not limiting (or putting fewer limits on) their responses. In qualitative work, what is lost in generalizability is gained in both local specificity and the range and depth of data available.

Still, qualitative work does not simply reflect the experiences of the research participants. The qualitative researcher too plays an active role in generating, producing, and shaping data (Charmaz 2003; Flick 2008; Green 2010). The qualitative interview, perhaps, is best able to capture the meanings people impute on their own experience because they narrate it in their own words. Still, the researcher—to varying degrees—guides the topics that the interviewee addresses, and, in the end, the researcher chooses how to analyze, interpret, and frame the passages of text. While there is so much *potential* to better or more fully capture meaning and interpretation through qualitative research, it is in no way inherent in the method.

Nor does participant observation simply reflect social life. For instance, field notes are largely documented in the words of the researchers (with the exception of “direct quotes” from the field site); so, at the level of data collection, the meanings,

interpretations, and interests of the researcher infiltrate the process. Realities are not discovered by the researcher; they are “made and remade” (Rabinow 2007:150). Research creates a hybrid “object or product” through the collaboration of the researcher and the informant (Rabinow 2007:153). Of course, a benefit of participant observation is that the author gets to see—first-hand—social life in action. Since qualitative methods provide the *opportunity* for researchers to give voice to and directly observe phenomena that are largely missed by other methods, the qualitative researcher has a duty to the discipline and to her research participants to carefully attend to intended meanings, contexts, and full narratives of the participants and to be explicit about her role in the research process (Reinharz 1992; Trish Green 2010). The remaining pages of this chapter are dedicated to making the methods of this research study and my role in it as explicit as possible.

Methods

In this section, I transition from a discussion of my interpretations of what qualitative research can and should do to how I actually did my research. This dissertation is a qualitative multi-method study aimed at exploring the lived experience of anxiety and medical diagnoses from the perspective of the person diagnosed. To this end, I conducted in-depth interviews with 40 people who have been diagnosed with an anxiety disorder and eight months of participant observations at anxiety disorder support groups. In other words, I talked with people retrospectively about their experience before, during, and after medical diagnosis (interviews) and also observed, in a natural setting, as they reflected on their experiences of anxiety and collaborated to learn how to better manage

their symptoms (participant observation). This has allowed me to explore: meaning-making about physical distress that leads to treatment seeking, the social bases of the diagnostic process, and lived experience after diagnosis.

In-Depth Interviews

One component of the method was in-depth interviews with 40 individuals diagnosed with an anxiety disorder. The main criterion for participation was that the interviewee had to have been medically diagnosed with a panic disorder, a generalized anxiety disorder, and/or agoraphobia. 83% (N = 33) of the interviewees had been diagnosed with a panic disorder; 75% (N = 30) had been diagnosed with a generalized anxiety disorder; and 30% (N = 12) had been diagnosed with agoraphobia. 25% (N = 10) had been diagnosed with all three disorders; 38% (N = 15) had been diagnosed with two of the disorders; and 38% had been diagnosed with one of the disorders (N = 15).

Still, the interviews did not represent an uncomplicated picture of the lived experiences of people diagnosed with at least one of three particular forms of anxiety disorder. Anxiety disorders are highly comorbid, and, likewise, the majority of the interviewees reported maintaining multiple mental health diagnoses. More precisely, 68% (N = 27) reported a comorbid mental health disorder, with the most common being depression and post traumatic stress disorder. Other co-morbid mental health disorders included: social anxiety disorder, eating disorders, bipolar disorder, dissociative identity disorder, attention deficit disorder, substance abuse, and obsessive compulsive disorder. While the common thread in all of these interviewees was the lived experience of an anxiety disorder, the presence of other mental health symptoms made the experience of anxiety far more complicated for the person diagnosed and in my analysis.

Howard Becker observes that actual cases rarely fit the neatly into a single shared category; they, rather, suggest what Wittgenstein calls “family resemblances” (Becker 1998:129). That is, there is something fundamentally similar about these people and their experiences, but they also have characteristics that set them apart. The family resemblance of anxiety, complicated by social variation, allowed me to explore the themes common to all of the interviewees, while drawing analytic insight from what sets them apart. This delicate balance between similarity and difference guided my approach to the research design, sampling strategy, and analysis.

The strongest commonality among the interviewees was fear, in a variety of shades: anxiety, terror, nervousness, panic, worry, dread, apprehension and so forth. This fundamental commonality proved a formidable challenge in securing interviews. One such anxiety-related obstacle was getting the recruitment material to this often hard-to-reach population. To this end, I employed a wide range of recruitment strategies. I began by putting up fliers in public places, like coffee shops, libraries, community centers and leaving fliers at local support groups and clinics. About 28% (N = 11) of the interviewees were recruited in this fashion. While distributing fliers at publically advertised support groups, three support group leaders offered to participate in the study. I also conducted participant observation at support group (which I discuss in a later section), and, in the process, two support group members approached me to participate as interviewees in the research study.

While talking with another interviewee, Lori, who was recruited through a flier near her home, I asked her if she had ever been to an anxiety support group. She was amused, “No! I would be too nervous. [laughs] I wonder how an *anxiety* group would

turn out! [Laughs loudly]” Lori’s experience of panic rendered the notion of an anxiety disorder support group absurd, even comical. Her response prompted me to reflect on *who* I was accessing in interviews and at the support groups. Most directly, I was likely missing a large proportion of people with anxiety: who are not comfortable around other people, do not leave their homes, do not go to coffee shops, to libraries, to community centers and so on. Specifically, I was concerned that I was missing people who had severe panic disorders and/or agoraphobia.² There was one obvious way I could try to reach these people: the internet. I posted recruitment material on a public website seeking volunteers for the study. The majority (45%; N = 18) of the interviewees were recruited through this online site.

Another obstacle to securing interviews was building trust *before* meeting for the interview. Many of the people who contacted me expressed hesitancy about meeting with someone whom they did not know, simply based on seeing a flier or an ad on the internet. But a few factors worked in my favor. Like Emily Martin, who found that her university affiliation put many of her interviewees at ease and validated her project (Martin 2001), my interviewees, similarly, reported that they were assured by the fact that I had a *University of New Hampshire* e-mail address and an office located on the university campus. Also, and quite fortuitously, a college news publication, *The College Letter*, featured my research in a very positive light, which was subsequently displayed prominently on the UNH graduate school website. Three interviewees indicated that they had read the article, which prompted them to contact me and participate in an interview.

² While the DSM-IV indicates that agoraphobia can only be diagnosed in tandem with a panic disorder, suggesting a causal relationship, two interviewees identified with agoraphobia to the near exclusion of a panic disorder. Notably, proposals for the DSM-V suggest the separation of panic disorder and agoraphobia. In other words, agoraphobia will likely become stand-alone diagnosis within the next few years.

The article provided a new venue to recruit participants, but it also legitimated the project to the reader, providing them assurance that my intentions were good and the process was safe. The other way the project was lent credibility was through personal referral; two of my interviewees were referred to me by previous interviewees.

While the interviewees were largely recruited through convenience sampling, which is typical of qualitative studies with hard-to-reach populations, the recruitment methods were tailored to the unique situation of the interviewees. Traditional “flier-ing” was accessible to individuals with anxiety who were able to move easily around their towns and regions; sharing recruitment materials with support groups and clinics gave individuals who were actively seeking therapeutic interventions and medical treatment access to the study; and posting the recruitment materials online and snowball sampling made the information available to individuals who were housebound. These recruitment strategies connected me to people who had the common experience of anxiety, but also with diversity in where they were in their illness experience (from an initial diagnosis to complete recovery), the severity of their anxiety-related symptoms, and the degree to which the disorder interfered with everyday living. The commonalities and the variety provided a rich portrait of experiences of anxiety disorders across the life course.

Once I made contact with a potential interviewee, the next obstacle to securing an interview was to help the interviewee feel comfortable enough to follow-through and meet for the interview. In the end, I was stood-up as many times as an interview came into being. While “no shows” are an expected feature of interviewing, the frequency at which it happened in this study suggested that anxiety may have played a role. After I noticed a pattern of about every other interviewee not showing up for the interview, I

decided that I needed to take another approach. First, I made additional efforts to prepare the (potential) interviewee for the interview process. I gave them a thick description of the type of questions I would be asking, assured them of their rights as an interviewee before we met (“You can stop the interview at any time,” “You do not have to answer any questions you do not want to answer,” and so on), and encouraged them to bring a supportive person along to the interview (which is common practice among anxiety disorder support groups).³ Generally, I think this helped the people I talked with feel more comfortable before and during the interview—as it would most interviewees—but I did not get the sense that these efforts actually reduced the number of no shows.

What I found to be more helpful in reducing “no shows” was to offer multiple mediums for the interviewee. While the majority (65%; N = 26) of the interviews were conducted in person, I also offered the prospective interviewees the option of conducting the interview over the telephone (25%; N = 10) or through e-mail (10%; N = 4). Certainly, I would prefer the detailed observation afforded by in-person interviews, but, at the same time, an exclusively in-person interview approach would leave out the voices of people who have severe anxiety and were unable—at that point—to participate in a face-to-face interview. Interviewees were clear that they were grateful that this range of options was available to them. For instance, Melinda actually preferred to meet in person. We met in a coffee shop, while her husband sat at another table across the room. It was reassuring for her to have her husband nearby, to meet in a neutral public place, and to talk face-to-face. She explained that she dreads talking on the telephone, to the extent that she has lost close friendships after moving because she couldn’t bear to talk on the telephone. She identified this discomfort as a component of a generalized anxiety

³ Only one interviewee brought a supportive person (her husband) with her to the interview.

disorder. As such, meeting in person was the most comfortable way for Melinda to participate in the study. Conversely, Tina—who I talked with over the telephone—was diagnosed with agoraphobia, rarely left her house, and was nervous to have someone come into her home. If I was only conducting in-person interviews, Rachel (and other people with this particular experience of anxiety) would not have been able to participate in the study. Likewise, e-mail interviewing proved to be a powerful way for people with severe social anxiety to participate in the study. While much is lost in the translation from interviewee-to-text and then text-to-researcher (and *vice versa*), far more is gained than is lost by being able to talk with people who otherwise would not have had the opportunity to be heard.

More about the Interviewees

Qualitative sampling involves a precarious balance of homogeny and diversity which allow for, respectively, in-depth analyses of common themes and critical reflections on distinctions in the data. The risk of homogeny is that the study becomes overly descriptive and falsely universal, and the risk of diversity is that you will lose the common thread that pulls the narratives together. This balance is further challenged by issues of sampling, like those discussed in the foregoing section. In this current section, I describe my interviewees as a group. In some regards, my interviewees were very much alike. They all had anxiety disorders, most lived on the east coast, and shared many demographic features. This allowed for the in-depth analysis of common themes and stories in their illness narratives. There was also, of course, diversity among my interviewees. They were at different points in their illness experiences, came from different economic backgrounds, and had different levels of education, among other

variations. These illness narratives in both their homogeneity and complexity “present the sociological mind with the bodied stuff on which to feed... complex specificness, their circumstantiality” (Geertz 1973:23).

The gender composition of my interviewees posed the most significant challenge in sampling and analysis, while also offering some of the most significant insights. Here is the problem: researchers have established that women are almost twice as likely as men to be diagnosed with an anxiety disorder (Kessler et al. 2005) and men are significantly less likely to talk about feelings of anxiety (Simon and Nath 2004). In other words, fewer men than women have an anxiety disorder diagnosis and men who do have an anxiety disorder diagnosis would be less likely to talk about it than women. Likewise, I anticipated that it would be a challenge to locate men with anxiety disorders who would be willing to talk with me about their experiences of anxiety. I began by convenience sampling, as outlined earlier, and was contacted nearly exclusively by women. In response, I attempted purposively sampling men by posting fliers and online ads specifically recruiting men with anxiety disorders. The response to these efforts was meager. No men responded to the online ads, and only a couple of men responded to the fliers. I also attempted snowball sampling from my current interviewees (especially the men), but, despite the fact that many of the interviewees reported personally knowing men with anxiety disorders, not a single interviewee was able to refer me to a man who would be willing to talk with me. Despite my efforts, 85% (N = 34) of the interviewees were women. My best guesses as to why so few men participated in the interviews were that fewer men are diagnosed with an anxiety disorder, men are less willing to talk about anxiety in general, and that my gender identity (as a woman) may have made the

interview even more difficult for some men. But, as luck would have it, the support groups were absolutely flush with men. So, the combination of participant observation, a close analysis of the men's illness narratives, and a careful review of interdisciplinary literature on the topic allowed for an analysis of the gendered experience of anxiety. In the end, one of the most striking differences between male and female interviewees was the length of time between treatment seeking and diagnosis. The average time for the female interviewees was 3.8 years, while it was 15.8 years among the male interviewees; this pattern was mirrored among the support group members (I take up this discussion in chapter six).

Additionally, I find striking differences in how men talked about anxiety in the interviews and how they talked about it during support group meetings. In short, men were far more forthcoming about their experiences of anxiety in the group setting. In chapter six, I explore some of the reasons why this might be, with a particular focus on how support groups are conducive to open discussions of anxiety among men. The differences in the content of these narratives across mediums, however, may also have quite a bit to do with gender dynamics during the interview itself (see Williams and Heikes 1993). Indeed, my gender (as a woman) may have posed significant challenges for men in fully expressing gender deviant emotions, especially fear (Zillmann et al. 1986). Moreover, my age (late twenties) may have further complicated the interaction. While beyond the purview of this particular study, future researchers might explore gender dynamics in interview-based discussions of fear and anxiety.

The majority of my interviewees lived in New Hampshire or the surrounding states, and, according to 2010 census data, New Hampshire is composed of about 94%

white residents (United States Census Bureau 2011). Not surprisingly, all but one of the interviewees identified as white. The narrative of Ana—who did not identify as white—suggested that race and ethnicity are important factors in the illness experience. Ana identified as “mulata” and explained that her mother was black and her father was Indian and she grew up in a Spanish speaking country. She explained that the plurality of racial and ethnic identities “affected [her] tremendously.” Ana connected some of her experiences of anxiety to immigration and racial discrimination and attributed her distrust of pharmaceuticals to growing up in a culture that favored more “natural” medicines. Race, ethnicity, and immigration profoundly shaped Ana’s illness experience. In my analysis, I remained attentive to the lack of racial and ethnic diversity among the interviewees and aware that this study largely represents the views and experiences of a specific group of people: who identify as white and primarily live on the east coast. But, as anthropologist Clifford Geertz observes, “It is not necessary to know everything in order to understand something” (1973:20). This study provides insight into a particular experience of anxiety, and other researchers can “plunge more deeply into the same things” (Geertz 1973:25) by capturing some of the diversities absent among my interviewees.

While diversity was a challenge to find in some regards, it was bountiful in other. As sociologist Howard Becker writes about on-the-ground, real world “cases”, every time we “find such a similarity, we will also immediately find such a difference” (Becker 1998:127). For instance, while the experience of anxiety was common to all interviewees, how long it had been since they were diagnosed with an anxiety disorder varied tremendously. The number of years between diagnosis and the time of the

interview ranged from less than a year (N = 5) to 37 years (N = 1) with an average of 12 years. As such, the location in the illness experience varied quite a bit in these narratives. This provided insight into the entire life course of the illness experience, from the months after diagnosis to decades of coping with a diagnosed disorder.

Similarly, treatment seeking started at a range of different ages. The average age at which anxiety-related symptoms intensified to the point that the interviewees felt that “something was wrong”⁴ was 20 but that age ranged from 9 to 40. The average age at which interviewees received a medical diagnosis⁵ for an anxiety disorder was 25. So, on average the interviewees went five year with anxiety-related symptoms and without a diagnosis (or treatment). Only three interviewees indicated that the time between onset and diagnosis was short, less than a few months. The longest time between onset and diagnosis was reported by a 69 year old interviewee who went 36 years without a diagnosis. As these statistics suggest, there were substantial differences in the interviewees’ narratives about the diagnostic process, which I take up explicitly in chapters five and six.

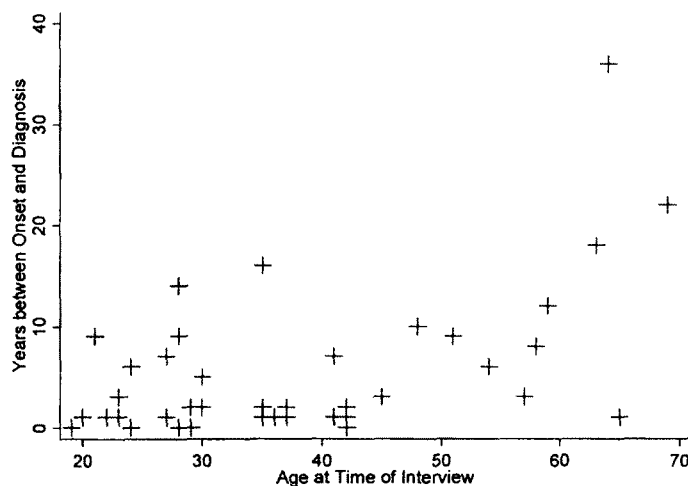
In that same line of thought, the age of the interviewee represented a source of variation among the interviewees. The average age of the interviewees was 38, and their ages ranged from 19 to 69. Age played a critical role in the interviewees’ narratives of diagnosis. In figure 1, I show the number of years between onset and treatment-seeking

⁴ The median, mean, and mode age at which anxiety-related symptoms intensified to the point that the interviewees felt that “something was wrong” were close (Median = 18; Mean = 20; Mode = 17)

⁵ The median and mean age at which interviewees received a medical diagnosis for an anxiety disorder were nearly equal (Median = 25.5; Mean = 24.5)

among the interviewees against their ages.⁶ Older interviewees generally reported longer periods of time between symptom onset and diagnosis than younger people. This trend is—at least in part—an artifact of older interviewees simply having more time to go undiagnosed; there are certainly young people, right now, suffering with anxiety-related symptoms who will not be diagnosed for a long time, who—because of my inclusion criteria—I could not locate to interview. Nonetheless, this trend highlights several interesting differences among the interviewees. Specifically, older interviewees allowed for the study of the experience of anxiety without a diagnosis over longer periods of time; older interviewees provided accounts of anxiety before an “anxiety disorder” was a medically familiar and treatable disorder; and younger interviewees narrated a contemporary diagnostic process for an anxiety disorder in a social context in which “anxiety disorders” were far more familiar.

Figure 1. Time elapsed between onset and diagnosis by age of the respondent



⁶ This table is not intended to generalize to any population, but, rather, summarizes trends among these particular interviewees.

While the diagnostic processes were quite varied, the choice to treat anxiety with medication was less so. The strong majority of the interviewees (83%; N = 33) reported that they were taking at least one medication to treat anxiety. While the interviewees were ambivalent about the meanings of, consequences of, and their future with medication, biomedical treatment was a common and long-lasting fixture of an anxiety disorder. One reason that many of the interviewees cited for their continued use of medication was that—despite treatment—they still experienced symptoms of anxiety; 95% (N = 38) of the interviewees report still experiencing some symptoms of anxiety. More optimistically, to varying degrees, the strong majority experienced *fewer* and *less intense* symptoms.

Interviewees also differed in their general responses to panic attacks, and factors, like comorbidity, seemed to play a critical role in how they reacted. For instance, while almost all of the interviewees, at some point, reported thinking that they needed serious medical intervention during a panic attack (with a few interviewees describing sitting outside of an emergency room “just in case”), individuals with comorbid disorders more frequently actually went into the emergency room for treatment. Specifically, 56% (N = 15) interviewees with co-morbid disorders reported going to the emergency room during a panic attack, while only 31% (N = 4) of those without a comorbid disorder reported such a visit. This suggests a difference in the intensity and confusion involved in the experience of mental illness and subsequent responses to the symptoms of anxiety between individuals with and without comorbid mental health disorders (see chapter four for an analysis and discussion).

The level of education among the interviewees varied from less than a high school degree to a doctorate. To give a more clear picture, 40% (N = 16) of the interviewees had a bachelor's degree or more, which is slightly higher than the New Hampshire average (32.4%; United States Census Bureau 2011). Three interviewees had a Master's degree and one had a PhD. One noticeable difference between interviewees with more and less education was that more highly educated interviewees tended to be more critical of medical intervention generally and of medicalization specifically. This trend is evidenced by the fact that less than 70% of interviewees with a bachelor's degree or more reported using medication, while over 90% of interviewees with a high school degree or less used medication. The lower rates of medication use among the more highly educated interviewees were not likely grounded in fewer symptoms or less distress, since the more highly educated interviewees (surprisingly) reported *more* sustained symptoms of anxiety than interviewees with less education.

There were also intimate connections between work and anxiety. The employment status of the interviewees was split down the middle, with 53% (N = 21) of the interviewees reporting being unemployed at the time of the interview.⁷ Those who were employed worked a range of jobs, including school aides, factory workers, social workers, administrative assistants, non-profit directors, journalists, university faculty, bloggers, dancers, and waitresses. Among those who were employed, many reported that work was a trigger for their anxiety disorder. Still, some of the interviewees viewed work as a distraction from anxiety, an escape from a stressful home life, and a source of meaning in their lives. Unemployment was also intrinsically connected the experiences of

⁷ Full time students (N = 2) were coded as "employed."

anxiety; 35% (N = 14) of the interviewees explained that they were unemployed and remained unemployed *because of an anxiety disorder*.

Family structure also varied among the interviewees. While 55.3% of New Hampshire residents are married, only 38% (N = 15) of the interviewees were married at the time of the interview. The role of marriage in the illness narratives was equivocal; many reported that their romantic partners helped them manage anxiety, while others cited marital strife as a source of further anxiety. Notably, several of the interviewees (and support group members) described losing a partner *because of their anxiety disorder*. Less than half (43%; N = 17) of the interviewees had children (with an average number of children at 0.9). Again, the relationship between children and anxiety was ambiguous (although children were rarely mentioned by the male interviewees). Many of the women described: an escalation in anxiety during pregnancy, guilt about “passing on” mental illness to their children, shame about using medication before, during, and after pregnancy, and the stress of parenting as a trigger for anxiety. On the other hand, some women reported relief from anxiety-related symptoms during pregnancy and that their children helped them cope with anxiety and gave them a reason to continue struggling to manage their symptoms. In short, the relationships between anxiety and the interviewees’ immediate social surroundings (e.g., family and work) were often ambiguous and complicated.

Approaching the Interview

In this section, I discuss my approach to the interview process. In this dissertation, I have addressed the life course of an anxiety disorder diagnosis through the experiences of people who have been diagnosed, and, accordingly, I wanted to hear about people’s

experiences of anxiety, from their very first symptoms of it through to the day of the interview. The type of interviews that are particularly amenable to this particular study and approach are personal narratives (Riessman 2003) or, more specifically, what Arthur Kleinman (1988) calls “illness narratives.” He writes, “The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering” (Kleinman 1988:50). That is, these are the thick descriptions that people who are or have been ill give that reflect their experiences but also give those experiences order. Illness narratives allow the researcher a glimpse into “what happened” but, as importantly, they also provide a lens onto meaning-making. Likewise, I am simultaneously interested in studying the development of “what happened” among the interviewees over the course of their illness and how they made sense of those often chaotic experiences of distress, the medical encounter, and diagnosis.

In order to assure that I captured illness narratives that covered the life course of an anxiety disorder, I asked open-ended interview questions specific to pivotal moments in the illness experience, such as, “When do you first remember experiencing anxiety?” and, “Can you tell me about the day that you were diagnosed with an anxiety disorder?” and, “When was the last time you experienced anxiety and/or a panic attack?” These types of questions tethered their stories to typical and common locations in an illness “career” (Karp 1997:56), which allowed me to trace the development of the narrative over time and to systematically compare those developments across interviews.

The dissertation is, then, structured in accordance with the sequencing of the illness narrative, with the first two findings chapters addressing narratives about experience *before* receiving a medical diagnosis. While, indeed, all interview data is

based on memory or recollections, these particular narratives pose unique issues of remembering. Most significantly, once a person receives a diagnosis, they are offered a new framework through which they view and interpret their (past and present) experiences (e.g., “dissociation”, “panic attack”, “adrenaline” etc.). Importantly, this framework and these concepts were not available to the research participants during some of the time that they were describing (before diagnosis), and, as such, they contemporarily (re)interpreted those early experiences with the aid of these medical frameworks and concepts. There is, unfortunately, no feasible way to gain unfiltered access to those experiences before diagnosis. Nonetheless, what can be offered is careful attention to how these medical frameworks and concepts are applied to “pre-diagnosis” experience and critical attention to how those frames have potentially re-shaped these illness narratives.

While I used a set of key questions that located the interviewee in an “ideal type” of an illness career that aided in temporally structuring the interview, I also employed “phenomenological interviewing” for the majority of the interview process. This represents an interviewee-guided investigation of lived experience, which is typical of feminist research (Reinharz 1992:21). Before the interviews, I memorized a set of questions that I knew, in advance, that I wanted the interviewee to address, but beyond those basic questions, I encouraged the interviewees to guide what we talked about and for how long. This balance between systematic data collection and interviewee guided narrative allowed for highly rigorous comparisons across all interviews, while still capturing topics, experiences, and ideas that I had not anticipated when developing the research project (Ely et al. 1991:66).

This narrative approach—germane to feminist research—often leads to sizable variation in the length of the interview (Reinharz 1992:25). Likewise, the average length of the interviews was 1 hour 27 minutes, and they ranged from about 45 minutes to 3 hours 22 minutes. All interviews addressed core research questions about illness experience, while the longer interviews often raised new questions to address in subsequent interviews. With these stories in hand, I noted changes within each narrative as the plot moved forward and studied the commonalities and distinctions across interviews.

Participant Observation

While “interviewing offers researchers access to people’s ideas, thoughts, and memories in their own words rather than in the words of the researcher” (Reinharz 1992:19), participant observation allows people to interact more “naturally” in their typical social environment. I conducted participant observation in order to capture another vantage on the experience of an anxiety disorder, to broaden the range of people I could learn from, and to ensure greater levels of reliability in my findings. Participant observation afforded a view on more dynamic and “real time” developments of the experience of an anxiety disorder, played a critical role in accessing the lived experience of hard-to-reach populations (especially men with anxiety disorders), and confirmed several salient themes in the interview data while pointing to some notable distinctions.

Clifford Geertz posed the question “what does the ethnographer do?” and replied, “He observes, he records, he analyzes... *veni, vidi, vici* [I came, I saw, I conquered]” (1973:21 – 20). But, as Geertz suggests, while ethnography is certainly this—observing,

writing, and analyzing—each of those activities, in the real-world of research, are far more complicated, challenging, convoluted, and epistemologically loaded. For instance, the ethnographer does not simply take in or objectively apprehend the social world, but, through her research, she plays a critical role in the construction of these realities (Rabinow 2007). Accordingly, ethnography demands a reflexive stance on the research process and the production of sociological “facts” (Smith 1990). In this section, I describe the concrete reality of how I conducted participant observation, avoiding an overly “veni, vidi, vici” approach to the description.

The objective of ethnography is “to go deep into a definable setting in which phenomena can be placed meaningfully within a specific social environment” (Holliday 2007:37). As such, I had to decide on and secure a definable social setting, which was no simple task. I wanted to observe in a setting with people who had been medically diagnosed with an anxiety disorder, were willing to talk about their experiences, and were willing to let me listen. The most obvious site was an anxiety disorder support group. So, I went about finding a group that would allow me to observe; I searched listings on local newspapers, scoured online support group sites, and contacted national organizations like *Anxiety Disorders Association of America* and *National Alliance on Mental Illness*. My requests to observe were consecutively declined by at least five regional anxiety disorder support groups and were simply not responded to by several others. The group leaders that did contact me explained that my presence might make group members uncomfortable and would not be conducive to their therapeutic intentions.

After several weeks of contacting group leaders and being turned down, I found a psychologist who allowed me to sit in on her bi-weekly support group, which happened to be in a rural location just shy of three hours from my home. I attended and took notes at five support group meetings over three months. The meetings were highly structured, with an opening activity based on answering a question about anxiety, such as, “What keeps you from a full recovery?” which was answered on a turn-taking basis. Then, each person had a limited amount of time (guided by the number of people in attendance, which ranged from five to fourteen members) to discuss their experiences of anxiety over the prior two weeks. In turn, the therapist would talk back-and-forth with each participant, employing various therapeutic techniques and occasionally asking other group members for their opinions and suggestions.

For ethical reasons, I stopped attending the group after those five meetings. One of the stipulations for my participation in the group was that I could not reveal myself as a researcher. The therapist was sympathetic to my academic ambitions, but was also—like the other support group leaders—apprehensive about what my (known) presence (as a researcher) would do to the group dynamics and how it would impact the group members. While I was not required by the UNH Institutional Review Board to reveal my identity as a researcher, I had always intended on full disclosure. After several exceedingly uncomfortable (informal) conversations with group members about my doctoral research and several evenings of typing field notes littered with stories that I felt were far too personal to share without the group members’ consent, I decided that I could no longer ethically participate in the group. I used these field notes in my analysis, but I chose only to include more typical and general stories from this group in my writing. I

feel that this approach to the data struck a balance between the pragmatic and effective use of this high quality data, while still respecting the privacy of those group members.

I immediately started looking for another group. After contacting support leaders (who had not yet responded) for a second time, one leader responded and was willing to be interviewed and to let me observe the support group. Unfortunately, the group was too far of a commute and too sparsely attended (typically zero to three members were in attendance) to commit to regular observation. Then, a few weeks later, I received another e-mail from a very congenial woman, saying that she would be happy to have me at her support group. She said that she had checked with the group and that they were in agreement that I could observe; they indicated, however, that I needed to identify myself as a researcher at the start of my first day at the group. I attended this support group from May 2010 to January 2011.

This support group was “patient-led,” meaning that there was not a medical practitioner (e.g., psychiatrist, psychologist, or therapist) who led the meeting or was in attendance. While there was one (lay) “leader” to keep discussion moving forward and in accordance with the group guidelines, the meetings were intended to be participant-run. The support group met for an hour and a half once a week in the afternoon. There was a core of about five people who attended almost every meeting, and most sessions included at least one new member and a handful of semi-regular members. The first half of the group time was spent reviewing an anxiety disorder related reading and the second half involved each member sharing personal anxiety-related experiences from the past week. I focused my note-taking on the personal narratives introduced in relation to the readings and the more general sharing that occurred in the second half of the group meeting. Over

the course of the eight months, I was able to document the weekly evolution of group members' narratives—especially those of the core group members—about anxiety in something close to weekly “real time.”

My role as an observer was far from stagnant in the support group. At the start of my field work in this group, I was clearly established as a researcher in the group. As such my participation was fundamentally limited to a “mute observer” (Ely et al. 1991:45), and I like to think I largely faded into the background during discussions. But, as I got to know the group members better, they discovered that I knew some basic facts about anxiety—borne out of my dissertation research—like prevalence rates, risk factors, types of treatments, and so on. Consequently, the group members started asking me questions during the meetings about anxiety. Sometimes these were questions that were appropriate for me to answer, like, “I know anxiety is really common. Jennifer, how common is it again?” On the other hand, there were specific medical questions that I was unable to answer, like, “What exactly is a neurotransmitter?” And, then, there were questions that I was unable *and* uncomfortable answering, like, “Do you think I should consider taking Xanax in addition to my anti-depressant?” Once these questions started to become a common fixture in the group meetings, I had to re-evaluate my role in the group. I had come to be viewed by the group as a quasi-medical professional and was becoming increasingly central to their conversations. I had inadvertently shifted from being a “complete observer” to a “complete participant” (Reinharz 1992:69). In response, I decided to redirect their questions by very clearly stating that I have no medical training, I am a sociologist (or “I study society”), and/or I am still a “student” (I think the

word “doctor” embedded in “doctoral candidate” may have thrown some of them off). In just a few weeks, I, once again, became a mostly mute observer.

The first two months, at the start of every group meeting, I introduced myself, handed out a flier with information about my study, and fielded any questions about my study (though they were rare). Over time, the group became weary of my speech and said that I no longer needed to introduce myself and my research at each meeting. I tried to introduce myself less often, about every other week, but the group members—on their n-th time hearing it—were clear that I should not continue with my introductions. I was grateful that they trusted me enough to excuse me from introducing my study to new members, but this put me in yet another ethical bind. As a guest of the group, it was not my place to force my introduction on them and to use their group time to benefit my study. But, at the same time, there were new members coming to the group weekly, and, especially when they came in late (which was typical), I was often unable to individually tell them about my role as a researcher before my observation. Moreover, after they shared their, often, extremely personal stories, it became increasingly dicey to inform them about my study. As I have already noted, I was not obliged by the group, the group leader, or the IRB to inform the members about my research, but, nonetheless, I was in an uncomfortable position. I have employed all of the data from my field notes in my analyses but only use the narratives of the group members who gave me informed consent as illustrations in the writing. This represented a fair balance to me: I was able to use all of the good information I gathered at the site but did not have to compromise my personal ethics by sharing stories that may not have been intended to be shared.

Interestingly, since some of the group members knew I was a researcher and others thought I was just a very quiet participant, I was able to critically reflect on my role in the group and the impact of my presence on the participants. The observable differences were subtle. The most obvious was that the member “in the know” treated me more like a medical expert and often tried to steal a glance of my notes. While I have already discussed the former, in response to the latter, I learned to write in (even more) messy handwriting and used codes for people’s names and common words and themes. Over time, the “regulars” seemed to lose interest in what I was writing—I think—because it was so cryptic. New members did not seem to notice my writing; it was normative for group members to bring a pen and paper to each session and to take notes on recommendations put forth by their peers. Accordingly, I was able to take my notes fairly freely, although I was conscientious not to write while a group member was sharing a very personal or distressing story (which would likely have been seen as a faux pas in this group). Rather, I took notes, in shorthand, after group members finished discussing the more sensitive topics. Another way I dealt with my impact on the group (which is common among and expected of ethnographers) was that I spent a long period of time observing the group, which is referred to as “prolonged engagement” (Ely et al. 1991:50 – 51). In short, I spent so much time with them that, over time, my presence was felt less and less.

Interviews and Participant Observation

Employing both qualitative interviews and participant observation allowed for the triangulation of data, which, in the most simple of terms, “means that an issue of research

is considered...from at least two points.” (Flick 2008:40; see also Ely et al. 1991:96 - 97). While many researchers view triangulation of data as one way to ensure greater validity and objectivity, some researchers, such as Norman Denzin, rather, see triangulation “as a strategy on the road to a deeper understanding of an issue” (Flick 2008:48). I tend toward Denzin’s interpretation. Combining these two forms of data offered more information about the subject, pointed to new areas to explore, and clarified the limits and strengths of each perspective.

Adrian Holliday describes the importance of collecting “interconnected” and “disconnected” data (Holliday 2007:39) in triangulation. Simply put, interconnection is what the research participants (as a group) have in common and disconnection is how they (as a group) differ. At a most basic level, the data collected at the support groups and in interviews were deeply interconnected. For one, participants in both methods described similar experiences of anxiety and comparable narrative arches over the course of their illnesses. Also, both groups were composed of people who had been diagnosed with some form of an anxiety disorder. And, almost all of the interviewees lived in the same region: the east coast. The connectedness of the groups provided broadly shared themes that eventually gave way to nuanced differences.

The disconnections—as much as the connections—between the two groups provided sources of analytic insight. Perhaps most significant to my study was the difference in the gender composition between the interviewees and the support group members. While the interviewees were predominantly women, at nearly all of the support group meetings, half or more of the members were men. Not only did this provide breadth to my understanding of men’s experiences of anxiety, it became a salient

research question: why were men plentiful at the support group meetings, whereas—despite my concerted efforts—very few men would participate in the interviews. This particular disconnect is discussed in detail in chapter five.

Another disconnection between the interviewees and support group members was their locations in the illness experience (from recently being diagnosed to largely recovered). Specifically, the interviewees tended to be fairly distant—years and decades—from their original diagnosis; as such, they provided thick descriptions of their experiences long after diagnosis. Conversely, the support group members were often a lot closer to diagnosis and less frequently reported reduced symptoms or recovery. One reason that the interviews drew people who were further along in their illness “career” was because the interview represented a way for interviewees to use their many experiences with anxiety, hard-earned coping tactics, and, to varying degrees, recovery to help others with anxiety and to inform the public in general about anxiety disorders. Below are samplings of interview quotes in response to the question, “How did you decide to participate in this study?” that exemplify the altruistic motives of the interviewees.

It's always my hope that I am going to connect with someone or someone is going to connect with me that is going to have the ability to raise awareness and at the very least have some resources or have some ability to help people that are in need, that are suffering with anxiety and don't know what to do with themselves. (James)

It's just the awareness of it. [Anxiety] shouldn't be a shameful thing. It's biological. I just think that [people need] education. It's nothing to be ashamed of. (Lori)

I have to say, when I saw the flyer, I thought, “Well, there is someone out there that is interested in this that is trying to find out how to deal with this. And, if my experience can be helpful, it's a really good thing.” So, I was just, I was

really happy to see that, thinking that I might be able to help people that have to go through this. (Andrea)

Since academic interviews are explicitly directed at advancing knowledge about a specific topic, my interviews largely drew people whose breadth and depth of experience with anxiety could offer something positive to the study of anxiety. Accordingly, many of the interviewees had years of experience with an anxiety disorder that they wanted to share.

Conversely, the *therapeutic* function of the support group drew people who were trying to figure out how to “get better.” As such, the support group attracted people who were newly diagnosed with an anxiety disorder and seeking help in dealing with their very unfamiliar symptoms, diagnosis, and treatment. The narratives of support group members fleshed out the experiences of anxiety right after diagnosis and gave more immediate and detailed descriptions of the time *before* diagnosis and of the diagnostic process itself. Further, participant observation allowed me to hear from people who—because of their still very intense symptoms of anxiety—may not have been *able to* participate in an interview. For instance, at the first support group I attended, a young woman, perhaps in her early-twenties, sat next to her mother (who was there for support) and spent the strong majority of each meeting with her eyes turned downward, focused on a wad of grey modeling clay that she methodically massaged; this ritual helped her manage her anxiety while in the group. While she would not have been able to participate in an in-depth interview, since a few quiet sentences over the course of several hours was the most she was able to manage, I was still able to catch small glimpses of her experiences of anxiety through our participation in the support group. For this reason,

participant observation was crucial to capturing the quiet and hidden life of anxiety of those still in the throes of it.

One other important distinction between interviewees and support group members was their level of identification with an anxiety disorder. While interviewees were highly identified with the disorder, many of the support group members were still simply coming to terms with having the diagnosis. This difference allowed me to study—across the two methods—the *initial* personal identification with a diagnosis, the social process of *becoming* identified with the diagnosis, and the long-term *consequences* of that identification. Overall, these empirical vantages on the experience of anxiety allowed me to study the entire life course of an anxiety disorder diagnosis, from the months and years before a medical diagnosis to the years and decades after diagnosis and into recovery.

Analysis

Physically Coding the Data

Before I describe my strategies of analysis, I want to discuss how I actually physically coded my data. I employed a combination of coding “by hand” and coding with the aid of a qualitative research software program (specifically, NVivo8). When I say “by hand” I mean that I printed out the transcripts and fieldnotes, read them closely, and marked coding in the text and the margins (my actual analytic strategy is discussed in the next section), and when I say that I used NVivo8, I mean that I organized, (re)organized, and analyzed my data with the use of a computer software program. Just to be entirely clear (because it is a very common misconception), the software does not do the analysis, but rather, it is a tool used to organize data and codes; it is just like

Microsoft Word does not write the paper, but, rather, the writer uses Microsoft Word to aid in the writing process.

This combination of approaches afforded the benefits of visceral and direct contact with the interview transcripts and field notes inherent in coding “by hand” and the incredibly efficient organizing capacity of NVivo. There is a lot of talk about the virtues and pitfalls of one medium of coding versus the other.⁸ While I find these debates to be important in developing the critical use (or rejection) of technology, I generally find them—based on my own experiences with coding by hand and with a software program—to be excessively polemic and divisive. Qualitative research software is neither likely to destroy nor revolutionize qualitative research; rather, it seems to me, each approach offers something unique and significant to the analysis of qualitative data. In the following, I briefly reflect on why I chose to employ both mediums of coding.

The single most important reason I chose to code by hand was to maintain visceral, immediate, and direct contact with entire sets of data. Qualitative research software, for all of its virtues, only allows the researcher to see a part of a page of data at any one moment and limits how quickly the researcher can move through the pages. The simple act of easily moving around entire narratives, setting tens of pages side-by-side, and being able to *see* patterns on these spread out pages made coding by hand an invaluable component of my analysis.

On the other hand, one of the major reasons that I decided to also use NVivo8 was because it is an incredibly powerful and efficient organizing tool. While some researchers have suggested that these programs are only of use for “the management of

⁸ See Bazeley 2002; Bazeley 2007; Crowley, Harré, and Tagg 2002; Richards 2002; L Richards 2002 for a more general review of qualitative research software programs.

larger dataset” (Green 2010:35), I find it hard to imagine even a “small” qualitative study not benefitting from a program like NVivo. Even “moderately” to “small” sized qualitative methods produce hundreds of pages of data, which is, simply put, a lot of information to manage. Qualitative research software facilitates a more efficient and quicker organization of qualitative data. For instance, NVivo allowed me to easily code as I read through my data, record and update operational definitions (which were hyperlinked to each code), view the codes all together in one sheet *or* in the original document, edit the codes easily *after* coding (and after refining operational definitions), and view my coding by important factors (such as gender, age, employment, before/after diagnosis, and so on) to make sociologically relevant comparisons. While all of this *could* have been done by hand, the time involved in this extensive of an analysis would have been immense. Combining coding by hand and coding with NVivo8 allowed me the insights garnered by immediate contact with the data and the speed and analytic power offered through qualitative research software.

Analytic Strategies

Now that I have described the mechanics of how I coded my data, I turn to the specific analytic strategies that I employed. I adopted an iterative and data-driven approach to analysis, as outlined by Herbert Blumer and reiterated and extended by Howard Becker (Becker 1998; Blumer 1969). At the core of this approach is the use of concepts or images to purposefully engage with research questions and the empirical data. To start, in a short list of topics that any good methods discussion should address, Blumer (1970) includes: a discussion of “the possession and use of a prior picture or scheme of the empirical world under study” (pgs. 22 – 23). Throughout my analysis I

paid close attention to the explicit images/concepts (codes, definitions, and so forth) and the implicit images/concepts (stereotypes, bias, assumptions, and so forth) that I developed throughout the research project. I came to this study with innumerable pictures of anxiety, medicine, diagnosis, gender, and so on, but, in this section, I will describe one specific image that brought me to this study, guided my inquiry, and was transformed through interactions with empirical data. I draw on this image to provide an archetype of how I conducted my analyses and how my images shifted in dialogue with the data.

