IT’S NOT ‘JUST A HEADACHE’:
THE LIVED EXPERIENCE OF MIGRAINES IN THE WORKPLACE

by

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Abstract

IT'S NOT 'JUST A HEADACHE': THE LIVED EXPERIENCE OF MIGRAINES IN THE WORKPLACE

by

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This research explores the self-reported experiences of people with migraines in the workplace by examining individuals' own accounts. Specifically, I analyze: the employment experiences, perceptions, and workplace challenges of people with migraine headaches. Using a qualitative approach, this study examines various aspects of migraines from the individual employee's perspective in order to explore different topics as they relate to the workplace. In particular, the study concentrates on factors surrounding employee disclosure of migraines at the workplace.

Migraine is a serious neurological disorder. However, migraines are often not viewed as the legitimate neurological condition that they are. Migraines, while typically not a visible condition, are an intermittently disabling illness. Since migraines are, for the most part, a hidden condition (not visible to others), in order for an employee to receive workplace support, it requires that other individuals know about and understand the employee's condition. If the employee chooses not to tell those at work about his/her migraines, the employee might not receive support. The choice to disclose a hidden illness at work may be complex and influenced by many factors. There is limited scholarly research in the area of sociology that pertains to migraines in the workplace.

The social construction of illness is a major perspective in medical sociology. This study presents a unique examination of individuals with a hidden disability, migraine headaches, in the workplace. This exploratory study investigates the impact of migraines on the individual’s work experiences, the consequences of migraines on their work (such as attendance, productivity, work performance), how work affects migraines, the processes involved in disclosure, the factors that contributed to their decision whether or not to disclose, their experiences with workplace accommodations, challenges faced at work, perceptions of stigma, and examines how a condition such as migraines affects one’s perceived self-identity in the workplace, and other related topics. I explored the different accounts that study participants offered to make sense of their workplace encounters in various situations and how they assigned meanings to their interactions in the workplace. Using a social construction frame to interpret and analyze their accounts, I examined the lived experiences of migraines in the workplace.

I conducted qualitative interviews with 40 individuals who get migraines, from various ages, educational backgrounds, employment settings, and working in different occupations, in a range of titles, from across the United States.

This study presents several findings. The majority of individuals in this study cited stressful work environments, or other factors in the work environment, as contributing to migraines. Overwhelmingly, the theme that I heard most often, regardless of occupation, and regardless of the specific topic being discussed, was the lack of understanding in the workplace regarding what migraines really are and how migraines are different from a ‘regular headache’. A related theme was that of people at work not taking migraines seriously. These attitudes most likely originate from lack of knowledge. I provide examples that illustrated dramatic stories of long term career impact, individuals who made life-changing decisions, and others who had other long-term opportunities that were affected by migraines. Migraines impacted not only people’s careers, but also interfered with goals and plans.

I examine interview data to analyze how the participants managed the issue of disclosing their disability in the workplace. I examined the underlying factors behind the decision whether or not to disclose. I found that there were a range of factors that went into the decision to disclose, to whom to disclose, and even how much to disclose. I examined the factors that each individual took into consideration to make the ‘disclosure decision.’ Some participants took many factors into consideration, including a complex weighing of risks vs. benefits, whereas for others it was more of a natural decision. The majority of people who chose not to disclose, did so for reasons relating to stigma. A condition like migraines can be very challenging to an individual’s identity.

My selection of migraine as the condition for this research was a strategic choice aimed at providing an answer as to how disclosure of a hidden disability is handled at the workplace. This research places this topic within the range of different theoretical approaches to the study of hidden disability and medical sociology. By studying people’s own accounts of their experiences in the workplace, this analysis reveals the subjective experience of illness. The issues of disclosure, stigma, embodiment and identity, disability, health/illness, discrimination, accommodations, and the individuals’

perceptions, insights, and experiences, all fall within the realm of medical sociology and sociology of disability.

The sociological study of migraines in the workplace has implications for these fields. For the field of disability studies, it can provide insight into the perspectives of persons with a hidden condition such as migraine. For the study of medical sociology, it focuses on the perceptions of people with a hidden illness on their everyday situations, which helps ground our conclusions empirically. This work serves to raise awareness of migraine as a legitimate neurological disorder. My study demonstrates the burden that migraine placed on peoples' careers, employment status, and ability to work. For many, work life was a struggle to maintain the worker identity they wanted to project.