I had an image of what I thought anxiety would “look like” before diagnosis. While I was certain that anxiety *could be* a devastating disorder, I anticipated that a good number of people with “normal fear” would be diagnosed as “disordered.” It is widely documented in much of medical sociology research that normal experience is pathologized in the doctor’s office (Lane 2007; Szasz 2003) to such an extent that scholars have, for instance, made light of overdiagnosis with spoofs on medicalization of experiences such as “happiness” (Bentall 1992). Accordingly, I assumed that the interviewees’ and support group members’ narratives about anxiety before diagnosis would *sometimes* fit the DSM criteria but, more often, their distress would, instead, represent a “normative” experience and emotion. In other words, I anticipated “discovering”—in these interviews and at the support groups—the (over)medicalization of normal experience by medical physicians. This was one of the key guiding images I brought to this research study: the overmedicalization of normal experience.

Another component of methodology that Blumer asserts should be addressed is the “asking of questions of the empirical world” (Blumer 1970:22 – 23). Howard Becker

explains, quite simply, that his “favorite way of developing concepts is in continuous dialogue with empirical data” (Becker 1998:109). This type of analysis is comprised of continually asking data (e.g., interview transcripts and field notes) research questions and allowing the data to inform your image of that slice of social life and to direct subsequent questions. Likewise, I came to my empirical research with stereotyped images of “anxiety”, but I quickly put these empirically vacant images in dialogue with the narratives of interviews and support group members. This process breathed life into the image, challenged my preconceptions, and pressed the analysis forward. For instance, after just a few interviews, I realized that the interviewees’ narratives about anxiety before diagnosis consistently represented intensely distressing experiences (non-normative experience) that surprisingly neatly echoed the DSM criteria of anxiety disorders. In short, there was *nothing* to suggest the overmedicalization of “normal” fear in these narratives (based on neither divergences of lived experience from the DSM criteria nor the level of intense distress experienced by the person).

My initial image of anxiety before diagnosis was swiftly discredited, which prompted me to rethink my coding scheme. To shake off these clearly stereotyped images, I began a dialogue with my data by conducting “initial or open coding” in which I coded each paragraph individually (Charmaz 2003:320). Because of how I asked my interview questions, there was a loosely chronological order to the interviewees’ narratives, which, as I coded, helped reveal a loosely chronological pattern in the “experiences of anxiety” codes (which was a code for all “first-person narrations of the experience of anxiety”) as I moved from the top to the bottom of the transcript. Specifically, the experiences of anxiety changed over time and generally became less

intense and interfered less with everyday living. Once I noticed this pattern, I began creating a new image grounded in these narratives; I discovered qualitative differences in how the interviewees described their experiences of anxiety *before* and *after* diagnosis and began coding for each.

As I have implicitly suggested, throughout my analysis, I employed what are often termed “sensitizing concepts” to engage with my data; sensitizing concepts represent “a starting point in thinking about a class of data of which the social researcher has no definite idea and provides an initial guide to her research. Such concepts usually are provisional and may be dropped as more viable and definite concepts emerge in the course of her research” (Hoonard 1997:2). That is, I came to my data with a “provisional” image (or a sensitizing concept) that guided my approach to the data but was also responsive to the data.

In order to fully employ these sensitizing concepts, I practiced “analytic induction” (see Flick 2008:30 for a brief summary), which begins with a rough definition (or “sensitizing concept”). In this case, my sensitizing concepts became “the experience of anxiety *before* diagnosis” and “the experience of anxiety *after* diagnosis”; these specific sensitizing concepts simply located (1) a topic in the larger narratives (“the experience of anxiety”) and (2) a general location in the illness narrative (“before diagnosis” and “after diagnosis”). In the next step of analytic induction, the researcher develops an explanation of the phenomenon. In this case, I surmised that anxiety “got better” after diagnosis and, as such, the experience of anxiety became less intense and less problematic, which—at one point—fit nicely with the data. In the following step of analytic induction, the researcher applies the new explanation to another case (e.g.,

another interview or set of field notes). Almost immediately, I saw that my explanation was weak, especially in two regards. First, I found that some of the experiences of anxiety after diagnosis were actually *more intense* than before diagnosis. Second, I found that some of the interviewees—even when they described less intense symptoms that interfered far less with daily life—did not describe themselves as “better” and almost never saw themselves as “recovered” (even when their symptoms no longer obviously met the medical criteria of an “anxiety disorder”). In the next step of analytic induction, the researcher, responding to the new data, reformulates a new hypothesis. Then, the process starts all over again by applying this new explanation to more data. My eventual hypotheses related to these specific concepts and analytic approach are discussed in chapters seven and eight.

Analytic induction represented an ongoing analytic process that allowed me to continually refine my analyses and explanations. Over time and with each new interview and set of field notes, the broad strokes of my analyses and explanations became increasingly nuanced and resistant to alteration. Nonetheless, I have no doubt that with more and different data one could continue to develop this analysis for quite some time. Overall, keeping my images/ concepts/ explanations in close dialogue with the interviews and field notes facilitated an iterative, responsive, and empirically-grounded analysis of the data.

The final element of my analysis was writing about the images that I developed and discovered through analytic induction, as they are document in this dissertation. I have tried to complete this final analytic step in keeping with the advice of Howard Becker (1998):

Sociologists often know no intermediate stop between the raw facts of the case and the largest, most general categories of social analysis. Thus, they may describe the findings of their research on, say, drinking alcohol, and jump from that to talk about identities or self-conception or some other highly abstract aspect of social organization or interaction. As a rule, our research doesn't have anything new to say about self-conception or identity (p. 125)

Following Becker's critique I keep my analysis—in its present rendering—closely tethered to the empirical data, where, as Becker argues, it has the most to offer sociologically. While I still connect my empirical research to broad concepts and theoretical traditions in sociology, I conscientiously situate the contributions of my findings in the local specificities of the study, carefully framed within the broader context of theory. For instance, I demonstrate how medical diagnosis of an anxiety disorder concretely changes the lived experience of physical distress, while situating this empirical argument in phenomenology, sociology of the body, and constructionism (see chapter eight). But, beyond these brief assertions about my final analytic steps, I will let these methodological claims be tended to by the writing in the subsequent chapters, since I agree entirely with Geertz (1998), who writes,

Theoretical formulations hover so low over the interpretations they govern that they don't make much sense or hold much interest apart from them. This is so not because they are not general, but because, stated independently from their applications, they seem either commonplace or vacant (p. 25)

In the findings chapters of this dissertation, (chapters three through eight), I have attempted to contribute to theory building by offering empirically grounded findings and by suggesting modest, but concrete, connects to sociological debates.

CHAPTER THREE

BODIES, OBJECTS, AND SOCIAL INTERACTION: IDENTIFYING DISORDER BEFORE DIAGNOSIS

*Fear is a tyrant and a despot, more terrible than the rack, more potent than the snake.
Fear is many-eyed and sees horrors where normal vision only sees the ridiculous.*
Edgar Wallace 1916

This fear is at the core of this dissertation, a fear that terrorizes when it is not obvious to “normal vision” why one would feel terror. Generalized anxiety disorders, panic disorders, and agoraphobia are full-body and mind events, often in response to “mundane” situations. These experiences are not the same as “normal” anxiety felt, perhaps, on the first day of school or in the hours before getting married. Certainly, those experiences can be—when one is nervous—uncomfortable and distressing, but they are qualitatively different from the experiences documented in this chapter and the next. The fundamental difference is that “normal” fear is easily integrated into social experience, while the fear associated with anxiety disorders profoundly disrupts social life (official DSM criteria for anxiety disorders are in appendix C). This present chapter addresses how people eventually diagnosed with an anxiety disorder came to see their distressing experiences as disordered, before any medical encounter or diagnosis. Simply put, I address the social process by which the interviewees described figuring out that “something was wrong.”

Before diagnosis, the physical, mental, and emotional experience of anxiety led the interviewees to drastic—but not necessarily effective—measures. The fear felt by these men and women sent them to emergency rooms, pressed them to be hospitalized, and kept them locked their homes for weeks or months at a time. Anxiety disorders profoundly disrupted and sometimes ravaged the lives of those who experienced them; it broke up marriages and ended life-long friendships. The periods of time when the interviewees struggled to figure out what was wrong with them were marked by confusion, false starts, and disrupted social networks. All of the interviewees discussed, often at length, their experiences of anxiety before diagnosis and described the intensification of distressing sensations that disrupted their lives. Eventually, the intensity and haphazardness of the experience of anxiety pressed the interviewees to seek diagnosis and treatment. This chapter addresses the very beginnings of their illness experiences that mark the start of a long journey to diagnosis and treatment seeking.

The interviewees' narratives, as a whole, contribute to an understanding of how mental illness is intersubjectively identified before, during, and after diagnosis. Much social science literature on health and illness has focused on the challenges of diagnosis and the professional construction of illness categories (Horwitz and Wakefield 2007; Conrad and Schneider 1980; Kutchins et al. 1997; Brown 1987). There is also a long tradition in medical sociology focused on the doctor-patient relationship, originating with Parsons (1951) that continues today (Akerkar and Bichile 2004; Ball and Lillis 2001; Kenny et al. 2010). This chapter and the next draw on and shift those disciplinary foci to the processes by which *individuals* with distressing symptoms come to identify an appropriate illness and diagnostic category during the weeks, months, and even years

before there is a doctor who contributes to the diagnosis.

This approach is based on several observations. For one, there has been a push in constructionist work to study not only categories but also the people that fill and re-shape them. Categories, including diagnostic categories, are upheld at least partially by the individuals who identify with them (Hacking 1999); as such, in this dissertation, equal consideration is given to the category itself and to the person who identifies with it. As Ian Hacking argued, the construction of categories is a dialectic in which people create categories and categories “make up people” (1999). In this chapter and the next, I address how people come to locate a category—specifically, “anxiety disorder”—in which they can fit.

Researchers have shown how diagnostic categories are forged by groups like social movements and professional organizations (Brown 1995; see also Conrad 2005). And while these institutionalized categories are beyond the control of any single individual, for these categories to persist they have to be reified in the lives of people; diagnostic categories depend on people who identify with them. Like the original groups who forged these diagnostic categories, individuals experiencing a constellation of symptoms have to do the work to re-discover these illness categories, supporting diagnoses that were created at the institutional level. While much social science literature focuses on the institutional creation of diagnostic categories, this chapter and the next offer a study of *patients*’ efforts in locating and supporting a diagnostic category *before* medical intervention. I argue that the construction of a category depends on experiences at the micro level as much as it does the institutional level.

In these illness narratives (Frank 1997), much of the work of grappling with

discomfort, distress, and illness happened before the interviewees visited a doctor. In a word, illness happened within, outside of, and *before* the doctor-patient relationship (Kleinman et al. 1978). Diagnoses are co-created by patients and doctors and depend heavily on the narratives of the patient, especially those with mental health issues that often have no organic measures. In short, for the diagnosis to exist, “the patient must speak” (Jutel 2009:289). These chapters point to the intersubjective creation of the patient narratives that allow for diagnosis; they also address the preliminary construction of an illness category *prior* to medical intervention from the perspective of those who are ill. As such, this chapter and the next focus on the experiences of anxiety before it becomes an “anxiety disorder” with a particular focus on how the interviewees came to view their experiences as potentially pathological.

The Anxiety Experience

The initial impetus to seek medical intervention was, unequivocally, intense physical sensation; the diagnosis of anxiety disorders began in the physical body. As Phil Brown argued about the sociology of diagnosis, “we are, after all, talking about phenomena which occur in people’s bodies. If we do not take seriously this reality, our search for socially constructed definitions will be very shortsighted.” (Brown 1995:37). The body, physical sensation, and the meanings of those sensations guide the eventual location of a diagnostic category. Categories depend on bodies formed to fit them, and people depend on categories to make sense of their bodies (Hacking 1999). It is, as Brown observed, folly to ignore the profound interconnection between bodies and categories.

Likewise, I found that the physical body played a basic and vital role in the interviewees' initial identification of pathology. The following paragraphs address the lived visceral experience of anxiety among the interviewees, which served as the first basic signs for them that "something was wrong." The interviewees' narratives—which emphasized the intense physicality and chaotic nature of their original symptoms—help elucidate how an anxiety disorder could severely disrupt a person's life and could serve as a fundamental pressure to seek professional help.

The physical sensations of anxiety that the interviewees most frequently experienced were very much the same descriptions one might hear about "normal fear." These sensations included: dizziness, heart palpitations, insomnia, nausea, racing heart, chest pain, stomach pains, sweating, and trembling. But, interviewees reported that it was the emergence of distressing sensations and experiences that were *not* conventionally associated with "normal fear" that suggested to them that something might be seriously wrong. For instance, Kalli's main symptoms of a panic disorder were, "heart palpitations, like I ran 10 miles, the sweating and shaking. I get nausea . . . It will make me sick [vomit]." Notably, unexpected symptoms often accompanied the common symptoms, which repeatedly caused alarm. Kalli experienced classic physical sensations associated with fear, including heart palpitations, sweating, and shaking, but she also experienced vomiting, which is not often experienced with "normal" or non-disordered fear. Unexpected symptoms were experienced as especially distressing and signaled to the interviewees that something was wrong and that this was not a "normal" response. Similarly, Lori discussed lightheadedness—a more typical symptom of anxiety—but also talked about blurred vision, disembodiment, and feeling as though she would faint.

The main symptom for me is I feel really lightheaded, I feel like I'm in a dream. It's the hardest thing to explain. I can't even define it as dizziness. I don't feel dizzy, I just feel really lightheaded and I feel like things kind of look blurry, like I'm in a dream. They say a symptom is you feel like you're out of your body and that is absolutely how it feels. And it's terrifying because, especially if you're driving, you don't want to feel out of your body; you want to feel in control. And you have absolutely no control. You feel like, it feels like you're in a dream. I always feel like I'm on the verge of fainting.

Lori discussed symptoms of “normal” fear—lightheadedness—but also described feeling as though she was out of her body. The sensations of disembodiment and loss of control were incredibly distressing for Lori, again signaling that something is amiss.

Notably, Lori contemporarily makes sense of these distressing sensations by categorizing them as “symptoms” that “they say” (presumably medical experts) are typical of anxiety disorder. Lori eventually managed the sensation of being out of control, in part, through medical nosology or classification (which I discuss in greater detail in chapter seven), but years passed before she was offered the sense-making tool of diagnosis. Interviewees continually asserted that unexpected symptoms accompanied the more typical symptoms of fear; before diagnosis, these symptoms intensified the overall experience and provided the interviewees evidence that there may be an underlying pathology.

Although there were few constants in the initial experience of anxiety across interviewees, there were several loose categories of experience that emerged and pointed to pathology. For instance, many interviewees reported feeling as though their bodies were unable to *accurately* perceive the world. They experienced symptoms like: cotton mouth, swelling sensations across the body, hot and cold flashes, “raised level of feeling,” and sensory overload. For instance, Darla has a phobia of vomiting that was exacerbated by distressing sensations in her mouth.

With the anxiety, I got cotton mouth. I thought I was going to swallow my tongue.

It felt like it was swelling up. I couldn't swallow.

Her tongue was not actually swelling up, but the sensation was so strong that Darla believed it was swelling and, in turn, was unable to swallow.

Another set of symptoms clustered around problems of the brain, like: feeling drunk, disassociation, depersonalization, and vertigo. For Example, Jill reported feeling depersonalization, which is a sense that one is removed from immediate experience and that one's surroundings are unreal. She explained,

I remembered a term from therapy that fits my symptoms: depersonalization. I feel very dissociated from my surroundings. It's really weird; I can tell you, logically, that this is a chair, or a box, or whatever it is, but it doesn't *seem* like a box, as if I don't recognize it. But I do, of course ... does that make sense?

For Jill, her brain seemed to fail to fully connect objects to memory or knowledge.

Familiar objects and places became unfamiliar and problematic. There was a startling rupture in the experience of her immediate surroundings. Depersonalization was unusual enough that Jill asserted that the symptom was “weird” and asked if her description made sense. Discussions of less typical symptoms of fear were consistently buttressed with disclaimers, embarrassment, and clarifications indicating that the interviewees knew that there was something “wrong” with this way of experiencing the world.

Like Lori, Jill too made sense of the chaotic experience of anxiety before diagnosis by employing a category supplied by a therapist, “depersonalization.” In these narratives, the instability of the experience of anxiety was—eventually, although tenuously—balanced by the stability of the medical diagnosis. However, before diagnosis, the experiences of anxiety were marked by complete chaos and confusion.

Another common set of symptoms were related to breathing, which recalls the

root of the term anxiety: most likely derived from the Germanic root “angh” meaning “too narrow, to constrict, or to strangle” (Glas 2003:3). These sensations included: a tight chest, hyperventilation, needing to gasp for air, and subsequent numbness in face, hands, and feet. A few interviewees reported passing out while having trouble breathing during a panic attack. Losing consciousness was among the symptoms that the interviewees reported to be most severe and troubling, along with: vomiting, mute-ism, immobility, and loss of bodily control. These especially distressing experiences most clearly signaled the crescendo of anxiety and panic in the illness narratives.

Objects of Fear

While distressing sensations in the body certainly signaled to the interviewees that something was wrong, social exchanges with significant others—centered on these bodily experiences—definitively marked them as disordered. As Peggy Thoits has suggested, I find that “informal labeling by others appears to precede mental health utilization for a large majority of distressed persons” (Thoits 1985:239); interviewees collaborated extensively with significant others to establish that “something was wrong” long before seeking diagnosis or treatment. Additionally, the interviews suggest that “objects” served as important bridges between physical distress and the social experience of anxiety. Specifically, objects provoked distressing bodily sensations, and significant others held the interviewees accountable for their (deviant) physical responses.

Much of the following discussion involves this deceptively complex term: “object.” In symbolic interactionist literature, the range of entities encompassed by the term “object” is much larger than in everyday vernacular. Symbolic interactionist Herbert

Blumer provides three basic types of objects: physical, social, and abstract. Physical objects are concrete and tangible, like: elevators, highways, and grocery stores. Social objects are roles played out by social actors, such as: doctors, cashiers, and strangers. Abstract objects are ideas, like: eternity, the vastness of the universe, and the afterlife (Blumer 1969:11). The objects indicated in the preceding sentences were specific sources of fear for the interviewees and serve as examples of how I use the term “object” throughout this dissertation. Blumer (1969) further expands the definition of “object” to include “anything that can be indicated to or referred to” (p. 11). Following the wide range of objects—central to the anxiety experience—referenced in the interviews, I take up this broad and encompassing definition.

When interviewees described anxiety or a panic attack, they expressed an emotional and/or physical experience prompted by a specific object. These accounts represent a typical emotional experience indicated in the sociology of emotions, in which there is: an object, an identified emotion, and a physical response (see Lupton 1998). For instance, imagine a child approaching a towering, twisting rollercoaster with each turn punctuated with a unified scream. As the child approaches the front of the line, he notices that he has a sour stomach and his hands begin to tremble. He recognizes that he is scared. This is a typical, non-disordered, depiction of how individuals experience emotion. In this case, there is a clear object causing distress (roller coaster), the identified emotion of “fear”, and a physical response (sour stomach and trembling).

However, the pliable nature of objects can complicate the experience of emotion. As Blumer wrote, the nature of the object takes on the meaning it has for the “person for whom it is an object” (1969:11). The nature of any given object can multiply and inspire

a range of appropriate or, more to the point, inappropriate responses. For instance, an elevator for many interviewees was transformed from a mundane object into, say, a coffin rocketing into the stratosphere. It becomes an unapproachable, unusable object. For example, one interviewee, Mae, recounted developing a fear of driving, which gave way to a fear of highways. Eventually, even looking at a map caused Mae distress. The map itself came to represent terrifying isolation to Mae. The object (driving, the highway, or the map) took on a meaning specific to Mae's experiences, beliefs, and fears.

Importantly, the nature of an object is not only dependent on one person's meaning for it. The nature of an object depends also on the understandings of the family, community, culture, society, and so on. As such, an elevator *is* a relatively mundane object, as a shared object. But, in the lifeworld or *Lebenswelt* (Schütz 1970:271–3; 320) of someone who is afraid of elevators or, moreover, a phobia of elevators, they are in no way mundane but, rather, terrifying. This disjuncture was a source of great strife for the interviewees. Likewise, Mae found little understanding for her fears of driving and highways from her family and friends and recalled their hurtful teasing about drugging her and putting her in the trunk to get her to go on the highway. Her interpretations of these objects were not viewed as legitimate. Others did not share the meaning of the objects of her fear, and, as such, the multiple “natures” of objects became powerful signs of disorder and sources of ridicule.

Deborah Lupton (1998) illustrates how divergent understanding of an object can become a sign of disorder. She discusses a typical and acceptable experience of emotion in which a physical experience is tightly linked to an appropriate causal object.

A person undergoing an important job interview may find herself experiencing certain bodily sensations she interprets as “feeling nervous.” These sensations

may include a tightened stomach, rapid breathing, pounding heart, a feeling of hotness, sweaty palms, jerking movements of the foot, a dry mouth and throat, quavering voice and flushed neck and face. Members of the interview panel will come to the conclusion that the individual is “feeling nervous” rather than, for example, demonstrating anger or fear, both of which emotions include similar bodily processes (p. 23).

In this case, these bodily symptoms are understandable because they are tethered to a socially recognized—and thus “reasonable”—object (a job interview), and this is a “normal,” culturally relevant, response to this object. The nature of a job interview, and all that it involves, is typified as anxiety-provoking (see Schütz 1970:25 on the importance of typifications in mediating “immediate human experience” and “pre-established cultural interpretations”). Likewise, Lupton (1998) notes that the interpretation of these experiences as “normal” is dependent on “culturally specific understandings that such situations” generate this type of emotion or response (p. 23).

Among the interviewees, their experience of objects often differed profoundly from their family, friends, and coworkers’ experiences of objects. Seemingly mundane objects became sources of confusion and concern. The objects interviewees perceived as anxiety-provoking were not generally understood to incite fear. This is what I refer to as an *object-response disjuncture*. That is, the individual’s experience of the object does not match the “pre-established cultural interpretation” (Schütz 1970:25).

Peggy Thoits describes a similar concept, “norm-state discrepancy” in which individuals “are aware of discrepancies between their private experiences of emotion and the states prescribed by emotional norms” (Thoits 1985:227). My discussion builds on Thoits’ norm-state discrepancy by explicitly and empirically addressing the role of objects in the identification pathology and the external (as opposed to an analysis focused on “private experiences”) and social nature of this process.

Fear is not a Historical or Cultural Constant

Before turning to the interviews, I will take a moment to point to the culturally contingent meanings of objects and appropriate emotional responses. While there is relative consensus among Americans about what should and should not be feared, there is nothing *inherent* about those distinctions. For instance, talking in front of a group is far less dangerous than driving a car, but it is more socially acceptable in America to fear public speaking than it is to fear driving. This example points to a collective subjectivity forged around fear, echoing the phenomenological terms “recipe knowledge” and “typification” (Berger and Luckmann 1967). Fear does not represent an asocial cost-benefit analysis. We, groups of all sizes, come to widely held agreements about the objective reasonableness of fear, which is not tethered to some set of immutable laws or inherent standards. In that same line of thought, sociologist Iain Wilkinson (2001) observes that:

There is no objective value-neutral means of assessing the reality of risk, rather, what we come to believe about the magnitude of the dangers we face is, in the last instance, determined by a qualitative decision.... Accordingly, in the social context of everyday life, the language of risk is conceived as ... an attempt to articulate and defend a preferred point of view on reality (p. 105).

This “preferred point of view on reality” is often a shared one, but, as Wilkinson notes, it is not an inherent or fixed one. In a society that valorizes independence and is—arguably—obsessed with cars, a fear of driving flies in the face of the general “preferred point of view on reality.” On the other hand, public speaking holds less cultural currency and is less valued; fear of such an undesirable task makes solid cultural sense.

The constructed nature of risk assessment is further evidenced by the fact that acceptable fear varies over time and across groups and cultures. For example, Walter Cannon (1957) writes about a geographically and temporally distant fear, which is specific to youth in a tribe in Congo in the late 1600s.

A young [man] on a journey lodged in a friend's house for the night. The friend had prepared for their breakfast a wild hen, a food strictly banned by a rule which must be inviolably observed by the immature. The young fellow demanded whether it was indeed a wild hen, and when the host answered "No," he ate of it heartily and proceeded on his way. A few years later, when the two met again, the old friend asked the younger man if he would eat a wild hen. He answered that he had been solemnly charged by a wizard not to eat that food. Thereupon the host began to laugh and asked him why he refused it now after having eaten it at his table before. On hearing this news the [boy] immediately began to tremble, so greatly was he possessed by fear, and in less than twenty-four hours was dead (p.182).

The fear of eating a hen, banned by a wizard, makes virtually no cultural sense in the contemporary United States. If one were to show signs of intense fear after eating a bite of chicken, this would be a convincing sign, in the modern western world, of some sort of pathology. Conversely, this fear made good sense within that particular historical and cultural context.

A recent New York Times article "Lifting the Veil of Fear to see a few Benefits of Fever" (2011) provides a more proximate example of differences in acceptable fear across groups. The article is written by a pediatrician who attempts to bridge doctor and patient understandings of fever among children. She begins by explaining "as a pediatrician, I know fever is a signal that the immune system is working well. And as a parent, I know there is something primal and frightening about a feverish child in the night." A fever for a physician is a good sign; the body is working. For a parent, it is a

sign that something is *not* working; their child is sick. The author recounts a specific incident with a worried mother:

One recent night, I talked to the mother of a toddler with fever and abdominal pain. I was more worried about the pain, and about whether he was drinking enough to stay hydrated; she was more worried about the fever, and no matter what I asked she kept coming back to that number on the thermometer. Finally, I got so worried the child was dehydrated that I told her to go to the emergency room. And when she got there, she told them she was scared because the child had a high fever (Klass 2011:1).

Physicians—based on a particular stock of knowledge—fear certain objects, while mothers fear entirely different objects. But, arguably, this disjuncture is not solely grounded in access to medical knowledge. Appropriate fear is also a social expectation. For instance, if a mother did not fret over a high fever, her partner, friends, and perhaps even the doctor might think her cold or uncaring. Conversely, if a physician were to worry loudly about a fever, her coworkers and patients may not trust her temperament or knowledge as a physician.

To the point, fear is not stagnant, fixed, or necessary. Emotion is culturally bounded and largely prescribed. Across groups, cultures, and time, the objects of fear and the expected intensity and manifestations of fear vary profoundly. De-naturalizing the culturally and historically specific objects that “should” and “should not” inspire fear opens the imagination up to the possibility of fears—fears that many may find to be irrational—as being meaningful within the lifeworlds of those with anxiety disorders.

Fear is not obvious. It is accomplished simultaneously in the subjective world of interpretation and in prescribed and often rigid social landscapes. While there is certainly flexibility in meaning across social space, the brut reality remains that individual people live in firm social realities that provide little give or accommodation. Specifically, there

are serious personal consequences to individuals with anxiety disorders who are unable to adhere to local and specific socially expected responses to various objects.

Two Variations on the Object-Response Disjuncture

Before the interviewees were diagnosed with anxiety disorders, an object-response disjuncture provided one of the first indications for them that something was “wrong.” Similarly, Allan Horwitz and Jerome Wakefield (2007) observe that, when diagnosing depression, there are two basic criteria for identifying “normal sadness.” These two criteria speak directly to the experiences of the men and women whom I interviewed with anxiety disorders. First, normal responses are “inherently context specific in the sense that they respond to a specific range of the ‘right’ stimuli” (Horwitz and Wakefield 2007:28). That is, for sadness to be normal, the individual must respond with sadness to a situation that is, in fact, sad. Second, normal sadness is “roughly proportionate to the magnitude and permanency of the loss” (Horwitz and Wakefield 2007:28). In other words, the reaction of the individual must match the response called for by the situation.

Likewise, interviewees (unintentionally) pointed to these two criteria in their narratives about experiences before and after they encountered any medical intervention. Specifically, interviewees reported responding fearfully to objects that “should not” inspire fear and experiencing too intense of fear in response to mildly or somewhat fear-inducing objects. Further, interviewees reported experiencing social pressure—even coercion—to experience, respond to, and treat objects “appropriately.” While the experience of anxiety was a profoundly embodied and internal experience, the initial

identification of anxiety as disordered or abnormal was a deeply intersubjective and social process.

The object-response disjuncture was both explicitly pointed out by someone else and implicitly derived by drawing on a shared stock of knowledge (Schütz 1970; Berger and Luckmann 1967) or Mead's generalized other (Mead 1938:152–3). Mead argues that we “become a self by responding to [ourselves] in the attitudes of other selves. This involves the assumption of the community attitudes where all speak with one voice in the organization of social conduct” (Mead 1938:152). As such, we all have a general sense of the appropriate attitude to take toward objects. Likewise, the interviewees knew that their responses were not typical or normal. This knowledge, built into the self over the life course, was reaffirmed and solidified in social interactions after they began experiencing symptoms of anxiety. Mead continued, explaining that “in so far as these attitudes of the others call for the identical response of his own, the organization of the social act is reflected into his act” (Mead 1938:153). The interviewees, to their dismay, found that the “organization of the social act” was not reflected in her or his act.

This chapter sharply divides the objects into two categories: objects that people think should *not* cause fear and objects that they thought could reasonable cause some fear. Although, this distinction was not always obvious; the interpretations of objects are scattered across a continuum of experience. For instance, driving across town “should” cause little to no distress, while taking a trip to Antarctica “should” cause a significant amount of distress. Somewhere between these extremes are trips across the country, to Russia, to Sudan, and to Iraq. The intensity of and the ordering of most distressing to least distressing events/objects are open to a limited range of interpretations within a

specific cultural context; there is no obvious dichotomy. While there is both a socially agreed upon spectrum of how fear-inducing an object is, there is also latitude for “normal” subjective appraisals of that object.

With this challenge in mind, the data was coded by how the *interviewee* thought the object “should” be responded to. In the first section, “Fearing the Mundane,” interviewees explained that the object that they feared should not cause fear. In the second section, “Scary, but not THAT scary,” interviewee articulated that the object was justifiably fear-provoking, but they felt that their fearful responses were out-of-proportion to the object. The distinctions in the coding were based on the interviewees’ subjective appraisal of the “objective” nature of the object. Accordingly, the same object was sometimes coded in both categories, depending on how it was interpreted by the interviewee. For instance, driving for several of the interviewees was an object that *should not* cause fear, but driving for another interviewee was described as a reasonably fear-inducing object. These incongruencies point to the flexibility involved in interpretation and the challenges in establishing criteria for “normal fear.” The following sections point to two general ways that that interviewees drew on the generalized other, objects, and subjective experience to begin to identify and name an anxiety disorder.

Fearing the Mundane

First, many interviewees found that the object causing them fear “should not”, indeed, cause fear. For instance, interviewees reported fears caused by talking with a cashier, being out of their homes, riding elevators, eating new foods, taking a walk, and being in the grocery store. Lori reported similar experiences. Lori is a thirty-four year old mother of two and in a long term relationship with her partner, who is a busy and

moderately successful businessperson. Lori is a full-time student and completes all of her coursework online. Lori hopes to attend graduate school for nursing, but has doubts that, with her experiences of anxiety, she will be able to attend classes. She has fears of driving, being in groups of people, and being in closed rooms, which she anticipated would make graduate classes very difficult. Lori has experienced anxiety as long as she can remember, but she explained that the panic has escalated over the last three years.

Lori indicated that there are objects in her life that cause her anxiety that she doesn't think should cause anxiety at all. For instance, going to sleep became an object of fear for Lori. She explained,

I was even scared to go to sleep. I stayed up really really late doing homework, like one o'clock in the morning and even then I felt scared to go to bed without the TV on. *It sounds kind of childish thing, to need the TV on to sleep.*

Lori found that her fear of sleeping or going to sleep kept her up into the night, later than she would have liked. She started to leave the television on to help her transition into sleep. Notably, she referenced keeping the televisions on as "childish." In other words, she felt that an adult should not be afraid to sleep and should not need a television on to aid in falling asleep. There was a disjuncture for Lori between what sleep meant to her and what sleep *should* mean and involve. This interpretation was supported by her partner. Lori explained,

My partner did not want the TV on. She couldn't sleep. She didn't understand that I needed it on to have something distracting me. So I would let her turn it off, and it would make the anxiety worse. And, I had to sit with my thoughts.

Her partner did not interpret sleep as an object that warranted fear nor did she allow for the accompanying need for the television. Lori's own ideas about the fear of sleep being "childish" and her partner's rejection of sleep as fear-provoking created tension within

Lori and between Lori and her partner. In the end, the normative view on the object won out; Lori was expected to treat sleep “appropriately,” without the television. In this case, not only did the disjuncture in the meaning of sleep indicate to Lori that something was “wrong,” her partner solidified her experience and interpretation of sleep as inappropriate.

Similarly, Skye narrated several instances in which she felt that the objects that she feared should not be feared at all. For instance, Skye lamented that she has a fear of plans changing.

If I'm thrown into a situation that I hadn't planned for or haven't expected, I usually shut down and just say “I can't be here.” I just leave. If my friends tell me, “Okay, we are going to the cafeteria tomorrow at noon,” I can prepare myself a little bit. I don't spontaneously do anything. I wish that were different. I wish I could just think “I want to do this and just go do it.” Or somebody could just say, “Hey, let's go to the park” and I would say, “Okay.” If I haven't planned it into my day or haven't thought about it, I can't do it. I need time to be like, “Okay, what park are we going to? What is it gonna look like? Who's gonna be there? What time of day? What's the weather's gonna be like?”

Skye was not afraid of cafeterias or parks in particular; rather, she was scared of changing plans, spontaneous activity, and new places. Skye was aware that there was another, more acceptable, way of approaching spontaneous activities. I then asked Skye how long she needed to prepare to go somewhere. She indicated that it varies quite a bit, depending on the activity and her state of mind. Often she simply can't go.

Sometimes, if I'm trying to calm myself down, I can just be okay with it right away, sometimes it gets worse and I can't handle it. [If she is given too much warning] I obsess about it and then it's just like “no. It's going to be bad. I can't go.” Sometimes I just avoid it. It can go either way. It's different how long it takes me before I can go somewhere. My boyfriend knows me, if there's something I don't want to do or I'm not going to do, he won't tell me where we are really going until we are there, which in some ways is really bad because I go into this horrible panic.

The “normal” view of the object, in this case “going out,” dominated the intersubjective experience that Skye described. Skye’s boyfriend would trick her into going to a new place or somewhere they hadn’t planned. She is pressured into perceiving the object as it is *supposed* to be viewed. Nonetheless, this alternative view is not how Skye experienced spontaneous activities and, as such, often found herself in the midst of a panic attack.

Again, there was an internal and an external tension. Internally, Skye knew that her experience of spontaneous activity was not the “normal” way of experiencing it and wanted to respond differently, appropriately. The external tension, in this case, was between Skye and her boyfriend. This tension manifested as coercion to treat the object appropriately and Skye’s subsequent experience of panic. Skye’s understanding of her fear as abnormal was supported, even amplified, in the relationship with her boyfriend. Skye was literally forced to confront fear-inducing objects and pressured to treat the object “normally.” Social relationships highlight object-response disjunctures and press individuals to continually face social indicators of pathology.

Tina also discussed experiencing mundane objects as anxiety-provoking. Tina lives with her husband and his five children. She is in her late thirties and has experienced anxiety on and off since she was very young.

I've always been somewhat anxious. I went through in high school where I was agoraphobic [undiagnosed]⁹, and I couldn't really go anyplace except for school. I gradually grew out of that.... I've always had some anxiety if I had to fly or, you know, go in an elevator, places that were hard to escape from. I guess that's claustrophobia, I don't know. I've always thought that, but this new phase of anxiety started about maybe three years ago.

When I asked her to describe for me what this new phase of anxiety was like, she explained,

⁹ As an adolescent, Tina was not diagnosed as having agoraphobia. Rather, she reflected on the social, physical, and mental experiences at that time and *now* labels it agoraphobia.

At first I'm just really anxious, just anxious feeling, nervous, jittery, and trembling and then I start getting those flashes of unreality. Which is just the worst feeling and then that starts escalating the anxiety and then I go into this full-blown just other altered consciousness, horrible state of unreality. It's just horrible.

For Tina, this severe anxiety posed the most serious threat while she was away from her home. As such, she preferred to stay home where she felt she was less likely to have a panic attack, and, if she was to have a panic attack at home, she would be free from the gaze of others and would have the resources to help her cope with the panic. After describing what she meant by severe panic, she described a specific fear of going for a walk, which she did not think should be a source of fear.

I mean, like, if I'm walking, I feel like I won't make it home. *It's just completely irrational*, but I feel like I'm swimming in this alternate, like, in this alternate universe and I won't somehow make it home even though it's just a 10 minute walk to get home.

While on a walk, she often felt like she wouldn't make it back to her home and felt detached from reality or in another reality. These are very real subjective experiences, but, at the same time, she explained that it is an "irrational" feeling because *objectively* she is only ten minutes from her home. The normative interpretation of a walk triumphs over Tina's initial subjective experience of feeling marooned and in a state of unreality. As a consequence, she dismissed her experiences as irrational. The tension between her subjective experience of walking and the "appropriate" experience of going for a walk is clear. Accordingly, Tina attempted to treat going on walks appropriately; she later explained that she made herself take a walk almost every day, often provoking panic attacks.

Interviewees often experienced largely "mundane" objects as fear provoking and were encouraged, however gently or coercively, to treat these objects appropriately. Lori

was afraid of sleep; Skye was afraid of new places and changing plans; and Tina was afraid of walks. All three indicated that these were objects that *should not* cause fear. Lori and Skye both had partners that pressed them to treat these objects of fear “appropriately.” Lori was not allowed to have the television on to help her transition to sleep, and Skye’s partner would trick her into going someplace unfamiliar or unexpected. Tina pressed herself to take walks despite her fear, motivated by the knowledge that her fear was not “normal.” Interviewees continually reported *attempting* to discipline their bodies to react to objects appropriately, despite physical discomfort and fear (Foucault 1995). For these interviewees, the physical world, the social world, and their subjective/embodied worlds collided, pressing them to *attempt* to behave, experience, and respond in accordance with the normative view of objects.

It would be a mischaracterization to say that the interviewees *wanted* to continue to experience these objects as fearful and that significant others alone forced them to interact “appropriately” with them. Rather, interviewees, as active members of the social world, desperately wanted to “appropriately” interact with these objects, but, to their dismay, none of interviewees were able to sustain a consistently “normal” relationship with these fear-provoking objects. And, this inability amplified the sense that “something was wrong,” pointing to pathology.

The pressure exerted on the interviewees, by themselves and by others, to treat, or at least to attempt to treat, objects “appropriately” mirrors Parson’s sick role, which demands that the sick patient sincerely try to get better (Parsons 1951). The “sick role,” for these interviewees, began long before visiting a doctor. They were expected to correct their deviant subjectivity at the first signs of disorder. These expectations

surrounding normal fear, again, amplified the sense that there was something amiss, and interviewees' lives and experiences continually had to be reshaped to accommodate the more acceptable meanings of these objects.

Scary, but that THAT scary

In the second form of the object-response disjuncture, the interviewees felt that their fearful response was too great for the arguably anxiety-provoking-object. In these cases, the object was widely understood as being anxiety-provoking, but the interviewees' response was interpreted by themselves, their families, and others as being too fearful. For instance, at a support group a woman in her sixties—who does not have an anxiety disorder—attended the group to get advice for her brother—who has a panic disorder and agoraphobia. At that time, her brother was unable to leave his home and could not attend the group. She shared with the group that when her brother was younger he was very nervous to go out on dates. At this point, her discussion of his nervousness seemed perfectly “acceptable.” Dates are widely thought to be anxiety-provoking. She explained, however, that on multiple dates he hyperventilated to the point that he has passed out during dinner. Several group members sighed, a few mumbled supportive phrases, and the group facilitator nodded knowingly. The fact that the man had passed out on multiple occasions was a clear indicator to the group, him, and his family that there was something wrong; his response to an understandably uncomfortable situation was too extreme for him and his family to define as “normal.”

One interviewee, Kalli—who is in her early forties and lives in a rural town in New England—was physically attacked at her workplace three years prior and has suffered with the symptoms of a panic disorder and posttraumatic stress disorder ever

since. Kalli developed a fear of driving, and she explained that she felt that her fearful response to driving was out-of-proportion to the object. I asked her to tell me about a time that she felt nervous while driving.

Actually, I had to go to Boston recently, and I got lost in Chinatown, *which is scary*. There was homeless people running up to the car. I was just sweating, it first started with this sweating and I shake all over and then my heart is racing, really bad. And, I'm having pains in my chest, like chest pains. I was hysterically crying because I couldn't get out. I couldn't get out of Boston. I felt like I was suffocating. There was an officer there that kind of helped direct me to get me out. It took me a little while, but I was panicking really really bad.

Driving and getting lost in downtown Boston, especially for someone used to driving in a more rural location, can easily be understood as an anxiety-provoking event. Kalli stated in an objective tone that getting lost in Chinatown in Boston “is scary.” From there, her response escalated. At first, she sweated. Then, her heart started racing, and she began to have chest pains. She increasingly felt trapped and began to cry, which she described as “hysterical.” In this case, Kalli’s description of “panicking really really bad” was understood by her as an out-of-proportion response to the arguably anxiety-provoking experience of getting lost in a major city.

Similarly, Lori described her fear of living alone. For Lori, living alone was a reasonably anxiety-provoking object, but she found her response to be out-of-proportion to the object. When I asked Lori if there was anything that she wished she could do that she can’t because of anxiety, she responded,

I've never been able to be alone ... I guess, but in the most basic way: I've never lived alone. I could never. When I was twenty I bought a house because I got money from that car accident. I bought a house and I rented every single room so I would have people living with me constantly. I needed a lot of people around me. For a brief period, I lived alone when I was twenty, before I bought my house, and I could never sleep. I was terrified, all of the time.

Lori explained that she had gone to great lengths to not be alone and, when she was alone, she had panic attacks. Lori also discussed how she had never been able to be single and had stayed in unhealthy relationships in order to not be alone. Like many of the interviewees, Lori found that her fears drove much of her behavior, keeping her from doing certain things, while forcing her to do others. Likewise, Skye discussed a fear of driving after a car accident.

I know where this fear [of driving] came about. My sister was driving and we got in a bad car accident one time.... If it's unpredictable, if I'm taking a left turn, I don't know when to go. I have bad judgment of time and speed. I worry all of time. People make fun of me if they're driving with me and they're sitting in my car, "Why didn't you go?" "I just wasn't sure." Everything is really hard and stressful, like driving.

After a car accident, a "bad" one at that, fear of driving became socially acceptable and driving became an understandably anxiety-provoking object. But, this was a short-lived exception. Skye explained that her friends, her therapist, and her family felt that several years after the accident that this fear of driving should have dissipated, and, as such, Skye interpreted her contemporary fear of driving as being irrational.

Also, her apprehensions about driving appeared to be aggravated by her friends teasing. She questioned her ability to react while driving, which was mirrored by her friends making fun of her for not "knowing" when to go. The anxiety involved in driving for Skye was amplified and the abnormality her fearful response was reified by her friends' goading. I then asked Skye if she drives at all. She responded,

I try not to avoid it because I know that it is something that will have to be a part of my life forever. The less I do it the harder it will be. I just keep doing it. For driver's ed, I waited a year before I took my test because I was that panicked. I was like "I don't want my license. I don't want to drive. I don't like driving".... When I'm driving, I'm always looking around. "Is someone gonna hit me?" Or, "am I not gonna see someone?" So I'm just on high alert the whole time. If I don't

have to drive, with my boyfriend I'm like, "Can you drive?" *He really just always just drives.*

Again, Skye pushes herself to treat driving appropriately, despite her fearful response, her history of a car accident, and her perceived inability to "know when to go." But, in stark contrast to Skye's experience with her boyfriend tricking her into going someplace new, when it came to driving, her boyfriend happily agreed to drive for her. Perhaps his willingness was due to the fact that a fear of driving, especially after a car accident, is more widely accepted than the fear of new places and changing plans. It could also be explained by the fact that the fear of driving may not impinge on the lives of others in the way refusing to go to, say, a new restaurant or a concert might. Interviewees continually reported having "exaggerated" responses to typically anxiety-provoking objects. Kalli cried hysterically when she got lost driving in Boston; Lori could not be alone without provoking a panic attack; and Skye struggled to force herself to drive years after a car accident.

There was an implicit continuum in the narratives, described in these last two sections, about how anxiety-provoking the object was thought to be and of the intensity of fear felt and expressed in response to the object. There is a general agreement, within particular communities and cultures, about the amount of fear one should experience in response to any given object, and the interviewees increasingly felt that they were unable to match their responses to this standard.

Further, interviewees consistently met more resistance from their immediate family and their friends when they responded fearfully to objects that were not understood to cause fear at all than when they had "exaggerated" responses to objects widely understood as acceptably causing *some* amount of fear. Importantly, those objects

that were understood not to cause fear were often more fundamental to a “normal” social existence. For instance, eating, sleeping, and walking outside of the home were events that were: feared by some of the interviewees, sanctioned by themselves and their families, and core to successful participation in social life. On the other hand, for example, a fear of driving can be more easily accommodated by allowing others to drive, taking public transportation, and staying closer to home. As such, the willingness and ability to drive was less vital to maintaining normal social relations. Arguably, the more mundane an object is perceived and the more essential that object is to successful social relationships and performance, the more strictly the relationship with that object is maintained and the more severely deviations from those meanings are sanctioned.

How “essential” any given object or activity is to successful social participation is deeply dependent on the social, cultural, interpersonal, and physical conditions. For instance, Ingunn Moser and John Law (2007) observe—in a case study of a woman with a physical disability—that “if the networks are in place, if the prostheses are working, then there is ability. If they are not, well then, as is obvious, there is disability. So here's the proposition. Disability is about specific passages between equally specific arrays of heterogeneous material” (p.201). That is, if the physical and social environment accommodates the individuals in it, there is no disability. In the case of these interviewees with anxiety disorders, if there were good “passages” or accommodating environments, such as ample public transportation options, grocery delivery services, and bedrooms in which the televisions could be left on, anxiety would not have to same grip or meaning that it had in their narratives. As it was, those passages were sorely lacking,

and the interviewees suffered beyond the immediate sensations, due to a lack of accommodation within a specific social context.

While a social constructionist perspective provides evidence for the possibility of differently structured social worlds and a vantage on a more flexible social existence, these interviewees—on the individual level—existed in rigid, obdurate social and physical environments. There was a nearly inescapable disjuncture between the individual experience of objects and the general typifications of objects that pointed to disorder for the interviewees and prompted social sanctions, dealt out by friends, family, and acquaintances. These intersubjective realities amplified the experience of anxiety, redirected the interviewees' action, and magnified the object-response disjuncture. The first indications of pathology emerged around a wide range of objects in social relationships with significant others within specific and local contexts.

Conclusion

This chapter addressed the interviewees' first indications of disorder before diagnosis. While much health and illness literature focuses on the professional and institutional construction of illness (Brown 1987; Conrad and Schneider 1980; Horwitz and Wakefield 2007; Kutchins et al. 1997), this chapter opened up a discussion of how individuals—along with various social collaborators—began to co-construct their illness experience before diagnosis. Medical sociology focuses primarily on the illness experience during—and to a lesser extent, after—diagnosis, perhaps because diagnosis is an undeniably social process and signals formal entrance into illness and the medical system. While this study, too, discusses the diagnostic process and the illness experience

after diagnosis, this chapter and the next expand that discussion to address the experience of “pathology” before diagnosis.

A broader scope of study—extending back, before diagnosis—offers much to the sociological study of health and illness. First, it provides a fuller view of the illness experience, which often begins years before diagnosis. Also, this approach addresses the construction of the illness narratives, accomplished by patients and their significant others, before they enter the doctor’s office. These narratives, constructed before diagnosis, (1) are what bring the individual to the hospital or clinic and (2) provide a part of the evidence used by physicians for diagnosis (Jutel 2009:289). Accordingly, these social processes are vital to understanding treatment seeking and the diagnostic processes. Lastly, the identification of illness before diagnosis is a deeply social—sociologically rich—process, which further illuminates strong connections between social norms, medical diagnoses, and illness experience.

While distressing sensation in the body signaled to the interviewees that “something was wrong,” the physical experiences of anxiety were not, in and of themselves, the clearest indicators of disorder. Indeed, many of these physical responses, in other contexts, could be construed as “absolutely normal.” Identifying experience as disordered was a decidedly social process. The interviewees’ physical experiences and interpretations were deeply connected to the physical and social worlds around them; specifically, their bodies reacted “inappropriately” to specific objects in the environment which prompted responses from significant others. That is, objects that were largely mundane to others were sources of intense fear for the interviewees and, in response, significant others encouraged, demanded, or coerced the interviewees’ to treat objects

“appropriately.” The individual experience of the object did not correspond to the “pre-established cultural interpretation” (Schütz 1970:25), and, as such, this object-disjuncture served as a powerful sign of disorder.

There were two specific ways in which interviewees’ responded “inappropriately” to objects. For one, they reported responding fearfully to objects that “should” not inspire fear. And, two, they experienced too intense of fear in response to—what they thought *should* be—mildly or somewhat fear-inducing objects. Again, interviewees reported experiencing social pressure to experience and respond to objects “appropriately,” and in the illness narratives, the normative view on the object continually won out. Likewise, the interviewees, too, badly wanted to interact with objects “appropriately”, but, much to their disappointment, they were unable to sustain a “normal” relationship with these objects.

How an object is perceived by significant others and the generalized other impacts how severely the “deviant” is sanctioned. The more mundane the object is understood to be and the more essential the object is to successful social performance, the more ardently the relationship with that object is monitored and the more severely deviations from those meanings are sanctioned. While the “natures” of objects are not inherent, the interviewees, nonetheless, were forced to grapple with their inability to respond to objects in a singular and socially expected way. Distressing sensations, confusing objects, and social interactions (as social control) converged and loudly indicating pathology to interviewees.

CHAPTER FOUR

FEARLESS FEAR: THE (MIS)IDENTIFICATION OF PHYSICAL AND MENTAL DISORDER

If I didn't know that I had the anxiety disorder, if I had never experienced it before, I would say, "Yes, take me to the hospital! Something is definitely wrong!" But since I know what it is, I know what it feels like, and I've had it in the past, I just deal with it until it goes away. (Skye)

Skye's quote encapsulates much of what I discuss in this chapter. That is, I show how over time anxiety became an increasingly *physical* experience, which made it challenging for the interviewees to interpret it as "fear," and, as such, they often thought they were suffering from a more medically consequential illness (like a heart attack) and would seek immediate medical attention, often in an emergency room. Importantly, as Skye suggests, diagnosis—simply having a name for these sensations—could entirely re-make the experience of this physical distress. For the interviewees, diagnosis played a critical role in the management of distress. Notably, interviewees often went years without a diagnosis. In part this chapter addresses why, with very intense symptomology and active treatment seeking did so many of the interviewees suffer with these symptoms for so long without a diagnosis (or treatment).

One explanation was that an anxiety disorder, before diagnosis, could easily be (mis)interpreted as a number of other illnesses. Skye, whose words opened this chapter, is

a college sophomore in her late twenties but looks even younger; she looks much like a typical undergraduate student: healthy, energetic, and vibrant. Despite her healthy appearance, Skye suffers debilitating panic attacks. She has experienced symptoms of anxiety as long as she can remember and was diagnosed with a generalized anxiety disorder and panic disorder at age sixteen. Skye described her experiences of panic attacks.

It's like my whole body is just caving in. That is the physical feeling. My heart is racing. I'm sweating. I'm dizzy. I physically feel ill. I feel like I'm going to pass out or just fall over and crumple up into a ball. It's just absolute panic. I feel like I'm going to die. . . . I have difficulty breathing.... I feel sick to my stomach. My muscles get very shaky.

Skye described a chaotic set of symptoms, including: racing heart, sweating, dizziness, difficulty breathing, shaking, and nausea. The physical experiences of anxiety without a category (or diagnosis) are confusing and easily mistaken for a variety of physical and mental illnesses. These symptoms, taken together, illustrate why Skye felt that she—if she had not had a diagnosis—would have demanded to go to the emergency room.

The intense and confusing physical sensations that Skye described were common among the interviewees. For instance, Darla described similarly distressing symptoms. Darla is also in her late twenties but has had very different life experiences than Skye. She had her first child at age seventeen and another child a year and a half later. She never finished high school and has been unemployed most of her adult life. She has a noticeably thin and frail frame, which she explained was due to the fact that she has trouble eating because of anxiety-induced nausea and a fear of vomiting. Despite their differences, these two women's descriptions of anxiety were quite similar; they discussed feeling dizzy and having trouble breathing. Darla described her experience of anxiety:

I would get chest pains. My fingers and my elbows would turn numb. I got shaky. I was hyperventilating to the point where I was dizzy and lightheaded. I felt like I was going to pass out. I was getting hot and cold flashes. Like, I couldn't live. I just crumple up into a ball.

Skye and Darla even used the exact same language of “crumpling into a ball” and both recalled feeling as though they were going to die. Another interviewee, Kalli, echoed Skye’s experience of sweating and shaking during a panic attack when asked to describe a typical panic attack: “The first thing I would say is that it just comes on and you sweat, you shake all over, and your heart races and you have chest pain.” And, like Skye, Lori discussed a racing heart and lightheadedness:

my neck turns red and my face turns red and that's basically what I look like, and inside I just am going crazy, like my heart is beating, I'm shaky....I can't see straight.

Despite the variation in the details of the experiences, there was a fundamental similarity in the anxiety experiences: the symptoms were initially experienced as profoundly confusing and were difficult to identify as “anxiety.”

One potential explanation for this difficulty is that an anxiety disorder diagnosis does not fit the experiences of the interviews, but this was not the case. The diagnoses generally fit the interviewees’ symptoms incredibly well. For instance, the *Diagnostic and Statistical Manual IV* defines the criteria of a panic attack as the sudden onset of four or more of the following symptoms:

1. Palpitations, pounding heart, or accelerated heart rate
2. Sweating
3. Trembling or shaking
4. Sensations of shortness of breath or smothering
5. Feeling of choking
6. Chest pain or discomfort
7. Nausea or abdominal distress
8. Feeling dizzy, unsteady, lightheaded, or faint
9. Chills or heat sensations

10. Paresthesias (numbness or tingling sensations)
11. Derealization (feelings of unreality) or depersonalization (being detached from oneself)
12. Fear of losing control or going crazy
13. Fear of dying

The above symptoms closely mirror the interviewees' narratives about panic attacks before diagnosis. The poor fit of the diagnosis was not the fundamental problem that they faced in locating a diagnosis.

The challenge for these interviewees, instead, was making sense of seemingly disparate and chaotic physical experience *before* the diagnostic category was offered. The onset of any combination of the above thirteen criteria would reasonably cause alarm, provoke confusion, and simulate other illnesses. The diagnostic category serves a vital sense-making function; it organizes experience into meaningful entities. Accordingly, the interval between the onset of symptoms and diagnosis was marked by profound confusion and perpetual (mis)interpretation.

Most interviewees suffered with these symptoms for months and years before receiving diagnosis and treatment. Skye was a rare exception; she was diagnosed shortly after the onset of intense symptoms. After Skye described a typical panic attack, I asked her, "Have you ever gone to the hospital or the emergency room while having a panic attack?" Skye answered my question with an unhesitating "no."¹⁰ Skye was diagnosed with an anxiety disorder at a young age and has had the rare opportunity to work with the same, supportive, therapist for over a decade. Skye still sees the therapist every other week for ongoing cognitive behavioral therapy. Nonetheless, Skye explained that she certainly would go to the hospital if she did not know that her symptoms were *actually*

¹⁰ In chapter eight, I discuss some contradictions in Skye's narrative about treatment seeking that complicate the role of diagnosis in experience.

anxiety. Even as someone who—all of her adult life—had identified these symptoms as anxiety, Skye could easily see how the symptoms could be construed otherwise.

Skye recognized the incredible power of the category “anxiety disorder.” Since she was armed with a label for her symptoms, she could name the experience “anxiety” and “just deal with it until it goes away.” As Skye predicted, many interviewees—who did not have a diagnosis—did go to emergency rooms, not knowing what to make of their experiences. Before diagnosis, many interviewees were unable to identify these distressing sensations as indicators of a panic attack or signs of an anxiety disorders and often (mis)took them for signs of other illnesses, such as: schizophrenia, heart attack, epilepsy, and asthma. Interviewees reported that their initial experiences with anxiety were confusing, and it wasn’t until they received a diagnosis of an anxiety disorder that they were able to make sense of their experiences.

Emotional Accounts

Most of the people I spoke with spent months or years without the arsenal of a name for their experience, in large part because they were unable to translate their physical experiences into emotional ones. Sensible emotional experiences depend on what Norman Denzin (2007) termed “emotional accounts,” which are “self-justifying” explanations for emotions that provide a “reason...for the emotion that is currently felt” (p. 57). Account-making is a component of the intersubjective transformation of physical sensation into coherent and meaningful experience. That is, accounts—that are honored in particular communities (Blumstein et al. 1974)—allow people to make sense of

disparate and confusing physical symptoms and bind together physical and social experience.

For instance, if a set of negative physical sensations—such as, a racing heart, chest pain, and shortness of breath—has a *physical* account, such as a “heart attack,” the sensations are construed as a physical malady. In this example, the physical account of a heart attack justifies the racing heart, chest pain, and shortness of breath. Further, the specific type of account provided directs action, which, in this case, would presumably be: swallowing an aspirin and calling an ambulance. But, if the same set of negative physical sensations are given an *emotional account*—such as “panic”, “anxiety”, or “fear”—they can become an emotion or, eventually, a mental health issue.

While the underlying physiology of the physical sensation is ostensibly objective, how sensation is named profoundly guides the subjective experience of it (Grosz 1994) and subsequent behavior, especially treatment-seeking (see Fadiman 1998). The slippage between physical, mental, and emotional experience points to the messiness of embodied experience (Bordo 1987) and the central importance of language in structuring *durée* or “streams of consciousness” (Schütz 1967:45). This chapter demonstrates how meaningful objects, emotional accounts, and—eventually—diagnoses facilitate discrete reflections and shape experience from the *durée* (Schütz 1967:45).

While most interviewees went months or years without emotional accounts for anxiety or panic, one interviewee, Erin—when asked to reflect on her first experience of *severe* anxiety—expressed a somatic experience with an immediate and satisfactory emotional account. Erin, a nineteen year old daycare provider, recounted her first experience of severe anxiety at age twelve.

I just remember laying in bed and all of a sudden I felt like I couldn't breathe. I was lying in bed with my mom and I was telling her [how I felt] and she told me it was anxiety. She has it too so she knew what I was talking about when I told her how I felt. I really had thought I was dying.

In this excerpt, Erin provided the basic components of an emotional experience. She had the physical sensation of not being able to breathe. The immediate reason or account she gave for her physical sensations was that she was dying, a typical account given by many of the interviewees before diagnosis. But, through an efficient and stable social exchange with her mother, the physical sensations were transformed into fear with an emotional account of “anxiety.” In other words, the emotional account of an “anxiety disorder” or “panic attack” transformed Erin’s experiences of “dying” into an experience of fear. The category of anxiety played a vital role in re-shaping the meaning of Erin’s physical experience.

While Erin’s experience provides an excellent typification of the successful social identification of an emotion and an anxiety disorder, it was an anomaly in the data. Far more frequently, there was a sizable gap between interviewees’ first experiences of anxiety and eventual diagnosis. As such, interviewees struggled to make sense of their physical symptoms of anxiety without the emotional account of an anxiety disorder. The interviewees’ illness narratives suggest that the intensification of distress, an increasingly physical experience, and the falling away of explanatory objects (object-less fear) made locating an emotional account challenging and pressed them to seek medical treatment. In these cases, an anxiety disorder diagnosis, eventually, served as an emotional account, albeit a medical one.

One interviewee, Carly, provided a detailed narrative about the chaos of physical sensation before receiving an anxiety disorder diagnosis and her (failed) struggle to make sense of those distressing experiences on her own. Carly reflected,

I constantly had a high feeling. I always thought it was the toxins burning off, but it turns out that can be a symptom of anxiety. I just had this really bad high feeling. It felt like either just a regular high, where I couldn't do anything, or I had a lot of paranoid high type feelings as a symptom of anxiety. And, *before they knew I had anxiety*, I had really bad neck pain and vertigo that didn't go away. Neck pain combined with dizziness just doesn't sound healthy I had constant vertigo for like 20 days [in a row]. I didn't know what the vertigo was. I got tested for everything, and [the doctor] said it was anxiety. But, 20 days of constant vertigo? I got a CT scan of my head and once they didn't find anything, well, it's nothing severe at least. My doctor's like, "You need a psychiatrist."

Carly experienced disparate, intense, and distressing physical sensations that she was unable to make sense of. She constantly worried that she was going to fall over from the vertigo or pass out from the dizziness. She decided to go to the doctor, thinking that perhaps she was just "burning of toxins," but she also worried that she had an "autoimmune disease or Lyme disease," or perhaps, at worst, a brain tumor.

Before diagnosis, the "high feeling" and dizziness would exacerbate Carly's anxiety. But, after diagnosis, Carly utilized this new category to manage her distressing physical sensations. For instance, she explained that when she experienced vertigo and the "high feeling" she just "kind of let[s] the high feeling come, I just pretend I'm baked ["high"] and go with the flow." With diagnosis, as a powerful resource, she was able to silence her original interpretations of physical experiences and reformulate them as a part of an anxiety disorder and even as, ostensibly, enjoyable. Before diagnosis, however, there were few meaningful ways to rhetorically and practically manage this physical distress.

“It Comes and Gets me”

The word “panic” originates from Greek god “Pan,” who lurked in the forests and whose presence would strike fear in men as they passed him. Pan did not need to be seen by the forest-walkers to inspire fear; his invisible presence could induce a, seemingly, causeless panic (Glas 2003). This sense of object-less fear, on which the term panic was built, remains salient in the experience of panic disorders today. In this section, I discuss how—as anxiety intensified for the interviewees—the explanatory object (discussed in the previous chapter) falls away, leaving them with, what I term “objectless fear.” For instance, Tiffany recounted her first experiences of severe panic,

It was literally the sensation of crawling or jumping out of my skin. Just so skittish. Almost like the feeling of being followed all of the time. Like I was in a dark forest and things were jumping out at me. I was just constantly on edge and on guard. Tightness in the chest. Nausea.

Tiffany’s story literally recalls the Greek mythology of Pan lurking in the dark forest, while simultaneously pointing to the centrality of object-less fear in the experience of anxiety. Nothing-in-particular caused Tiffany to feel as though her skin was crawling or to feel “skittish.” This serves as an example of object-less fear: the physical sensations of fear devoid of an apparent causal object.

As demonstrated in the previous chapter, the presence of an object that is perceived to—appropriately—cause an emotion is an important component of a sensible emotional experience (Denzin 2007; Horwitz and Wakefield 2007; Lupton 1998). Objects stabilize physical experience. For instance, tears and an aching chest point to “sadness” at the funeral of a loved one; they indicate something entirely different—“joy”—at the birth of a healthy child; but, they make little—emotional—sense on a warm, sunny day at a lively park. Objects, with socially agreed upon meanings, provide

one important mechanism that connects physical experience to emotional accounts. And, as these objects fall away, experience becomes increasingly confusing and, often, distressing.

Similarly, ethnomethodologists have long acknowledged that *language* is “indexical”; that is, its meaning is dependent on context, such as “when and where” the words are uttered (Heritage 1984:140). In a similar way, *experience* is indexical in that stable meanings of experience depend on the context of sensation. When there is no specific object that *causes* physical sensations—such as trembling, sweating, and vomiting—the onus of interpretation is on the individual and becomes an increasingly tenuous accomplishment. Likewise, in these illness narratives, object-less fear continually gave way to (mis)interpretation of sensation.

Early in the interviewees’ anxiety narratives, they described objects—albeit inappropriate ones—that caused them fear. In these narratives, the interviewees knew there was an object (perhaps, an elevator or an empty house) that was causing them to, say, shake and sweat. But, eventually, as I discuss in this chapter, that object or set of objects fell away and the distressing physical sensations emerged on their own, striking at will. Without an object, these seemingly random physical sensations became increasingly difficult to tether to an emotional account.

In the following, I provide narratives from interviewees about object-less fear. Lori fittingly used the phrase “it comes and gets me” to describe the experience of object-less fear. There is no object that mediates “anxiety” and the physical sensation. Anxiety acts on its own accord. In the beginning of her illness narrative, Lori explained that, in order to experience intense fear and the associated physical symptoms, she needed to be

going to bed, alone, or driving over a bridge. Later on, she found that she no longer needed an object to inspire the physical sensations:

When I have panic attacks it's very strange. I describe it to people like, "It comes and gets me." I'm not thinking about it. I don't even feel nervous, but the attack just comes and gets me.

For Lori, there was no warning and no reason for this panic; it would just appear, out of nowhere. Randy echoed the sense that panic could strike without warning. "But it can happen at any time. The weird feeling of unreality [Randy's main symptom of anxiety] can hit sometimes unexpectedly." And, another interviewee, James used the simile of panic being like a tornado, conveying this same sense of the random, irrational violence of a panic attack.

A panic attack is like a twister, it's like a tornado. It comes rushing on you real fast and it lifts you in such an uncomfortable way that you are moved to do the irrational things. In my case, an irrational thing would be to run like hell, looking for the nearest exit. I'm at a mall, even though I'm with someone, and they have no clue what the heck is going on. All of a sudden I'm gone. That's how I would describe a panic attack. It's a tornado, it takes me away, without really giving me the ability to think rationally or reasonably about my next action because my next action is only for one reason and purpose, and that's to leave the panic. To get out of the environment to do what I have to do.

Panic is completely detached from any perceivable object for James; there was no longer was a specific object needed to inspire this distress. Tina also mirrored this feeling of object-less fear.

It doesn't seem like it [panic] is controlled by anything external. It's just totally just how I'm feeling that day.... There isn't much external that influences how I'm going to feel.

While Tina described panic as a more general and more internal event rather than something discrete that approaches from the outside, she, like the other interviewees, maintained this same sense that sometimes nothing-in-particular *caused* her experience of

fear. Blair similarly explained,

It [fear] emerges out of nowhere. A good example would be, I am driving down the road, it's peaceful calm sunny day—whatever—and all of a sudden I get this huge palpitations where it feels like my heart is being squeezed as hard as it possibly can and it almost feels like the exact opposite happens right after and then all of a sudden I am in an anxiety attack. But nothing happened to trigger it. It just happens.

The body reacted, sometimes violently, to—what seems like—nothing. This represents an archetypical description of object-less fear among the interviewees. Acontextual fear further complicated the successful interpretation of these sensations as “anxiety” or even “fear.” Object-less fear gave way to physical sensation devoid of the emotional account of fear, what I refer to as fearless fear.

A Physical Experience

Many of the interviewees' initial experiences of *severe* anxiety were primarily physical ones. The phrase “severe anxiety” denotes experiences of anxiety that interviewees identified as the most intense and distressing. On the whole, severe anxiety was described as a fundamentally physical experience. Likewise, studies have found that when individuals with anxiety visit a physician, they most frequently report physical symptoms without reference to emotional or mental symptoms (Shearer 2007:484; see also Katon, Von Korff, and Lin 1992). This trend is replicated in my data; interviewees reported increasingly physical symptoms that drove them to seek treatment. By the time many of the interviewees visited the clinic or hospital, they were experiencing *exclusively* physical symptoms.

In a review article on cross-cultural symptom presentation among individuals with panic disorders and major depression, Kirmayer (2001) observes that panic disorders are

under-diagnosed, which costs the patient and the medical system both time and money. He calls for the better diagnoses of anxiety disorders through a more comprehensive knowledge of the various ways that anxiety can present in a clinical setting. Part of the problem, he notes, is that patients often present with primarily or entirely physical symptomology; we writes, “Only 15% of patients with current major depression or panic disorder presented any psychological complaint” (Kirmayer 2001:24). He offers a possible explanation, which is that

These somatized presentations probably represent what is called "ticket behavior" in the family medicine literature: a somatic complaint is an appropriate and non-stigmatized reason to seek help from a biomedical practitioner. This is so even if the individual recognizes that there are social and psychological causes or contributors to the illness (Kirmayer 2001:24).

While my data support Kirmayer’s claim that the somatic presentation of anxiety makes diagnosis challenging, these illness narratives do not support “ticket behavior” as an explanation. To begin, embarrassment about symptoms was not at the core of the interviewees’ narratives. Generally speaking, the interviewees were incredibly open about the range of experiences they felt with anxiety, and almost never refused to answer even the most private questions about the disorder. Moreover, interviewees were clear that when they initially went to the clinic or the emergency room, they were desperate for help and, as such, provided all possible information. Also, it is a mistake to assume that mental symptoms are more stigmatizing or embarrassing than physical ones. Many interviewees indicated that some of the physical symptoms of anxiety were equally or more embarrassing than the mental or emotional symptoms, such as emitting a foul smell, profuse sweating, or loss of bowel control.

Further, almost all of the illness narratives pointed to a time when the

interviewees *thought* they were experiencing serious physical illness, and these interpretations were often the primary drivers in treatment seeking. In other words, the perception that their symptoms were indicators of physical illness was the *reason* many sought treatment. For these patients, by the time they went to the doctor's office they authentically presented with primarily physical symptoms. These data suggest that the falling away of explanatory objects and the lack of an emotional account renders the physical symptoms of anxiety difficult or impossible to interpret as emotion. Accordingly, patients narrated their symptoms as they perceive them—often as signs of *physical* illness.

Since these experiences were so utterly visceral, many of these interviewees did not even mention the emotion “fear” while describing their initial bouts with these severe symptoms of anxiety. Many of the people I spoke with did not come to identify their experiences as “fear” for long periods of time because the sensations they felt did not resemble a fear with which they were familiar. While the symptoms the interviewees experienced were very real, as Merleau-Ponty (1945) observed, “the real has to be described” (p. xi). In other words, the very real and intense experiences felt by interviewees were reflexively incorporated into their life worlds, but with these chaotic and diverse symptoms, the available accounts—such as, “heart attack”, “asthma”, and “epilepsy”—fell short of sufficiently describing the sensations.

An anxiety disorder is both a set of emotions and a medical category. Emotions, like medical categories, are constructs that, in the lives of people, that need to be continually identified, built, and employed. The category of “fear,” among the interviewees, was not always easily applied. This application was difficult, in part,

because their physical sensations did not unequivocally point to the emotion of “fear.” It has been widely observed that the physiology of any one emotion can be nearly identical to a variety of other emotions, and a single emotion can manifest along with a wide range of physical sensations. For instance, Bourke writes

For even fear is located within the corporeal self, it is clear that the body refuses to surrender to ambiguous signs of the emotion. Different fears elicit very different visceral responses: adrenaline often overwhelms individuals afraid of being attacked, while individuals terrified of contracting tuberculosis suffer no such physiological response. Moreover the glandular secretion in the range of arousal experienced by the heart and skeletal muscles can be identical for angry and for frightened people (2003:114).

This observation can be extended. Not only do emotions often feel like other emotions or feel differently in diverse contexts, the physical symptoms of fear—eventually attributed to anxiety—were initially confused with various physical and mental illnesses. That is, sensations can be organized and interpreted in multiple ways, and the “correct” interpretation is not always obvious or easily accomplished. Emotions, or names for emotions, serve to bind together events and sensations. In the midst of seemingly random and terribly distressing physical symptoms, with no apparent causal object, it became impossible for interviewees to name these sensations “fear” or “anxiety.” As such, they described purely physical experiences to their physicians.

The stories interviewees told about their first experiences with severe anxiety closely approximated what Arthur Frank calls “chaos narratives” (1997:98). That is, they recall not being able to make sense of their illness experience, being lost in bodily sensation, and feeling a sense of deep despair. These chaotic and severe physical symptoms were often the experiences that most clearly drove individuals to seek a diagnosis. And, it is only through a series of interpersonal, textual, and medical

encounters that they tethered the physical sensations they experienced to “fear” and later to an “anxiety disorder.”

Notably, the *medical* wedding of sensation to diagnosis was also difficult to accomplish. For one, “in the primary care physician's office, this constellation of [physical] symptoms can look like the symptoms of numerous other medical conditions” (Allgulander 2006:102). Additionally, among surveyed family physicians, only 13% reported being familiar with treatment protocols for generalized anxiety disorder and 17% with panic disorder, compared to the 88% reporting being familiar with the protocols for depression. As a consequence, as Allgulander reported, only 30% of individuals with an anxiety disorder have been diagnosed (2006:101). Likewise, when the interviewees went to emergency rooms, psychiatric hospitals, and clinics, presenting entirely physical symptoms (which are actually a large proportion of the criteria for anxiety disorders indicated in the DSM), many were misdiagnosed or turned away altogether (this is discussed in more detail in chapter five). The interviews and previous literature highlight the difficulty of identifying an anxiety disorder for those who experience it, the intersubjective work patients and doctors have to do to reach a satisfactory diagnosis, and the challenges physicians face tethering physical symptoms to emotional disorder, especially anxiety disorders.

Narratives about Primarily Physical and Objectless Symptoms

In this section, I describe—through an illness narrative—the experience of primarily physical and objectless experience of anxiety before diagnosis. Andrea, a married mother of two in her late thirties, narrated an archetypical example of someone

experiencing primarily physical and object-less symptoms and who was unable to successfully categorize those sensation. Andrea began her illness narrative by providing the context the listener needs to understand her physical experiences. She begins,

It was Memorial Day weekend, and I remember my husband saying “take a long weekend.” I said, “I’d better go to Seattle and see my family.” [My parents and I] had kind of mended things, still a little shaky, but I still missed my family. I go out for a weekend, and I don’t know what happened. I think it was a combination of the stress of going back to that work environment, the stress of some of the underlying things with my family. I think I might have also had sun poisoning.

Before Andrea told me about her specific physical experiences, she provided a post-hoc account of why they might have developed: she had subterranean tensions with her family, a stressful work environment, and was physically stressed by sun poisoning. With this background in place, Andrea proceeded to narrate her first “serious” panic attack.

I was on the flight back [to New England] on Monday. It wasn’t like Seattle to Boston or Seattle to New York. It was Seattle to LA to Boston. As we were flying into LA on a plane, my body just completely shut down, *anxiety*. The crew on the airplane, they thought I was drunk because I couldn’t talk. *It was anxiety*. I think the sun poisoning and dehydration [pause] it was bad. So we flew into Los Angeles, I’m by myself. I’m thinking, “I need to get to my next plane, but I can’t move.” They put me in a wheelchair, and they start wheeling me to my terminal, but I missed my plane. They were like, “Do you feel okay?” I felt my heart was racing, like I would pass out. I didn’t know what was wrong with me! I thought I had vertigo, and they said, “You know what? We’ll get you a hotel room and you rest until you feel better.” I don’t know how I got on the bus and got there, but I got in the hotel and I laid down.

It is notable that as Andrea described the physical symptoms she experienced, she interjected, twice, that these were in fact components of “anxiety.” The very intense symptoms, like being unable to walk or talk, were impossible—at the time—for Andrea to tether to “anxiety.” As such, she made the effort to fill in that gap for me, in case I too was unable to identify these symptoms as “anxiety.” The confusion of her first severe

panic attack was profound, and, in her narrative, Andrea deftly navigated her contemporary clarity on the situation, while articulating the chaos of those moments.

While in the midst of this first severe panic attack, she attempted to tether these experiences to sun poisoning and to vertigo, but those physical accounts were not well-suited to her sensations. With somatic symptoms and without an acceptable account or a clear causal object, Andrea struggled and failed to make sense of these distressing sensations. This attempt, on Andrea's part, was representative of most of the other interviewees, who also tried to give physical accounts for their distressing sensations.

While embodied experience can be read as an individual event, it simply is not. Andrea narrated a clearly intersubjective process by which these bodily experiences were defined "serious." First, the flight attendants thought she was drunk. This evaluation was in direct contrast with Andrea's lived experience: she was not drunk. There was, indeed, a missing object in this account, which was alcohol. She, rather, was simply unable to talk for no obvious reason at all. The accounts offered to her did not fit her experience and, as a consequence, magnified the sense that something was seriously wrong. Not only was her taken-for-granted lived-experience of being able to easily communicate ruptured, those around her also were unable to make sense of the situation.

Second, she was put in a wheel chair, which is a powerful symbol of illness. People with certain disabilities, the elderly, and very ill people are commonly understood to use wheelchairs. The general typifications and shared meanings of wheel chairs suggested to Andrea—who did not have a disability that requires a wheelchair and was not elderly—that she was very ill. And, again, the reason she was put in the wheel chair was because she could not walk, which served as a profound rupture in her taken-for-

granted experience of her body.

Lastly, the airline paid the bill to put her up in a hotel, which was another indication that something was seriously wrong. Large corporations offer these types of services only in extreme circumstances. Andrea came to know that there was a serious problem at the intersection of unexpected and undesirable bodily experiences, the confusion among the flight attendants as to her mental state, and the airline's powerful practical and symbolic response. The fact that these details, about experiences such as the free hotel stay and the use of a wheelchair, emerged in Andrea's narrative were not arbitrary. Indeed, these types details have staying-power in memory and in narratives because that have meanings that help structure and contextualize experience and, in this case, because they represent significant ruptures in everyday experience.

Despite the fact that Andrea knew *something* was wrong, she was unable to tether the experience to a sensible account. She listed a number of physical symptoms (racing heart, vertigo, and feeling like she would pass out) and exclaimed, "I didn't know what was wrong with me!" The physical experience and intersubjective exchanges pointed to pathology but did not provide a satisfactory account. Andrea continued,

When I woke up, I felt like the [hotel] room was spinning, and it was crazy, and I called my mom, and I couldn't hold the phone. I felt like my whole body wasn't working. I said, "I don't know what's wrong with me. I just can't move. It's just really bad and scary, and I feel awful." So, [my mom] called security for the hotel, and they came up and got me and took me to a hospital, and I was in the hospital for three days.

Basic bodily functions were lost to Andrea over those three days. These bodily symptoms prompted her mother and the hotel security to bring her to the hospital. Up until this point, each physical sensation and each interaction escalated the alarm surrounding this event. Andrea recounted these moments as some of the most disturbing

in her life. After three days in the hospital, she was disappointed to find out that the physicians

Didn't diagnose me with anything. My husband flew out. I couldn't get on the airplane by myself; I couldn't leave the hospital by myself; I was, like, frozen. So he came out and got me. I came back [home].

She left the hospital without a diagnosis, medication, or advice to take home with her.

She was left to make sense of her experience on her own (Nettleton et al. 2004). She left the hospital still “frozen,” by which she meant that she was unable to go anywhere without assistance. As such, she relied on her husband to escort her home. Then, she recalled,

I started going back to work, and it got worse and worse each day. The sensations got worse. I remember being in the back clinical area just curled up on the floor, just thinking, “Why is this happening to me? Why is this happening? I don't understand it. This really sucks.”

Andrea's confusion came to the fore. The symptoms had reached a new level of intensity and any semblance of an explanatory object was missing. There was no longer heat exhaustion or dealing with family stressors that could even tentatively explain her symptoms. She later explained that the symptoms continued even after quitting her job. After months of physical distress, with no significant reprieve, Andrea was at a complete loss for an explanation.

Andrea's first experiences with severe physical symptoms of anxiety are illustrative of many of the interviewees' narratives. The core components are: intense negative physical sensation, an objectless experience, failed intersubjective accounts (especially diagnosis), and a state of profound confusion. Andrea had no idea why she was experiencing these sensations or what they indicated was wrong with her.

Causal Ordering of the Anxiety Experience

Like Andrea, most interviewees did not interpret the objectless physical symptoms, before diagnosis, as caused by fear or anxiety. Rather, many of the interviewees reported experiencing severe physical distress that seemed to *lead to* feelings of fear. That is, they would experience *physical* distress, interpret it as a *physical* illness, and then feel fear in response to this new object: serious physical illness. Most commonly, they described distressing physical sensations such as heart palpitations, chest pain, and shortness of breath, and only after some period of time with these symptoms, they reported *becoming* afraid that they were having a heart attack. In other words, when the interviewees discussed primarily physical experiences before diagnosis, the causal ordering was generally flowing from physical sensation to fear.

The interviewees were not alone in their confusion about the nature and etiology of anxiety. Historically, the causal ordering of anxiety has been problematic for physicians, researchers, and patients alike. Medical professionals have linked anxiety and panic to a diverse range of illnesses: from inner ear disorders to cardiovascular disorders to epilepsy to rabies (Berrios and Link 1999).

Most famously and enduringly, Jacob Da Costa—a physician and surgeon—observed 300 soldiers during the American civil war and was among the first to make an empirical etiological connection between anxiety and the heart, which he termed “irritable heart syndrome” (Glas 2003; Skerritt 2009). He argued that weakness in the heart—indicated by rapid heartbeat and heart palpitations—once irritated by life events would lead to anxiety. While Da Costa’s theory had the most enduring influence, in that

same time period, excessively tight army uniforms and certain curvatures of the spine were also hypothesized to cause anxiety (Skerritt 2009:18).

Similarly, dizziness was once thought to cause anxiety; what is now considered a *symptom* of anxiety (dizziness) was once considered its *cause*. Later, Carl Westphal—psychiatrist and originator of the term “agoraphobia”—argued that anxiety causes dizziness, which remains the accepted causal ordering today (Glas 2003:23).

Nonetheless, between WWI and WWII, over fifty years after Westphal’s writing, researchers and physicians re-introduced the idea that hyperventilation—and thus dizziness—was the root cause of anxiety (Skerritt 2009:22). And, contemporarily, deep breathing (or Yoga’s “pranayama”) is commonly employed to help manage anxiety, suggesting that breathing is a key component in the anxiety experience, beyond being a symptom of it (Brown and Gerbarg 2005; Wilhelm, Gevirtz, and Roth 2001).

Likewise, even today there remains some controversy about the causal ordering of anxiety and physiological disturbance, specifically about the connection between the heart and anxiety disorders. For instance, recent studies have suggested that “low cardiac vagal tone,”¹¹ observed in both adults and infants, may actually contribute to anxiety (Craske and Waters 2004:204) suggesting that, perhaps, “weakness” in the heart causes (or, at least, contributes to) anxiety. In a word, the interviewees, in their confusion about the etiology of anxiety, are in exceedingly good company. Physicians and psychiatrists have historically had and today still have a difficult time establishing the causal ordering of anxiety disorders.

The nature of anxiety, symptoms, and causes are not obvious or given. They had to be established over many decades of systematic study and are still somewhat

¹¹ The vagal tone is an impulse from the vagus nerve that slows the heart.

contentious. With this history in mind, the interviewees' inability to identify these experiences as fear and the interpretation of the symptoms as pointing to physical illness are not surprising. Anxiety disorders are intersubjective accomplishments founded on a lengthy, sometimes convoluted, medical history. The subjective identification of "anxiety" involved analogous amounts of confusion and (mis)understanding.

Anxiety Mistaken for Physical Illness

In this section I provide interview data on the interviewees' (mis)interpretation of bodily symptoms as physical illness before diagnosis. Just shy of half of the interviewees described going to the emergency room, convinced they were in need of immediate medical attention for a life-threatening physical ailment. The interviewees' high rates of emergency room visits mirror general trends among individuals with anxiety disorders, who are disproportionately more likely to utilize emergency rooms and inpatient hospital services (Katon et al. 1992; Marciniak et al. 2004). This high rate of utilization has been tentatively linked to somatic presentations of mental illness, which is prevalent among those with anxiety disorders; somatizing patients with mental health issues utilized medical care at twice the rate of similar nonsomatizing patients (Barsky, Orav, and Bates 2005). The interviewees' narratives suggest that confusion about how to interpret those somatic symptoms is at the core of these high rates of medical utilization.