Aside from its contribution within the field, my study offers valuable information to family members, employers, policy makers, and practitioners who want insights relating to work. This exploratory empirical analysis contributes to the literature in medical sociology, disability studies, and occupational sociology, by including the first-person accounts and narratives of individuals with migraines. I explore understanding of the experience of migraines in the workplace within the wider scope of the lived experience of an invisible, episodic disability. This study offers a useful report through which the personal accounts and lived experiences of people with migraines at the workplace can be examined.

ACKNOWLEDGEMENTS

I watched my mother endure migraines for her entire life. However, she did not have to work outside the home. As a teenager, I began getting migraines too. Living with migraines in the workplace meant that I faced a number of challenges and I had to fight constantly against stereotypes. I wanted to research something different, something that had not been studied before. There are many people I wish to thank for bringing this project to fruition.

The National Headache Foundation does an excellent job of disseminating information about migraines. I thank the National Headache Foundation for their cooperation in distributing recruitment announcements about this research to members of their organization.

To my Committee: For Barbara: Thanks for stepping in when I needed you to, thanks for all the words of encouragement, thanks for not letting me give up when I wanted to, thanks for telling me that it really was time to let it go and stop fixing, thanks for responding to all my emails, and thanks for introducing me to my favorite disability-related book. You were a constant source of guidance. For David: Thanks for introducing me to the field of disability studies, thanks for being at my side during the FMC, thanks for teaching me how to ‘do’ qualitative methodology, thanks for your patience, thanks for sticking with me. For Ed: Thanks for being my champion, thanks for all the assistance you provided through the years: you will never be my ‘number three.’ All three of you have inspired me in different ways. I appreciate the time you took to make suggestions. Your comments and insights helped make this a stronger study and encouraged my academic growth.

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I thank all of the participants in this research, people with migraines from across the country, who provided the data for this study. They so generously shared their time and their stories with me. Their stories were emotionally charged, powerful, and some were heartbreaking. I hope that one day we will find the answers and relief that we seek.

I am grateful for the pets that I've shared my life with over the years, for being my constant companions: Tommy, Randy, Ginger, Kitty, Sheena, and now Bernie.

To my friends and colleagues: thank you for your support, patience, and love, and thanks for sharing my life, even when you didn't agree with me... Now you can show me what else is out there besides school.

To Pratik: who patiently read through some drafts, and for all your late-night last-minute computer advice, idea-bouncing, and technical expertise.

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To the two men in my life, one who was there at the first half of this journey and one who was there to see last half: Eddie and Vincent: Thanks for putting up with me and for being there. Vincent: thanks for your help in reading drafts, your ongoing support, and for understanding about the time sacrifices necessary to complete this project.

To one special constant in my life, Jerelyn, thanks for allowing me to think that this might be possible. I am especially grateful to you for giving me courage about this project. This is dedicated to her. I was able to finish this because of her encouragement. She is a constant source of encouragement and strength, and she has tremendous compassion for others.

It’s hard to believe that this journey has finally ended and the dissertation is a reality. I’ve lived through divorce, several job changes, moving many times, the death of both parents, death of friends, death of pets, my own sickness and near-death, and many other life changes, while working on the PhD, but I never gave up. Being a student at CUNY has been a constant in my life for so many years. I am both happy and sad that it is over. One of my professional goals has been realized. I express my deepest appreciation and thanks to the people who have contributed to this milestone.