All interviewees, at some point, at least entertained the notion that their symptoms were indicating some sort of physical illness. For instance, Bridget explained that she has gone to the hospital on multiple occasions after experiencing a wide range of distressing symptoms.

I get chest pains, like something is pressing into my chest.... I also get a dream-like feeling, like, I'm in a fog. It's really strange. I've been to the hospital a couple times because I thought there was something seriously wrong.

Bridget was unable to classify these very typical symptoms of anxiety as “anxiety” and came to the conclusion that something must be “seriously wrong,” and went to the hospital to seek medical care. Other interviewees worried that there was something physically wrong but decided not to go to the hospital. For instance, Ana thought she might be having a heart attack.

Well, I was having a lot of chest pain. I thought it was gonna be a heart attack or something like that. I was feeling like out of body.... My whole body would be out of whack.....I didn't understand what was going on and this could happen from a few minutes to a whole day or two with that uncertainty going on.

Ana described common symptoms of a panic attack: chest pain and dissociation. These sensations mirrored what Ana thought a heart attack might feel like. Without a causal object, an emotional account, or a diagnostic category, Ana made sense of these physical sensations by naming them a potential heart attack. Likewise, Tiffany felt chest pains, which prompted her to go to the emergency room.

I ended up in the emergency room at two in the morning because my chest pains were so bad.... It was just the worst chest pains I had ever felt. I didn't know what it was. My mom brought me [to the emergency room] in the middle of the night. They just kind of thought it was muscular or something or that I pulled [a muscle] which to this day... I think it was anxiety.

Once Tiffany had an anxiety disorder diagnosis, she re-interpreted this experience as a panic attack. But, at the time, no one fully understood why she was having these intense chest pains. Not only was Tiffany unable to establish an emotional account of “fear” or “panic”, the physicians were unable to offer her a diagnosis of an anxiety disorder. It was common for interviewees to discuss failed attempts—by themselves, their families, and

the medical community—at making sense of their physical symptoms.

Lori also experienced distressing symptoms that she was unable give a satisfactory name. Like Tiffany, Lori's symptoms mirrored another illness.

I always feel like I'm on the verge of fainting, I'm always on the verge of it. There is epilepsy that runs in our family which I don't have, but I was scared that this is what happens before you have a seizure. I was scared I was about to have a seizure.

The combination of family history and the sensation of nearly fainting prompted concerns for Lori that she was having a seizure. The type of symptoms, context, and personal history influenced what illness the interviewee thought they were experiencing.

Experience is indexical in that its meanings depend on the context in which it emerges (see Heritage 1984). For example, Harley was already sick with pneumonia, as such, interprets the distressing physical sensation with complications of pneumonia:

One time I thought, I mean, I was really sick, I had pneumonia at the time. So, I went in [to the emergency room] thinking I couldn't breathe. I went thinking that the pneumonia was making it hard to breathe, and they were talking to me, and they realize I could definitely breathe. I just thought I couldn't breathe because I was so nervous. So that time they told me I was having an anxiety attack. They hooked me up to oxygen, just to make it easier to breathe. But, they gave me Lorazepam that time because that was before I was actually prescribed it. That just calmed me down so I could breathe, and were like, "Yeah, you had a panic attack."

In this case, Harley was told definitively that her experiences were a panic attack, which was buttressed by the fact that the medication relieved her symptoms. In each of these narratives, the interviewees originally interpreted distressing physical symptoms as signs of physical illness; only after an escalation in the symptoms did they begin to feel fear. In other words, before diagnosis, they interpreted the causal ordering as physical sensations causing normal fear.

Anxiety Mistaken for Insanity

The other common (mis)interpretation of anxiety among interviewees, before diagnosis, was that they were going insane. Notably, the feeling that one is going insane (when one is not actually going insane) is formally recognized by the DSM-IV as a symptom of a panic disorder. However, in the narratives of these interviewees, the (mis)interpretation that one was “going crazy” was framed as a *consequence* of other symptoms of anxiety rather than as a symptom in its own right. So, in these accounts, the idea that one was going crazy was a second order interpretation of physical, emotional, and mental experience. While the interpretation of symptoms as physical illness was typical among individuals with fully somatic experiences (as was discussed in the previous section), interviewees who experienced a combination of intense mental distress (such as racing thoughts, obsessions, “what if” thinking, and morbid preoccupation) and physical distress more commonly interpreted these symptoms as indicators of serious mental illness (or psychosis).

Again, the interviewees’ confusion about anxiety and insanity echoes past debates in the medical community. Historically, there has been a tight connection in the medical field between anxiety and insanity. Up until the mid-nineteenth century, anxiety was understood to have the potential to lead to insanity, and severe cases of anxiety were classified as insanity (Berrios and Link 1999). But, Freud’s work on “anxiety neurosis” clearly marked anxiety as neurosis, not psychosis, which is a distinction that is maintained today. Still, the majority of the interviewees—at one point of another—(mis)interpreted their mental, emotional, and physical symptoms as indicators of insanity.

For instance, Randy recalled sitting with his parents in the living room of their small suburban home, watching “Angel Heart,” a 1987 thriller. In the film, the main character was investigating a series of horrific murders, only to discover that he was subconsciously repressing the truth that *he* was the murderer. As the plot unfolded, Randy’s mind began to race. In line with the plot, he began to worry, “How do I know what is real and what is not real?” “Who am I?” “How do I know this is who I really am?” The questions completely overwhelmed. Randy became increasingly disoriented and felt completely and utterly lost in his own parent’s living room. He explained that he had to—simply had to—get out of the house, away from the movie and from the terror. He ran out the front door, without a word.

Randy took a long walk and tried to gather himself. After several hours, he was calm enough to return to home. He sat down with his parents and “came clean” about what had led to his abrupt escape. Randy confided in his parents that he was terrified that he was “going crazy” and needed help sorting out these thoughts. Years later, Randy came to identify this series of events as a panic attack, but at the time he thought that he was “losing his mind.”

Randy was not alone in thinking he was “going crazy.” The majority of the interviewees at some point temporarily categorized the symptoms of panic as “going crazy,” which was a broad category made to accommodate startling experiences like depersonalization, racing thoughts, tremors, dizziness, and disorientation in “objectively” safe conditions. Below are a series of excerpts from interviewees’ recollections of thinking they were “going crazy”:

[A panic attack] is sort of like being really drunk, I guess. It used to really freak me out - again, it seemed a precursor to seriously unpleasant

insanity.... I never felt the ‘typical’ panic, you know, like you think you are having a heart attack or dying. I was always afraid of something more psychological, basically *that I was going crazy*.... I had no idea what it was, aside from evil demons from the sky coming to suck my soul out the top of my head. I didn't *really* think that, but I was open to the possibility that was exactly what was happening. (Marcy)

....

I didn't know what it was. It wasn't until I had a pretty severe one where I almost got in a car accident. I swerved off the road into a ditch because I was having a panic attack driving.... I called my partner and I was like “it happened again. What is going on with me?” *I thought I was going crazy*. (Lori)

.....

I had a fear of collapsing, fear of embarrassing myself, loss of control, feeling trapped. *I thought I was gonna go crazy*. (Bethany)

.....

I had no idea what it was. *I just thought I was insane*. I was having these crazy feelings. *I just thought I had some horrible form of insanity*. I didn't know that it was just anxiety and panic, which is actually somewhat common (Tina)

Interview after interview I heard the phrase “I thought I was crazy.” A person’s first bouts with severe panic often, as Schutz and Luckmann (1973) describe, “explode” their taken-for-granted nature of reality (p. 11). Since panic of this magnitude is not often discussed (or admitted to) publicly, the terrifying dynamics of anxiety burst open current categories of everyday experience and left those having a panic attack without a clear framework to make sense of those experiences. In this study, it is only through a series of interpersonal, textual, and medical encounters that interviewees were able to—eventually—translate distressing sensation into “fear” and, then, later to an “anxiety disorder.”

Conclusion

The majority of the interviewees—at some point—temporarily categorized panic as “physical illness” or “going crazy.” In the most severe moments of panic, interviewees described being unable to leave their bedroom for a week at a time, injuring themselves trying to “escape” a panic attack, and completely losing control of their body. These are by no means the interviewees’ typical or long-term experiences of anxiety and panic, but they are the very real and terrifying extreme moments that completely “exploded” their taken-for-granted nature of experience. These are the experiences that interviewees struggled to make sense of and led them to believe that were insane or had a serious physical illness.

This chapter showed the central importance of objects and emotional accounts in the apprehension of a sensible emotional experience. Without objects to which sensation can be tethered and without “emotional accounts” (Denzin 2007) to organize those sensations, interviewees’ interpreted their symptoms as severe physical and mental illnesses. Without the sense-making tools of objects, emotional accounts, and diagnoses, interviewees reported going to the emergency room repeatedly in attempts to relieve their symptoms. Notably, at the time, they did not name their experiences “fear”, “anxiety”, or “panic”; rather, they went to the hospital indicating illnesses like “heart attacks”, “asthma”, and “epilepsy”. Unfortunately, with the—difficult to diagnosis—somatic expressions of anxiety, many interviewees went undiagnosed and untreated for long periods of time. These narratives—recounting failed intersubjective accounts—mirror large-scale trends of under-diagnosis among individuals presenting with anxiety disorder.

Accordingly, interviewees continued—until diagnosis—to seek medical care at clinics, emergency rooms, and hospitals.

Further, confusion “between” mental and physical illness points to the well-documented limits of, Cartesian, mind-body dualisms. Cartesian thought sharply delineates between *res extensa* (the body) and *res cogitans* (the mind). Objections to this philosophical and methodological approach are plentiful; they point to the interconnectedness of mind and body, the detrimental bifurcation in academia between mind-studies and body-studies, and the fact that researchers are fully embodied and can never achieve a Cartesian methodological approach (Bordo 1987; Turner 2008). Moreover, scientific research has continued to show the intricate connections between mind and body and that the boundaries between the two are blurred at best and false at worst (Sapolsky 2004). This study contributes to academic research and theory that address the problematic distinctions between mind and body.

This chapter not only supports the notion that mind/body distinctions are arbitrary and unproductive, but, moreover, it demonstrates how language structures the individual and social *experience* of the body/mind. Interviewees used a wide range of accounts to make sense of unanticipated streams of experience. Importantly, physical accounts rendered these sensation physical events, while emotional accounts, eventually, rendered those same sensations psychological and/or emotional. Sensation is experience structured by language within a specific social landscape; how sensation is structured into experience is malleable and flexible (see Grosz 1994 on Lacan and imaginary anatomy). Individuals reflect on a stream-of-experience, which firms up a discrete moment and solidifies a perceivable entity (e.g. a panic attack or a heart attack). These accounts and

reflections not only define sensation, they also direct action and re-shape experience. Specifically, in this study, distressing sensation given a physical account sent interviewees' to emergency rooms, clinics, and hospitals and hindered an anxiety disorder diagnosis.

CHAPTER FIVE

GENDERED EXPRESSIONS AND EXPERIENCES OF ANXIETY

As I discussed in the preceding two chapters, anxiety disorders are a generally difficult to reliably diagnosis. Social variations (gender in particular) further complicate the diagnostic processes. The interview data and previous research, presented in this chapter and the next, suggest that gender plays a critical in the diagnosis (and misdiagnosis) of anxiety disorders. In the present chapter, I discuss the gendering of the expression and experience of anxiety, which, I suggest, may hinder anxiety disorder diagnoses among men and, conversely, hasten them among women.

The anxiety story has long been a woman's story, albeit one often told by men (perhaps most famously by Sigmund Freud). Within this specific cultural context, anxiety and fear are predominantly "female" emotions. At the most basic level, women are more likely than men to feel and talk about fear (LaFrance and Banaji 1992:178; Simon and Nath 2004; Shields 1987). Further, women express fear more intensely than men in response to the same fear-inducing stimuli (Schienle et al 2005:277). Women are also more likely to experience pathological fear; more precisely, women are *twice* as

likely as men to be diagnosed with an anxiety disorder (Kessler et al. 2005). In short, women experience and express anxiety more frequently and more intensely than men.

While fear is portrayed as a feminine emotion, expressed more openly by women, and declared as pathology more often among women, men, obviously, also experience fear. While the previous two chapters have addressed a *general* social experience of anxiety among the interviewees, this chapter addresses the *gendering* of anxiety and, in particular, examines the largely ignored experiences and expressions of fear and anxiety among *men*. I find that gender represents a critical factor in the varied experience and expression of anxiety and fear.

Fear: Gendered Female

While men certainly experience fear, anxiety, and apprehension, fear is most commonly associated femininity. So much so that gender differences in fear are almost entirely taken-for-granted. For instance, emotion researcher Stephanie Fields describes a *Doonesbury* cartoon that captures how engrained it is that fear and anxiety are *female* emotions. She writes,

In one typical Father's Day cartoon, a neighbor compliments Bruce on the tie that his son made for him and then notes that fatherhood must put its own special perspective on things. "You bet!" Bruce replies, "It's brought me in touch with feelings I have never felt before – guilt, anxiety and the fear that I will never measure up to his expectations" (Shields 2002:132).

As the adage goes, it's funny because it's true. Men are not typically expected or allowed to feel and express anxiety, but fatherhood represents a social role in which anxiety (among other emotions) is an increasingly acceptable emotion for men to feel. Even so, the humor of the cartoon hinges on a general understanding that men do not *typically* feel

anxiety (or guilt) and that it is notable and interesting when they do feel anxious. Put differently, the cartoon would lose all salience and humor if it was a *mother* saying, “It’s brought me in touch with feelings I have never felt before – guilt, anxiety and the fear that I will never measure up to his expectations,” because “we all know” that women feel anxiety (and guilt!) on a regular basis. The gendering of fear is so pervasive that it is invisible until the expected gender dynamics are disrupted.

Early on, second wave feminists tethered gender and parenthood to a socially induced anxiety among women. They pointed to the plight of the housewife as a potent source of anxiety. For instance, Betty Friedan, in *The Feminine Mystique*, argued that anxiety and the subsequent use and abuse of tranquilizers was common among women because of a rift between the firmly held belief that being a housewife and mother will be fulfilling and the reality that it was not (Friedan 1963; Tone 2008:178). In this rendering, (pathological) anxiety is something that is particular to the social condition of womanhood.

Feminists were not alone in connecting motherhood and anxiety; it was actually a common association in the 1960s. For instance, at the time, the original biomedical treatments of anxiety—tranquilizers—were popularly referred to as “mother’s little helpers”: a phrase that firmly linked anxiety to gender and motherhood. This term was guaranteed a place in the English language—at least for a while—after the Rolling Stones released their song “Mother’s little helpers.”

This gendering of anxiety and its treatment extended well into the future. Jonathan Meztle conducted an analysis of the *The American Journal of Psychiatry* and *Archives of General Psychiatry* from 1964 to 2001, documenting the continued

connection between motherhood and anxiety—which he refers to as “Momism”—in pharmaceutical advertisements (Metzl 2003:87). Linda Blum and Nena Stracuzzi (2004) published an article in *Gender & Society* that demonstrates that while the overt gendering of anti-depressants (a common treatment for both depression and anxiety) has waned, there remain insidious and latent gendered messages in popular media about antidepressant medications. Whether obvious or subtle, the gendering of anxiety disorders and their treatments has been pervasive from before the 1960s to today.

This gendering of fear begins in very early childhood; researchers have consistently demonstrated that fear is gendered as early as preschool (Birnbaum et al 1980). For instance, one study found that when preschoolers were presented with a gender-neutral emotional situation—such as, “this child is playing behind a tree during a game of hide-and-seek when the child steps into a hole and can’t get out. The child is very SCARED”—the preschoolers were significantly more likely to identify the “scared” child as a girl (Birnbaum and Chemelski 1984). Anxiety is so deeply gendered that by the time children are three or four—when they are just beginning to internalize the concept of gender—they already “know” that fear is a female emotion.

Overall, anxiety and fear are continually and repeatedly linked to womanhood. Women feel and express more anxiety and fear than men; young children already believe that fear is a woman’s emotion; and anxiety and its treatments have persistently been linked to motherhood. And, perhaps most importantly to this study, anxiety *disorders* are gendered female. With all of this attention on female fear, what do we know about men’s fear? Well, simply put, not much. The feminization of fear and anxiety renders men’s

fear largely invisible and perpetuates the cultural imagination of the brave male and the fearful female, which are, arguably, detrimental to both men and women.

This dissertation too came all too close to replicating this feminization of anxiety, but this chapter and the next—drawing on empirical studies from a wide range of academic disciplines and a close analysis of male interviewees’ and support group members’ narratives—attempt to remedy that bias. In order to address the inadvertent silencing of fear among men in this research study, I first had to become cognizant of the gender bias in my own methodology. For instance, the majority of the interviewees were women, and, as such, a disproportionate amount of the findings and theory are built on the narratives of women. Further, the literature I have read and rely on emphasized the female experience of anxiety. I was completely immersed in women’s stories about anxiety. So much so, that when I interviewed men, I was frustrated by *how* they told their stories and *what* stories they told. They did not seem talk about “anxiety” at all; they refused to talk about their own experiences of anxiety; and they seemed to ignore or skim over the physical components of anxiety. In short, they did not tell me the narratives that I had grown accustomed to hearing from women.

After some time and distance grew between me and those conversations, my own frustration and the striking differences between the men’s and women’s narratives became objects of serious intrigue. Why was I so irritated? And, why did men tell such different stories than women? In short, I was irritated because their stories were not the stories I had expected to hear and they were different stories because, as I will argue, for a number of social reasons men experience and express fear and anxiety differently than

women. This chapter and the next address the lesser-known illness narratives of men diagnosed with anxiety disorders.

Differential Illness Experiences by Gender

In medical and psychiatric practice, diagnoses have increasingly been conceptualized as entities with characteristics independent of the people who experience them (Horwitz 2010). That is, in medical practice, any given illness has been increasingly viewed as independent of the ill person and as experienced similarly by various types of peoples. Conversely, empirical medical, psychological, and social science research have demonstrated that physical discomfort and illness are often *differentially* experienced and manifest across social groups. Histories, bodies, and beliefs shape the experiences of seemingly objective physical conditions.

For instance, Pound and colleagues (1998) conducted in-depth interviews with 40 individuals who had a stroke ten months prior, and found that the impact of the stroke depends, in part, on the life history and experiences of the ill person. “For the majority of people in this sample, the stroke did not suddenly disrupt a previously unproblematic life ... crises were not unusual in these people’s lives.” The stroke was not something that could be “bracketed off” but was a part of the “ebb and flow of their lives” which was “already characterized by struggle and hardship” (Pound et al: 497-498). As such, strokes impacted people differently depending on their life histories and social context.

Likewise, much empirical research shows that gender plays a vital role in structuring the experience of illness and discomfort.¹² Research on pain has been especially revealing, consistently finding gender differences in the experience and expression of pain (Berkley 1997; Goodenough et al. 1999; Sullivan, Tripp, and Santor 2000;). For instance, in a study of over 41,000 people, researchers compared the pain tolerance to mechanical pressure on the Achilles tendon between men and women (Woodrow et al. 1972). They found that men tolerated the pain for far longer than women. In another study, subjects had heat (50°C / 120°F) applied to their forearms and were asked to report levels of pain, while they underwent PET scans of their brains (Paulson et al. 1998). This study found that women had slightly more activity in their brains when the heat was applied and reported higher levels of pain. Study after study, women consistently reported higher levels of pain in response to the same stimuli.¹³ Karen Berkley asserts that “when carefully reviewed, evidence can be found for sex differences in virtually every sensory realm” (Berkley 1997:371).

¹² Discussions of brain research and gender—especially when employed as evidence in an analytic argument about gender differences—can be read as problematic and controversial (Lorber 2011). However, I hope that a few clarifications can forestall this controversy in my own argument. First, I am not employing this neuro-scientific evidence to make an argument about (biological) sex differences, but rather, to introduce (social) gender differences in the study of fear, which is traditionally treated as a biological phenomenon. Second, I refuse a stark society-body distinction that suggests that the body is devoid of and separate from the social, but, rather, along with feminist biologist Ann Fausto-Sterling, I argue that social conditions and the body are deeply and inextricably entwined (Fausto-Sterling 2008). As such, gender differences in physical/emotional experience and brain imaging reflect a social/biology that cannot be separated into social experience or the physical body. Lastly, I do not use these social/biological differences as cause to support or justify gender inequality, but, instead, argue that this difference is a product of different and unequal social experience.

¹³ Importantly, research suggests that different types of pain activate different areas of the brain, which are reflected in brain imaging studies (Apkarian 1995). Still, gender differences have been identified across these studies, with some showing women with more activation and some with men showing more (Paulson et al. 1998; Berkley, Zalcman, and Viviana Simon 2006). Despite this variation in *which* gender shows more brain activity during pain experience, research suggests that gender—in varying ways—plays a critical, although not well understood, role in physical experience (Berkley 1997).

While gender differences in physical experience are certainly intriguing, there is a critical caveat to be made. We are not born with them; they develop over time. Research suggests that differences in pain perception emerge as we age, which points to the critical role of socialization in the experience of pain. One such study examined the differences in pain perception of needle injection among 3 – 15 year old patients (Goodenough et al. 1999). They found that older children reported less pain than younger children. They also found that before age eight, there were no gender differences in pain perception, while, among children eight and older, girls reported more pain than boys. While the precise *reason* for gender differences in the perceptions of physical stimuli are still contested, there is good evidence that the differences are prevalent (based on reliable empirical evidence), physically experienced (neuro-imaging suggests measurable physiological gender differences), but are not inborn (the gender differences emerge over time). This chapter addresses the gendered differences in the experience and expression of anxiety as a social process. Specifically, I find that men talked less about anxiety than women, and they perceived the physical symptoms of anxiety differently than women.

The Gendered Expression and Experience of Anxiety

Women are popularly believed to be, broadly speaking, more “emotional” than men (LaFrance and Banaji; Simon and Nath 2004; Shields 1987). Men are widely thought to be more stoic, measured, and rational, while women are more frequently thought to be sensitive, expressive, and in touch with their feelings. Recent research has attempted to dismantle this stilted, binary cultural construct. For instance, Simon and Nath (2004) used *General Social Survey* data from a representative sample of Americans

to examine whether women are actually, on average, more “emotional” than men.¹⁴ They find that women are *not*, across-the-board, any more “emotional” than men. By and large, men and women report similar levels of emotional experience.

Notably, there are a couple of exceptions to this gender symmetry. Specifically, women report more *anxious* feelings and are more likely to *express* their feelings, especially anxious ones. That is, men and women report experiencing similar levels of emotion in general, but women more frequently feel fear and are more likely to talk about emotions. While the authors assert that the “*expression* of emotion may be more heavily socialized than the *experience* of the emotion” (Simon and Nath 2004:1167; see also LaFrance and Banaji 1992), fear and anxiety present an exception to this generalization: both the *experience* and *expression* of fear appear to be gendered. In this section, I focus on the *expression* of anxiety as a gendered phenomenon.

Arlie Hochschild was among the first social scientists to theorize the differential management and expression of emotion (Hochschild 1979). She conceptualizes “feeling rules” as social expectations about what feelings should or should not be felt and expressed, depending on the actors’ specific social location. She goes on to explain that “emotional management” is the assemblage of efforts to control the expressions of emotion, in accordance with feeling rules. Importantly, feeling rules and emotional management vary by gender (Hochschild 2003:162). In line with empirical research on

¹⁴ “Emotional experience” was measured by the authors as follows: Respondents were asked how many days in the previous week they felt “calm,” “contented,” “at ease,” “happy,” “excited,” “overjoyed,” “proud,” “fearful,” “anxious,” “restless,” “worried,” “blue,” “sad,” “lonely,” “outraged,” “mad,” “angry,” “ashamed,” and “embarrassed.” In order to assess whether women report emotions more frequently than men in general, we computed a summary measure of all feelings by adding scores on these 19 feelings; this measure ranges from 4 to 107” (Robin Simon and Nath 2004:1145).

emotions and gender, these concepts suggest that men and women are socialized to manage and express emotion differently.

Neuroscience research supports the claim that men and women regulate and express emotions differently. For instance, Schienle and colleagues (2005) conducted an experiment with 41 women and 51 men that utilized an fMRI to examine changes in brain activity before, during, and after viewing fear-inducing, disgust-inducing, and neutral photographs. The fear-inducing photos depicted attacks by animal and by humans. They also conducted a self-report survey to estimate the levels of fear and disgust experienced by the subjects. The researchers found that while women reported higher levels of fear, men and women had similar levels of activation in the brain—with the exception of the bilateral amygdale, in which men actually had *higher* levels of activation. In short, in this study men appeared to have slightly stronger neurological responses to fear-inducing images but *reported* less intense responses. Much like the social science literature on emotion, this neurological research suggests that men and women regulate emotion differently. In this case, men do more emotional management of fear.

Arguably, feeling rules are self-imposed, at least in part, because abiding by them is rewarded and breaking them is punished. For instance, one study examined whether or not the perception of physical attractiveness could be amplified by gender-appropriate expressions of fear (Zillmann et al. 1986). Using an experimental design, the researchers had male and female confederate students (students that are privy to and serve as controls in the research design) watch a horror film with opposite sex research participants. The confederate would systematically respond fearfully, neutrally, and with mastery

(laughing, making jokes, etc.) during the film. After watching the film, the research participants were asked to rate the attractiveness of the other student (the confederate).¹⁵ The second half of the experiment involved the two students (research participant and confederate) completing a task together. The confederate made systematic errors in the task, and the research participant was given the opportunity to correct the confederate in order to be more successful in the task. The study showed that (1) women find men more attractive when men demonstrate mastery over fear and (2) women are less likely to correct men after the men show mastery over fear. This study indicates some of the powerful incentives for men not to express feelings of fear. That is, when men do not show fear, women are more likely to find them attractive and listen to what they have to say.

Expressing Anxiety

Social science, psychological, and neurological research all strongly suggest that the expression of anxiety is mediated by gender. In the following, I outline several ways that the interviewees and the support group members differed in their expressions of anxiety. Specifically, I examine gendered differences in whether or not they talked about anxiety experiences, how they talked about anxiety, and where they talked about anxiety.

Gender differences in the emotion of fear extend to pathological fear. There is much consensus in empirical research that women have anxiety disorders at significantly higher rates than men, with women nearly twice as likely as men to be diagnosed with an anxiety disorder (Kessler et al. 2005). Interestingly, the people that I interviewed were

¹⁵ The male-female pairing and the measurement of attractiveness point to blatant assumptions about heterosexuality. The study could be (and, perhaps, should be) replicated taking into account sexuality, which would most likely strengthen the results.

largely aware that women were more likely to be diagnosed with anxiety, but few believed that men actually experienced less anxiety than women. Rather, they—much like sociological literature on mental illness and emotion (Hochschild 1979; Thoits 1990)—asserted that gender norms prevented men from acknowledging, discussing, and confronting fear and anxiety.

For instance, Sarah, who had a well-managed panic disorder and led anxiety support groups, explained why it *looks like* more women have anxiety than men:

It's not because men don't suffer from this; it's because most men don't want to *admit* they suffer from this. And a lot of them become dependent on alcohol or drugs, self-medicate ... because of men's masculinity. They feel as though it's a weakness.... A lot of men are married and have kids and they are the ones who are supposed to carry the load, when they feel as though they can't even carry their own thoughts. It's a huge struggle for men, because of their masculinity.

Based on discussions with her male clients, Sarah interpreted the lower rate of diagnosis of anxiety disorders among men as a consequence of gendered expectations about things like stoicism, strength, and male family duties. Sarah held the popular view that feeling rules—guided by gender—limited what emotions men felt comfortable expressing. Similarly, Arthur Kleinman argues that symptoms and disorder hold “special significance not just in society as a whole but in the distinctive life worlds shaped by class, ethnicity, age, and gender” (1988:24). That is, illness has meanings that are shared but are also directed and constrained by specificities of the lives of people.

Another interviewee, Roger, explained that his career—as a semi-professional boxer—constrained his expressions of fears, which were eventually diagnosed as an anxiety disorder. Even though Roger was a successful semi-professional boxer and had a lot of status among the other fighters, anxiety did not integrate well into this hyper-

masculine profession, and as such, Roger was resistant to telling even his closest friends or his family about his experiences of fear.

To me panic was weak... Before Claire Weekes [a prominent anxiety disorder self help author]¹⁶, all I had was shame. I didn't know what it was. I hung around fights. Guys were fighting people, they didn't care who they were beating up [pause]. I had a lot of talent. I was fighting down in New York.... They had a fight lined up with a guy that wasn't as good as me. They said I would kill him. The fight wasn't a big deal. But, I woke up in the middle of the night with a panic attack.... Everything that goes up must come down, and I crashed.... I literally went in the ring and got pummeled. I had all of the talent; I just had this disease. That is what ruined my fighting. I never wanted to fight after that. That was the end of it. That is my biggest regret of this illness.

Panic destroyed his boxing career, and—sadly for Roger—it was only through ending of his career that he felt empowered to talk about this crippling panic. Roger did not tell anyone about the panic attacks or seek diagnosis until years after his boxing career fell apart. The shame and embarrassment about fear in this hyper-masculine context kept Roger from articulating these fearful experiences.

Not only did men resist talking about anxiety, there were also notable gender differences in *how* men and women talked about anxiety. Men talked *around* anxiety, while women talked *about* anxiety. The above quote from Roger is illustrative. He states that he had a panic attack but gives no indication of what it *felt like*. Rather, most of his discussion focused on the fight and his pugilistic talent. When Roger did talk in detail about anxiety, he generally “spoke through” Claire Weeke’s characters or people that he knew with anxiety disorders. For instance, after long discussions about Claire Weeke’s and her patients, I tried to get him to talk about his own experience of anxiety by asking, “What are your triggers?” He deftly navigated the question,

¹⁶ Claire Weekes is a well-known author of anxiety disorder self-help books including: *Help and Hope for your Nerves* (1990) and *Peace from Nervous Suffering* (1983). Her books were referenced by several interviewees as core components of their recovery process.

Anything can make me fearful. It's just that if it worries me, it gives me a feeling that I can't handle it. Not that I'm afraid of it, it's that I can't handle my feelings in that situation. I was at the [support group] meeting one night, a young girl, her name was Cindy and she said she goes into the mall but she has to go back out because she can't stay. I said to her, "And you know what you're afraid of?" she says, "No." I says, "You are going to the mall, and you are practicing going to the mall, and you are afraid to be in there, but you don't know why." She says, "No I don't, I just keep running outside." I says, "You are afraid of being afraid." There is nothing in the mall that she was afraid of. She was afraid that the panic would get so bad that she couldn't handle it, so she runs outside. I says, "You got to learn to deal with yourself, not the mall. The mall isn't the problem. The panic attack is." That's what I have to learn. I had to learn to deal with panic attack, not the situation.

He begins and ends this narrative with general statements about "anything" being able to cause him anxiety and ends with a lesson that he hoped to internalize about the nature of fear (a lesson that *he* actually *taught* to Cindy), but the substance of this narrative was actually about *someone else's* experience of anxiety. Repeatedly, despite my efforts, Roger evaded talking in detail about his own experiences of anxiety and, instead, substituted the narrative of other support group members, his friends, and characters from self-help books. Likewise, the other male interviewees also avoided talking about their own experiences of anxiety. For instance, William and Jon spent more the interviews talking about the stigma of mental illness and peoples' responses to it than about their experiences of anxiety; and Stan and Paul, respectively, talked more about previous employment and ex-girlfriends than about their experiences of anxiety.

Only one male interviewee—James—spent the majority of the interview talking about his own experiences with anxiety. Still, much like Roger, he spent much of the interview giving me advice—for me to share with other interviewees and to include in my dissertation—about the best way to cope with anxiety. For instance, as I was wrapping up the interview, I asked, "Is there anything else you want to tell me before we

end the interview?” James reformulated this question for me, and responded, “In other words, what advice can I offer?” He went on to advise people with anxiety to seek treatment immediately but to be careful not to take whatever pills they “throw at you.” While the men, especially James, were prone to advice-giving, it was a rarity among the women, who more often *asked* for advice. For instance, Kalli, after I asked if she had anything she wanted to add, asked me, “When do you think this [panic] will go away? My therapist told me not to think about it, but what do you think?” Of course, I told her that I, unfortunately, do not have any special insight, but I wished her the best. Women consistently asked me for help or insight, while the men offered their insights.

In other words, men repeatedly provided “de-centered narratives” —which are illness narratives that describe *around* the first person experience of illness—while women largely provided experience-centered narratives. The de-centered narratives were in stark contrast to the other thirty-four interviews with women in which the majority of each interview addressed the lived experience of anxiety. While women were very comfortable talking about their experiences, men remained vague about and distant from their own experiences. Men and women differed in both their *willingness* to talk about anxiety and *how* they talked about it.

Men and women also differed in *where* they were willing to express emotion. Specifically, men demanded a safe-space to discuss feminized emotions, like fear, while women shared fearful feelings in more varied contexts. The gender composition of the interviewees and the support group members in this study speaks directly to the issue of men’s reservations about discussing anxiety. First, men responded to the advertisement for this study—posted on a popular internet site and in public spaces across New

England—at a much lower rate than women. Only 15% of the interviewees were male, while—if the demographics of the interviewees matched aggregate patterns of anxiety in the population—about 30% of the interviewees would have been men (NIMH 2011).

In stark contrast, the anxiety support groups were flush with men. At most of the meetings, over half of the group was composed of men, and at several of the meetings I was the only woman in attendance. Many of these men have attended the groups for years and have established a rapport with the other group members. The groups provided a safe space for men to talk about their experiences of anxiety. Perhaps the safe, anonymous, closed setting of an anxiety support groups was conducive to men sharing fearful experiences.

Support groups have several advantages over interviews in eliciting personal narratives. First, support groups are sustained over long periods of time, often years. This provides ample time for the members to become increasingly comfortable sharing their experiences. Conversely, interviews are, most commonly, a one-time visit, which provides interviewees little time to adjust. Second, in support groups, members are assured that they are talking with others who have experienced anxiety and, therefore, will be more likely to understand their experiences. It is arguably much more comfortable to share embarrassing symptoms with people who have experienced similar symptoms. Third, the support group is explicitly therapeutic and benefits the participants more if they share personal narratives. In contrast, the interviewees are explicitly *not* therapeutic. The incentive to share personal stories in the interview setting is entirely altruistic, and, as such, the motivation to share openly in an interview is arguably weaker than it is in a support group. Lastly, it is common and encouraged to attend support groups with a

family member or friend to ease the transition into the group. This social support facilitates successful, regular attendance and integration into the group. While interviewees were told they could bring a support person to the interview, no one did. This is not the normative approach to an interview; for instance, it would be generally frowned-upon to bring, say, your mother or romantic partner into a job interview. Conversely, it was quite acceptable, even common, to bring a mother, father, sister, best friend and so on to a support group. This combination of factors provides a positive space for individuals to share very personal experiences.

Accordingly, the men in the support group were far more forthcoming about their fearful experiences than the men I interviewed. While it could be argued that there were different *kinds* of men at the support group, I have some evidence that this is, at least, not the whole explanation for the differences in the men's narratives between the support group and interview settings. Specifically, one of the male support group members, Stan, agreed to meet with me for an interview after the first evening that I attended the group. In the interview, Stan talked primarily about his previous employment, projects he was working on around his house, and his five outdoor cats, while he only made passing mention of an anxiety disorder. Conversely, over the next several months in the support group, I witnessed Stan describe connections between the death of his father and experiences in Vietnam to his experiences of dissociation and bursts of anger, while in the interview he did not talk about his father or experiences of anger and actually looked back on his time in Vietnam somewhat fondly. The support group facilitated an entirely different narrative for Stan than the interview. While the support group and advertisements for interviews may draw different types of men, the inconsistency

between Stan's support group and interview narratives suggest that the medium of the narrative, in part, shapes how the story is told.

The following two excerpts are from fieldnotes at a support group at which a new member and her husband attended. The first excerpt demonstrates atypical and collectively discouraged behavior in the support groups setting, exhibited by the new member's husband.

At group today, a new member joined ("Lidia"), and her husband came to support her. The husband continually rolls his eyes at her stories, leans back in his chair with his arms folded across his chest, and checks his watch. I notice several of the members widening their eyes at him and frowning in his direction... Lidia explains that she was diagnosed with panic disorder and agoraphobia a year ago and is at her wits' end with the symptoms. She struggles to leave her house without her husband and has several severe panic attacks each day. She says that she has lost thirty pounds in the last few months. This is not an especially surprising revelation; she is very thin, which is even evident through her thick sweater and loose jeans. She looks ill: pale and slow moving.

I include notes on Lidia's husband's behavior because it highlights the type of behaviors that are generally not condoned or exhibited in the group. While these are certainly behaviors that the group members may encounter outside of that room, the group represents a social space in which the members are generally free from stigmatized responses to their experiences of anxiety. For instance, Lidia's husband attempted to distance himself from his wife's fear. He rolled his eyes when she described something that indicated intense fear—like not being able to leave the house without him. Conversely, in the group, it was normative to engage with and support someone who was telling an anxiety story. He also distanced himself from the group, actively disengaging from the conversation; he pushed his chair back from the table, checked the time (repeatedly), and looked out the window while group members shared. Certainly, at

group people often looked bored, but it was extremely rare to actively and physically disengage, especially when someone was sharing a personal anxiety story.

Much more in line with the ethos of the support group, in support of Lidia, Mitch and Jack—two regular group members—openly discussed their experiences of anxiety, that simulated agoraphobia (although neither man was diagnosed with agoraphobia).

While Lidia is talking about her weight loss, her voice starts to crack, and she looks like she is about to cry. Mitch quickly jumps in. He says that he knows exactly what she feels like and re-assures her that she is not alone. He says that, at one point, he was unable to go more than couple of miles from his home. And, he says that after he went one place, he would have to come home before he could try to go to another place. He says he “was like a puppy-dog” so attached to his house. He thrust his arms back and forth to animate his travels from home to the store back to home to the pharmacy back to home and so on. Jack chimes in saying that he could relate to this story, too. He says that he used to not be able to go to the grocery store. He would get in the store and the fluorescent lights would make everything feel unreal. It would begin to feel as though the aisles were narrowing, closing in on him, and he would have to rush out of the store before buying his food. He listed other places he could not go, like crowds, weddings, restaurants, sporting events.... He says that he would stay home and miss important events; this avoidance lasted for years.

Mitch and Jack talked openly about their experiences of anxiety at group on a weekly basis. This supportive and engaged ethos provided the group members the space to more openly share otherwise stigmatizing experiences. This environment appears especially beneficial for men, who, in other contexts, are less likely to have their experiences of fear validated and are generally less apt to share fearful experiences. As such, the men’s tendency to be candid about their experiences of anxiety was far more typical in the support group setting than in the interviews.

Notably, while men were more forthcoming in the groups setting, there were no obvious differences in how women told their stories in the interview and in group settings. That is, women articulated their personal experiences of anxiety openly in both

settings. The difference in response and content between interviews and the support group among men suggests that men may be less likely to report anxious feelings in unfamiliar settings to unfamiliar people (such as, in interviews, surveys, doctors' offices, emergency rooms).

Similarly, in a mixed-method study on the gendered experience of pain, Gillian Bendelow (1993) describes a male research participant who was reluctant to report his experiences with a panic disorder in the survey portion of the study. She writes,

“An unemployed white actor, aged 24, had described a toothache as his worst experience of pain in the questionnaire. In the interview, however, he claimed that he felt unable to mention an ongoing condition he had experienced over the last few months which caused him much more pain and anguish. He revealed that he had been experiencing ‘panic attacks’, which he described as a feeling of ‘depersonalization’:

I felt totally separate from whatever was going on—it’s like an inner terror, it is like a physical pain at times, it’s like a vice on my temples and an incredible pressure on my head that it does produce a headache but essentially it’s just a brooding feeling in my skull. He had sought treatment through his doctor, and had been referred to a psychologist, but was very reluctant to accept that there might not be a physical cause” (Gillian Bendelow 1993:283)

This excerpt illustrates the difficulty men have exposing fear, even in the impersonal, anonymous survey format. After Bendelow developed a rapport with the man, he was more comfortable expressing fear. In the same article, Bendelow explains that “males felt an obligation to display stoicism. Several male respondents felt that expressing pain would brand them as ‘sissy’ or ‘effeminate’” (Gillian Bendelow 1993:287).

Although the mediums of Bendelow’s research (survey and interview) are different than mine (interview and participant observation), the lesson is analogous. In Bendelow’s study, this man refused to talk—at all—about his experience of panic in written format, while the rapport built in the interview forged space for him to

acknowledge fear. In my study, I find that the interview setting limited the breadth of what men would talk about, while the dynamics of the support group facilitated an expansion of what men would say. Both observations point to the importance of context in guiding whether or not men talk about stigmatized emotions and what they are willing to say. The gendered nature of fear makes disclosing feelings of anxiety and panic difficult for male interviewees, and the social context shapes whether or not and how men tell anxiety stories.

Feeling Anxious

In this section, in addition to the *expression* of anxiety, I suggest that the *experience* of anxiety may also be socially conditioned and gendered.¹⁷ Sociologists of emotion have argued as much for decades. For instance, Hochschild extends her discussion of feeling rules and emotional management beyond expression to include experience. She quotes Erving Goffman—who maintained a performance-based approach to emotion—writing, “When they issue uniforms, they issue skins”; Hochschild extends this claim to reach inward to “two inches of flesh” (Hochschild 1979:556). In other words, Hochschild argues that not only do people manage their presentation of emotion on the surface of the body, they also manage their inner feeling, which she calls “deep acting” (Arlie Hochschild 1979:558), and—over time—deep acting becomes a natural way of experiencing the world.

Social and medical scientists have long argued that prior experiences and attitudes toward sensation shape the experiences of it (Bates 1987; Bendelow 1993). The idea that physical sensation is subjective is not a new one. Since the early 1960s, gate-control

¹⁷ As discussed earlier, Simon and Nash’s survey study (2004) indicates that while the general experience of emotion was not found to be gendered, *anxiety* was experienced differently by men and women.

theory has suggested “that psychological and cognitive variables (heavily influenced by socio-cultural learning and experience) have an impact on the physiological processes involved in human pain perception and response” (Bendelow 1993:275).