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CHAPTER ONE: INTRODUCTION

My Story

I once had a job that I enjoyed very much. I worked on a college campus for three years as an Assistant Director (a managerial title), had a certain degree of autonomy and respect in my position, got along very well with my supervisor, had clerical support from a part time assistant, and I was paid a very good salary. In addition, the job required interaction with both faculty and staff in many different departments, and I had many friends there. The managers' union provided tuition reimbursement that helped towards my PhD degree, the college campus was located only a half hour from my home, and as an added plus, I had recently been reclassified into a higher title since I had taken on additional job responsibilities. I was a dedicated, responsible worker, with excellent job evaluations and an above average attendance record. Then one day, out of the blue, the bad news hit. The President of the College decided to re-locate our three-person department to a different building. What was the problem? The building that we were moving to was an older building on campus, and it was entirely without windows. I felt my heart sink as soon as I heard the news. Being confined to a windowless building, in the absence of any natural daylight, for 8 or more hours a day, every day, was a migraine trigger for me. I tried to convince the College administration why this relocation would not work for me, but they did not understand. So we moved. And I endured the situation for as long as I could. I began getting frequent, severe migraines with nausea and vomiting. I remember running out to the bathroom and vomiting. I remember hanging on to the toilet bowl and leaning my head against it because of the throbbing pain in my head. I remember having to leave work early so many times and bringing a plastic shopping bag onto the bus so that I could vomit. I remember feeling guilty for calling in sick to work because of a migraine. I remember taking more and more migraine medication, more than I should have, so that I could keep going in to work. The medication was supposed to be “as needed” but I began needing it more and more. All the while, I was pressing for the department to be moved to another building, but there was no action on that front. I remember my boss telling me that I looked like a ghost because I was so pale all the time. I remember shaking and shivering from the pain, while trying to sit at the computer. I had to start taking a daily preventive medication in addition to taking the “as needed” medication more and more to control the migraine attacks. I remember getting off the bus along the route home and vomiting into the garbage pail at the corner and someone asking me what was wrong. Finally, I remember being taken to the hospital because I took too much medication. In the Emergency Room, the doctors told me that my blood pressure had gone so high that I could have had a stroke. After about six months, I ended up having to take a medical leave of absence from that position. Eventually, I knew I could not return there, so I applied for a transfer to another facility. I was so desperate, that I accepted a position that was almost two hours away from my home, in a lower title, and at much lower salary level. The Director of the department where I had been working left shortly after I did. The new Director was successful in getting the Office relocated back to the original building, where it rightfully belonged. I filed a Worker’s Compensation claim, went to court several times, and was successful in regaining my lost sick time from the medical leave. However, almost five years later, I still remain in that position that is far from my home, at the lower salary and lower job title. I sometimes wonder if I will ever be able to get back to the career level and salary that I once had attained.

The above is *my story,* an example of what can happen when migraines are not taken seriously in the workplace. There are stories of 40 other individuals contained in this study. I study the experiences of people with migraines at the workplace, by speaking with individuals who get migraine headaches.

I conducted 40 qualitative interviews with individuals in different occupations as an exploratory analysis of this topic. The people whom I studied for this dissertation all experienced migraine headaches while in the workplace. This study investigates the impact of those migraines on the individuals' work experiences, the processes involved in disclosure of migraines, and explores perceived self-identity and stigma in the workplace.

Chapter 1 of this study is provided as an Introductory Chapter. I have organized Chapter 1 into six sections. In the first section, I introduce the purpose of the study and provide the reader with the statement of the problem. In the second section, I provide some basic information on chronic illness, medical sociology, and disability. The sociological study of migraine in this dissertation must be understood within the context of each of these areas. In the third section, I introduce some basic migraine information. This is provided to give the reader an introductory background; a more thorough review is provided in Chapter 2, Review of the Relevant Literature. In the fourth section, I discuss the importance and practical significance of researching chronic illnesses, and in particular, migraines. The fifth section contains information about my relationship to the research. This section discusses why I chose this topic, aside from the fact that I found it professionally and personally interesting, and contains some comments about how being a person with migraines presented both opportunities and challenges as a researcher. The sixth and final section of this Chapter provides an overview of the remaining chapters of the dissertation.

Statement of the Problem / Purpose of the Study

People who experience migraines in the workplace may be stigmatized as weak or self-indulgent if they need to take time off from work or if they request other accommodations. Migraines are often not viewed as the legitimate neurological disorder that they are. Migraines, while typically not a visible condition, are an intermittently disabling illness.

How do we critically assess/challenge the assumptions about migraines in the workplace? Using a qualitative approach, this dissertation examines the experiences and perceptions of people with migraines in the workplace. It reveals people's own accounts of their experiences.

Much attention has been given in the literature to work-related causes of chronic illness and the impact of chronic illness on work productivity. Less attention has been paid to the management of chronic, episodic illness from the employees' perspective.

Sontag states:

> "Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick. Although we prefer to use only the

> good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place." (Sontag, 1978, p. 3)

Specifically, this study examines the workplace experiences and explores perceptions (including perceived self-identity) of people with migraine headaches, using a qualitative interview methodology.   "Disability" is no longer defined only as persons with visible physical disabilities, but also more broadly includes "hidden" or "invisible" disabilities.   This research addresses many topics including identity management, accommodations, and disclosure management. What does it mean, sociologically, to have a migraine in the workplace?

Many factors are involved in the decision to disclose and how much to disclose. Once disclosed, there are expectations as to how the disclosure is to be received. There are also consequences of disclosure that may do more harm than good. This dissertation examines what is behind the decision whether or not to disclose, the underlying factors that go into this decision, as well as the consequences of disclosing and the reactions to disclosure. The second related question is what happened with those who did not disclose. Within the participants' stories are the depths of the experiences of the individuals who live with the chronic illness of migraines.