Research shows that the types of emotions (normal and pathological) that people experience are deeply gendered. For instance, men have higher rates of externalizing disorders (in which emotions are expressed outward), and women have higher rates of internalizing disorders (“feelings focus more on the self”) (Rosenfield 1999:354). While the interviewees are all diagnosed with an “internalizing” disorder (anxiety), men—when describing anxiety—described more externalizing *symptoms* of anxiety (especially demonstrations of rage). Likewise, studies have demonstrated a striking difference in the bodily expressions of anxiety between men and women; while women demonstrate “motor retardation and vagueness,” men demonstrate fear through “hostility” and “body agitation” (Howell et al. 2001: 170). Another study found that “females self-reported more physiological symptoms” of emotions than men, including those associated with fear and anxiety (Shields 1984; LaFrance and Banaji 1992:186). Anxiety is a mutable experience that hinges on past experience and social context. In this section, I address how gender shaped the physical experience of anxiety and panic among the interviewees.

Angie’s narrative about differences between her husband’s and her own experiences of anxiety neatly demonstrate the gendered differences in the manifestations of anxiety. In particular, her experience of anxiety was more internalized *and* more physiological. First, she described her own experience of anxiety.

My chest gets very, very tight. I definitely struggle a lot with being able to concentrate on stuff. [pause] There's lots of things going on and it ends up being in my head, this vicious cycle of what if, what if, what if? And then I come back to the same place of “What is gonna happen? What if this

happens?" If I'm trying to focus on something else, that's not really going to happen. So that's what's going on in my head. And like I said, my chest gets really tight. Although I don't know what it is, there is a change in my breathing. I can't exactly tell you what changes in my breathing, but I know there is a change. I couldn't say that I specifically stopped breathing, but afterwards I know if I take a deep breath and focus on my breathing a little more, that does help. And, definitely some increase in heart rate.

Angie's symptoms—obsessive worrying, tight chest, difficulty breathing, and rapid heartbeat—are "classic" indicators of an anxiety disorder. Her symptoms represent a physiologically potent but still internalized manifestation of anxiety.

Later in the interview, Angie explained that her husband also has anxiety: "Barry has some of his own issues with anxiety that he struggles with and doesn't quite know how to deal with. He lost his temper at work, one too many times, and they let him go." I was surprised by her unhesitating connection between anxiety and losing one's temper, and I asked "Do you and your husband experience anxiety differently?" She blurted out,

Oh my god, yes! [laughs] He gets very anxious over what people are going to think. He gets worried about being on time. He worries about what people are going to think about his performance and how he does his job. So, he gets very anxious over that, and *he deals with it by getting angry*. And he will get very angry. Not to the point where he will hurt people, but there have been times where he has gotten so anxious, and he keeps it in until there is a final breaking point, and something happens, and he will end up slamming doors and peeling out of the driveway. He has thrown things a couple of times, punched things a couple of times, but he has never hurt me. I have been worried about whether he was going to hurt himself. He has talked about, in those moments of complete rage, "I'm better off dead!" And those things have really bothered me, and I have talked to him about it. But, when he gets in those moments, he can't see anything. [pause] Yeah, he deals with the stress and the anxiety completely differently. He gets anxious over money as well. He gets so frustrated with it...and sometimes it comes out as absolutely losing it, but other times he is very vocal about his frustration.

In contrast to Angie's description of her almost completely internalized experience of anxiety, she describes her husband's violent externalization of anxiety. Like previous studies have suggested, Angie and Barry differently manifest anxiety. Interestingly, like

the other male interviewees, Barry's experience of anxiety was not described in the "typical" physiological terms (even those visible to his wife): like sweating and shaking. Barry's expression of "anxiety" actually looked a lot more like "anger" or "rage." Perhaps the social sanctions against male expressions of anxiety or fear—discussed in previous sections—facilitated these embodied externalizations and violent expressions.¹⁸

Like Barry, the male interviewees less frequently reported experiencing the physical symptoms of anxiety, while the female interviewees frequently did. One explanation, suggested in the previous section, is that men do not talk about the, perhaps, more embarrassing, feminized physical symptoms of anxiety (feeling faint, heart palpitations, trembling, and so on). Another explanation is that men actually *experience* and *interpret* bodily sensations—including those associated with fear—differently than women.

For instance, for years Roger only perceived the psychological symptoms of anxiety (excessive worrying), and for years he did not notice the tell-tale physical signs of an anxiety disorder because he was desensitized to them from a lifetime of boxing.

I boxed from the time I was nine years old. I used to run races. I was always in great shape. So when this guy [a therapist] told me about Claire Weekes, he's telling me "when you're having panic attacks your heart beats fast and you have trouble breathing."

I says, "No."

He says, "Of course you do."

I says, "No, I don't."

He says, "Of course you do. Everybody does."

I says, "No, I don't."

He says, "You have to."

I says, "I don't." [pause]

He says to me, "You know why you don't?"

I says, "No."

He says, "You do. You just don't care."

¹⁸ "Cutting" was an analogous way some of the female interviewees externalized their experiences of anxiety, but, notably, cutting still represents a self-directed expression of emotional pain.

My heart doesn't bother me. I ran and worked all my life... I never paid any attention to my heart or the breathing neither.

It was not until the physical symptoms were brought to his attention by his therapist that Roger even noticed they were happening. A racing heart and difficulty breathing were common, daily experiences for Roger. In addition to a lifetime of boxing, he also worked physically demanding jobs in construction, delivery service, and mill work. The experiences of a body accustomed to being hit in the face, falling down, and lifting heavy weight all day long is going to be qualitatively different from a body that has never been hit, has not fallen since childhood, and works a sedentary desk job. Roger offered an interesting observation: his experience of anxiety was shaped by prior bodily experiences.

Previous empirical work supports the claim that certain types of physical activity can reduce the perception of the symptoms of panic. For instance, researchers have found introspective exposure (IE) to be an effective treatment for panic disorder. The objective of IE therapy is “to learn to reduce the automatic fear response to bodily sensations by prolonged exposure to these bodily sensations” (Arntz 2002:329). In other words, the objective is to learn to interpret specific bodily sensations—like a pounding heart, dizziness, and sweat—as signs of something other than fear. This is accomplished through exposure to these physical symptoms, provoked by activities, such as running up-and-down stairs (sweating and racing heart), spinning in a chair (dizziness), and breathing through a straw (difficulty breathing and dizziness). Research shows that exposure to these bodily sensations, with an explanation besides fear (for instance, spinning, running, and so on), reduces the experience of panic. In short, participating in physical activities that cause bodily sensations similar to those felt in fearful situations helps people interpret their bodies differently. The effectiveness of IE strongly suggests that physical experiences can be learned to be

interpreted differently (see also Becker 1997:41-53 and Esala and Del Rosso 2011 on learning to experience bodily sensation differently). If a few months of therapy can reshape people's experiences of their bodies, a lifetime of differential experience should be able to do at least that much.

Outside of the lab, in the “natural” world, these daily physical activities—like, work and leisure—are strongly gendered. For instance, even though women increasingly work in physically demanding jobs and participate in aggressive, violent sports, most women still do not; these activities remain profoundly gendered. Also, the top three jobs for women, as of 2009, were administrative assistants, registered nurses, and elementary and middle school teachers (Dept. of Labor 2009a), which are all emotionally demanding professions but only moderately physically demanding. On the other hand, women are strikingly underrepresented in the most physically demanding jobs, such as: logging (less than 1% female), carpentry (1.5% female), firefighting (3.4% female), and construction (6.9% female) (Dept. of Labor 2009b). Additionally, recent studies have shown that males are more physical active from youth into late life (University of Exeter 2009). Males also have greater access to especially aggressive sports in high school, college, and beyond, such as football, boxing, weightlifting, and wrestling. Accordingly, men and women—with markedly different bodily experiences—may actually come to experience anxiety differently.

A study on “unexplained arousal” (Gerdes 1979) provides powerful evidence that men and women experience the physiological components of fear differently. Researchers injected men and women with epinephrine (or adrenaline), which simulates the physical experience of fear. They found that while men and women had similar physiological responses to the epinephrine, women were better able to *perceive* those

physiological changes (Shields 1984; Gerdes 1979). That is, women noticed the sensations associated with “fear,” while men felt little to no difference in their bodies. This research suggests that men are less sensitized to the physiological experience of fear, while women are more attuned to it. In other words, women are more likely to *feel* fear.

Likewise, it was not until *after* diagnosis and *after* several discussions about his panic attacks that Roger noticed his racing heart and labored breathing; those sensations were normalized to such an extent that he did not interpret them as disordered or even as problematic. The perception of the same bodily processes is gendered to the extent that men and women feel the physiology of fear differently. The gendering of bodily experience—like raised heart rate, sweating, and muscle fatigue—may desensitize men to a number of the tell-tale signs of an anxiety disorder.

Conclusion

Based on interview data, participant observation, and previous research, this chapter suggests that gender structures the expression and experience of anxiety. These gender differences have significant implications for empirical research and medical practice. Specifically, these findings contribute to sociological research on “self labeling”, epidemiological research, and the potentially differential rates of diagnosis of anxiety disorders between men and women.

First, the *expression* of anxiety is quite different between men and women, with men less likely to discuss their experiences of anxiety with family, friends, and physicians. This suggests that men may suffer with the physiological, mental, and emotional symptoms of anxiety for long periods of time, unable or unwilling to ask for

help. While Peggy Thoits suggests that individuals with deviant emotions will “self-label” and seek medical treatment, which suggests a patient-initiated diagnosis. This dissertation provides empirical support for her claim but also evidence that self-labeling may represent a gendered process with men less likely to self-label “anxiety.” As a consequence, there may be different rates of diagnosis between men that do not reflect differences in their actual experiences of anxiety.

Further, the inability of men to express anxious feelings provides preliminary evidence that anxiety disorder prevalence rates may be underestimated for men. That is, if men are less likely to comfortably talk about anxiety, they are also less likely to report—perhaps, in medical and social science surveys—having anxiety-related symptoms. As a consequence, prevalence rates of anxiety may not represent the anxiety-related experiences of men.

Additionally, how men talk about anxiety is different than how women talk about it. Men provided “de-centered narratives,” which may potentially pose challenges for health care professionals in diagnosis and treatment. De-centered narratives evade descriptions of the lived experience of anxiety. If men resist talking about their own experiences of anxiety, it becomes increasingly difficult for medical practitioners to systematically categorize their symptoms. While this study addresses narratives about anxiety stories after diagnosis, future research could examine gender differences in how men and women describe anxiety to their physicians before diagnosis. The medical community may benefit from more information about differences in how men and women tell illness stories and more guidance about how interpret those narratives (see also Charon 2001; DasGupta and Charon 2004).

Men also differed in where they were willing to tell their anxiety stories. While women openly shared personal anxiety stories in multiple settings, men were noticeably less forthcoming than women in the interview setting but similarly forthcoming in the secure, familiar, and therapeutic setting of a support group. This suggests challenges for researchers and healthcare professionals. Men may not talk openly about anxiety in the, often, impersonal and fast-paced clinical setting, which makes the accurate diagnosis of an anxiety disorder challenging. As for research, social scientists are well aware of how important an accommodating setting is in data collection, especially when addressing sensitive topics; these findings suggest that this is especially true for men being asked to express gender deviant emotions. Future research could address how rates of anxiety differ for men across various data collection methods.

Not only did men *express* anxiety differently than women, the interviews, support groups, and previous research studies strongly suggest that men *experience* bodily sensations differently than women. Specifically, men are less aware of the physiology of anxiety. That is, men were less likely than women to notice symptoms like a fast beating heart, shortness of breath, and sweating. While women are socialized to persistently and strictly regulate their bodies (i.e. women should not sweat, burp, or look disheveled but should always keep their legs crossed, maintain an upright posture, and smile), men more frequently participate in work and leisure activities that allow, even demand, their bodies to expand (sweating, getting dirty, and being angry during sports and at work). As such, women are more attuned to the largely unfamiliar physiological experiences of fear, while men are often desensitized to them. Although the physical experience of anxiety difficult to study, evidence suggests that the experience of anxiety is, at a minimum,

different for men and women and most likely contributes the subsequent expression of anxiety.

CHAPTER SIX

ANXIETY DISORDERS AS GENDERED DIAGNOSES

This chapter shifts the focus of the last chapter from the individual's gendered expression and experience of anxiety to the intersubjective and medical accomplishment of anxiety as disordered, with a focus on how that process is gendered. While the previous chapter addressed gendered experiences and expressions of anxiety, this section examines how gender operates in social exchanges and in the diagnostic process. In the interviews, the most obvious interactions that supported the differential experience of anxiety disorders were those between the interviewees and their doctors. Men and women both reported resistance from their physicians to an anxiety disorder diagnosis but in very different ways. In this section, I draw in interviewees' narratives about their journeys from active treatment seeking to diagnosis in order to explore the gendered variation in the intersubjective establishment of anxiety as disordered.

This project could be accomplished in many ways; for instance, one could, instead, study interactions surrounding anxiety between husbands and wives, workers and employers, or between friends. For the purposes of this study, interactions between patients and doctors were especially relevant, because doctor-patient interactions were universally experienced by the interviewees (unlike marital and work relationships) and

intrinsically linked to the *formal* recognition of anxiety as a disorder. This chapter explicitly picks up where chapter five left off, which addressed the gendered experience and expression of anxiety. This current chapter explores how those experiences and narratives are translated into a diagnosis. This chapter is also building on chapters three and four, which addressed the *informal* construction—among interviewees and their friends and family—of anxiety as pathological. These daily interactions pressed individuals toward active treatment-seeking, and active treatment seeking is the core of this present chapter. That is, this chapter is based on an analysis of the interviewees’ narratives about the time between when they decided to seek treatment and the time at which they were diagnosed.

Overall, women had a much easier time than men establishing an intersubjective and medical account of “anxiety” with their physician. Many of the female interviewees simply went to the doctor and were promptly told, “You have an anxiety disorder.” For instance, Marcy described the time that lapsed between treatment seeking and diagnosis succinctly, in two long sentences.

I had them [panic attacks] every few days, then with increasing frequency until I would have probably four or five full-blown panic attacks a day. Finally, about a year or so later, I was just simply freaking out and the same guy [who I was with when I had my first panic attack] brought me to my doctor, who diagnosed me [with an anxiety disorder] *immediately* and gave me Xanax.

Marcy suffered with the symptoms of anxiety for a year, without an explanation, which was typical among the interviewees. But, when she sought a medical diagnosis, the establishment of an “anxiety disorder” was swiftly accomplished, which was more common among the female interviewees.

Similarly, Ana spent a lifetime with mild symptoms of anxiety and several years with intense symptoms before she sought treatment. I asked Ana, “How did you learn that you had an anxiety disorder?” She responded,

Because somebody told me, well she didn't tell me, she suggested that maybe I should go and talk to a doctor concerning that because it sounds like it could be an anxiety disorder. I didn't know what that was. Then, I went to the doctor. I told him all of this that I was having [symptoms] and that they have been going on for a while... *So, he said that I have anxiety disorder.* And, that's how I knew.

For Ana, finding out she had an anxiety disorder was as simple as getting advice from a friend, asking her doctor, and receiving an answer. Again, the path from treatment-seeking to diagnosis was direct and fast. About half of the female interviewees, once they began seeking treatment, reported a fast and efficient diagnostic process. Although this finding suggests that women might be diagnosed with an anxiety disorder *too* easily, this was not how the interviewees narrated their experiences. Rather, diagnosis was often framed as a long-awaited answer to a nagging question (see chapter eight on the range of responses to diagnosis).

The ease of diagnosis among some women may be, in part, explained by the fact that anxiety is an emotion that is easily and commonly attributed to women. As such, the intersubjective accomplishment of a disorder based on anxiety comes easier for women. In this context, people—in this case medical practitioners—are better able to *see* symptoms and experiences as “anxiety” among women.

Similarly, medical sociologist John McKinlay (1996), in his article “Some Contributions from the Social System to Gender Inequalities in Heart Disease”, argues that there is not a 1:1 ratio of true prevalence (actual incidents of illness) to statistical rates (reported incidents of illness). Rather, he suggests, environmental, personal, and

system factors mediate the relationship between true prevalence and rates. Simply put, there are a lot of roadblocks between the experience of illness and the data that is collected and reported, which distort the statistical picture of various illnesses, like gender bias among medical practitioners.

This chapter, in combination with the previous chapter, puts forth an analogous claim: there are many barriers between the physiological expressions of anxiety and the social recognition of an anxiety disorder. And, these barriers—specifically gender ideology—direct the experience, expression, and, now, the apprehension of anxiety as a disorder.

McKinlay (1996) uses heart disease as an illustrative object of study and opens his paper with an excerpt from a *New York Times Magazine* article (Henig 1993) that gives a face to the underdiagnosis of heart disease among women.

Paula Upshaw was a 36-year-old respiratory therapist from Laurel, Maryland. In 1991 she had a heart attack; as a health professional she was more knowledgeable than most about her symptoms—they were the so-called "classic" signs of a heart attack (terrible chest pain, numbness on her left side, sweating, and nausea).¹⁹ She says, "they never ever considered my heart . . . they were all sure it was my stomach." At her insistence (she was an assertive patient) she received three separate electrocardiograms. But, she reports, the emergency room physicians said her symptoms were normal (for stomach problems) and they sent her home to take antacids and ulcer medications. Her heart condition was not diagnosed until she made a third visit to the ER on a Friday evening and refused to go home. Even though she was eventually admitted to the hospital, she says no one was even thinking about her heart. The following day, a cardiologist on weekend duty was flipping through a stack of Saturday's electrocardiograms which included Paula Upshaw's. Paying no attention to gender, he asked, "Who's the 36-year-old with the massive heart attack?" (p. 1)

¹⁹ Interestingly, these also represent the "classic" signs of an anxiety disorder. This suggests, as McKinlay does, there are multiple ways to interpret symptoms.

McKinlay proceeds to argue that, in addition to personal influence (such as patient characteristics), system influences (especially physician influence) contribute to the underdiagnosis and subsequent inaccurate rates of heart disease among women. That is, physicians do not *see* women's symptoms as indicating a heart attack, and, as such, women fail to receive a diagnosis of heart disease. Similarly, my data suggest that the gendered nature of anxiety and anxiety disorders make the personal *and* medical recognition of anxiety especially problematic for men.

Up until now, my discussion of the differential experience and perception of anxiety has primarily centered on, what McKinlay (1996) calls, personal factors: the patient's experience and expression of illness. This section addresses system influences, specifically how medical professionals' gendered readings of symptoms shape the diagnostic process. McKinlay argues that "the influence of physician behavior on epidemiological rates is probably greater than all other social system influences combined" (1996:10). McKinlay's study shows how the gendering of coronary heart disease (CHD) inhibits the accurate diagnosis of women with CHD. Similarly, I focus on how the gendered interpretations of anxiety disorders shape the intersubjective establishment of "anxiety" among men and women.

The Pathological Woman and Comorbidity

Before I turn to intersubjective establishment of an anxiety disorder among men, I address the fact that while many of the women I interviewed reported an easy time seeking diagnosis, a good number reported some struggle. There were two major

problems that these women faced in the intersubjective medical establishment of anxiety: the pathologizing of normal (female) life events and co-morbidity.

First, normal life processes among women hindered in the recognition of an anxiety disorder. For instance, Stephanie discussed how pregnancy made it difficult to identify her symptoms as a sign of a worsening anxiety disorder. She began by explaining that her *initial* diagnosis of anxiety was unproblematic.

I think I was one year post partum from my first daughter. I was just having a really hard time, and I knew I had to do something. I went to my PCP (primary care provider) and kind of described my symptoms. He was like, “Oh yeah, you have GAD” [Generalized Anxiety Disorder].

The initial diagnosis was very straight-forward and representative of many of the female interviewees’ experiences of diagnosis; Blair described the symptoms, and her PCP named the disorder. But, Blair continued,

Well, I got pregnant with my second daughter. This time the symptoms didn't get worse *after* my pregnancy; they got worse *during* my pregnancy.... I was having heart palpitations, just a gross amount. I would literally be sitting on the couch and all of a sudden it felt like I just went for a brisk run. My heart would race; it felt like it was coming out of my chest. They [the doctors] ended up saying my youngest daughter was pushing up, so it was putting pressure on my heart [causing the racing heart and palpitations].

Even though Blair had already been diagnosed with an anxiety disorder, the heart palpitations were attributed to a complication in her pregnancy. Pregnancy masked a worsening disorder and obscured the intensification of the symptoms of anxiety. Blair made a clear and explicit distinction between diagnosis “before” and “during” pregnancy, pointing to the greater difficulty of receiving as accurate diagnosis during this (pathologized) life course event and physical state. After she gave birth, the heart palpitations continued. Her doctor did not relent and acknowledge that the heart palpitations were not associated with pregnancy until one full year after her second

daughter was born. He subsequently increased her dosage of a benzodiazepine, and she almost immediately felt better.

Similarly, several interviewees reported the onset of anxiety during adolescence and having counselors and family doctors dismiss their symptoms as a part of growing up, which involved things like “hormonal changes” and middle school or “high school drama.” *When* the female interviewees sought treatment—during “normal” life stages or pathologized ones—mattered in whether or not the symptoms were understood as a “disordered” (see Fausto-Sterling 1992; Martin 2001 on the scientific construction of women's bodies as pathological).

The other obstacle to diagnosis faced by many of the interviewees was co-morbidity with other mental illnesses. Simply put, the massive number of symptoms experienced by interviewees with multiple diagnoses made the establishment of satisfactory, fitting, and settled diagnoses difficult. For instance, Kathy—who maintains a diagnosis of dissociative identity disorder, agoraphobia, panic disorder, and bipolar disorder—spent years searching for the right set of diagnoses. Kathy experienced a wide range of symptoms, including: hearing voices, heart palpitations, loss of consciousness, tremors, insomnia, hot flashes, vomiting, paralysis, mutism, and self injurious behavior. With this wide range of symptoms, her physicians and psychiatrists struggled to find a fitting set of diagnoses. Her symptoms fit in multiple diagnostic categories. And, after each failed attempt at treatment, the medical professionals repeatedly re-categorized the symptoms and prescribed a different set of medications. Kathy explained,

In the beginning I was diagnosed with so many different things. It took seven years to actually get [an accurate] diagnosis. [I was diagnosed with] schizophrenia. I was obsessive compulsive. I was psychotic. I was paranoid schizophrenic. For all I know, one of my “alters” may be [laughs]. She [the

alter] tried to kill me. She thought that if she was in charge, if she killed me, she would be in charge. She didn't consider us the same body.

In the interview Kathy casually, jokingly discussed her “alters,” which is short for “alternative personalities.” But, before she was diagnosed with dissociative identity disorder (which she explained is the “fancy way to say multiple personalities”), she described the “alters” in terms of “hearing voices.” Accordingly, the psychiatrists that Kathy went to (mis)took dissociative identity disorder for several variants of psychosis, including multiple forms of schizophrenia. Unfortunately, with the changing diagnoses, Kathy was repeatedly prescribed and then taken off potent psychotropic medications. She recalled,

I was locked up six months at a time in a hospital because I was not normal. They couldn't get an accurate diagnosis. At one point I was taking 12 different pills a day. I was taking haldol, thioridazine [pause] we joked and said I used to “do the Thorazine shuffle” because I couldn't really walk while I was on Thorazine. I had to shuffle. I can remember trying to journal and trying to read it later and it would just be wiggly lines.... I would walk around with a fireproof safe filled with pills. I was a walking pharmacy.

Since the psychiatrists confused a symptom of dissociative identity disorder—especially, hearing voices—for a sign of schizophrenia, they treated her with Thorazine, which has the side effects of nervousness, shaking, and rapid, irregular heartbeat. So, when Kathy experienced these types of symptoms (which are now tethered to a panic disorder), they were dismissed as the side effects of Thorazine. The combination of (mis)diagnosis and biomedical intervention left important symptoms—that pointed to disordered anxiety and panic—unnoticed.

In addition, Kathy's medical team established an etiology of her symptoms. The causal ordering of symptoms and disorder are inherent in the diagnostic and treatment process, even though they are explicitly stricken from the diagnostic and statistical

manual (Horwitz 2010). For Kathy, the primary symptom and diagnosis were, respectively, hearing voices and schizophrenia. Her complaints about feeling nervous were dismissed as *secondary* to the symptoms and treatments of schizophrenia. “Normal” anxiety is a typical response to the symptoms of schizophrenia and a component of the side effects of her medications; as such, Kathy was not explicitly treated for an anxiety “disorder.” The latent medical ordering of experience highlights certain symptoms while dismissing others, which obscured potentially useful diagnoses. It was not until Kathy had the formal diagnosis of “dissociative identity disorder”—which currently has no biomedical treatment—that she was able to be diagnosed with and treated for an anxiety disorder.

It was typical for interviewees with co-morbid disorders to struggle to find a satisfactory diagnosis, and many remained skeptical of their current diagnoses. Ronald Epstein and colleagues argue that overly certain and rigid diagnoses not only result in “overtesting and overtreatment” but can also “increase patients’ sense of vulnerability ... and create an adversarial relationship between patients and the health care system” (Epstein, Quill, and McWhinney 1999:218). This seems to be especially problematic for individuals with co-morbid disorders.

Like Kathy, many interviewees with co-morbid disorders were treated with too many, too strong, and unbeneficial medications. Also, they reported distrust for the medical system and their current diagnoses and treatment. For instance, Lauren, a college student at a prestigious New England university, at the time of the interview, was diagnosed with generalized anxiety disorder, obsessive compulsive disorder, and an “apprehension disorder”, but these diagnoses remained in flux. She lamented,

I've seen so many different therapists, and they diagnosed me with different disorders. So, they don't really know what my problem is exactly.... How come people don't know what I have? Why do they keep disagreeing? What is my problem? ... I would think that they could generally agree. So, I just don't know how one person said "I did have that" and another person said "I didn't have that."

Lauren has been in and out of therapists' offices since she was eleven years old; she is currently 22 years old; and she is still not satisfied with her diagnoses or treatment.

Interviewees with co-morbid disorders struggled to find stable diagnoses, and many continue to tweak the still ill-fitting labels.

This patient frustration is largely grounded in a problem in the ideology of medicine and in our culture in general about "disease specificity"; that is, "diseases are conceptualized as distinct, objective entities that are common to afflicted patients" (Chiong 2001:90; Rosenberg 2002) even though physicians are often confronted with "unclear, unconnected, and mysterious" symptoms (Brown 1995:39). In the face of disorganized, chaotic, and fluctuating symptoms, physicians expect and are expected to locate specific diseases which are matched by specific treatments. This paradigm of "disease specificity" (Rosenberg 2006:412) "structures the expectations of patients and physicians" (Chiong 2001:90). However, with mental illness (along with comorbid illnesses, chronic illness and biologically unspecified illnesses) this is often an unreasonable expectation. The disjuncture between patient expectation and the reality of diagnosis and treatment leads to high levels of patient dissatisfaction (Kleinman et al. 1978).

Mis-Diagnosing Men

Even with the difficulty establishing anxiety as a disorder among women with co-morbid disorders and confounding and pathologized life-events (like pregnancy and puberty), the narratives about diagnosis among men stood in stark contrast. Men had a different, often more difficult, experience intersubjectively establishing an anxiety disorder diagnosis with a medical professional.

In this section, the de-centered male illness narratives about fear meet the interpretative ear of the medical professional. Importantly, how the medical professional hears and understands the illness narrative guides the diagnostic process. On the whole, men's symptoms were interpreted by physicians, as signs of very serious illness. Notably, while women often reported having their symptoms dismissed as a normal part of their bodily constitution during pregnancy and adolescence, men were diagnosed with (and treated for) more serious physical illnesses.

For instance, James currently has a diagnosis of panic disorder and posttraumatic stress disorder. After initially seeking treatment, he went years without an anxiety diagnosis. Instead, he was treated for epilepsy. Notably, an accurate epilepsy diagnosis is notoriously problematic, and it is not at all uncommon for panic disorders to be misdiagnosed as epilepsy and for epilepsy to be misdiagnosed as a panic disorder²⁰ (Scheepers, Clough, and Pickles 1998; Chadwick and Smith 2002). James recalled his experience of misdiagnosis,

I noticed that I started getting dizzy a lot. To the point where I thought I was going to pass out. I went to see my [primary care physician] PCP, and my PCP didn't really understand what was going on with me, but he knew that

²⁰ Additionally, there is overlap in symptoms and treatment between panic disorders and epilepsy, and recent research suggests that there may be some common underlying physiology (Aroniadou-Anderjaska, Qashu, and Braga 2007; Vazquez and Devinsky 2003).

there was something that probably ought to be looked into. He sent me to a neurologist, who took some family history and, as it happened, my grandmother had epilepsy. A few other maternal relatives have epilepsy, so he thought maybe I had epilepsy.... He started me on a regimen of some [anti-seizure] medications that only served to make me feel worse.

James described symptoms of dizziness, weakness, shaking, and confusion, which are all typical symptoms of anxiety. But, his doctors interpreted this combination of symptoms as epilepsy.

Still, James “held the diagnosis in question”; he explained, “I wanted to believe them because they were professionals. I had to assume they knew what they were doing.” But after some time with lingering hesitations and intensifying symptoms, James asked to see a professional in psychology.

He [the neurologists] sent me to a psychiatrist, who confirmed the diagnosis of epilepsy. It really didn't make any sense to me. I told them that it didn't make any sense to me because I didn't really have any of the other symptoms. It was just dizziness, confusion, some trembling, and sometimes this raised level of feeling or feeling out of sorts. But, the neurologist and the psychiatrist were both convinced that it was epilepsy.

The general physician, a neurologist, and psychiatrist all agreed that James had epilepsy, despite the fact that James did not believe the diagnosis, the symptoms were more consistent with anxiety, and the anti-seizure medications did not alleviate his symptoms.

I asked James why he thought they were unable to diagnose him with an anxiety disorder. He replied,

I think there is a bias, and I want to talk about it. I believe that there is a gender bias. I believe that my difficulty has especially been due to the fact that I am a male. Not only am I a male, I am an educated male, which really sucks because people have an even more difficult time understanding. I'm supposed to be perfect; I'm supposed to be stable; I am supposed to be learned. All of these things! I am not supposed to be sensitive. I am not supposed to have these weaknesses. I am not supposed to have these life difficulties and struggles because *nobody wants to look at it*.

As the symptoms progressed, James became less concerned about the stigma of expressing his distress, and, subsequently, went to multiple medical practitioners and repeatedly described his symptoms. James explained that while his resolve to hide these stigmatized symptoms weakened, other people continued to do the work to salvage his masculine, educated presentation. Notably, James *himself* identified his gender as the single most important reason that he was unable to successfully express his experiences of fear; others simply would not accept his interpretation and refused to see fear.

Notably, James saw his general lack of stigma and abundance of status as a hindrance in his diagnosis. In the final pages of *Stigma*, Goffman wrote that there is only one “unblushing male in America” (Goffman 1986:128) (which, of course, rightly implies that no woman is ever unblushing). Goffman goes on to list the characteristics of the unblushing male, most of which James exemplified. James was a “white urban, northern, heterosexual protestant” and has a “college education” and is “of good complexion, weight and height” (Goffman 1986:128). By these measures, James was almost unblushing. This ideal type of an unblushing man that Goffman hints at what R.W. Connell termed hegemonic masculinities, which are “collective images or models or masculinity” that pattern men’s behavior and facilitate male dominance over women and other men (Connell and Messerschmidt 2005:832, 841). A core difference (among others) in their discussions of masculinity is that Connell places an emphasis on masculinities (instead of masculinity) and that she explicitly asserts that we should “...eliminate any usage of hegemonic masculinity as a fixed, transhistorical model” (Connell and Messerschmidt 2005:838; Connell 2005). In other words, masculinities, including hegemonic masculinities, vary across and within cultures. We should not

expect to find any single unblushing male but, rather, many slightly blushing men, in various shades of pink and red.

Nonetheless, Connell and Messerschmidt assert that these various collective images continue to have a range of “gendered consequences”, and they suggest health as a potential site for these gendered consequences (2005:841). Indeed, health and illness, in terms of diagnosis and treatment, appear in these narratives to be mediated by cultural ideas surrounding masculinity and femininity. In particular, the continuous policing of masculinity by physicians disrupted and challenged the diagnostic process.

The doctor’s office became a space where James was offered the opportunity to shed the stigma of his symptoms and take on the sick role, in which he would be exempt—within certain constraints—from responsibility for his illness (Parsons 1951). While the diagnosis he was offered (epilepsy) was not free from stigma (Schneider and Conrad 1980), epilepsy better fit criteria of the sick role—in that it was viewed as entirely out of the control of the ill person—and also did not threaten the gender identity of the patient. Conversely, anxiety disorders are often understood (however inaccurately) to be within the control of the ill person and to directly threaten masculinity.

Goffman, in *Interaction Ritual*, observes that not only do individuals do face-work for themselves, social actors do face-work for each other (Goffman 2005:27). In James’ interpretation, the doctors—by refusing to see anxiety in a man—did (unwanted) face-work for James. In all likelihood, these medical practitioners truly believed that James had epilepsy, but, at the same time, it is equally likely that gender bias made it easier to see epilepsy than an anxiety disorder in this nearly unblushing male patient.

Despite his attempts at candor while describing anxiety, James observed that others—especially and most consequentially, physicians—remained resistant to viewing his experiences as “fear,” which is understood as a patently female and “weak” emotion. No longer were the obstacles to diagnoses located within the individual; it became clear that there was a network of gendered beliefs and ideology, beyond the individual, that hindered the recognition of anxiety in men. In a word, because of his gender, the medical community rendered his experience of “anxiety” invisible. As such, James felt that the medical professionals went to incredible lengths to give this “weakness” another name, in this case “epilepsy.”

James lamented that it wasn’t until he “lost 40 pounds in one month” that his psychiatrist acknowledged that James did not have epilepsy. He shortly thereafter diagnosed James with a panic disorder and posttraumatic stress disorder. James was, eventually, put on an antidepressant and the maximum dose of a benzodiazepine to manage his symptoms.

At the time of the interview, over ten years had passed since he was diagnosed with an anxiety disorder, but James remained angry with the entire medical community. He strongly and vocally resented being put on unnecessary medications and felt that the delay in treating the panic disorder led to a far more severe and chronic illness. He angrily explained that he will only go to a medical practitioner to get a prescription for his anti-anxiety medication and nothing else.

Lori experienced very similar symptoms and also had family members with epilepsy. But, unlike James, who never thought he was having seizures, Lori often thought that she was having or about to have a seizure. She told family, friends, and

medical professionals that she was concerned that she had epilepsy, but Lori was never even referred to neurologist or tested for epilepsy.

This pattern was consistent across the 34 interviews with women; women presented intense symptoms but were not diagnosed with more serious physical (e.g. epilepsy) or mental (e.g. psychosis) illnesses. On the other hand, men's symptoms were reformulated into more gender neutral or male gendered disorders, to the extent that they were misdiagnosed and "over-diagnosed," that is, given an inaccurate and more serious diagnosis than an "anxiety disorder." These interviews suggest that gendered ideas about fear and the related symptoms may indeed lead to an *under-diagnosis* of anxiety disorders among men.

As I have suggested, in addition to being diagnosed with more serious illnesses (such as epilepsy), men were diagnosed with more "gender-appropriate" disorders, like substance abuse. Interviewees commonly *reported* co-morbidity of anxiety and substance abuse; this specific co-morbidity is also found at the national level (Bukstein, Brent, and Kaminer 1989; Conway et al. 2006; Merikangas et al. 1998). That is, both men and women *reported* using and abusing alcohol and drugs, in addition to having an anxiety disorder. But, while male interviewees and male support group members commonly reported being *diagnosed* with substance abuse/dependence issues, only one woman described a diagnosis of substance abuse/dependence. Likewise, in the population, men are 50% more likely to be diagnosed with a substance abuse disorder than women (Kessler et al. 2005).

The co-morbidity of anxiety and substance abuse and the gendered nature of each disorder made the diagnosis of anxiety increasingly difficult for male interviewees. Since

substance abuse is so strongly gendered male and anxiety so strongly gendered female, the men in this study were often diagnosed with substance abuse issues, while their symptoms of anxiety went unnoticed. Conversely, while many female interviewees self-reported excessive drinking behavior and drug use, they were never diagnosed with alcohol dependency or substance abuse; further, women's substance use behavior did not interfere with an anxiety disorder diagnosis.

William—who was eventually diagnosed with panic disorder and agoraphobia—was originally (mis)diagnosed with alcohol dependency and did not receive an anxiety disorder diagnosis for several years after the onset of severe symptoms, including dissociation, racing thoughts, and obsessions. William explained,

I was first diagnosed with alcohol addiction. So that sort of dominated in the beginning and that was what I was treated for. And the other stuff [symptoms of anxiety] was considered symptomatic of that.

This quote recalls themes from chapter four: diagnosis moved disorder into a new causal position (alcohol addiction “caused” his symptoms). “Alcoholism”, as a diagnostic category, was meant to explain all of William's symptoms, but William did not find that abstaining from alcohol or attending Alcoholic Anonymous meetings addressed his symptoms.

I kind of framed everything around alcoholism. I got involved with recovery for alcoholics. A lot of the anxiety stuff would become more manic; it took about three years of intense anxiety after I got sober [to realize there was something else wrong]. I met a guy who also had anxiety, and he kind of helped me out.... I never really felt like I fit that model [of someone with alcoholism]. But it was something that I sort of accepted, because it is better than feeling like I was crazy. So, I sort of took on that. I mean I don't think of myself that way anymore.... I never felt comfortable with that diagnosis.

William was eager to find an explanation, besides insanity, to explain his experiences, and—as a consequence—he was all-too-happy to accept a diagnosis of alcohol

dependence. But, the treatment for substance abuse—abstinence and support groups—only served to more clearly exposed his symptoms of anxiety. Alcohol “treated” panic, albeit poorly, and without it, the symptoms worsened. After years of intensifying symptoms, William rejected the alcoholism diagnosis. I asked William when he knew that something was definitely still wrong. He recalled,

Well, I guess over the years it just kept coming back into my life, creeping back in. I moved to St. Louis to go to college and that's when it got the worst. I ended up having about 2 miles zone that I couldn't leave, luckily the school and where I lived was all in that zone. You know, I could walk or ride my bike. That felt fairly safe within the area. [But, then] I started to have really bad panic attacks on public transportation where I felt completely out-of-control. I had one where I sort of lost control of my body; I was alone, by myself; there were strangers on the subway. I started pacing back and forth and then sort of started stumbling. So I mean there were experiences like that. It just began to make me feel like I need to protect myself. I need to stay closer to home.

William's, eventual, inability to leave his “safety zone” provided the evidence necessary to diagnose him with a panic disorder and agoraphobia. William spent almost a decade of his life without diagnosis or treatment, suffering with the symptoms of anxiety.

When William sought medical intervention, the physicians more easily saw his symptoms as pointing to a male gendered disorder: substance abuse. Gender obscured some symptoms, while highlighting others, leading to a gender-biased diagnosis. Gendered disorders, like an anxiety disorder, influence *how* physicians see, organize, and make sense of a constellation of symptoms. As a consequence, men with anxiety-related symptoms spent longer amounts of time seeking a fitting diagnosis and were consistently misdiagnosed, overdiagnosed, and overmedicated.

Conclusion

This chapter addressed challenges to the intersubjective establishment of an anxiety disorder. Gender and diversity of symptomology appear to structure the diagnostic process. I found that the more diverse the symptoms the more arduous the diagnosis and that gender obscured diagnosis for men, while women had a much easier time locating an anxiety disorder diagnosis.

Since women express anxiety more freely, do so more easily across social space, and experience anxiety in the medically typified way, it is not surprising that the female interviewees had an easier time locating an anxiety disorder diagnosis. Still, some of the female interviewees did have trouble with diagnosis. There were two common reasons cited by interviewees for these difficulties. First, (ab)normal female life processes complicated the anxiety disorder diagnoses. Gender does not simply hinder diagnosis among men and foster it among women; gender serves as an institutionalized component of social life that is differentially meaningful across the life course. Specifically, gender and gendered life processes intersected with the experience of fear, complicating diagnosis. Second, co-morbid disorders complicated the diagnosis and treatment of anxiety. One of the inherent problems of rigid diagnostic categories is that the physical and mental experiences that they are meant to order are fluid, expansive, and often resist these molds. As such, interviewees with many diverse symptoms struggled to locate a satisfactory set of diagnoses. Often, at some point during the diagnostic process, anxiety was lost, as a normal consequence of a more serious disorder or as a side effect of medication.

The intersubjectivity involved in formally “defining the situation” (in this case, diagnosis) means that the interviewees could not define their experiences as they wished, but rather, they were compelled to collaborate with a medical practitioner to define their experiences. The diagnostic process explicitly draws on a network of ideas—both formally codified (DSM) and informally maintained (gender bias)—that guides the outcome. The interviewees’ narratives about treatment seeking revealed a robust network of gendered beliefs and ideology, beyond the individual, that hindered the recognition of anxiety among men. That is, even when men were willing to name their experiences “fear” or “anxiety,” physicians resisted, opting to diagnose these men with more gender-appropriate or gender-neutral disorders, like epilepsy, schizophrenia, and alcohol dependency. Interviewees suggested that gender obscured some of their symptoms, while it highlighted others, leading to a gender-biased diagnosis.

These findings suggest that despite relatively similar symptomology, men may be less likely to be diagnosed with an anxiety disorder (and to receive treatment for an anxiety disorder). As such, men may suffer with debilitating symptoms longer than women and their course of illness may be longer and more severe because they do not receive treatment promptly. These interviews also indicate that prevalence rates of anxiety disorders among men may be underestimated.

While this chapter suggests that men are underdiagnosed, it is equally possible that women are too easily diagnosed with anxiety disorders. Perhaps it is all too convenient and natural-feeling for doctors to see women’s symptoms as “anxiety.” But, the interviewees’ narratives, however, do not provide evidence for this; specifically, the female interviewees’ descriptions of their symptoms fit the DSM criteria very well, and

the interviewees were largely relieved to have a diagnosis. The argument certainly could be and has been made that the DSM criteria is too general and encompasses too much experience and that there is an element of false consciousness among the interviewees, but this debate is beyond the scope of this chapter (see Lane 2007; Kutchins, Kirk, and Kirk 2003; Szasz 2003 among others for a discussion). This chapter suggested, in the most descriptive of terms, that women more quickly and easily received an anxiety disorder diagnosis, while men had a noticeably more difficult to accessing an anxiety disorder diagnosis.