This dissertation represents an attempt to study various aspects of migraines as they relate to the workplace. In the process, it places this topic within a range of different theoretical and methodological approaches to the study of disability and medical sociology.   This research study explores how individuals with migraine headaches handle various workplace experiences.

How is disclosure of hidden disabilities handled in the workplace? My selection of migraine as the disability/condition of study is a strategic choice aimed at providing a unique answer to this question.   I examine how people with migraines assign meanings to their interactions in the workplace. As I describe, the social construction of a migraine in a given context is contingent on the lives of the individuals or groups that are doing the constructing.

Also, since not all migraines in the workplace are disclosed in the same way, this has an impact on the circumstances as well. For example, some people choose to disclose whereas for others, the migraines becomes evident, or they did not necessarily want to disclose but were 'discovered.'

This dissertation aims to analyze how disclosure is structured or patterned, the paths workers take through this decision, and the reactions of co-workers and supervisors to these individuals. This dissertation focuses only on individuals with migraine headaches. This limitation is partially practical; a good deal of scholarly work already exists on other hidden disabilities.

I use qualitative inquiry and a semi-structured, open-ended interview process, seeking the personal stories and experiences of the individuals in this study through a series of focused, qualitative questions. I chose this method because I believed it was most appropriate for this type of study: listening to the participants talk about what is on their minds, collecting and producing descriptive data from their spoken words. I chose a social constructionist approach because it is designed to encourage people to talk about what is important to them. I study a non-representative sample of 40 individuals, the majority of whom were recruited through the cooperation from the membership of the

National Headache Foundation. Participants were self-selected and represented a wide range of occupational titles. I use telephone interviews and in-person interviews. The interview itself is modeled around an interview guide consisting of six major sections: 1) a discussion of the employee's migraine condition; 2) a discussion of the workplace; 3) the effect of the illness at work; 4) disclosure and reactions; 5) work adjustments sought and received; and 6) demographic and background information. The methodology is discussed further in Chapter 4, Methodology/Research Design.

Chronic Illness, Medical Sociology, and Disability

Migraines fit into the category of chronic illness.

> "While chronic illness, such as rheumatoid arthritis, do not fit the more taken for granted understanding of disability – usually because they are less visible or invisible – they still comply with the criteria set forth by the United Nation's definition of disability in that they restrict the ability of a person to perform the activities of daily living…It bears remembering that there is no precise or universally accepted definition of disability: defining disability is a practice of power wherein the category can be contracted or expanded in accordance with the vested interests of the definer." (Jung, 2002, p. 178)

The definition of disability is examined further in Chapter 3, Definitions of Disability.

Conrad (2007) made the following observation about the changing nature of the field of medical sociology over time:

> “…the 1970 publication of Eliot’s [Freidson] *Profession of medicine* … fundamentally shifted the parameters of medical sociology… and the ways in which issues around health and illness could be sociologically examined... By 1970, medical sociology was already an established, though probably undervalued, intellectual area in sociology. Central concerns of medical sociology were the various forms of social epidemiology, utilization of medical services, illness behavior, the sick role, studies of hospitals as organizations, doctor-patient interaction, research on medical socialization, and so forth. In retrospect one can see several approaches to medical sociological topics emerging before this time. One thread was the Chicago-trained fieldwork types who were studying patients, illness and medicine largely from what might be called ‘insider’ perspectives. These researchers were asking questions about patient perspectives, the impact of medical institutions on health, patient careers and illness identities, professional socialization and professional influence and conceptualizing doctor-patient relations…. (Conrad, 2007, p. 142)

It is this type of ‘insider’ perspective -- an illness identity analysis -- that is employed in this dissertation.

Brief Information on Migraine, Understanding Migraine

Migraines are worthy of study for several reasons: Migraines are a national health issue and an important target for raising awareness. The following is some basic introductory information on migraine; an expanded review is provided in Chapter 2, the Review of Relevant Literature.

Migraine is a chronic neurological disorder that produces episodic attacks characterized by pain, associated symptoms, and often temporary disability (Stewart, Shecter, & Lipton, 1994). The severity of migraine varies among individuals, ranging from mild pain with no disability to agonizing, completely incapacitating pain (Stewart, Schecter & Lipton, 1994). Treatment for migraine differs according to the severity of illness and other factors (Lipton & Silberstein, 2001).

Migraine is characterized by attacks that vary in frequency, duration, severity, and symptomatology; this variability exists among different sufferers and in the individual over time (Holmes, MacGregor, & Dodick, 2001; Stewart, Shecter, & Lipton, 1994). The symptoms of migraine vary but most commonly include aura, headache, and nausea (Holmes, MacGregor, & Dodick, 2001). The headache is usually throbbing, unilateral in over 70% of cases, and moderate to severe in pain intensity (Scher, Stewart, & Lipton, 1999). There are debates about the nature of migraines. I provide further information about this in Chapter 2, Review of the Relevant Literature.

The disability caused by migraine ranges from mild headache with no disability to intense pain with associated symptoms, such as vomiting, that produces prolonged incapacitation (Stewart, Shecter, & Lipton, 1994). In a given patient, the severity often varies among attacks. Not surprisingly, the people who are more disabled by migraine account for the great majority of lost work time associated with migraine (Stewart, Lipton, & Simon, 1996; Von Korff, Stewart, & Simon, 1998). Migraine-related disability contributes to suffering and drives the high indirect costs of reduced work productivity (Ferrari, 1998).

A United States study indicated that women (68%) were more likely than men (57%) to consult a physician for migraine, and that older people, especially those over 50 years of age, were also more likely to consult (Breslau & Rasmussen, 2001). Features of the migraine attack were also associated with consultation, again with some differences between the genders. For women, pain intensity, the number of associated symptoms, attack frequency and duration, and the presence of headache-related disability were positively correlated with consultation compared with only nausea and vomiting in men (Breslau & Rasmussen, 2001). I provide figures about the incidence and prevalence of migraines in Chapter 2, Review of the Relevant Literature.

Measuring migraine severity helps target patients who differ in their treatment needs (Lipton, Stewart, & Simon, 1998). However, measuring severity/impact of migraine is challenging because of the episodic occurrence of attacks and variation in impact from one attack to the next (Holmes, MacGregor, & Dodick, 2001; Stewart, Shecter, & Lipton, 1994). In a single individual, headaches may vary in level of pain, duration, associated symptoms, and disability (Stewart, Lipton, & Dowson, 2001).

Our current conception of migraines is part of a socio-historical process that included conceptions of this illness that are inconsistent with our current ideas. Migraine has been associated over the years with misdiagnosis and stigma, and our current conceptualizations regarding migraine and current approaches to treatment are different from those of years past. Below is a fascinating example containing a description of historical information about how migraines were perceived:

> “In 1878, physician William Henry Day struck a figurative blow that hurt the next several generations of migraine sufferers…Migraine, to that point, with the writings of such experts as Edward Liveing (1873), was understood to have its origins in the sorts of things migraine patients *did* (they worked too hard, slept too little, fretted too much)…Day shifted attention from what migraineurs *did* to who they *were.* ‘*Such persons’*, he said of migraineurs, ‘go on working against time with an ardour and zeal which they feel to be irresistible (1878**,** p.186, emphasis added). ..Day invented the ‘migraine personality’, an idea that was to dog migraine patients for at least a hundred years…migraine patients, as a class, were described as untrustworthy…known to feign headaches for personal gain…also ‘up to 90% have a psychogenic basis for their complaint’ (Diamond & Dalessio, 1973, p. 81) and they ‘may overuse or abuse their medications’(Diamond & Dalessio, 1973, p. 94)” (Segal, 2007, p 227-228).

Significance / The Importance of Researching Chronic Illness - Migraines

According to the National Headache Foundation (2010), “…migraine and other headache disorders cost the US more than $31 billion and 9% of all lost labor annually…20% of all Americans will experience some form of migraine this year…” (NHF Headlines, May/June 2010, p.11.)

This topic is worth studying in a practical sense because the sociological study of migraines in the workplace has implications for many fields. For the field of disability, it can provide insight into the perspectives of persons with a hidden disability/condition such as migraine. This work fits into both medical sociology and the study of health and illness. It focuses on the perceptions of people with a chronic illness, on their everyday workplace situations. Concentrating on everyday situations helps ground our conclusions empirically and allows us to find ways to improve the lives of people with migraines. This work also serves to create more understanding about the lives of these individuals and raises awareness of migraine as a legitimate neurological disorder. There are also implications for workplace/industrial/occupational sociology, in the areas of workplace accommodations and workplace identity. This analysis, therefore, will make a significant contribution to the field of sociology.