CHAPTER SEVEN

AFTER DIAGNOSIS: BECOMING “IRRATIONAL”

It's this nasty thing that rules my life. It's there for every decision I make. Every decision I make is based on: how is this going to affect my anxiety? It's just something that's always on my brain. Eat dinner. Take a shower. Manage anxiety. It's just on the list. (Carly)

Carly's quote exemplifies how anxiety became embedded in the interviewees' everyday thinking, behavior, and habits. Managing anxiety became as core to Carly's day as showering and eating, and it infiltrated all of her decision-making, from the mundane to the most significant. After diagnosis, “anxiety disorder” secured a central place in the lives of interviewees, transforming their senses of self, remaking social relationships, and challenging their definitions of “normal” experience. In this chapter, I address how an anxiety disorder diagnosis fundamentally changed the interviewees' day-to-day experiences, behaviors, and perceptions.

Throughout this chapter, the phrase “after diagnosis” will appear again and again. Intuitively, this phrase is linked to a decidedly medical experience, most often located in a physician's office. This is only part of what I intend to convey through the phrase “after diagnosis.” The words a doctor speaks, like “You have an anxiety disorder,” have significant consequences that reach far beyond the walls of her or his office, into the

everyday experiences of the person diagnosed. As such, when I write “after diagnosis,” I am referencing all of the changes in the interviewees’ social lives and lived experiences after those medical words are uttered. Specifically, “after diagnosis” represents a time in which “anxiety disorders” secured an important place in the lives of the interviewees and impacted a range of other areas of their lives.

Anxiety itself took on new meanings after diagnosis. In the most basic way, diagnosis gave “anxiety” a more tangible form and a more “active voice.” In other words, before diagnosis, the symptoms of anxiety were conceptualized as responses to external stimuli or inexplicable physiological responses (see chapters three and four). After diagnosis, an “anxiety disorder” became the known *cause* of these same thoughts, feelings, and physical sensations. Diagnosis introduced a new agent in the lives of the interviewees: an anxiety disorder.

Naming “anxiety” was a critical and transformative moment for the interviewees. For instance, Sarah—who had struggled with anxiety for decades—told me about the first time she was informed that her physical experiences were actually “anxiety.”

It wasn't until my late teens until I had a bad panic attack. And my father took me to the emergency ward because I thought I was having a heart attack ... the nurse who was taking care of me, after they took me off the EKG, whispered in my ear “you're just having an *anxiety attack*.”

This was the first time Sarah heard the phrase “anxiety attack.” She was eventually formally diagnosed with a panic disorder and a generalized anxiety disorder. Simply naming her experience changed her relationship with the sensations in her body completely. Although Sarah recalled being a very nervous child, it was not until she was diagnosed with an anxiety disorder that she clearly connected the chest pain, irregular heartbeat, and sweating to this “nervous propensity.” Likewise sociologist Peggy Thoits

observed that is it “only through language [that] we know *what* we feel and, implicitly, why: a cultural label is placed on a conjunction of situational cues, physiological sensations, and bodily gestures” (Thoits 1985:232–3). Sarah was given a bit of language that allowed her to name what she felt and *why*, and these words were transformative. Once the “nervous propensity” was given a name and a form, Sarah, like the other interviewees, could see an “anxiety disorder” as an entity *causing* sensation. The “anxiety disorder” now caused the physical symptoms and her general nervousness.

As it was with many of the other interviewees, Sarah described a causal inversion after diagnosis. She came to view anxiety as something that facilitated or inspired physical, emotional, and mental experiences. Anxiety moved to the core of experience and pressed sensation outward. For instance, Sarah ran a self help group and requested that individuals keep discussions of distressing symptoms to a minimum because, she explained,

People who have an anxiety disorder, if you say, “I have a headache,” they will say, “Oh my gosh, my head is hurting!” They internalize everything. That's why they are anxious. Everything gets internalized.

The logic behind this guideline, as explained by Sarah, represented a typical inversion of experience after diagnosis. In this new rendering, an anxiety disorder became the cause of anxious thinking and physical symptoms.²¹ An anxiety disorder became a known social object, with all of the potential to inspire the fear that driving, tall buildings, and discussions of death once had (see Esala and Del Rosso 2011 on the agential potentials of non-human non-physical objects). Without question, this was the most common causal ordering narrated by interviewees *after diagnosis*. Diagnosis brought into being “anxiety”

²¹ Notably, this specific logic is quite common; not talking about distressing symptoms is a typical guideline for anxiety support groups and is included in the *Anxiety Disorder Association of America* support group guidelines.

for the interviewees, and, as such, anxiety disorders instigated changes in the lives of the interviewees.

The main objective of this chapter is to examine how diagnosis changed the interviewees' everyday experiences and how they responded to those changes. I discuss three interrelated key findings. First, the diagnosis solidified for the interviewees that their perceptions of the world were largely inaccurate and that their feelings of fear, anxiety, worry, and apprehension were irrational and unfounded. While diagnosis provided a medical explanation that certainly ordered and explained their distressing experiences, the meaning built into an anxiety disorder diagnosis—that something was biologically and psychologically wrong with them that hindered their accurate and appropriate response to everyday situations—remained a salient theme in their narratives. In a word, an anxiety disorder diagnosis officially confirmed that their worldview was irrational. Second, as interviewees came to view their perceptions as skewed and their feelings as irrational, they trusted their own assessments less and less and relied more and more on significant others to evaluate everyday situations in their lives. As such, diagnosis prompted substantive changes in the interviewees' social relationships. Third, diagnosis facilitated the expansion of what experiences the interviewees felt were disordered; previously “normal” and “common” responses were increasingly categorized as components of an anxiety disorder.

Labeling Theory

Labeling theory provides an apt sociological framework for the main objective of this chapter, which is to explore the implications of medical diagnosis in the everyday

lives of individuals with anxiety disorders. Labeling theory is especially well suited to frame the findings of this chapter since it conceptualizes the naming (or labeling) of experience as a potent and consequential process. Labeling theory addresses the application of a label (such as a diagnosis) and the consequences it has for the person who is labeled, which mirrors the main objectives of this chapter. Before discussing the specific implications of labeling theory for the present study, I will outline what exactly labeling theory entails.

A label is a definition applied to a person indicating what *type* of person they are (Jo C Phelan and Bruce Link 1999). Sociologists have long been interested in labels and for good reason. For one, labels are one critical way that groups are identified and organized (like, teachers and students, Catholics and Lutherans, men and women, sane and insane). Also, labels arguably have serious social consequences. They have the potential to reify differences and create hierarchies (think gender and race) and to sort people on a macro scale (think demographic segregation by race, ethnicity, and religion). Labels, as I have already suggested, are also intrinsically linked to core sociological concepts and perspectives, like stigma, stratification, symbolic interaction, and constructionism.

While all sociologists have an implicit interest in labels, labeling theorists are more specifically interested in the various types of labels and the specific consequences of those labels. There is no single type of label; rather, the variations of labels are many. For instance, a label can be informal or formal. A person could be labeled informally as “energetic” or formally as having “attention deficit hyperactivity disorder” (ADHD). Formal labels are developed by institutions and applied by the professionals associated

with those institutions (for instance, the court system and a judge, the county hospital and a doctor, or the university and the dean), while informal labels demand no formal institution and can be applied by almost anyone (like, friends, co-workers, or the barista at your favorite coffee shop). Formal labels have strong cultural meanings that can be enacted in a wide variety of settings and are much more difficult to resist or conceal (Phelan and Link 1999:141). For instance, someone labeled ADHD necessarily reveals the disorder to her doctor and pharmacist, is likely has to share this information with her romantic partner, and to some extent reveals “disorder” each time she takes medication in a public place. On the other hand, someone informally labeled “energetic” can more easily hide this information from his doctor, pharmacist, and romantic partner and can conceal this “energetic” trait from strangers simply by presenting as, say, tired. Also, while someone who is labeled “energetic” may be nearly identical to someone who is labeled “ADHD,” the meanings associated with those labels are very different and are arguably much more negative for the label ADHD.

Likewise, labels can also be deviant or normal (Phelan and Link 1999). For instance, a person can be given a deviant (and formal) label like “mental illness” (Thoits 1985) or a normal (and formal) label like “college graduate.” Labeling theory has primarily been interested in the application and consequences of formal deviant labels. Specifically, much of the theory and empirical work has addressed the label “mentally ill,” which is an increasingly formalized (and specialized) label that has strong negative meanings attached to it.

Link and colleagues (1989) provide a succinct discussion of traditional labeling theory and mental illness—focusing on the *consequences* of being formally labeled as

“mentally ill”—which was an argument originally put forth by Thomas Scheff (see Scheff 1999).

Once labeled, an individual is subjected to uniform responses from others. Behavior crystallizes in conformity to these expectations and is stabilized by a system of rewards and punishments that constrains the labeled individual to the role of a ‘mentally ill person.’ When the individual internalizes this role, incorporating it as a central identity, the process is complete and chronic mental illness is the consequence (Link et al. 1989:402)

Traditional labeling theory posits that the prejudiced treatment of the labeled person by a range of others is internalized. In turn, he or she comes to see him or herself as mentally ill, in the very stereotyped way in which he or she has been treated. And, finally, this internalization gives way to a chronic course of illness. While the focus—as it is in much of the labeling theory literature—is on mental illness, the theory can be applied to all sorts of labels: deviant or normal, formal or informal. Still, formal labels remain the easiest to identify and measure, and deviant labels arguably have the most deleterious consequences.

Implied in the above discussion is the concept of “stigma.” Erving Goffman defines stigma as a discrediting attribute, and he continues to explain that stigma should be viewed as manifest within “a language of relationships” (Goffman 1986:3). That is, “stigma” does not reside in the characteristic of the person that is stigmatized; rather, stigma exists in the relationship between the perceptions of others and the characteristic of the individual within a specific social context. Edward Jones, drawing on Goffman, explains that stigma is the relationship between an “attribute and a stereotype” (Jones 1984; see also Link and Phelan 2001). Both of these conceptualizations, rightly, place the negative meaning of an individual characteristic in the social relationship. There is nothing inherently stigmatizing about mental illness, but the social meanings of mental

illness and the label “mental illness” have real consequences for the “marked” person (Jones 1984).

The critiques of labeling theory have been many—perhaps most famous were those advanced by Walter Gove (Gove 1970; Gove and Fain 1973)—including the arguments that symptoms (not labels and social standing) explain the identification of primary deviance and the subsequent labeling, stigma is not as prevalent or as consequential as labeling theorists have posited, and diagnosis and treatment helps (not hinders) recovery from disorder. These critiques have been judiciously responded to by proponents of labeling theory. As a result, labeling theorists have developed an approach that has come to be known as “modified labeling theory” (Link et al. 1989; Phelan and Link 1999). They make three amendments to traditional labeling theory—put forth by Link and colleagues (Link et al. 1989)—that are especially relevant to this chapter. First, while they concede that all members of society are exposed to and internalize messages about what it means to be “mentally ill” (Link et al. 1989:402), they emphasize the variability in those meanings and the beliefs people have about mental illness. Second, traditional labeling theory arguably put too much emphasis on the mistreatment of labeled people by others, and, in response, modified labeling theory places a stronger emphasis how the labeled individual thinks other people will respond to the label. As such, the meaning that the individual maintains about his or her own label is increasingly important in modified labeling theory. Last, traditional labeling theory asserted that the label itself created mental illness. Modified labeling theory, however, asserts that there are real and significant variations in the experiences and behaviors of people in the population that can be meaningfully classified as “deviance” and, as such, they focus

primarily on the *consequences* of assigning the label, including things like shame and lowered self-esteem (Link et al. 1989:403)

Likewise, I find that the initial experience of an anxiety disorder diagnosis provoked very different responses among the interviewees. For some the diagnosis was a relief, while for others it was devastating. Importantly, in all cases an anxiety disorder diagnosis suggested that there was something fundamentally wrong and irrational about how they experienced and responded to the world around them. I also found that a perfectly accurate, reasonable, and legitimate diagnosis still re-shaped the illness experience for the individual in unintended and negative ways. That is, much like modified labeling theory, this study suggests that while there is deviant behavior and real distress being “accurately” labeled, there remain significant consequences for this labeling. The unintended consequences of the medical label “anxiety disorder”, as described by the interviewees, are documented and discussed in the remainder of this chapter.

Diagnosis: Secures Thoughts, Feelings, and Behaviors as “Irrational”

Having an anxiety disorder diagnosis indicated to the interviewees that there was something medically and psychologically wrong with how they perceived and responded to the world. In *Anxiety in a Risk Society*, Iain Wilkinson observes that medical and psychological researchers “have been predominantly concerned to explain how neurotic individuals are made vulnerable to anxiety as a consequence of their own *(mis)interpretations* and *(mis)appraisals* of the situation in which they find themselves” (Wilkinson: 16, *emphases my own*). Likewise, the interviewees largely came to

understand their experiences of anxiety as physiological, emotional, psychological (mis)evaluations of the world. They viewed themselves as having a “faulty process of reasoning which leads [them] to over-estimate the reality of a prospective danger and underestimate the capacity to keep themselves from harm's way” (Wilkinson: 71).

Ideas about abnormality and irrationality are built into the formal diagnostic measures. At the most basic level, diagnosis “operates as a tool for separating out abnormal behavior from normal behavior” (Crowe 2000:70; see also Brown 1995). While diagnosis provides an official medical name for distressing experience, diagnosis, especially one suggesting mental illness, also officially confirms abnormality. Although interviewees already had a sense that something was “wrong” before diagnosis (as discussed in chapter three), the medical classification of their experiences as “disorder” solidified their concerns. This is not to say that the interviewees were across-the-board unhappy with their diagnoses. As modified labeling theorists have observed, all members of a group internalize the meanings of labels—in this case of an anxiety disorder diagnosis—but *they do not all internalized the exact same meanings* (Link et al. 1989:402). Likewise, many interviewees expressed relief to finally have a name for their discomfort. For instance, Lori explained,

When I was diagnosed with panic attacks, it just felt like, “Wow, that makes sense. Now everything in my life makes sense.” It's kind of like a moment of clarity. I felt really, actually, in a strange way, really good about it. Somebody gave me an answer, and I wasn't crazy. It had felt like I was crazy.... Finally, “No, you're not crazy. You have an anxiety disorder.” I was like, “Okay. I can deal with that.” You know? It was clarity for me and actually a good thing in my life to know what it was.

For Lori, an anxiety disorder diagnosis served as an “aha!” moment, in which all of her “crazy” experiences made sense. This type of response to diagnosis recalls my discussion

in chapter four about the sense-making function of diagnosis. That is, a name (specifically, a diagnosis) can help people more easily manage and make sense of distress. In this case, Lori described relief that an anxiety disorder diagnosis excluded the possibility that her distress indicated that she is “crazy.”

Another interviewee, Lane, was concerned when her doctor prescribed her and “anti-depressant” and immediately asked if that meant she had depression.

I mean, I was relieved when she told me it was anxiety not depression, because *I just see depression as more serious illness*. The anxiety, I was like all people feel anxiety sometimes. It's not a big deal. Everybody has some form of anxiety. Mine is just worse. So, I was actually relieved when she told me it was anxiety and not depression.

For Lane, the word “anxiety” had a very different meaning from the word “depression.” And, as such, having her experiences named anxiety, instead of depression, was a relief. This was not the only way that interviewees delineated between and “ranked” these two specific disorders. Some interviewees indicated that it would be better or easier to have depression, and others suggested that anxiety and depression were actually very similar illnesses.²² As modified labeling theory suggests, the meanings people have for illnesses vary and, in turn, uniquely shape their responses to diagnoses.

While many interviewees were relieved to have a name and an explanation, others were not. For instance, Ana struggled with the diagnosis,

Getting diagnosed with an anxiety disorder was scary. It was scary because I consider myself “Ana.” And that's all I consider myself and not anything else. To me I'm universal. I never thought that I would *have something*. It made me feel [long pause] I think I'm still, I think I am in a little bit of denial

²² This last claim may have the most empirical medical support. There is contentious debate in the psychological literature as to whether or not depression and anxiety are actually distinct entities. Anxiety and depression are highly comorbid, entail many of the same symptoms, and are effectively treated with many of the same medications (David Goldberg, Kendler, and Sirovatka 2010; Lecrubier et al. 2008; Ballenger 2000; Dunlop and Davis 2008; Moffitt et al. 2007; Kroenke et al. 2007; Durham et al. 2003; Bruce et al. 2005; for some dissent see: Kessler et al. 2008; Beesdo et al. 2010).

still with that. It's like I say it, but I don't really believe it because I'm trying to be the same person.

For Ana, the diagnosis left a mark. No longer was she just “Ana,” she had “something.” An anxiety disorder diagnosis did not simply explain something for her; it solidified that something was *wrong* with her.

While the initial responses to diagnosis certainly varied from interviewee to interviewee, there was one clear constant. An anxiety disorder unequivocally indicated that there was something “wrong” with how they perceived, experienced, and responded to the world. For the interviewees who had previously thought they had more severe disorders, like schizophrenia or epilepsy, the diagnosis of anxiety was a relief. Much like Pound and colleagues’ study on stroke patients (1998)—first discussed in chapter six—the interviewees’ interpretations of their diagnosis depended heavily on life experiences before diagnosis. Nonetheless, an anxiety disorder diagnosis, for all of the interviewees, indicated that something was wrong, albeit something not as serious as schizophrenia or epilepsy. In other words, while the direness of an anxiety disorder diagnosis depended largely on the historical and social background of the interviewee, diagnosis universally indicated that *something* was amiss, specifically that they did not have a “rational” view of the world.

The connection between fear and irrationality is not a new one. Fear, to varying degrees, has long been equated with irrationality, an inability to see the world clearly. From the age of Hippocrates to the late 1600s most illnesses were understood as the result of excesses or deficiencies of humors, or bodily fluids, including: blood, phlegm, yellow bile, and black bile. An excess of black bile—which was purported to damage intellectual function—was the primary cause of many of the symptoms we now

categorize as “anxiety.” In later conceptualizations, anxiety was caused, more specifically, by black bile that was warmed, creating a vapor that clouded the mind and created a sensation in the brain like “the darkness of night, which induced a causeless fear in many people” (Glas 2003:6). It was understood as a state created by imbalances in the body that caused *intellectual malfunction* and *irrational fear*. Although, over time, the details have changed substantially, the fundamental tenet that anxiety and panic are irrational responses remains largely unchanged. Overall, interviewees agreed with Hippocratic physicians: in the midst of panic, the mind is clouded as though in “the darkness of night.”

Not all that different from the Hippocratic physicians, the interviewees too viewed anxiety as obscuring accurate perception. For instance, Sarah described anxiety and panic as deeply skewing perceptions of reality. She aptly explained, “When you look through the eyes of fear you never see things clearly.” Seeing one’s self as having an anxiety disorder brought the interviewees’ ability to be rational and “see things clearly” into question and challenged their self concept. As an analogy for having an anxiety disorder, Sarah described a fear often felt by brides before their wedding to illustrate how anxiety distorts reality.

People say, “All brides always get anxious before their weddings,” that “it’s normal.” It’s normal? The question directly above the bride is, “Do I really want to get married?” This is a major life change, and they are in fear mode. *Fear overcomes every other emotion*. She says, “I don’t know if I love him.” *Of course you don’t know! You’re in fear*. You are shut down. All you are is in fear mode. So, *you got to learn how to come out of that so that you can see things clearly*.

In other words, when you are afraid, experiencing anxiety or panic, you cannot be rational and cannot accurately assess reality. The (now metaphorical) black vapor clouds

the bride's minds, making her unable to access her (relatively more) reasonable and honest emotions, like love. Sarah maintained that fear keeps people from accessing reality and that they must learn to see past it.

Still, fear is not easily managed. Even after people learned to see fear as irrational, they continued to struggle to control the feelings and thoughts associated with it. Many of the interviewees talked about the irrationality of *knowing* that there was no danger, but still *feeling* fear. For instance, Mary who was diagnosed with a generalized anxiety disorder and bipolar disorder talked about fears that plagued her in the evening.

I mean anxiety is sometimes, well, I *know* something isn't scary, but I'm still reacting to it as if it is. You see what I'm saying? I go to bed anxious because I'm thinking about a bad relationship I had or whatever but I know, in that moment, that the relationship was in the past. *I know I'm free from danger, but I'm still feeling anxious.*

Mary *knew* the fear was “irrational,” but she could not help but feel scared. Likewise, Bethany—who had been diagnosed with agoraphobia which eventually kept her in her home for months at a time—explained her frustration with her “irrational” need to stay home, “I would sob. I am an intelligent accomplished woman and why in God’s name can’t I walk down the street? It was crushing.” Bethany struggled reconcile the image of herself as an intelligent and accomplished woman and this woman who can’t leave her house and walk around the block. The combination of the intensity of anxiety—which was difficult to ignore or suppress—and the suggestion of irrationality built into an anxiety disorder diagnosis instilled in the interviewees’ a sense of an increasingly irrational self and challenged their self concepts.

Interviewees reported feeling deeply embarrassed about their experiences of anxiety and their inability to control them. While many of the interviewees were certainly

embarrassed about their distressing sensations, thoughts, and behaviors *before diagnosis*, the interviewees became increasingly secretive about them *after diagnosis*, suggesting that diagnosis amplified their embarrassment. Many interviewees explained that others would not be able to empathize since their experiences were so completely and officially “irrational.” For instance, Penny, a journalist, described several of her specific fears to me. She was afraid of inadvertently plagiarizing, becoming an abusive mother, and discovering that she has cancer, despite the fact that she carefully cites all of her sources, has a loving and caring relationship with her children, and has no indications of cancer. Before diagnosis, Penny talked at length with her grandmother, boyfriend, and a few close friends about these worries, seeking advice about how to confront them as legitimate problems. After diagnosis, she came to see these fears as wholly irrational, unfounded, and as manifestations of her anxiety disorder. Accordingly, she explained that she no longer talked to people—besides her psychologist and her (now) husband—about her anxiety disorder.

I don't really trust a lot of people to talk to about it. It's a very private to me. The fears are embarrassing. I worry that people are going to be like, “Oh, she abuses her children, or she is a plagiarist” I'm not, but why plant a seed? ... Also, because they [the thoughts] are just so irrational, it's embarrassing. I think, like, “*What? What was I thinking? That doesn't make any sense.*” *It's just so embarrassing to have lost that kind of control.*

After penny was diagnosed with an anxiety disorder, a clear disjuncture developed between what her thoughts *were* and what she thought they *should be*. This embarrassed Penny and prompted her to keep these thoughts and feelings private. For the interviewees, an anxiety disorder pointed to and confirmed an often mortifying inability to be rational, reasonable, and in control.

Again and again interviewees asserted that their perceptions of the world, because

of anxiety, were distorted. For some of the interviewees, anxiety became something they had to see past in order to accurately perceive the world and assess risk. For instance, James explained,

Anxiety takes me on the road to nowhere. I can get nothing accomplished when I am anxious. I can't think rationally. I can't think reasonably. It takes every ounce of energy that I have, when I am in that condition, to really try to pull it together enough to process it and work my way through it.

In James' rendering, anxiety became an agent, keeping him from productivity, rationality, and reasonableness. But, somewhere in the midst of this chaos, there was a piece of him that remained rational that could overcome the irrationality of anxiety. It became his task to "pull it together," see the rational course of action, and move past anxiety. Diagnosis formed an anxiety disorder that was continually described as obscuring accurate perception. Anxiety became an agent that could distort perception and an object that had to be maneuvered around. The tangibility of an anxiety disorder, as an agent, was reminiscent of the black bile that was once thought to obscure rational perceptions.

Diagnosis confirmed for the interviewees that their perceptions of the world were irrational. The physical, emotional, and mental distress and their negative evaluations of those experiences were substantiated and enhanced through diagnosis. And, even though diagnosis was interpreted differently by the interviewees, there was a common thread that ran through all interviews: that an anxiety disorder indicated pathological irrationality. Accordingly, interviewees' concept of self was increasingly imbued with irrationality, which gave way to an insidious distrust for their own interpretations of their everyday reality.

Diagnosis Distrust: Losing Faith in an Ability to Correctly Perceive the World

Not only did an anxiety disorder diagnosis suggest to the interviewees that their perceptions of the world were irrational, the interviewees reported losing the ability to determine when they were being rational and when they were being irrational. For instance, Jon said, “I tend not to trust how I feel or view it as realistic anymore.” He went on to describe wanting to help a close friend who was going through a difficult time, but he eventually started to worry that his help was excessive.

I tried to be helpful. My friend, my best friend, when I was around her, with her husband, I was going over to her house everyday and trying to help clean and stuff like that. I try to do things like that. I think it came across the wrong way. I thought it seemed [to her husband] like I was moving in on the situation [their family life]. Then, I tried to communicate preemptively that, “I’m not moving in on the situation.” You know? But I guess I shouldn’t have said that? Basically I kept trying to preempt things. I don’t know. It just doesn’t work out for me.

Jon’s interview was littered with stories about his inability to accurately assess social situations and to acceptably express his worries and concerns. Jon, like many of the interviewees, questioned his ability to respond appropriately to social situations because he did not trust his own assessment of what situations should or should not cause worry, anxiety, or fear.

For many of the interviewees, as the perceived irrationality of anxiety developed into a profound distrust for their own worldview, they reported dealing with this uncertainty by relying on trustworthy significant others to do the task of sense-making for them. Certainly, the felt inability to “appropriately” assess and respond to risk was one of the reasons that the interviewees initially sought and received an anxiety disorder diagnosis. As such, it is sensible that they would question their own experiences of fear

and rely on the interpretative frames of trustworthy others to help navigate these confounding emotions. Nonetheless, this arguably logical progression had significant and unintended consequences for the interviewees.

Almost all interviewees, at some point, relied on medical and psychological professionals to help them learn how to “step back” from anxiety in order to accurately assess the situation. This common approach to dealing with anxiety clearly recalls the previous discussion about how anxiety clouds accurate perception, rendering the “patient” irrational. Melinda discussed her positive experiences with a therapist who tried to help her learn how to be more “objective.”

It's very grounding to have [my therapist] say, “Well, let's step back from the anxiety for a few minutes. Let's step back from this and see what is real and what is not real and what you can do about it.” That's been really helpful.

Melinda found her therapist's re-definition of what was “real” and “not real” to be very useful in seeing past anxiety. Again and again interviewees reported a deep distrust for their own experiences of the world and a continued reliance on *others* to make sense of it for them.

Importantly, interviewees did not only rely on medical professionals to help them assess their interpretations of everyday life; they also relied on significant others (especially romantic partners) to help them distinguish between rational and irrational thinking, feeling, and behavior. Accordingly, significant others in the lives of the interviewees (beyond medical professionals) were given substantial definitional power and, as such, the content and nature of these social relationships were significantly altered.

For instance, Roger explained that when he would start to worry about everyday

problems, his wife would say things like, “Come on Roger, this is what you have,” meaning that there isn't *really* a problem, it's just that he *has* anxiety, which does not allow him to accurately discern between normal and threatening events. Throughout the interview, Roger repeated, again and again, “It's what I have” when describing irrational thoughts and behavior that he attributed to anxiety. Any and all marginally irrational thoughts were tethered to “what Roger has”: an anxiety disorder. Roger continually turned to his wife to assess his perceptions of the world. When he thought he might be over-reacting to stressors, he would ask his wife for her (non-disordered) opinion. He explained, “I have to ask her about ten times for me to be convinced that she is right. I know she is right, but I'm not convinced. When she convinces me, I'm able to let it go.” Roger turned to his wife to convince him that his assessment of a given situation was wrong and to help correct his irrational thinking. Roger had to force himself to perceive his experiences differently, and, to that end, he became dependent on his wife's “non-disordered” interpretations.

Likewise, when I asked Penny if her husband was helpful while she was having a panic attack, she responded,

Oh yes! He is very good with that. He's a scientist you know. He will ask me, “But is that probable?” [Is it probable that what she is worrying about will become reality?]. And he is like, “Okay, *that doesn't make any sense* because of this, this, and this.” He is very good at, “Don't worry about it; it's not going to happen.” He will say things to me like, “For that thing to happen, this would have to happen, this would have to happen, and this would have to happen.” It's like an experiment to him, a scientific experiment. “All of these things would have to happen before, and that's not going to happen. And do you think all of those things are likely to happen? So what are you worried about?”

Like James, Penny relied on her husband to be objective for her. She went as far as to compare his rational thinking to a science experiment. Since her husband does not have

an anxiety disorder, his view of the world was imagined to be (like a science experiment presumably is) value-free, objective, and rational. Embedded in the interviewees' turning to significant others to gauge their assessments of the world is the pervasiveness of the distrust anxiety disorder diagnoses instill in the "patient."

In the interviews, without the interpretive assistance of "non-disordered" significant others, some of interviewees often struggled to delineate between rational, logical fears and anxiety-disorder-induced fear. For instance, Angie explained that her husband lost his job about a year ago and has only recently found a new but lower-paying job, and she also lamented that her own job as a teacher's aide was on a year-to-year contract. Money was tight and neither had much in the way of job security. After a lengthy discussion about her concerns about losing her job the following year and not being able to pay their bills, I asked, "Do you think it is likely that you will lose your job next year?" Angie replied,

I don't know. I think it is the anxiety. If I take a step back and look at the way things are going, I've gotten very good feedback from my boss and from other people I'm working with. I've been allowed to move on to the next step and run some meetings. I've been able to write reports. They talked to me about coming back next year. It's really completely ridiculous to worry about. Unless they completely blindside me, which I don't think is going to happen, I've gotten a lot of positive feedback. It just blows up in my head. I don't think it's realistic for me to worry about based on the conversations I have had. I don't think it's realistic to worry about, but I do.

Angie was not confident about how to categorize these thoughts and feelings. Were they rational worries or disordered anxiety? They certainly could be construed as reasonable responses to financial uncertainty. The tension between Angie's *felt* anxiety and her objective, detached assessment of her job security were quite evident. Angie called her worries "ridiculous"; she, then, quickly amended that by suggesting that her employer

could “blindside” her; but, in the end, she concluded that would not happen and her job security was not “realistic to worry about.” Although there was a clear struggle for the interpretive power between rational fear and irrational anxiety, the anxiety disorder prevailed. In the end, legitimate fear about job uncertainty was transformed into irrational worry generated by an anxiety disorder.

While the distinction between rational fear and irrational anxiety was evident in most of the interviewees’ narratives, Penny among the few interviewees who explicitly reflected on and challenged this thorny distinction. She explained,

I probably need to spend more time working on the daily anxiety, decompressing, but I've been so busy working on big issues. I know my mother has daily anxiety that she self-treats; she takes a hot bath every day. [Pause] My parents are both seriously ill, too. There is some legitimate anxiety going on. And that's the other thing, *there is some difficulty separating out the legitimate anxiety*. There are things you *should* worry about. Both of your parents are on chemo; that's probably something you should worry about. You are not sure what job you are going to have next year; that's a genuine worry. It's not irrational to worry about that. So separating out, I think that has been helpful too, sort of allowing myself to worry about things that are legitimate, normal worries. And then, saying, “That's a realistic fear that you may not have a job next year. Okay, let's look at that.” It is not however realistic to think you passed out on the floor of your office and plagiarized, and you don't remember it. I think learning the distinction between the different kinds of anxiety that I present with has been something that has stayed with me. *It's a lot of work*.

Penny explicitly contrasts “irrational/disordered anxiety” with “legitimate/genuine anxiety.” For Penny, disordered anxiety included her original symptoms, like compulsive worry about impossible past events. On the other hand, legitimate worry represented concerns about things like losing one’s job or a parent being terminally ill. Still, Penny was clear that making that distinction, between legitimate and disordered fear, has not been easy and has been “a lot of work.”

Even while Penny described her attempts at delineating between rational and irrational fear, there were indications that the distinctions between the two remained unclear. For instance, when describing both types of anxiety, rational and irrational, she used the phrase, “The different kinds of anxiety *I present with.*” People do not “present with” non-pathologized, normative feelings. One would never say, “Last summer I presented with love”; rather, one might say “last summer I fell in love.” Instead, people “present with *symptoms.*” While Penny worked diligently to delineate between normal and pathological fear, it was evident that she still, unintentionally, framed “legitimate” fearful emotions as pathological. For all of the interviewees, an anxiety disorder diagnosis, to varying degrees, transformed what was once “legitimate worry” into “disordered fear” and complicated the distinction between the two.

Similarly, for many of the interviewees, there remained a tension between their subjective interpretation of their experiences of anxiety and panic as understandable and rational and general “objective” interpretations of their anxieties as pathological and irrational (as implied by the diagnosis). For instance, Skye provides a typical example of this subtle tension that weaved throughout the interviews.

I have this anxiety about people I care about dying. Every time I hang up the phone or say goodbye to someone, particularly my boyfriend, my mom, sister, and dad, I honestly feel it’s the last time I’ll talk to them. *I try to tell myself it’s an irrational fear, but it really isn’t, considering that we could all die at any time.* So I constantly feel the need to call and check in.

Skye made the fundamental and true observation that people die, sometimes unexpectedly. As such, it felt quite rational to her to take the extra care to be in close contact with loved ones. But, she also knew that this concern and worry-driven behavior was not acceptable to others. Thus, she expressed a tension about categorizing these

concerns as either a part of an anxiety disorder or a rational response. Here, Skye exemplifies how an anxiety disorder diagnosis can transform “rational” fear into pathology, while also pointing to the difficulty and, sometimes, the incompleteness of that transformation.

The basic act of formally naming an emotion “disordered” complicated the experience of that emotion. Fear became a volatile category. Any expression of fear, worry, or apprehension either demanded a painstaking examination by the interviewee and their significant others or it was quickly subsumed by the anxiety disorder category. After an anxiety disorder diagnosis, any and all variants of fear became problematic and demanded the critical attention of the interviewees.

For the interviewees, the anxiety disorder diagnosis and the continued affirmation by significant others that their perceptions were invalid gave way to a profound distrust in their own worldviews. Diagnosis reshaped the interviewees’ conceptions of their selves; the interviewees became “irrational” selves that were not to be trusted to accurately evaluate everyday experiences. Diagnosis also changed social relationships; interviewees became increasingly dependent on important people in their lives to help them assess their perceptions, feelings, and behaviors. In turn, significant others, by not validating the experiences of the interviewees, confirmed, again and again, the meaning of diagnosis. That is, they affirmed that the interviewees were consistently unable to accurately and rationally perceive the world. Slowly, the suggestion of irrationality embedded in diagnosis infiltrated the interviewees’ senses of self, perception, and their intimate social relationships.

Conrad and Schneider (1980) assert that great power is derived from and much of social control is exerted by being able to define behavior. In the case of diagnosis, this power is primarily located among the medical professionals and within the medical institutions (Conrad and Schneider 1980). At the same time, the meanings and implications of diagnoses (and other definitions of behavior) are not fully contained by any profession or institution. While medical institutions and medical professionals certainly derive much power and exert much social control through diagnosis, that power and the implications of that power extend into the social world, often in ways (presumably) not intended (Merton 1936).

For instance, while irrationality and abnormality were implicitly and explicitly embedded in the diagnostic category “anxiety disorder,” the insidious nature of those meaning in the lives of “the patient” were not intended in the diagnosis. Rather, through the support of (often well-intentioned) significant others, the name “anxiety disorder” came to implicate the entire life world of the labeled person. While the diagnosis was intended to help bring the “patient” back to a “rational” state, it simultaneously introduced another source pervasive self-doubt. Unfortunately, one of the unintended consequences of an “anxiety disorder” diagnosis, was that the label delegitimized a wider range of the interviewees’ perceptions and pressed them to further question their ability to be rational, to accurately assess the world around them, and to delineate between the components of an anxiety disorder and those of “normal” perception (see Conrad 1992:223 on the consequences of medicalization).

Diagnosis Everything: The Slow Creep of Disorder

This current section unquestionably represents a study of medicalization, although there are two important caveats to be made. First, most medicalization theory and research examine the institutional naming of disorder (like in the DSM) or the initial diagnosis of disorder at the individual level. In contrast, this section explicates how after diagnosis, in the life worlds of the interviewees, more and more of “everyday experiences” were enveloped by the explanatory power of an “anxiety disorder” (Zola 1983:295). In other words, I shift from the focus in much medicalization literature—on how medical institutions and professionals medicalize experience—to a focus on how individuals, after diagnosis, continue to medicalize their own experiences (in collaboration with significant others).

The second clarification is one directly addressed by medical sociologist Peter Conrad, which is: what exactly is meant by medicalization? Medicalization literally means “to make medical” (Conrad 1992:210), but the question becomes, “to make *what* medical?” Most medicalization theory focuses on behaviors and experiences that are conceptualized as “originally” *non*medical issues and documents how they *become* medical issues (Conrad 1992:211). In this type of work, the phenomenon of medicalization itself is problematized, based on the premise that newly medicalized experiences and behaviors *should not* be defined as medical issues.

Although this is the popular trend in medicalization literature, it is not an inherent or necessary approach (Conrad 1992:212). One can also take the approach that the “natural state” of any behavior is either unknowable or neutral. Accordingly, this approach resists taking a moral stance on how behavior and experience *should be*

defined, which avoids the same definitional power-grab that medical practitioners and the DSM authors have been charged with.

In that line of thought, I actively try *not* to consider or evaluate whether the interviewees' "medicalized" (or non-medicalized) interpretations of their experiences are objectively "accurate." This represents what phenomenologists and social constructionists call "bracketing," which is a "methodological device of phenomenological inquiry consisting in a deliberate effort to set all ontological judgments about the 'nature' and 'essence' about things, events, etc., aside. Thereby, the 'reality' of things and events is not denied but 'put in brackets.'" (Schütz 1970:316 – 317). Accordingly, the objective of this section is *not* to argue that interviewees wrongly attributed "normal" experience to anxiety after diagnosis, but rather to explore how experience and behavior are defined by people, how that changes over time, and the implications of those changes in the lives of people. These aims follow from Goffman's description of a symbolic interactionist approach to reality; he writes, "We will want to know what kind of impression of reality can shatter the fostered impression of reality, and what reality is can be left to other students" (Goffman 1990:66; see also Turner 1992:105).

In chapter four, I showed how, even before diagnosis, many of the interviewees interpreted some of their fear-driven behavior as irrational, like being unable to drive to work, walk down the street, or go out to dinner with an old friend. These types of activities were understood, in the common stock of knowledge, to be safe everyday practices. Subsequently, there was a profound rupture between the interviewees' experiences and general expectations, and this suggested pathology to the interviewees.

In this current section, I discuss how, after diagnosis, smaller and smaller ruptures between experience and expectation were defined as symptoms of anxiety. Specifically, after diagnosis, interviewees came to define increasingly mild distress and (once thought to be) proportionate responses to major life events as indicators of an anxiety disorder. In short, after diagnosis (and even when the symptoms of anxiety had waned), interviewees continued to name their (previously defined) “normal” experiences “anxiety.”

The medical diagnosis altered what experiences were categorized as “normal” or “abnormal.” As Goffman notes, once a person is stigmatized or labeled “minor failings or incidental impropriety may... be interpreted as a directed expression of his stigmatized differentness.” (Goffman 1986:15). In other words, after diagnosis a wider variety of experiences are explained by diagnostic categories and are subsequently viewed as medical issues. Importantly, both the marked person and the people observing him or her (doctors, romantic partners, co-workers, and so on) come to re-interpret the stigmatized person’s actions through the lens of stigma. That is, the person with, for instance, an anxiety disorder, actually comes to see *himself* and *his own actions* in terms of the disorder. Scheff (1999) notices a more broad and general (but analogous) propensity among psychiatrists to be especially sensitive to indications of mental illness and to see mental illness where others may not (pgs. 101-110), due to their professional knowledge about and experience with mental illness. Both of these observed tendencies were expressed by the interviewees. That is, as the interviewees started to see themselves through the lens of disorder and as they learned more about the signs and symptoms of anxiety, they interpreted a wider and wider range of their own experiences, feelings, and behaviors as disordered.

Responses to “Real Problems” become “Disorder”

When describing episodes of anxiety after diagnosis, interviewees increasingly narrated fundamentally reasonable responses to events that would conventionally be thought to provoke anxiety in terms of an anxiety disorder. After diagnosis, anxiety was increasingly employed to help explain and neutralize distressing life events. Quite often, distressing events were described as “triggers” that set off an anxiety disorder. This description, arguably, represents a medicalized version of a socially appropriate response to major life events. In short, an anxiety disorder diagnosis changed how interviewees made sense of (previously defined) normal responses to distressing events. For instance, before diagnosis interviewees described anxiety-related symptoms in response to mundane objects (like, taking a walk, being alone for more than a few minutes at a time, and going to a local park), but after diagnosis the interviewees increasingly described anxiety-related symptoms in response to major life events (like the death of a loved one, losing a job, and being unable to financially support their families).

For instance, after diagnosis and treatment, Blair still experienced severe panic attacks on a weekly basis; unfortunately, that much stayed the same. What did change after diagnosis was that Blair began to categorize (previously defined) typical, normative worry as a component of an anxiety disorder. Blair was a single mother with two children, one with special needs, and, while they were both still under five years old, she lost her job due to the symptoms of her anxiety disorder. She applied for social security disability and was approved. But, she explained, they were unable to give her the “lump sum” of money for two months. She continued, “Pretty much for almost two months I was supposed to live off of \$62, because that’s all I had. Things like that, like, send *my*

anxiety through the roof.” Blair had to figure out how to survive on \$62 dollars for two months, supporting two children. For Blair, after diagnosis, “anxiety” took the place of a reasonable fear-response to an incredibly stressful situation. Arguably, if a patient presented with concentrated worry about having no money and losing one’s job while trying to support two children, it would not or, some will argue, should not (see Horwitz and Wakefield 2007) lead to an anxiety disorder diagnosis. But, since Blair already *had* the diagnosis, a more broad range of experiences were subsequently engulfed by the “anxiety disorder” category.

Another interviewee Andrea described similar classifications of her experiences. Even though she no longer experienced severe panic attacks, she still categorized her experiences of worry as indications of a panic disorder. She described her family’s precarious financial position as a trigger for anxiety.