This exploratory empirical analysis contributes to the literature in both medical sociology and disability, by including the first-person accounts and narratives of individuals with 'migraines' into disability studies. The field of 'disability studies' construes the discipline to be based primarily upon the experiences of people with disabilities (Albrecht, Bury & Seelman, 2001). This is a strong justification for taking the experience approach that I use in this study.

Ruth O'Brien, a prominent disability studies scholar and professor, discusses a prominent theme in disability studies:

> "The field of disability studies emerged, in large part, because of the frustration that persons with disabilities felt about how doctors and other professionals involved in rehabilitation turned the individual – the

> person with an impairment – into the problem…Persons with disabilities must take responsibility for their impairments and figure out ways of circumventing the obstructions before them. The consequence of this disability model means that the individual should accommodate society, rather than having society accommodate those with disabilities.”
> (O’Brien, 2004, p. 155).

This sentiment is echoed by other scholars such as Simi Linton: “Disability studies protests the individual explanation, arguing that it is ‘ablism,’ or discrimination in favor of the able-bodied” (as quoted in O’Brien, 2004, p. 155 – from Linton’s *Claiming Disability*, p 9).

Therefore, this current research is based on and relevant to many different disciplines. It has the ability to bridge the disciplines of medical sociology, sociology of health and illness, disability studies, work and occupational sociology, and to some extent, feminist studies. I locate this study within an interdisciplinary context, even though it is primarily based upon sociological methods and theories.

My Relationship to the Research

I have been a person with migraines (PWM) since I was a teenager. When I initially sought to find a dissertation topic, I wanted to research something that would be able to fit into my three main fields of interest --- disability, medical sociology, and sociology of the workplace. I have been employed since I was 16 years old, and dealing with migraines in the workplace always has been a concern for me. I’ve had negative experiences; the most dramatic experience is the one that I outlined at the beginning of this Chapter. However, there have been others. There have been times when stress was a trigger and affected my ability to perform. Once during a stressful period when I was responsible for coordinating a four-day conference along with my colleagues, I ended up missing part of the conference because I had to stay in the hotel room with a migraine. At another job, where a 10-day business trip was required once a year, I was always miserable on the travel days because airline travel is a trigger, especially when changing time zones. I've been in situations in which having migraines at the workplace affected the way I felt about both myself and my job performance. I've had bosses and co-workers who understood and were empathetic, but I've also worked with bosses and co-workers who were completely the opposite.

I began to wonder about other people's experiences. How did other people handle their migraines in the workplace? Did they let co-workers and supervisors know about their migraines, or did they try to conceal them? Was it different for men than for women? What about in different occupations? Were their migraines taken seriously? I was interested in finding out about the experiences of other people in different types of occupations and workplaces.

I did a preliminary literature review and discovered that there was extremely little scholarly research in this area. I knew that I had found a topic of both personal and professional interest, to which I could make a contribution to the literature. Using a qualitative research method approach allowed me to hear the stories of the 40 participants.

Being a person with migraines presented both opportunities and challenges as a researcher in a study such as this one. I found that I could identify with the participants in this study, and more often than not, I was familiar with the names of the medications and treatments that they provided and the symptoms that they shared with me. Some of the participants asked me if I got migraines too, and many voiced appreciation at being able to share their stories with someone who "understood." Yet, at the same time, it presented a challenge in that I had to constantly remain on guard to stay neutral in my role as researcher, and to not provide any guidance or advice to the participants in this study.

Organization of the Dissertation

This dissertation is organized into seven Chapters, followed by an Appendix and Bibliography. Chapter 1, Introduction, is an introductory chapter, describing the purpose of the study, providing some background, and outlining the organization of the dissertation. Chapter 2 provides a review and examination of relevant literature that provides the framework for this study: models of disability, social construction, stigma, the sick role, health and illness, chronic illness, migraines, self-identity, disclosure, the Americans with Disabilities Act, and a brief theoretical perspective. I review the incidence of migraine and chronic illness overall. Chapter 3 contains material relating to various definitions of disability that are relevant to the study in order to provide the reader with a broad perspective within the larger literature. This includes the difficulty inherent in defining disability, sociological definitions, the legal definition according to the Americans with Disabilities Act, specific cases presented before the Supreme Court and analysis of the rulings and the implications. Chapter 4 outlines the full description of the research design and qualitative methodology I use for this study. This includes a discussion of the choice of research method, a description of the research questions, selection and recruitment of participants, key measurement issues, data collection and study procedures I use, protection of study participants, and data analysis and interpretation. In this Chapter, I also explain my reasoning about why qualitative inquiry is an appropriate research method for this study.

Chapters 5 and 6 are the data and analysis chapters. These chapters contain a description and analysis of a series of themes and patterns that emerged from the 40 participant's stories about their work and their experiences with migraines.

In Chapter 5, I concentrate on the portion of the workplace data relating to three main areas: 1) the relationship between migraines and work, including effects, experiences, and consequences, 2) workplace accommodations, and 3) career impact. Within these three broad areas, I focus on the following seven topics: 1) effects of the workplace on the person, such as work environment or stress, 2) effects of the workplace on the person, with a focus on work-related triggers, 3) workplace challenges, such as lack of understanding and bad experiences, 4) what a migraine feels like, 5) consequences of migraines on work, including attendance/absenteeism, productivity/work performance, and other consequences, 6) workplace accommodations, and 7) life-changing career impact, such as missed opportunities and career choices.

In Chapter 6, I concentrate on the portion of the workplace data relating to the three main areas of disclosure, stigma, and self-identity. Within these three broad areas, I focus on the following seven topics: 1) the decision to disclose or not to disclose, 2) factors involved in disclosure, 3) reactions and responses to disclosure, 4) factors involved in non-disclosure, 5) ‘passing’ strategies and hiding/coping mechanisms employed in non-disclosure, 6) perceptions of stigma (if any), and 7) perceived self-identity.

In Chapter 7, the final chapter, I present five main areas: 1) a summary of the research and demographic data, 2) the findings/conclusions of the research, 3) a brief discussion of recent developments: in migraine treatments, and in legislation pertaining to the Americans with Disabilities Act (ADA), 4) the limitations of this project, and 5) the implications of the findings, along with an identification of possible directions for future research. I then provide my closing thoughts.

The Appendix contains the consent forms, recruitment letters, and the interview guide. A bibliography follows the Appendix.

CHAPTER TWO: REVIEW OF THE RELEVANT LITERATURE

This dissertation examines the social construction of migraine headaches in the workplace. I explore various issues relating migraine to disability and/or medical sociology, such as disclosure, stigma, labeling, the definition of disability, and workplace accommodations. Therefore, this Chapter 2, Review of the Relevant Literature, touches upon all of the following areas: Models of Disability, Social Construction, Stigma, the Sick Role, Labeling, Deviance, Legitimacy, Passing, Health and Illness, Chronic Illness, Disclosure, the Americans with Disabilities Act, Social Identity and Self-Identity, and some theoretical perspectives. Since it would be impossible to cover all aspects of these broad concepts, I concentrate on what is most relevant to my research. Chapter 3 covers the Definitions of Disability.

Although volumes of books and journal articles have been written to explain various aspects of migraines, mostly from a medical, neurological, psychological, or economic standpoint, there is limited scholarly research in the highly significant area of *sociology that pertains to migraines in the workplace*. When sociological literature was found, it pertained mostly to interpersonal issues, such as: the effects of migraine on spousal relations or child care, or the physician/patient relationship. Nothing on the sociology of migraine as it pertains to employment (with the exception of economic burden/impact) appears to be available.

1. Understanding Migraine

Migraine is a neurological disorder. Advances have been made over time in the understanding of the epidemiology and underlying mechanisms of migraine (Silberstein, Lipton, & Goadsby, 1998; Sacks, 1999.) Several effective new acute and preventive therapies have been introduced over the years. However, migraine remains relatively under-recognized, under-diagnosed, and under-treated (Lipton, Diamond, & Reed, 2000.)

Migraine is a heterogeneous condition that results in a spectrum of disability within and among different individuals (Stewart, Shecter, & Lipton, 1994). Disability from migraine can be measured as time lost from paid work, household work, school, and family, and from social and leisure activities (Lipton, Stewart, & Goadsby, 2001). While it can be relieved by successful treatment of the headache during an attack, migraine-related disability can be severe and imposes a considerable aggregate burden on the affected individual and on society (Lipton, Stewart, & Goadsby, 2001). People with migraines who have no health insurance are less likely than those with health insurance to receive proper treatment (Wilper, Woolhandler, Himmelstein, & Nardin, 2010).