There is a lot of anxiety with my husband's employment... we had a couple of really bad years. I feel that it is finally getting better, but I'm scared it's going to get bad again. There were a couple of years, we were poverty level, and it was difficult.... So, what triggers the anxiety is finances. Are we going to be able to pay rent? A couple of times during the winter my husband had to go out and get oil for our [heater] because we ran out of heating oil. I don't want to be in that spot again. That's a really big trigger. If we're ever in that spot again, I don't want to go through it.

Again and again, interviewees cited financial strain as a “trigger” for anxiety. Arguably, it is common, typical, and normal—within this specific cultural context—to respond to an inability to pay rent or afford heat during a New England winter with worry and anxiety. But, after diagnosis, anxiety provoked by a stressful event or situation became a confirmation of an anxiety disorder rather than a legitimate response to a real problem.

A key critical insight offered by medicalization research is that medicalization individualizes social problems, which was repeatedly evidenced in the interviewees’

narratives. Conrad noted that, as a society, “We tend to look for causes and solutions to complex social problems in the individual rather than in the social system” (Conrad 1975:19). The same is true when it comes to the medicalization of experience. Conrad continues, “Rather than seeing certain behavior as symptomatic of problems in the social system, the medical perspective focuses on the individual diagnosing and treating the illness, generally ignoring the social situation” (Conrad 1975:19). Likewise, Scheper-Hughes asserts that “a sick body implicates no one. Such is the special privilege of sickness as a *neutral* social role, its exceptive status. In sickness there is (ideally) no blame, no guilt, no responsibility... society and its ‘sickening’ social relations are gotten off the hook” (Nancy Scheper-Hughes 1993:174).

In that same way, anxiety, fear, and distress grounded in structural problems were individualized through an anxiety disorder diagnosis. Interviewees reported: being forced to quit their jobs because they could no longer work at their previous pace and intensity, being unable to support their families’ basic needs, struggling to find employment each year, and finding social security disability insurance to be an insufficient support. In response to these significant stressors, interviewees experienced and expressed worry, but, in the end, the interviewees and their significant others delegitimated and discounted these (once rational) concerns by re-naming them symptoms of an anxiety disorder. Worries, provoked by external socio-economic conditions, were transformed into indicators of individual pathology rather than objective social problems. These data suggest that the individualization of social problems not only occurs at diagnosis but extends into the ongoing illness experience that is re-created in ongoing and informal micro-level relationships.

Mild Distress becomes Disordered

In addition to distress in response to major life events, increasingly milder distress was consumed by the anxiety disorder diagnosis. That is, after diagnosis, interviewees described mild distress like “feeling awkward” or “kind of uncomfortable” in terms of symptoms of an anxiety disorder. These categorizations stood in stark contrast with their symptoms *before diagnosis*, like being wholly unable to talk, eat, or walk accompanied by other symptoms like vomiting and uncontrollable tremors. After diagnosis, anxiety came to encompass more and more mild distress, which, is arguably a normal component of life within this specific social context. Certainly, this expansion in the meaning and reach of “anxiety disorder” can be partly explained by the fear that these more mild forms of distress will give way full-blown panic attacks. While the reason for this expansion is understandable, it nonetheless creates and re-creates a more powerful and consuming diagnosis. Through this process, anxiety (and, thus, illness) comes to explain more and more of the patient’s everyday life.

For instance, Andrea described her apprehension about being in crowds and meeting new people. She described some of her experiences of anxiety as a “general tension ... [sometimes caused by] being around crowds of people. I do okay with small groups of people. But if I have to mingle in a large crowd or something I don't do well.” Apprehensions about mingling at a party were wholly distinct from the reasons that Andrea originally sought treatment. Rather, she initially sought treatment after losing control of her body, intermittently losing the ability to speak, and eventually not being able to leave her home. It was only after diagnosis that Andrea, much like the other

interviewees, extended to explanatory power of the diagnosis to include more minor distress.

Likewise, Lauren categorized feeling uncomfortable at parties as a symptom of anxiety. After describing a variety of interventions she had tried in attempts to treat and manage anxiety, I asked Lauren what her symptoms were like now compared to how they were a few years ago. She responded,

Yeah, [I'm better] compared to the past. I feel better but, like, I am more anxious than most in general. In social situations right now I will feel uncomfortable, often in large crowds and with people. I don't know.... I could just be at a party and I would just feel really uncomfortable the whole time. I just don't know what to say. I will either avoid it or feel really uncomfortable and want to leave.

Lauren came to view feeling “uncomfortable” at a party and wanting to leave as a symptom of anxiety. In much the same way, she described an awkward encounter with an old friend.

And there's this girl I knew from my high school and once we had a fight or something. She's in this organization [that I am a member of] and I didn't want to [work] with her. It just brought back bad memories that just really made me anxious when I saw her.

Still, Lauren continued to participate in the organization and to interact with this former friend. Some of what Lauren, after diagnosis, came to categorize as “anxiety” had no obvious implications for how she led her life; she described going out to parties and continued to volunteer with her former friend. While Lauren still experienced some of the same sort of anxiety she felt before diagnosis—like heart palpitations, night terrors, and insomnia—she broadened the meaning of “anxiety disorder” to include a much wider range of experiences, like feeling “uncomfortable” and awkward.

Overall, an anxiety disorder diagnosis increasingly explained normative responses to very distressing events and milder everyday distress. Diagnosis—long after the doctor declared the diagnosis—encroached on more and more of the interviewees’ everyday lives. That is, medicalization happened well beyond the walls of the doctor’s office; it continued in the everyday worlds of the patients. Importantly, this expansion served to neutralize and individualize social problems (like unemployment) and to expand the reach of stigma to increasingly normal components of life experience.

Conclusion

The implications of diagnosis for the interviewees were several. At the most basic level, diagnosis gave anxiety a tangible form and moved it to the center of experience. Before diagnosis, anxiety and sensations were interpreted as *consequences* of external forces, but after diagnosis, an “anxiety disorder” became the explanation for a wide range of distressing physical, emotional, and mental experiences. This shift is especially important since it places anxiety disorder in an agential position, ideally poised to reshape the interviewees’ perceptions and experiences.

One significant implication of diagnosis was that it confirmed that the interviewees’ world views were “irrational” and “inaccurate.” As modified labeling theorists posit, formal labels—like an “anxiety disorder” diagnosis—are both pervasive and persistent. In other words, this formal label “anxiety disorder” transformed an inkling that “something was wrong” into widespread confirmation that their perceptions were fatally flawed. As a consequence, interviewees developed a deep distrust for their own perceptions and assessments of their own experiences.

As a tactic to cope with this pervasive self-doubt, interviewees turned to significant others (most often spouses, parents, and therapists) to help them “accurately” interpret the “rationality” of their perceptions and responses. This represents a significant transference of power. While the interviewees explicitly gave substantial interpretive power to their medical provider by asking for a diagnosis, they also, unintentionally, handed over interpretive power to the other actors in their social worlds. Not only did the doctors and the diagnoses delineate for the interviewees’ between normal and abnormal experience; the interviewees’ family and friends received increased definitional power as the patient came to distrust their own perceptions.

As well-intentioned as the doctors, therapists, families, and friends may have been, diagnosis facilitated a pervasive medicalization of experience. With anxiety as a powerful explanatory and causal object, significant others increasingly defining experience as symptoms of anxiety, and interviewees growing accustomed to naming their experiences disordered, more and more of their life worlds were co-opted by the anxiety disorder diagnosis. The explanatory power of an anxiety disorder continued to expand after diagnosis, consuming previously defined “reasonable” responses to stressful events and increasingly mild mental, emotional, and physical distress.

The implications of this diagnostic expansion are many. First, this expansion represents the medicalization of individual responses to social problems. Specifically, the anxiety disorder diagnosis (often long after diagnosis) came to neutralize the unjust nature of social problems like unemployment, underemployment, and the lack of social support for mental health needs (see Conrad 1975; Scheper-Hughes 1993). Interviewees

interpreted their distress about unemployment as symptoms of anxiety instead of legitimate worry (or even anger) about sometimes dire financial situations.

Second, this expansion provides insight into the chronicity²³ and the variation of anxiety disorders over time. While the objective diagnostic criteria of an anxiety disorder does not (often) change for the researcher or physician, the subjective meaning of the diagnosis can shift dramatically for the patient over time. Accordingly, an “anxiety disorder” at diagnosis and an “anxiety disorder” ten years later may actually have little in common. As such, it is important to carefully consider how illness experiences and expressions transform over time because: patients may be taking strong medications with serious side effects to treat far more mild symptoms in the years after diagnosis, there may be more effective treatments for the type of distress described later in the illness narratives, and prevalence rates—which direct medical and research funding—may be overestimated.

Third, this diagnostic expansion is significant for medical sociologists. Specifically, I found that while medical diagnosis was a powerful moment in the lives of the interviewees, some of the most dynamic social action resided outside of the clinic and well after diagnosis, in the relationships between the interviewees and their significant others (especially their husbands, wives, parents, and children). In the interviewees’ everyday life and within their personal relationships, the meanings of an anxiety disorder became deeply integrated into how they viewed themselves and the world. As this happened, what “anxiety” was able to explain expanded dramatically. These findings suggest that medicalization extended and largely occurred well beyond the medical

²³ Anxiety is widely considered a chronic disorder; depending on the measures and sample, about half of individuals diagnosed an anxiety disorder demonstrate a chronic course of illness (Durham et al. 2003; Bruce et al. 2005).

researchers' laboratories, the DSM's pages, and the physicians' offices; medicalization infiltrated and flourished in the social networks of the patient and expanded for *years* after the initial diagnosis. In short, the everyday worlds of patients—long after diagnosis—represent a fruitful, yet understudied, site of medicalization.

Lastly, these interviews suggest that the experiences of disorder are qualitatively different at various moments in the life of the interviewee, which provides a word of caution to social scientists studying health and illness. One section of an illness narrative can provide potent evidence that the diagnosis and treatment of a disorder was a sound and prudent decision based on a good match between symptoms, individual distress, and the diagnostic category, while other portions of the same narrative can suggest that diagnosis and treatment were wholly unfounded and signal overmedicalization (similar to description in portions of this chapter). Likewise, there is potential for the researcher who is eager to legitimize a disorder to pay closer attention to those moments when the symptoms are most intense, while there is a parallel opportunity for the researcher who is interested in discovering that a disorder is overmedicalized to note those moments when the symptoms are less intense. A balanced and fair study of medicalization requires careful study across the entire illness narratives in order to better capture variation in the illness experience and expression over time.

After years of experiencing anxiety and years of being socialized into what anxiety means (namely irrationality), interviewees indicated a bifurcation of experience. On one hand, their experiences made sense to them; for instance, they *knew* why they are not able to drive to the neighboring town. On the other hand, they understood that their experiences and behavior were deemed irrational; for instance, they *knew* that there is

something “wrong” with not being able to drive to the neighboring towns. The interviewees described their experience of this bifurcation in at least two specific ways. First, they found it increasingly difficult to distinguish between these two logics. That is, they struggled to *know*, at any given time, if their behaviors and perceptions were “normal” or “abnormal.” Second, they allowed anxiety to explain increasingly more of their everyday experience. More and more of their everyday experience become signs of pathology. These unintended consequences of diagnosis were far from ideal; the former caused the interviewees distress and confusion and the latter facilitated the expansion of stigma into other, previously untouched, areas of their lives.

While diagnosis served an important sense-making tool for the interviewees, it also posed its own challenges in regards to stigma, identity, and meaning-making. While an anxiety disorder diagnosis helped the interviewees organize extremely distressing experience, it also simultaneously identified and confirmed irrationality and challenged their self concepts, altered their social relationships and placed them in a more dependent position in those relationships, and infiltrated other normative experiences, introducing stigma to previously uncontaminated thoughts, feelings, and behaviors.

CHAPTER EIGHT

THE BODY-CATEGORY DIALECTIC

This chapter continues the analysis and discussion of the interviewees' experiences of anxiety after diagnosis. While the previous chapter focused on how, over time, an anxiety disorder diagnosis encompassed more and more mundane and less distressing experience, this chapter describes how diagnosis came to explain more and more disparate, intense, and distressing *physical* sensation. I found that this particular expansion was propelled by a dialectical process between the body and the diagnostic category.

With the focus on the body in this chapter, a brief discussion of the body is in order, and any discussion of the physical body in the social sciences demands a discussion of mind – body dualisms and the “rationalistic bias” in the social sciences (Turner 1992:23). Dating back to Rene Descartes, in the western world, the mind has been conceptualized as distinct from and superior to the body. This distinction (and hierarchy), in theory and in practice, is what is referred to as a mind – body dualism. Accordingly, academic disciplines have largely focused on either the mind *or* the body, with disciplines like biology studying the body and disciplines like sociology focusing on the mind. Further, sociologists avoid analyses that address the physical body and remain

wary of essentializing and reifying the physical body, in large part, because previous reductionist scholarship—especially on gender and race—has provided support for practices like eugenics, segregation, and formal and informal discrimination (Gould 1996). Accordingly and understandably, sociology—like many other social sciences—has developed what Elizabeth Spelman (1988) refers to as somatophobia or a “fear of the body” (pg. 31), tending toward theorizing “a disembodied rational agent” (Turner 1992:23).

Nonetheless, this bias against studying the physical body has been debated, critiqued, and addressed by many academics, especially by phenomenologists and feminist scholars (see Davis 2007; Grosz 1994; Martin 2001; Merleau-Ponty 2002; Turner 1992). I situate my own research within a diversity of social science literature that emphasizes the importance of the physical body in understanding social experience.²⁴ Despite the range of work on the topic, the specter of essentialism looms large. One way to address the risk of essentialism and dualism in body-oriented research is to better theorize the body, although, of course, how to theorize the body is hotly contested (Grosz 1994). In this chapter, I draw heavily on theories of the body offered by phenomenologists and social constructionists, who view the body as multiple in nature and simultaneously organic and social, to theorize the body (Turner 1992). There are three specific ways that these theorists have framed bodies that I have found to be especially useful in this study. For one, every person *is* a body, which indicates that the body is a part of the self. In other words, the physical body is a core and essential component of lived experience and selfhood. Also, every person *has* a body, which

²⁴ For a sense of the wide range of social scientific thought that tends to the physical body, see (Davis 2007; Scheper-Hughes and Lock 1987; Pinder 1995; Freund 1990; Zola 1991; Frank 1990; Featherstone, Hepworth, and Turner 1991; Crossley 2001; Grosz 1994)

means that the body is also experienced as an object or an instrument that the subject (the person) can reflect on, act on, and act with. Lastly, the body is an actor, which suggests that the body, as an organic entity, can act on the person and in the social world. For instance, Alfred Schutz (1970) describes a writer that becomes hungry and tired as he works at his typewriter, and Schutz explains that, “Eventually, the physical states of the body intrude into his consciousness; he will stop and rest, or eat” (p. 43). All three forms of the body are present in this simple illustration; the embodied skill of typing is a part of the persons’ identity as a writer (the person is the body), the person acts on the body, making it sit, look, and type (the person has the body, in this case as an instrument), and the body, as an organic entity, presses the person to act—pressing the writer to go find food or to lie down for a nap (see also Berger and Luckmann 1967:180).

While the last two forms of the body suggest a dualism, the three forms of body occur in tandem, which give way to a unified bodily experience. At any given moment, we are our bodies, we manage our bodies, and our bodies move us to action. Importantly, these processes and outcomes vary widely across cultures, over time, and between types of people. That is, while still organic, bodies are deeply social objects, experiences, and outcomes. Throughout this chapter, I will talk about the body in these phenomenological terms, with a particular emphasis on *having a body* and the *body as actor*.

One objective of this chapter is to contribute to what Bryan Turner calls a “foundationalist framework,” which is “concerned to understand the body as lived experience” and “to understand how the biological conditions of existence impinge upon the everyday life” (Turner 1992:48). In the interviews, I found that the physical body (as

biologic actor) not only impinged on everyday life, but also challenged and changed how the interviewees thought about and experienced “anxiety.”

This chapter is organized around three interrelated arguments. First, I briefly reflect on the original function of diagnosis in the lived experience of the interviewees. Specifically, diagnosis offered the interviewees an effective tool to make sense of and manage bodily distress. This reflection provides a basic framework for the remainder of the chapter, in which I discuss how anxiety disorder diagnoses come to explain more and more *intense* and *physical* experiences. Accordingly, in the next section, I explore the dialectic between the body (specifically as an actor and as an object) and the diagnostic category “anxiety disorder” after diagnosis. Specifically, I discuss how the body and the anxiety disorder diagnosis evolved together, encompassing more and more disparate, intense, and distressing physical experience. In the last section, I describe the uncertain boundaries between the physical body and an anxiety disorder diagnosis. This section recounts moments and periods of time *after diagnosis* when the interviewees were not certain whether their physical experiences were a component of anxiety or an indication of more serious illness. Overall, this chapter addresses the intersection of the physical body and medical diagnosis and outlines some of the unintended consequences of that meeting.

Diagnosis: Silencing, Ordering, and Managing Bodies

As I have suggested in previous chapters, having a name for physical experiences can lessen fearful responses to those sensations. As Ian Hacking asserted, new names (categories, diagnoses, and so on) create “new ways for people to be” (Hacking

1999:161). In this case, changing the name of distress had the potential to change the meanings of those sensations and the range of responses to it. In this section, I discuss one specific way that diagnosis changed how interviewees managed their physical experiences of anxiety after diagnosis. That is, they learned to *distrust* and *ignore* distressing sensation in their bodies.

Distrust in the physical body is not a new phenomenon. Susan Bordo(1987) in her book *Flight to the Objective* describes how Rene Descartes signaled the most clear and decisive break from the physical body. His infamous text *Meditations* (Descartes 2008) provides an extensive phenomenology of the mind that deeply discredited the intellectual and practical value of the physical body and of sense perception (see Bordo 1987). That is, he argued that the senses deceive and, as such, they must be overcome through concerted mental effort in order to access truth. Bordo asserts that “it is hard to overestimate... the crisis in intellectual confidence that must have occurred” after Descartes and others (like Galileo) created a rift between sensory perception and accurate apprehension (Bordo 1987:33). She writes,

The loss of faith in the senses signals the recognition of a breach between body and world that had not existed for the medievals, for whom the body was regarded as a quite dependable epistemological guide. For Descartes..., what one smells, sees, hears, tastes, and touches can no longer be taken as a bridge to the world. That naïve connection was snapped decisively (p. 33).

Distrust in the body and in the basic senses, offered by Descartes, have been well integrated into our culture. In particular, the medical sciences flourish in a context in which people do not trust their own bodily experiences. In this study, I find that an anxiety disorder diagnosis fostered an extension of this distrust of the physical body. Before diagnosis, the signs that the body offered (in the form of physical sensations)

served as trustworthy indicators of: health or illness, safety or danger. After the anxiety disorder diagnosis, interviewees reported learning to distrust those indicators, which gave way to new ways of interacting with their bodies, namely, ignoring them. For instance, Lori explained how diagnosis made her physical symptoms less scary.

The fear has absolutely lessened [after diagnosis]. Knowing what it is I can say, “Oh, I’m having a panic attack. I know I’m having a panic attack. It will go away. I’m not going to faint. You are okay.” And it goes away. Where before I didn’t know what the heck was happening. I thought I was about to die. Definitely, knowing what it is helps. Knowing “you’re not gonna faint” and “you’re okay” definitely has helped.

Naming physical sensation simultaneously made distressing sensations more manageable and silenced the previously held meanings of those sensations. Specifically, for Lori, feeling like she was going to faint no longer served as a “real” indication that she might actually faint. Naming experience “anxiety” disconnected sensations (like dizziness) from consequences (like fainting). This represents a significant shift in how the interviewees interacted with their bodies after diagnosis. Diagnosis allowed them to effectively ignore, previously important, bodily signals.

Likewise, Carly also experienced dizziness and depersonalization before diagnosis, and she worried that she may have, among other illnesses, a brain tumor. But, after diagnosis, she was better able to ignore those sensations and, even, sometimes enjoy them by “kind of letting the high feeling come, I just pretend I’m baked [“high”] and go with the flow.” For Carly, diagnosis facilitated a different and more manageable interpretation of physical sensation.

Similarly, Marcy explained that after diagnosis and with some concerted effort, she “can [now] use rational observation to gauge the danger of a situation rather than [relying on] the thudding adrenaline.” This approach to the world is precisely what

Descartes called for: using reason to overcome misleading sensations in the body. In effect, Marcy silenced the adrenaline in her body, which is conventionally a telltale sign of fear and potential danger. A once powerful indicator of serious danger and an important call to action was pushed to the perceptual background and purposefully ignored. Among the interviewees, anxiety disorders fostered a general distrust for old interpretations of their bodies, which prompted them to try to ignore or to reformulate bodily sensations.

The powerful therapeutic function of diagnosis—as a sense making tool—provides the insight into how diagnosis continues to interact with the body well after diagnosis. Diagnosis took disparate physical sensations—sometimes experienced as indications of threatening conditions (like heart attacks, epilepsy, and anaphylactic shock)—and reordered them into medically benign symptoms of an “anxiety disorder.” Accordingly, after diagnosis, distress in the body was—to a large extent—neutralized. Re-naming distressing physical sensation made coping with the very same physical sensations profoundly easier for the interviewees. A similar process emerged later in the interviewees’ narratives: new and sometimes more distressing sensations emerged *well after diagnosis* and the anxiety disorder diagnosis expanded, encompassing those sensations and neutralizing some of their deleterious effects on the interviewee. The intended function of an anxiety disorder diagnosis—to help the patient make sense of their distressing experiences—continued, as an unintended consequence, for *years* after diagnosis.

After Diagnosis: Encompassing more and more Physical Sensation

In this section, I argue that well after diagnosis, though a dialectical process, the interviewees learned to experience increasingly more of distressing physical sensation as part of an anxiety disorder. To theoretically ground this main finding, I draw on work from Howard Becker (1997), Ian Hacking (1999), and Michel Foucault (2003). Specifically, Becker demonstrates how people re-learn to experience their bodies, Hacking describes a macro-level dialectical process between people and categories, and Foucault describes the slippage between local experiences of the body and general medical nosology (diagnostic categories). In this section, I discuss a dialectical process between the body and the diagnostic category through which people learn to interpret and thus experience their bodies differently. I find that there is a synergy between the body and the diagnosis that extends the explanatory potential of the diagnostic category to increasingly more physical experience, which, again, neutralizes (ever more) distress in the body.

Howard Becker (1997), in a study of marijuana users, makes a provocative argument that seemingly objective physical experiences (in this case, getting high) are, actually, deeply social in nature. In this interview-based study, he finds that new marijuana users *learn* to experience the physical effects of marijuana. That is, he finds that the effects of marijuana are not given, obvious, or objective, but, rather, the new user had to be socialized into appropriately experiencing marijuana use. Specifically, the new user had to learn to mechanically produce the effects of marijuana, to identify the specific effects of marijuana (as distinguished from other sensations), and to interpret those effects as consequences of marijuana use.

In the previous section, I argued that diagnosis helped the interviewees learn to experience physical sensation as a component of an “anxiety disorder.” Interviewees learned to identify the effects of an anxiety disorder and to see those effects as consequences of the disorder. For instance, Jill learned to identify the sensation of “adrenaline rushes” and to attribute them to an anxiety disorder. Importantly, she had to learn that the adrenaline rushes were *not* a sign of danger but, rather, a sign of her anxiety disorder. Likewise, Lori and Carly had to learn that dizziness was not an indication that they were about to pass out. Instead, they had to learn to interpret it as a medically benign symptom of anxiety. In short, the experience of an anxiety disorder was not obvious or given; rather, the interviewees *learned* to experience sensations as components of an anxiety disorder. This process continued explaining new and varied sensations well after diagnosis.

While it is beyond the scope of these data and this study to examine *how* the interviewees re-learned to experience their bodies, the dramatic changes in their reactions to distressing sensation after diagnosis (transformed, for instance, from rushing to the hospital to practicing deep breathing) suggest that how they experienced their bodies certainly did change and that diagnosis was a critical factor in that transformation. This current section demonstrates that this interpretive and experiential transformation extended well beyond the initial diagnosis. That is, years after diagnosis, interviewees reported that an anxiety disorder diagnosis continued to explain more new and surprising sensations in the body.

In this section, I also draw on philosopher Ian Hacking’s discussion of “dynamic nominalism” to frame the dialectic between the physical body and an anxiety disorder

diagnosis, which led to the expansion of what physical sensations and experiences were categorized as “anxiety” by the interviewees. While Hacking takes a decidedly more macro approach, his framework serves this study well. “Dynamic nominalism” presumes that “a kind of person came into being at the same time as the kind itself was being invented” (Hacking 1999:165). That is, categories and people emerge together. This represents a dialectical process—between labels and people—that “makes up people.” Hacking describes these two vectors: “One vector is labeling from above, from a community of experts who create a ‘reality’” and the other vector is “the autonomous behavior of the person so labeled, which pressing from below, [creates] a reality every expert must face” (Hacking 1999:168). In short, people’s behaviors (and identities) are shaped by communities of experts that offer labels, but the individuals who are labeled and placed in various categories, through their idiosyncratic behavior, simultaneously challenge and shape those very categories. Hacking argues that “the category and the people in it emerged hand in hand” (Hacking 1999:165); there is a synergy between official categories and individuals that give way to new types of people.

Something quite analogous happened among my interviewees: between the diagnostic categories and their physical bodies. The interviewees came to adopt and inhabit the professionally developed diagnostic category “anxiety disorder.” This category was fit to each of their own particular mental, emotional, and physical experiences at and before diagnosis. But, importantly, those experiences were in no way stagnant or fixed. And, as the body acted differently—producing altogether new discomforts and surprising signs—their own definitions of an “anxiety disorder” were challenged and often altered. Much like Hacking’s categories and people, the lived

experience of diagnosis and the physical body “emerged hand in hand” (Hacking 1999:165).

Categories (including medical diagnoses) can provide a valuable but, nonetheless, vague maps of bodily experience. Despite the rigor involved in the development of categories, the boundaries and contours of the category only loosely represent the lived reality of bodily experience. Further, the body is constantly changing, often leaving the map (or categories) increasingly ill-fitting. Similarly, Foucault writes that as illness is transformed into generalizable nosology (or diagnostic categories) the local is distorted by the general.

The organic space of the localization is really independent of the space of the nosological configuration: the second slips over the first, shifts its values in relation to it, and reflects them only at the price of an inverted projection (Foucault 2003:186).

Foucault suggests that general diagnostic categories are not necessarily (or even likely) connected to the local experiences they attempt to organize. While I make no specific claims about the distance between the general and the local, the interviews suggest that, as Foucault asserts, the diagnosis “slips over” the local experience (symptoms of anxiety), and “shifts in relation to it.” In other words, bodily experience and diagnosis interact in the life worlds of people, re-making physical experience and re-defining the diagnostic boundaries.

The redefinition of the body and the shifting of diagnostic boundaries were a never fully settled and remained an ongoing process. Well after their original diagnoses, interviewees reported learning that *more and more* of their physical experiences could be explained by the anxiety disorder. For instance, after diagnosis, Kalli developed several physical symptoms that she had not imagined could be caused by anxiety.

On my fingers and my hand, like, I ripped the skin off. I picked my skin. That's due to anxiety I guess. I have a rash all over my body from it, too... My hands, my fingers, the skin is ripped off my fingers. And my counselor said that is a part of the anxiety. I pick. I never did that before either. That's all new, too. And the skin rashes, I never had skin rashes before. I guess you can get skin rashes with anxiety, too.

Kalli's discussion pointed to the agential role of anxiety, a causal agent; here an anxiety disorder caused peeling skin and a rash. But, more to the point of this chapter, over a year after diagnosis, Kalli described a discrete expansion of what an anxiety disorder could *do*. Well after the original diagnosis, Kalli "discovers" that anxiety can explain even more of her physical experience. She continued,

I also have a lot of jaw pain. I come to find out this is all from this anxiety. I guess when you clench your teeth so much you cause a lot of jaw pain. I was having a lot of jaw pain, consistently. I can't tell you the pain. It was just ungodly. I went to a dentist, and *I was afraid that maybe there was an infection*. It was almost like my jaw was locked up. That's how bad my stress and anxiety was. I was biting down so much from the anxiety that he gave me muscle relaxers.

While jaw pain, at first, indicated to Kalli that she might have an infection, Kalli's dentist helped reformulate these sensations into a symptom of anxiety. Another interviewee, Ashley, similarly described breaking out in hives and her throat swelling, only to discover in an emergency room that her already diagnosed anxiety had caused these reactions.

Carly also described learning to view more and more of her physical experiences as components of an anxiety disorder after diagnosis. I provide a fairly lengthy discussion of Carly's narrative here for several reasons: it provides an exemplar of this diagnostic expansion, demonstrates the confusion and frustration inherent in this diagnostic expansion, and shows how social actors, bodies, and categories actively collaborate to extend what anxiety can *do*. To begin, several years after being diagnosed with an anxiety

disorder, Carly injured herself on a backpacking trip, which set off a chain reaction of events. She explained,

I went on a backpacking trip with two of my friends. I used to have a fairly fast hiking pace. We would plow up mountains in the winter. There was snow on the ground, and we would ski down slopes in our boots. They were running ahead of me, and I stopped to pick up my shirt. I hadn't been out hiking in a couple of weeks. I just started running down the mountain. I started losing control. I kept slipping and falling and falling. I tore my Sartorius. It's a hip flexor muscle; it connects your hip all the way down knee. It's really awkward because it's really hard to train... I stopped, twisted, and my backpack flipped. It was a second degree sprain, right where the muscle met the tendon. What made the incident worse was that I couldn't stop because I was in the woods. I popped aspirin because it was the only anti-inflammatory I had on me, which increases internal bleeding which—in a muscle—is really bad because it leads to hematomas and scarring. I was 25 miles from my car. I walked to my car. I lost range of motion. I just had to drag my leg.

This injury was devastating for Carly, not only because it was a serious injury, but also because it limited exercise, which was the main way that she managed her anxiety. She explained, “Exercise is foundational for me. If there is one key treatment I use for my anxiety, it's exercise and a healthy lifestyle.” The injury kept her from one major way that she managed her anxiety disorder. She continued,

I gave [my leg] a rest for a couple of weeks. After a month, most of it healed, but there was still a little pain. So, I went to my doctor, and there was tons of scar tissue. He had the accurate diagnosis, but he didn't give me the accurate treatment. He did the textbook treatments; when you have a second degree sprain ... you rest it six to eight weeks. The problem is I saw him a month after the injury and he said, “Six to eight weeks rest.” What should have happened, [since] the muscle is fully healed after three weeks, [was] maybe to give it one more week's rest, but the only thing that is going to make it better is stretching and non-weight-bearing exercise... I don't think he assessed my background as an athlete. I don't think he was aware how key exercise was to me. As I said, everything in my life revolved around physical activity: my job, my interests, my passions, my friends, my whole social life. He basically, without knowing it, took away my whole social foundation.

His treatment for the sprain effectively left Carly without the main way that she managed her anxiety and participated in both her professional and social life. She explained that, in combination with several stressful life events, the injury proved disastrous.

On other levels, I was in a really stressful point in my life. I left my boyfriend and thought it was for good. ... I was pulling a lot of hours at work. My job at the time was probably one of the most stressful jobs I worked... That and the stress of, "Oh my God, I'm not going to be able to do any exercise for eight weeks! What am I going to do? What am I going to do with my life?" ...

I basically just started drinking more. I had three or four beers at night. My stomach problems got worse with that. The buzz killed the anxiety, and it felt good. But, I would go into drunken rages, and after two months, I realized my drinking was also an issue for my stomach...

Then, I started getting this buckling knee pain, out of nowhere. My knees started buckling. I found out the knee pain is from anxiety... Some dude rear-ended my car and totaled it. I had no money, and I didn't have transportation. I was dealing with losing my boyfriend. I was about a month into losing the ability to do anything physically active. I had double shifts five days a week and I was having stomach problems. My knees just buckled. *They thought it was an overuse injury.* Five days later I got an ulcer, and that's when my summer started. Physical therapy didn't work. Other joints started to get pain too. My wrists got tight. My shoulders got really bad. *They thought—by the end of the summer—it was fibromyalgia,* until my doctor finally said, "It could be anxiety."

When Carly was unable to exercise, she experienced cascade of distressing physical symptoms. Joint pain, muscle pain, ulcers, and buckling knees manifested as disparate, confusing, and chaotic symptoms. After searching for an explanation, the doctors settled briefly on an overuse injury and then on fibromyalgia.²⁵ Only after months of intense emotional, mental, and physical discomfort did the doctors—who already knew about her anxiety disorder diagnosis—eventually tether these experience an anxiety disorder. Even after the doctors expanded explanatory the reach of her anxiety disorder diagnosis

²⁵ "Fibromyalgia is a common syndrome in which people experience long-term, body-wide pain and tender points in joints, muscles, tendons, and other soft tissues" (PubMed 2010)

for her, Carly explained that these physical symptoms remained difficult to tether to anxiety. When the doctors finally suggested it was anxiety, Carly was skeptical and asked,

“This can happen from anxiety?” They're like “Oh, yes.” *I didn't believe it.* I knew anxiety could cause some physical discomfort, but can it cause so much pain where I can't walk? *I doubt it.* So, I called up my physical therapists, [who is] probably one of the only health professionals I have ever trusted and fully relied on. She is just a very knowledgeable, intelligent woman. She is very honest. I said, “They think it is anxiety. Do you think that's legitimate? She said, “Well, yes. Cortisol increases your inflammation in the body, and the mind is a very powerful thing.” She always cited studies, which is great about her. She always backed what she said up with evidence. She said “I was reading an article in a journal the other day about a lady who basically made herself paralyzed with her mind. She became a quadriplegic just with mental stuff. There was no physical explanation for it.” That was a wake-up call. I was like “Shucks, maybe this really is happening.”

Carly's experiences were so far beyond the scope of what she thought anxiety disorders could “do” that, even after the doctors re-diagnosed her symptoms, she was unable to confidently tether her experiences to that diagnosis. Before she would accept this re-diagnosis and believe that these symptoms were caused by an anxiety disorder, she demanded a trusted second opinion and dramatic evidence from a scientific journal. Carly ended this particular discussion by providing the final evidence that convinced her that, yes, in fact, these symptoms were a part of her anxiety disorder.

I went on vacation, popping Tylenol and suffering. Halfway into the vacation my joint pain was virtually gone. By the time we got to the Badlands, I was hiking for the first time in six months. Mild, mild hiking, but it was awesome. Then, my joint pain started coming on because there was only one day until I had to fly home. I got home and it got really, really bad.

Carly removed important stressors (a demanding job, daily bills, and confrontations with an ex-boyfriend) and her physical “symptoms” relented. Then, when the stressors were reintroduced as she planned her return trip home (where all of the stressors resided), the

physical symptoms reappeared. This indicated to Carly that these new physical symptoms were, indeed, caused by stress, Cortisol, and anxiety. This was the final “trial of strength,” which are tests of claims that render the claim-maker either a “subjective individual” or an “objective representative” (Latour 1987:78). These trials of strength proved to Carly that her doctor’s claim that her symptoms were caused by an anxiety disorder were objective and true.

I draw out the process by which Carly *allowed* her interpretation of what anxiety “can do” to expand in order to demonstrate that the body (as an actor), the person, and the medical category (and all of its resources, like journal articles, physicians, physical therapists and so on) are actively engaged in negotiating to what extent the boundaries of the diagnosis can expand. There were no passive actors in this negotiation; the body, the person, and the medical category collaborated to transform the meanings of sensation, the experiences in the body, and the potential of an “anxiety disorder.”

The physical body and the explanatory potential of the diagnostic category developed in tandem. Physical experiences like hives, rashes, picking skin, and jaw pain, over time, were enveloped into the interviewees’ conceptions of what an anxiety disorder is and its potential consequences. As the body acted, the boundaries of the disorder broadened to accommodate these new experiences, and, over time, more and more physical experience could be explained by anxiety disorder.

Carly’s narrative exemplifies the main arguments of this section. First, the body sometimes acts beyond the parameters of the diagnostic category. These profound bodily disruptions gave many of the interviewees pause and pressed them to question whether these physical experiences could, in fact, be attributed to “anxiety.” For many of the

interviewees, these experiences placed them back into the throes of a confusion that had previously been relegated to the months and years *before* diagnosis. As ethnomethodologists have long observed, seemingly firm and stable realities are surprisingly easily disrupted or shattered (see Garfinkel 1967 on breaching experiments; also, see Mehan and Wood 1975:24 for a discussion). Likewise, an anxiety disorder diagnosis, as a tool for organizing experience, was often (temporarily) hindered by unanticipated bodily experiences.

Second, the dialectic between the physical body and the diagnostic category demonstrated one way that anxiety disorder diagnoses came to explain increasingly more of physical experience. That is, the body acted beyond the parameters of their original conceptualizations of what anxiety could “do,” and, in collaboration with medical practitioners, interviewees expanded the categorical boundaries of anxiety to encompass this wider range of physical experience. This process gave way to new definitions of “anxiety” and continued to transform the interviewees’ experience of physical distress. In this study, the body pushed against, shifted, and sometimes shattered the interviewees’ meanings for and explanatory boundaries of an “anxiety disorder.”

The fragility of the body served as a significant source of change in the lives of the interviewees and as a critical point of entry into this sociological study of bodies and diagnosis (Turner 1992:31). For instance, the fragile human body, crumbling under the physical sensations of panic, brought to the fore the stabilizing potential of the category (in this case diagnosis). The diagnosis allowed the interviewees to make sense of disparate and distressing physical sensations and to more easily interact with, inhabit, and manage their bodies. At the same time, the distressed body highlighted the analogous

fragility of the category and the strength of the body. That is, for the interviewees, the category “anxiety disorder” could not always contain the meanings, consequences, and demands of a distressed body. There is a powerful and interactive link between language and bodies that the study of diagnosis and the lived body bring to the fore.

After Diagnosis: Blurred boundaries

The previous section described when the boundaries of a diagnosis were challenged and then (fairly) neatly shifted to accommodate new physical sensations. But, in the interviewees’ narratives and in discussions at the support groups, this process was not always described as such an orderly and complete development. In this section, I discuss how the boundaries between an “anxiety disorder” and other serious physical illnesses sometimes became blurred and remained ambiguous.

For instance, at one particularly lively anxiety disorder support group meeting, Cindy recounted a panic attack in which her heart was pounding, she was sweating profusely, and she had sharp pains in her arm. Her aunt—who she was living with at the time—came into Cindy’s room to check on her and was alarmed by Cindy’s clammy and pale appearance. After Cindy told her aunt about her symptoms, the aunt was certain that Cindy was having a heart attack. Cindy, conversely, felt that the physical sensations were indicators of a panic attack and refused to go to the hospital. As it happened, she breathed deeply, waited, and after some time the symptoms subsided. In this case, Cindy was able, despite the urgings of her aunt, to contain her physical distress within the categorical boundaries of a panic attack.

At the end of Cindy's story, a man at the meeting interjected, loudly, "No matter what, when you have those kinds of symptoms, you need to go to the emergency room!" He went on to explain that he had a panic attack that led to *real* heart complications (see Martens et al. 2010; Scherrer et al. 2010 on the medical connection between anxiety disorders and heart conditions). He assured the group that if he hadn't gone to the emergency room, he may have died. In this case, the man maintained that the cause of his physical distress was anxiety, but unlike most other accounts of anxiety, these sensations led to a serious medical condition that demanded immediate medical treatment. The meanings and implications of anxiety and physical distress became muddled and served as a source of profound confusion in the group. An ultimately never-settled debate about how to respond to heart-related discomfort ensued.

Even after diagnosis, when experiencing intense physical symptoms, interviewees and support group members often recounted being unable to discern between serious physical illnesses requiring immediate medical treatment and the medically benign physical signs of a panic attack. As a consequence, even after diagnosis, many interviewees reported going to the emergency room only to find out that, once again, the sensations were signs of a panic attack. These narratives fluctuated between distress and relief, certainty and doubt, clarity and confusion. A common theme in these accounts was that relief was found in the medical model of an anxiety disorder, and doubt emerged from the, often messy, lived-experience of the body.

For instance, Blair described struggling to distinguish between panic and serious—perhaps life-threatening—illness. She grew up and continued to live in a small rural New England town, and, being such a small community, all of the doctors in the

area knew Blair and her diagnosis very well. Blair explained her frustrations with the very physical—and, as such, confusing—nature of panic.

Panic is not just mental; it's a full-body experience. Especially, like, when I went to the emergency room, I had a panic attack so bad that I had numbness around my mouth and down my throat, and I couldn't feel my fingers. All of the muscles up in my shoulder blades were locked up and going into spasm. I couldn't move. I couldn't get [the muscles] to release. Here I go to the emergency room to get breathing treatments, because I'm hyperventilating and I can't stop. So, [the doctor] is like, "Here, have some Ativan." It's hard to say, "Okay, I don't think this is going to work this time." I thought I needed the breathing treatments to open my airways because I'm getting the lack of oxygen to my extremities. How do I explain that to somebody?"

While in the midst of a severe panic attack, Blair questioned whether the intense physical sensations were actually a component of her panic disorder. Accordingly, she sought treatment at the emergency room, where the doctors tried to assure her that she was having a panic attack. Social pressure, from the emergency room physicians and nurses, kept her classifications in check by refusing her other, non-anxiety related treatments.

Still, Blair explained that—even though she had been repeatedly told that her difficulty breathing is *just* anxiety—she continued to go to the emergency room during intense panic attacks. She lamented, "I get the looks [from the doctors and nurses] like, 'Really? That's why you are here?' But, how do I explain to somebody, 'Please help me, because I can't breathe.'" The sensation that she "can't breathe"—despite the medical information that anxiety will not *stop* her from breathing—continued to challenge her conceptualization of an anxiety disorder and pressed her to go to the emergency to make sure it was not a more serious condition.

Similarly, Skye, who early on in our interview explained that she had "never gone to the emergency room" because of a "panic attack"; however, she later explained that

she had once had a panic attack that *triggered* a “real” and serious physical response that demanded medical attention in an emergency room.

Anxiety triggers my asthma usually. So, *I've actually almost died once from an anxiety attack where my asthma was triggered*, and I didn't have my inhaler. I had to go to the hospital. That was shitty. After that, I was like, “I need to learn how to deal with this better.” Even if I have my inhaler, I don't know if that would've really helped.

Skye did not say that anxiety “caused” her airways to close; rather, she said that anxiety triggered her asthma, and the asthma closed her airway. Skye articulated a precarious delineation between anxiety and a closed airway (or death). Even though Skye was clear that asthma mediated the relationship between anxiety and a near death experience, she was equally clear that there was a synergy between anxiety and asthma that explained *why* her throat almost completely closed. The boundaries of an “anxiety disorder” became (and remained) blurry in her narrative. For Skye, anxiety both could and could not cause death. Later in the interview, she explained that,

Even though anxiety is a physical thing when I'm going through, it's still something that my mind is controlling. I can take myself out of it. If I can calm myself down, I will be fine. My mom has a lot of faith in me like, “Okay you can do this. Just do it. I'm not taking you the doctor because there is nothing wrong with you.”

Skye attempted to limit the explanatory power of the anxiety disorder diagnosis. In this formulation, anxiety resided in the mind, could cause mild physical distress, could be handled through mental exercises, and could not cause serious physical harm.

Nonetheless, there were obvious tensions in Skye's narrative. While she asserted that she had never been to the emergency room for a panic attack, she also described going to an emergency room after she had a panic attack that triggered an asthma attack. Likewise, she asserted that panic attacks could not cause “real” harm and could be

managed through mental exercises, but earlier in her narrative she said, “I’ve actually almost died once from an anxiety attack where my asthma was triggered.” Skye tried to maintain and strictly enforce clear boundaries between what anxiety could and could not do, even when confronted with powerful evidence to the contrary.

Since panic and other illnesses are simultaneously physical events and lingual constructs—and are not necessarily immutable fixtures of nature—“the existence of vague boundaries is normal” (Hacking 1999:164). In other words, with the slippage between the category and the local experience of the body (Foucault 2003), one should expect confusing, sometimes contradictory, boundaries and experiences. The potential of anxiety disorders remained precarious in the lives of most of the interviewees. At a minimum, the boundaries shifted (but mostly expanded) and remade the interviewees’ perceptions of their bodies. At the extreme, the boundaries of an anxiety disorder became blurred, which left the interviewees with a brooding uncertainty about what anxiety could and, perhaps, would “do” next.

Conclusion

In this chapter, I discussed two specific implications of diagnosis for the physical body. One, I reflect on previous observations made in chapter four about how diagnosis allowed the interviewees to more easily manage and make sense of intense physical symptoms. Two, drawing on this general observation, I describe one way that diagnosis helped the interviewees manage their symptoms. That is, diagnosis allowed them to effectively ignore (or silence) a range of (previously distressing) physical sensations. There is obvious therapeutic value in diagnosis; it helped individuals to more comfortably

exist in their own bodies and resist extreme measures (such as emergency room visits) in response to physical distress.

At the same time, there are important—potentially deleterious—implications for how the interviewees re-conceptualized their own bodily experiences. Individuals diagnosed with anxiety disorders may ignore important symptoms (like chest pain, dizziness, and numbness in extremities), dismissing them as components of an anxiety disorder, while these symptoms may, indeed, be signaling more consequential origins (like a heart attack, epilepsy, or a stroke). While new, post-diagnosis conceptualizations of bodily experience are not “wrong” (indeed they may be far more representative of eventual consequences or they may, at least, be more functional), the potential latent consequences should be carefully considered. Changes in how patients experience, interpret, and respond to physical distress represent an important medical and sociological concern.

Further, once a person is diagnosed with an anxiety disorder, it may also become increasingly easy for medical practitioners to explain physical distress in terms of medically benign symptoms of anxiety (For instance, Blair and the emergency room physician). For that reason, two interviewees reported not telling emergency room staff that they had an anxiety disorder diagnosis for fear that their symptoms would not be taken seriously. Future research should examine how diagnosis improves, complicates, or simply changes the medical encounter.

The original function of diagnosis was to, in part, explain and order distressing experiences, but diagnosis did not just order distressing experienced before diagnosis and at diagnosis. Over time, an anxiety disorder diagnosis often came to explain an ever

widening range of physical experiences. In the previous chapter, I discussed how interviewees increasingly defined milder and (previously defined) “normal” distress in terms of an anxiety disorder. As such, the explanatory potential of an “anxiety disorder” extended into phenomena that, before diagnosis, would not have indicated an anxiety disorder. In this case, the diagnostic category itself seemed to sweep-up a wide range of mild “symptoms.” This present chapter addressed how the physical body acted chaotically, creating distressing sensation, which again expanded the explanatory capacity of an anxiety disorder. In this case, the body pressed the boundaries of the diagnostic category to extend over more distressing and physical sensation. Combined, these two chapters suggest that diagnosis—long after the doctor utters the original medical words—takes on a life of its own, explaining more and more of the “patients” mundane *and* extraordinary experience.

Lastly, this chapter focused on and considered the consequences of the dialectic between a diagnostic category and the body in the illness experience. I find that there is a synergy between language and the body that expands the explanatory power of the diagnosis. On the one hand, language (in the form of diagnosis) calms, silences, and orders the body. Here, the body is fragile; it falls into line after its expressions are explained away. On the other hand, the body also breaks language (or diagnoses) open, drawing the patient back into chaos. In this sense, the body is powerful, resisting stagnant and fixed definitions and explanations. In short, the body acts, diagnosis explains, and the body is quieted; but then, the body acts (again and differently), the diagnosis expands, and the body is (again) quieted. The body and the diagnosis shift in relation to one another, generating new experience, perception, and boundaries.

CHAPTER NINE

CONCLUSION

In this dissertation, I explored the social evolution of anxiety disorders through the narratives of people who have been diagnosed. This inquiry has focused on the time leading up to diagnosis, the diagnostic process itself, and the long-term personal, social, and medical consequences of diagnosis. The opening chapters on the time before diagnosis suggested the critical importance of physical distress in treatment seeking and of objects in the meaningful experience of distress and emotion. In short, a lack of congruence among objects, physical experience, and social expectation prompted research participants to seek medical attention. In the middle chapters, I addressed the diagnostic process itself with a focus on the gendering of fear and on anxiety disorder diagnoses. I found evidence that gender structures the experience and expression of fear and a patient's gender guides how a physician interprets their narratives. While women more promptly identified their experiences as fear and received efficient diagnoses, men struggled to make sense of their experiences as fear and to locate a sensible diagnosis. These chapters provided insight into the processes that contribute to the aggregate gendering of anxiety disorders, with women twice as likely to be diagnosed with an anxiety disorder. The last two findings chapters addressed the experience of anxiety after

diagnosis. These chapters explored the lay micro-processes of medicalization, documenting how medical understandings of experience infiltrated the lives of those who were diagnosed. Importantly, the reach of the diagnoses expanded substantially in the years following diagnosis, largely within the informal social relationships of the patient.

This study provided an empirical account of the lived experience of anxiety disorders and anxiety disorder diagnosis from the perspective of people who have been diagnosed. This approach represented a phenomenological inquiry into the illness experience, which gave privilege to patient experiences and illness narratives. My intention was to explore how experience and behavior were defined by people, how those understandings changed over time, and the implications of those changes in the lives of people. This allowed for a vantage on the intersubjective nature of illness and the role of social materiality in the illness experience. As I argued in the opening chapter, this approach was amenable to the study of social materiality, while simultaneously avoiding essentialism by locating the role of materiality in a local context and in intersubjective realities.

Social Materiality: Objects and Bodies

This dissertation was an empirical and theoretical move toward the study of social materiality in medical sociology. I have explored how physical distress, objects, and cultural concepts (such as fear) coalesced in subjectivities and intersubjectivities to give way to discrete illness experiences. In the case of anxiety disorders, it was the failure of physical experience, objects, and cultural concepts to align that prompted treatment seeking and then diagnosis.

Objects were critical in the identification and experience of illness. More generally, objects played a crucial role in meaningful social experience and exchange. In the opening empirical chapters, I demonstrated how objects had shared intersubjective meanings that were expected to be upheld by all social actors and how objects helped adhere subjective physical and emotional experiences. For instance, an “object-response disjuncture” represents a moment when an individual response to or interpretation of an object diverges from the socially expected one. The inability to interact with objects in the expected way became a sign of disorder and an initial impetus to seek help. This not only demonstrates the culturally contingent nature of anxiety disorders, but it also locates objects as critical to the identification and experience of anxiety. Moreover, these data suggest the central role of objects in social life; they demand our shared and socially prescribed responses for a successful social existence.

Objects also have a critical place in sensible emotional experience. For the research participants a pivotal moment in their illness narratives occurred when an object dropped out of their emotional experience, which I referred to as “objectless fear.” Without an object to tether the physical sensations to, the sensations became insensible or were reorganized as physical illness, such as heart attacks. In short, objects anchored emotional experience. In this dissertation objects were revealed as critical to the illness experience, treatment seeking, and sensible emotional experience.

This close analytic attention to objects and anxiety raises several important questions. For instance, do objects have analogous functions for the experience of other mental illnesses? I suspect that a similar trend would, indeed, emerge in other mental illnesses, like depression, bipolar disorder, and schizophrenia, since the role of emotions

and socially appropriate responses to the world are also at stake in these illnesses. I wonder, then, how objects figure into physical illnesses. Do objects figure prominently into the discovery and experience of physical illness? I, again, suspect that they might, since it appears that objects have a general social function in anchoring subjective and intersubjective reality.

Another important question about objects emerges (one that a faculty advisor has asked me on more than one occasion), “why this and why now?” In other words, why are people afraid of these particular objects (indeed, there are themes among these objects, including isolation, driving, elevators, germs, and so on)? Further, why do divergences in the experience of some objects inspire social sanctions while others do not? Lastly, why these patterns now and why here? While these questions are beyond the purview of this study and require an entirely different approach (perhaps a more macro-cultural approach), this study provides the groundwork for such an inquiry. I find that objects matter tremendously in the experience of fear and anxiety disorders in a multitude of ways, which gave way to the next question: why these objects and why now?

Not surprisingly, I also find that the body and physical experience figure prominently into illness experience; perhaps a more provocative finding was that physical sensation and the interpretations of it appeared to be profoundly structured by context, narratives, and diagnosis. There was a dynamic interplay between bodies and categories that transformed experience, interpretation, and action. For instance, bodies revolted: they moved, secreted, and vocalized in unwanted ways. The body in distress moved people to action, but, importantly, they were not in set or predetermined ways. Instead, bodies were experienced through cultural categories. That is, a body could shake, sweat, and

feel weak (in response to an “appropriate” object) and this could be categorized as normal fear. When the body introduced, say, vomiting or mute-ism, the cultural category of fear was burst open, and the body moved the person to action (often, treatment seeking). Bodies, objects, and cultural categories worked together to help people make sense of experience and direct action.

Notably, the relationship between physical experience and fear was not obvious or given. Indeed, many interviewees failed to interpret their physical experiences as fear for months, even years. In a profound way, bodily experience and action depend on categories and meaning making. Interviewees sought treatment for heart attacks, epilepsy, asthma, and so on when they were unable to “see” their physical experiences as “anxiety.” These observations provide insight into delayed diagnosis and misdiagnosis of anxiety disorders.

For instance, the inability to interpret physical sensation as fear is strongly gendered. Men were much less likely to perceive many of their symptoms as “anxiety”, such as increased heart rate and perspiration, in the cultural context in which men more often participate in aggressive sports and manual labor, which arguably disproportionately desensitize them to certain bodily sensations. Moreover, there are more social sanctions for expressing fear for men than there are for women, which may (1) dissuade men from expressing fear and (2) force them to develop a tolerance for the sensations of fear. These gendered forms of socialization, with a special attentiveness to bodily experience, help contextualize the differential rate of anxiety disorder diagnosis among men and women.

Attention to social materiality offers much to the study of illness. It allows insight into the processes by which individuals come to seek treatment and why certain illnesses and certain social groups are under-diagnosed (or over-diagnosed). Of course, the next question is how to use this information. At the most basic level, it should alert physicians to the possibility that men and women will express distress differently. While the physiology of fear may be the same among men and women, their experiences and expressions of it might be quite different. More broadly, this study suggests that the body speaks through cultural categories and it is important to be attentive to how those categories might filter and reshape experience and narratives.

Diagnosis and the Micro-Processes of Medicalization

Diagnosis served as a key social construct that served to reorder experience and help patients more effectively manage their distress. Notably, the consequences of diagnoses emerged in other, unintended ways that transformed patients' senses of self, power dynamics in personal relationships, interpretations of everyday reality, and the diagnosis itself. While this dissertation is largely a meditation on categories and experience, predominantly diagnosis and experience, I want conclude with a particular focus on the micro-processes of medicalization, which transformed the illness experience through an expansion of the diagnostic boundaries through everyday interactions.

I focus on these micro-processes here because they represent a rare empirical moment: the observable movement of institutional power into the everyday lives of people. Indeed, the processes of medicalization are largely located in medical institutions, since medicalization is the transformation of nonmedical phenomenon into

medical phenomenon. So, institutionally defined categories are an apt object of focus. As one might expect, then, much work on medicalization focuses on the institutional construction of medical categories. My dissertation extends this focus by tracing the movement of those constructs out of the medical complex into the lives of people and has revealed way in which those constructs unfolded, even mutated, in the lives of people. Surprisingly, I found that much of the process of medicalization happened in the everyday interactions of people and through ever evolving bodily experience.

The original symptoms described by the interviewees, before diagnosis, were often intensely distressing and often fit the DSM criteria quite well. Then, after diagnosis, the patient took those vaguely communicated medical definitions of their situation (diagnosis) out into the world with them. I found that medicalization then occurred in two distinct ways. First, patients often ceded interpretive power to (non-disordered) others, who often used the anxiety disorder category to explain increasingly mundane and “normal” fearful or anxious reactions. In this way, medical power was transmitted, via medical diagnosis, to the wives, husbands, children, and friends of the patient. To be sure, the DSM categorizes and re-categorizes experience as pathological; however, in these data the medicalization of once “normal” experience (as defined by individuals who have been diagnosed) also clearly occurred outside of the purview of the medical institution, while drawing strength from the authority of medical categories. This is important: the thorough study of medicalization demands attention to both the institutional and the informal ways in which nonmedical experience is defined as medical.

The second way that medicalization occurred was through the experience of new and more distressing physical experience. That is, the body in distress expanded the definitional scope of an anxiety disorder. Some of the time, the research participants were able to work with family and friends to re-categorize these increasingly distressing experiences as anxiety, but quite often they would eventually return to their physicians to re-diagnose these symptoms as anxiety. In these ways, the micro-processes of medicalization after diagnosis happen in the everyday lives of people and returned whence it came: the clinic.

There were two core implications of this synergy between bodies and diagnostic categories. One, once the diagnosis was in place, it was nearly impossible for physicians to see these intense symptoms as symptoms of anything other than an anxiety disorder. Two, interviewees struggled to know when to go to the emergency room, even when the symptoms they experienced would suggest, for instance, stroke or heart attack to someone without an anxiety disorder. These two consequences suggest that anxiety disorder diagnoses may later cause problems in the diagnosis of more medically consequential ailments. While diagnosis helps manage treatment seeking for less mortally consequential anxiety-related distress, it complicates treatment seeking when the stakes are higher.

A question at the core of this dissertation was how does diagnosis improve, complicate, or simply change the medical encounter? The answer is, plainly put, not simple. Indeed, diagnosis does all three. The question becomes, with this information in hand, how can it be used to improve the medical encounter? At a minimum, physicians could provide patients the full diagnostic criteria for the assigned diagnosis to place limits

on its expansion, help the patient sort through useful versus detrimental anxiety to reduce confusion, and provide guidelines for when to seek medical treatment to assure that patients continue seek medical intervention when it is necessary. Certainly, none of these solutions are simple or unproblematic. Still, they represent avenues of empirical inquiry that should be cautiously considered.

Studying the Life Course of Chronic Illness

This brings me to a final observation. Illness experiences are not stagnant, and, moreover, a complete study of the illness experience and of medicalization, I argue, demand attention to experiences before, during, and after diagnosis. Indeed, the nature of illness and distress changes dramatically from those chaotic months and years before diagnosis to having a name for distress to the months, years, even decades after diagnosis. Importantly, diagnosis and the experiences it seeks to categorize are dynamic and ever changing. The broad scope of study—before, during, and after diagnosis—allows for a thorough inquiry into illness experience and medicalization, both of which can be distorted by a solely cross-sectional view.

In this study, exploring experiences before diagnosis allowed for a better understanding of what brought the person to the clinic and helped elucidate the origins of the variety of narratives relied on in diagnosis. It also allowed for insights into the misdiagnosis, under-diagnosis, and, perhaps, the over-diagnosis among various social groups. Moreover, this focus on experience, social materiality, and the time before diagnosis helped me build on the fact that there are systematic differences in diagnosis

and begin developing an explanation as to why these differences emerged and have persisted.

The study of illness after diagnosis was equally, but differently, important to understanding the illness experience. For one, as I have discussed, it allowed insight into the extension of medical power and categories into the lives of people, and, moreover, allowed me to examine how this extension happened. In this study, a focus on experience after diagnosis revealed that much of medicalization happened in the everyday lives of patients through a series of interrelated micro-processes. This focus on illness after diagnosis has become increasingly important in modernity, as chronic illnesses are increasingly prevalent in the U.S., infectious diseases have been increasing eradicated, and once acute illnesses, like various forms of cancer and HIV/AIDS, are so productively treated that they effectively become chronic illnesses (Kleinman et al. 1978; McKinlay and McKinlay 1977; McKinlay and Marceau 2002). As such, much of the modern person's life, in the U.S., might be spent with a medical diagnosis, and, accordingly, much of social life is spent negotiating diagnosis and illness beyond the purview of the medical institution. With this epidemiological shift over the last century, medicine has largely moved from the hospital and the clinic into the everyday lives of people. This trend behooves medical sociologists to continue and to expand the empirical study of medicine in the lives of people in the months, years, and decades after diagnosis.

Mapping out illness from beginning to end is, indeed, an increasingly important modern project. Medical sociology and the medical field benefit from these narratives that reveal the social processes that move us toward the clinic, shape how we talk

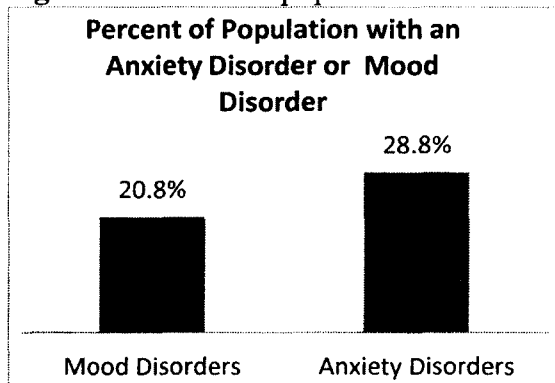
about our pain, and fill our lives understandings built by medicine. If we seek an understanding of illness, this endeavor demands a robust inquiry into the experience of it.

APPENDICES

Appendix A: Scholarly Coverage of Anxiety Disorders

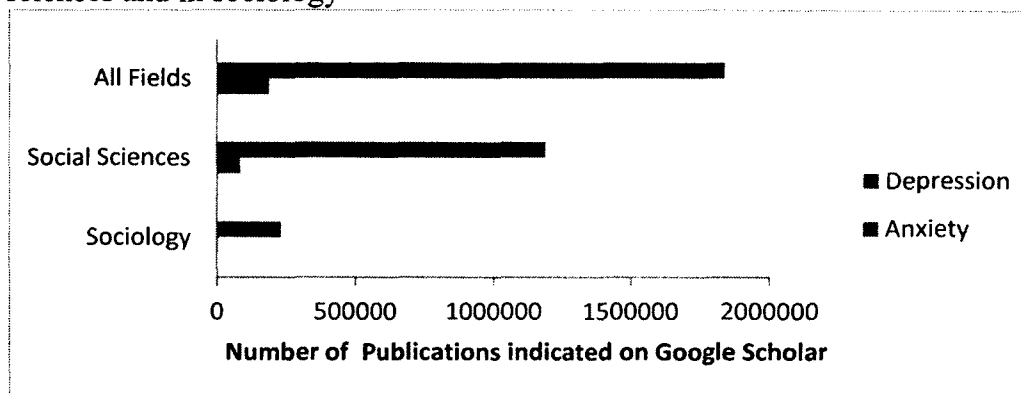
It is notable that while anxiety disorders are the most common of all mental health disorders, they are studied and reported on far less frequently than comparable mental health disorders. For instance, an informal search of scholarly articles on anxiety disorders and a single mood disorder (major depressive disorder) suggests that research is biased away from anxiety disorders. Figure 1 shows that even when you take into account all forms of a mood disorders, anxiety disorders are more prevalent in the population. Nonetheless and in stark contrast, figure 2, which only takes into account one type of mood disorder (“major depressive disorder”), clearly shows that depression is studied at a much higher rate than all forms of anxiety disorders combined across all academic disciplines. In short, while more people have an anxiety disorder (28.8%) than a mood disorder (20.8%), the scholarly research is deeply skewed toward mood disorders. Accordingly, part of the reason I chose to study anxiety disorders was the dearth of scholarly research in general and sociological research in particular on this topic, a topic that is deeply important to between a quarter and a third of the U.S. population, not to mention the families and friends of people who are diagnosed with anxiety disorders.

Figure 1. Percent of population with a mood disorder*



*Based on NIMH statistics (<http://www.nimh.nih.gov/statistics/index.shtml>).

Figure 2. Scholarly publications on depression and anxiety in all fields, the social sciences and in sociology*



*This figure was derived from a Google Scholar search of “depression”, “major depressive disorder”, and keywords for all types of anxiety disorders on October 28, 2010.

Appendix B. Historical Development of Medical Diagnoses

Diagnosis is a common factor in modern illness in the United States. Diagnosis is necessary if one would like health insurance coverage, leave from work, or medication. In order to have an illness socially validated, one must receive a medical diagnosis. People who are unable to receive a diagnosis suffer not only with uncertainty but also with a lack of social recognition (Nettleton 2006). However, this is fairly unique to modern medicine. Medical diagnosis has not always been a component of medical treatment, but, rather, it is a social phenomenon that has slowly emerged over last few hundred years. In order to fully appreciate the critical and contextual role of diagnosis in medicine, health, and illness, it is imperative to explore the socio-historical development of diagnosis that led to its prominence in the modern medicine.

Researchers often locate the origins of medical diagnosis with John Graunt and Thomas Sydenham in the 17th century; Graunt was concerned with maintaining a statistical record of morbidity and mortality and Sydenham was interested in “improving the clinical utility of common naming strategies” (Jutel 2011:192 – 193). While statistical record keeping of illness flourished in the 18th and 19th century as a relatively cohesive body of work, disease classification or “nosology” emerged disjointed and controversial. Nosologists were split between those who sought symptom clusters in the clinical setting and those who sought connections between disease progression and underlying organic states (Jutel 2011:194 – 197).

Today, there is a conglomerate of all three approaches in medical research and practice: epidemiology, nosology linked to underlying physical states, and nosology based primarily on symptomology. Arguably, diagnoses that link disease presentation to underlying physiology are the gold standard of medical nosology, and epidemiological studies that employ these types of diagnostic criteria are also assured more medical and scientific legitimacy nosology built on symptomology. Nonetheless, much of diagnosis remains based on the observation of symptom clusters that have no obvious underlying physiological bases. While a plethora of both mental and physical ailments lack a clear underlying physiological explanation (Kleinman et al. 1978), this problem is especially pronounced among mental health conditions, which have presented “a particular challenge to classification” (Jutel 2011:199). Accordingly, until the 1970s, “diagnosis had, at best, a minor role in ... psychiatry” (Mayes and Horwitz 2005:250). As such, the concerted study of mental health diagnoses is a relatively new endeavor firmly located in modern (“western”) medicine.

Today, diagnosis is a fundamental and expected component of mental health treatment. The development of the Diagnostic and Statistical Manual of Mental Disorders (DSM) by the American Psychiatric Association (APA)—especially the DSM-III—played a vital role in the advancement of the diagnosis of mental health disorders and the medicalization of mental distress. Currently, the DSM is the single most authoritative psychiatric diagnostic guide in the U.S. and is fast becoming the most authoritative at the global level (Wykes and Callard 2010:302; see also Watters 2010).

Before the APA introduced the DSM-III in 1980, mental health treatment was focused primarily on neurosis—a broad catchall for a range of mental distress—and personal problems that led to maladaptive behavior (Mayes and Horwitz 2005). As such,

mental health practitioners treated a wide range of patients with a common set of therapies, predominantly talk therapy. As such, experts in the psychologies treated an incredible variety of distress under a limited number of broad diagnostic categories. What the DSM-III accomplished was the systematic and categorization of mental disorder (Mayes and Horwitz 2005).

This codification was a product of a range of institutional forces that eventually led to the re-definition of mental distress as *medical* conditions, which, at the time, was a very controversial idea. Before the DSM-III, mental distress was more commonly conceptualized as a result of a person's life history and circumstance, while medical conditions were understood to be biological malfunctions. Likewise, there was a huge etiological chasm between mental and physical distress that was eventually bridged—however precariously—by the diagnoses outlined in the DSM-III. Of course, I would be remiss if I did not observe that while this debate may be settled in some corners of academia, it still rages in the much of the social sciences.

Mayes and Horwitz (2005) chart several key factors that led to the systematic classification of diagnoses. They argue that the following social forces, among others, contributed to the construction of the DSM-III: third party payers wanted clear distinctions between people who were “ill” and people who simply had “life problems”; social scientists argued that psychiatrists were treating the “worried well” instead of the mentally ill; and the Food and Drug Administration (FDA) demanded clearly defined disorders necessary to conduct efficacy testing. These demands and critiques, among others, begged for unambiguous distinctions between the mentally ill patient who needs treatment and the healthy person who is having a difficult time of it mentally and/or emotionally. As a consequence, through rigorous diagnostic categories, the DSM-III legitimated mental distress as a medical issue with all of the biological, genetic, and asocial trappings of a “real” disease.

Through the rigorous systematization of these medical categories, diagnosis fast “became a key component in psychiatric treatment” (Mayes and Horwitz 2005:250). The clear and concise diagnostic criteria helped legitimate the—then, relentlessly critiqued—psy-disciplines as a branch of medicine and opened up new ways of funding the discipline. The elaborate and putatively more precise diagnostic categories became the requisite passage point to insured patients, medical efficacy studies, FDA support for the biomedical treatment of mental illnesses, and the influx of pharmaceuticals, all of which gave way to medical legitimacy and professional and personal profit. Accordingly, there was an unanticipated rush to adopt and employ these new diagnostic criteria, which further fed the cycle of diagnostic systematization. In short, the DSM-III afforded the psy-disciplines medical legitimacy and helped forge pharmaceutical empires directed at medically treating mental and emotional distress.

The DSM is currently in its fourth edition, for which the APA made fewer structural changes and limited their revisions to more minor substantive changes to the diagnostic criteria. The DSM-IV has largely “reaffirmed and solidified the transformations of psychiatry and mental health that the DSM-III began in 1980” (Mayes and Horwitz 2005:264). And, the DSM-V is scheduled to be released in May 2013. This dissertation addresses a set of diagnostic criteria (“anxiety disorders”) included in the DSM-IV, that are currently being revised by the APA for the DSM-V.

Appendix C. DSM Diagnostic Criteria

Table 1. DSM-IV criteria for anxiety disorders addressed in this dissertation*

DIAGNOSTIC CATEGORY	MUST INCLUDE...	VARIATIONS	LIMITS
Panic Disorder	<p>Recurrent unexpected Panic Attacks</p> <p>At least one of the attacks has been followed by 1 month (or more) of one (or more) of the following:</p> <ul style="list-style-type: none"> a. Persistent concern about having additional attacks b. Worry about the implications of the attack or its consequences c. A significant change in behavior related to the attacks 	<p>The presence (or absence) of Agoraphobia</p>	<p>The Panic Attacks are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hyperthyroidism). The Panic Attacks are not better accounted for by another mental disorder, such as Social Phobia, Specific Phobia, Obsessive-Compulsive Disorder, Posttraumatic Stress Disorder, or Separation Anxiety Disorder.</p>
Generalized Anxiety Disorder	<p>Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities (such as work or school performance).</p> <p>The person finds it difficult to control the worry</p> <p>The anxiety and worry are associated with three (or more) of the following six symptoms (with at least some symptoms present for more days than not for the past 6 months).</p> <ul style="list-style-type: none"> 1. Restlessness or feeling keyed up or on edge 2. Being easily fatigued 3. Difficulty concentrating or mind going blank 		<p>The focus of the anxiety and worry is not confined to features of an Axis I disorder.</p> <p>The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hyperthyroidism) and does not occur exclusively during a Mood Disorder, a Psychotic Disorder, or a Pervasive Developmental Disorder.</p>

	<p>4. Irritability 5. Muscle tension 6. Sleep disturbance</p> <p>The anxiety, worry, or physical symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.</p>		
Specific Phobia	<p>Marked and persistent fear that is excessive or unreasonable, cued by the presence or anticipation of a specific object or situation</p> <p>Exposure to the phobic stimulus almost invariably provokes an immediate anxiety response, which may take the form of a situationally bound or situationally predisposed Panic Attack. The person recognizes that the fear is excessive or unreasonable.</p> <p>The phobic situation(s) is avoided or else is endured with intense anxiety or distress.</p> <p>The avoidance, anxious anticipation, or distress in the feared situation(s) interferes significantly with the person's normal routine, occupational (or academic) functioning, or social activities or relationships, or there is marked distress about having the phobia.</p>	<p>Common types: Animal Type, Natural Environment Type, Blood-Injection-Injury Type, Situational Type</p> <p>In children, the anxiety may be expressed by crying, tantrums, freezing, or clinging. In children, this feature may be absent.</p>	<p>The anxiety, Panic Attacks, or phobic avoidance associated with the specific object or situation are not better accounted for by another mental disorder</p>
Posttraumatic Stress Disorder	<p>The person has been exposed to a traumatic event in which both of the following were present:</p> <ol style="list-style-type: none"> 1. The person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others 2. The person's response involved intense fear, helplessness, or horror. <p>The traumatic event is persistently reexperienced in one (or more) of the following ways:</p> <ol style="list-style-type: none"> 1. Recurrent and intrusive distressing recollections of the event, 	<p>In children, this may be expressed instead by disorganized or agitated behavior</p> <p>- In young children, repetitive play may occur</p>	

including images, thoughts, or perceptions. themes or aspects of the trauma are expressed.

2. Recurrent distressing dreams of the event.
3. Acting or feeling as if the traumatic event were recurring
4. Intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event
5. Physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event

- In children, there may be frightening dreams without recognizable content.

- In young children, trauma-specific reenactment may occur.

Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:

1. Efforts to avoid thoughts, feelings, or conversations associated with the trauma
2. Efforts to avoid activities, places, or people that arouse recollections of the trauma
3. Enability to recall an important aspect of the trauma
4. Markedly diminished interest or participation in significant activities
5. Feeling of detachment or estrangement from others
6. Restricted range of affect
7. Sense of a foreshortened future

Acute: if duration of symptoms is less than 3 months

Chronic: if duration of symptoms is 3 months or more

With Delayed Onset: if onset of symptoms is at least 6 months after the stressor

Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:

1. Difficulty falling or staying asleep
2. Irritability or outbursts of anger
3. Difficulty concentrating
4. Hypervigilance
5. Exaggerated startle response

Duration of the disturbance is more than 1 month.

The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

**Obsessive-
Compulsive
Disorder**

Obsessions as defined by (1), (2), (3), and (4):

1. Recurrent and persistent thoughts, impulses, or images that are experienced, at some time during the disturbance, as intrusive and inappropriate and that cause marked anxiety or distress
2. The thoughts, impulses, or images are not simply excessive worries about real-life problems
3. The person attempts to ignore or suppress such thoughts, impulses, or images, or to neutralize them with some other thought or action
4. The person recognizes that the obsessional thoughts, impulses, or images are a product of his or her own mind.

Compulsions as defined by (1) and (2):

1. Repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly
2. The behaviors or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however, these behaviors or mental acts either are not connected in a realistic way with what they are designed to neutralize or prevent or are clearly excessive

At some point during the course of the disorder, the person has recognized that the obsessions or compulsions are excessive or unreasonable. (This does not apply to children.)

The obsessions or compulsions cause marked distress, are time consuming (take more than 1 hour a day), or significantly interfere with the person's normal routine, occupational (or academic) functioning, or usual social activities or relationships.

With Poor Insight: if, for most of the time during the current episode, the person does not recognize that the obsessions and compulsions are excessive or unreasonable

If another Axis I disorder is present, the content of the obsessions or compulsions is not restricted to it. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

*All DSM-IV criteria were collected directly from the American Psychiatric Associations website at:
(<http://www.dsm5.org/proposedrevision/Pages/AnxietyDisorders.aspx>)

Table 2. DSM-IV – non-codable disorders associated with anxiety disorders*

DIAGNOSTIC CATEGORY	MUST INCLUDE...	ASSOCIATED CODABLE DISORDER
Agoraphobia	<p>Anxiety about being in places or situations from which escape might be difficult (or embarrassing) or in which help may not be available in the event of having an unexpected or situationally predisposed Panic Attack or panic-like symptoms.</p> <p>Agoraphobic fears typically involve characteristic clusters of situations that include being outside the home alone; being in a crowd or standing in a line; being on a bridge; and traveling in a bus, train, or automobile.</p> <p>The situations are avoided (e.g., travel is restricted) or else are endured with marked distress or with anxiety about having a Panic Attack or panic-like symptoms, or require the presence of a companion.</p>	<p>Agoraphobia is not a codable disorder. Code the specific disorder in which the Agoraphobia occurs (e.g., 300.21 Panic Disorder With Agoraphobia or 300.22 Agoraphobia Without History of Panic Disorder).</p> <p>Consider the diagnosis of Specific Phobia if the avoidance is limited to one or only a few specific situations, or Social Phobia if the avoidance is limited to social situations.</p>
Panic Attack	<p>A discrete period of intense fear or discomfort, in which four (or more) of the following symptoms developed abruptly and reached a peak within 10 minutes:</p> <ol style="list-style-type: none"> 1. Palpitations, pounding heart, or accelerated heart rate 2. Sweating 3. Trembling or shaking 4. Sensations of shortness of breath or smothering 5. Feeling of choking 6. Chest pain or discomfort 7. Nausea or abdominal distress 8. Feeling dizzy, unsteady, lightheaded, or faint 9. Derealization or depersonalization 10. Fear of losing control or going crazy 11. Fear of dying 12. Paresthesias (numbness or tingling sensations) 13. Chills or hot flushes 	<p>Code the specific diagnosis in which the Panic Attack occurs (e.g., 300.21 Panic Disorder With Agoraphobia).</p>

*All DSM-IV criteria were collected directly from the American Psychiatric Associations website at:
(<http://www.dsm5.org/proposedrevision/Pages/AnxietyDisorders.aspx>)

Appendix D: Interviewee Characteristics

Table 3. Interviewee demographics and diagnoses

	Age	Gender	Married	Children	Education	Employed	PD*	GAD**	Agoraphobia
Lane	23	Female	No	No	BA	Yes	Yes	No	No
Angie	28	Female	Yes	No	MA	Yes	Yes	Yes	No
Wendy	41	Female	No	No	HS	Yes	Yes	Yes	Yes
Leah	24	Female	No	No	HS	No	Yes	Yes	No
Bridget	35	Female	Yes	Yes	BA	No	Yes	Yes	No
Blair	29	Female	No	Yes	HS	No	Yes	Yes	No
Patty	41	Female	No	No	MA	No	Yes	Yes	No
Mae	65	Female	No	Yes	BA	Yes	Yes	Yes	No
Darcy	35	Female	No	No	AA	Yes	Yes	No	No
James	51	Male	No	No	BA	No	Yes	No	No
Sarah	42	Female	Yes	No	HS	Yes	Yes	Yes	No
Darla	27	Female	No	Yes	< HS	No	Yes	No	No
Andrea	37	Female	Yes	Yes	HS	No	Yes	Yes	Yes
Tiffany	30	Female	No	No	BA	No	No	Yes	No
Penny	42	Female	Yes	No	PhD	Yes	Yes	Yes	No
Bill	41	Male	Yes	No	MA	Yes	Yes	No	Yes
Bethany	57	Female	No	Yes	HS	No	Yes	Yes	Yes
Melinda	36	Female	Yes	No	HS	Yes	Yes	Yes	Yes
Lindsey	28	Female	No	No	HS	Yes	Yes	No	No
Carly	23	Female	No	No	BA	Yes	No	Yes	No
Kathy	48	Female	No	Yes	HS	No	Yes	Yes	Yes

Mary	29	Female	No	No	BA	Yes	No	Yes	No
Stan	64	Male	No	No	AA	No	Yes	Yes	No
Harley	21	Female	No	No	HS	No	Yes	Yes	Yes
Barb	58	Female	No	No	HS	No	Yes	Yes	Yes
Ana	45	Female	No	Yes	HS	No	Yes	No	No
Lori	27	Female	Yes	Yes	HS	No	Yes	No	No
Paul	69	Male	No	Yes	BA	No	Yes	Yes	No
Tina	36	Female	Yes	Yes	BA	No	Yes	Yes	Yes
Lauren	22	Female	No	No	HS	Yes	No	Yes	No
Erin	19	Female	No	No	HS	Yes	No	Yes	No
Colleen	63	Female	No	Yes	HS	Yes	Yes	Yes	Yes
Kirstin	24	Female	Yes	No	BA	Yes	Yes	Yes	No
Jon	28	Male	No	Yes	HS	No	No	Yes	No
Emily	54	Female	No	Yes	HS	Yes	Yes	No	Yes
Ashley	35	Female	Yes	Yes	BA	Yes	Yes	Yes	No
Roger	59	Male	Yes	No	HS	Yes	Yes	Yes	Yes
Kalli	42	Female	Yes	Yes	HS	No	Yes	Yes	No
Skye	20	Female	No	No	HS	Yes	No	Yes	No
Marcy	37	Female	Yes	Yes	BA	Yes	Yes	No	No

*Panic Disorder (PD)

**Generalized Anxiety Disorder (GAD)

Table 4. Interviewee diagnosis timeline

	Age at Symptom Onset	Age at Diagnosis	Years between Interview & Diagnosis	Years between Onset and Diagnosis	Medication	Symptomatic?	Current Age
Lane	14	15	8	1	No	Yes	23
Angie	13	27	1	14	Yes	Yes	28
Wendy	22	24	17	2	Yes	Yes	41
Leah	10	10	14	< 1	Yes	Yes	24
Bridget	16	32	3	16	No	Yes	35
Blair	17	17	12	< 1	Yes	Yes	29
Patty	40	41	0	1	Yes	Yes	41
Mae	28	29	36	1	Yes	Yes	65
Darcy	18	20	15	2	Yes	Yes	35
James	29	38	13	9	Yes	Yes	51
Sarah	18	18	24	< 1	No	No	42
Darla	7	14	13	7	Yes	Yes	27
Andrea	23	25	12	2	Yes	Yes	37
Tiffany	13	18	12	5	Yes	Yes	30
Penny	22	24	18	2	Yes	Yes	42
Bill	19	26	15	7	Yes	Yes	41
Bethany	17	20	37	3	Yes	Yes	57
Melinda	27	28	8	1	Yes	Yes	36
Lindsey	24	24	4	< 1	Yes	Yes	28
Carly	15	18	5	3	No	Yes	23
Kathy	15	25	23	10	Yes	Yes	48

Mary	18	20	9	2	Yes	Yes	29
Stan	21	57	7	36	Yes	Yes	64
Harley	10	19	2	9	Yes	Yes	21
Barb	17	25	33	8	Yes	Yes	58
Ana	39	42	3	3	Yes	Yes	45
Lori	25	26	1	1	Yes	Yes	27
Paul	23	45	24	22	No	Yes	69
Tina	33	34	2	1	Yes	Yes	36
Lauren	9	10	12	1	Yes	Yes	22
Erin	11	11	8	< 1	Yes	Yes	19
Colleen	15	33	30	18	Yes	No	63
Kirstin	12	18	6	6	Yes	Yes	24
Jon	18	27	1	9	Yes	Yes	28
Emily	17	23	31	6	Yes	Yes	54
Ashley	28	29	6	1	Yes	Yes	35
Roger	19	31	28	12	Yes	Yes	59
Kalli	40	41	1	1	Yes	Yes	42
Skye	16	17	3	1	No	Yes	20
Marcy	16	17	20	1	Yes	Yes	37

Table 5. Summary statistics of interviewee characteristics

Interviewee Characteristics	Summary Statistic
Age	38 years (mean)
Gender	85% female
Education	38% had BA or more
Marital Status	35% were married
Children	43% had children
Employment	53% were employed
PD diagnosis	83%
GAD diagnosis	75%
Agoraphobia diagnosis	30%
Other Mental Health Disorder	68%
On Anxiety Medication	85%
Still Experiences Symptoms	95%
Years between Diagnosis and Interview	13 years (mean)
Age at Symptom Onset	20 years (mean)
Age at Diagnosis	25 years (mean)

Appendix E. IRB Approval

University of New Hampshire

Research Integrity Services, Office of Sponsored Research
Service Building, 51 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

22-Oct-2009

Esala, Jennifer
Sociology, Horton SSC
21 Exeter Street #2
Newmarket, NH 03857

IRB #: 4636

Study: Biomedicine Meets Biofeedback

Approval Date: 30-Jun-2009

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Expedited as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 110 with the following comment(s):

1. Currently, the researcher is promising not to use the photographs in presentations or publications. She may find, however, that the pictures are both quite compelling and of interest to her audience. The researcher should consider developing a second form that secures permission for specific pictures to be used for an identified purpose. If she wants to do this, she would need also to make a minor modification in the proposed consent form before its use. The IRB would need to review both documents prior to their use.

Approval is granted to conduct your study as described in your protocol for one year from the approval date above. At the end of the approval date you will be asked to submit a report with regard to the involvement of human subjects in this study. If your study is still active, you may request an extension of IRB approval.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, *Responsibilities of Directors of Research Studies Involving Human Subjects*. (This document is also available at <http://www.unh.edu/osr/compliance/irb.html>.) Please read this document carefully before commencing your work involving human subjects.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB



Julie F. Simpson
Manager

cc: File
Dillon, Michele

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