Definition. In his classic work, *Migraine,* originally published in 1970, neurologist Oliver Sacks provides this very powerful definition of migraine: "A migraine is a physical event which may also be from the start, or later become, an emotional or symbolic event. A migraine expresses both physiological and emotional needs: it is the prototype of a psychophysiological reaction." (1999, p. 7)

History. According to Sacks, "Migraine affects a substantial minority of the population, occurs in all civilizations, and has been recognized since the dawn of recorded history. If it was a scourge, or an encouragement, to Caesar, Paul, Kant, and

Freud, it is also a daily fact of life to anonymous millions who suffer in secrecy and silence." (1999, p. 1). Additional historical information can be found in Chapter 1.

Incidence. Incidence refers to the rate of occurrence, i.e., the number of new cases or events; the frequency within a certain time period. According to Sacks, "Figures are only available on the incidence of migraine headache (cephalgic migraine), and these vary between estimates of 5 per cent and 20 per cent for its incidence in the general population." (1999, p. 119).

Prevalence. Prevalence refers to how widespread something is, i.e., how many people currently have that condition; it includes the old cases diagnosed from earlier years plus new cases diagnosed this year. Many articles in the literature have discussed the prevalence and/or burden of migraine in the United States. Lipton, Stewart, Simon, Diamond, Diamond, and Reed (2001) used a self-administered questionnaire mailed to 20,000 households in the United States, and found the prevalence of migraine was 18.2% among females and 6.5% among males. Breslau and Rasmussen (2001) reviewed epidemiologic studies that revealed the considerable impact of migraine, in terms of the number of people affected and the consequences for the individual. They found that the prevalence of migraine varies with age, gender, race, socioeconomic status, and geographic location (Breslau & Rasmussen, 2001).

In terms of numbers, the National Headache Foundation currently estimates that there are about 30 million people with migraines in the United States (National Headache Foundation, NHF Headlines, Summer 2010, page 11). "According to the American Migraine Foundation, 36 million Americans suffer from migraines…with women being affected three times more often than men…" (North Shore Long Island Jewish Health Network, Vitality, Spring 2011, p. 10).

"Approximately 12% of the US population suffers from migraine, and up to 18% of women between the ages of 16 and 40 have migraine." (National Headache Foundation, NHF Headlines, Winter 2011b, Number 177, p.13)

Impact/ Disability/ Effects/ Burden. In one of the studies mentioned above, Lipton, Stewart, Diamond, Diamond and Reed, (2001) found that 53% of the individuals with migraine reported that their headaches were so severe that they caused substantial impairment in activities or required bed rest. Approximately 31% missed at least one day of work or school in the previous three months because of migraine.. Stafford and Shoquist state: "About 28 million Americans have migraine headaches. According to the National Headache Foundation's report on the American Migraine Study II, about 53 percent of migraine sufferers have headache pain that causes severe impairment or forces them to retreat to bed." (2003, p.11)

Other studies conducted have found that about three-quarters of individuals with migraines have a reduced ability to function during attacks (Holmes, MacGregor, & Dodick, 2001; Stewart, Shecter, & Lipton, 1994), with more than half reporting severe disability or the need for bed rest (Stewart, Shecter, & Lipton, 1994). Two population-based studies conducted in the United Kingdom and the United States showed that about half of individuals with migraine experienced significant (moderate to severe) health-related disability (Stewart, Lipton, & Kolodner, 1999; Stewart, Lipton, & Sawyer, 1999). The consequences of attack-related disability are seen in defined roles, including employment, household work, and non-work activities. Moderate to severe migraine attacks can cause lost time from work. Using diary data in a population sample, one study (Von Korff, Stewart, & Simon, 1998) showed that, on average, individuals with migraine who were in paid employment missed 4.4 days of work per year and experienced the equivalent of 12 additional days of lost work time per year due to reduced productivity from attacks. The most severely affected individuals accounted for most of the reduced work performance.

Holmes, MacGregor, and Dodick (2001) reviewed the burden of migraine on individuals and on society. They found that headache-related disability results in suffering for migraine patients and their families, drives the direct medical costs of treatment, and counts for the high indirect costs of illness resulting from reduced work productivity (Holmes, MacGregor, & Dodick, 2001). Headache-related disability affects most aspects of daily life, including employment, household work, and non-work activities (Holmes, MacGregor, & Dodick, 2001).

Lipton, Stewart, Simon, Diamond, Diamond and Reed (2001) found that over half of individuals with migraine reported that work productivity was reduced by at least 50%. One study found that migraines can cause people to lose an average of four to six days of work each year (Wilper, Woolhandler, Himmelstein, & Nardin, 2010).

Impact on Employment/ Unemployment. In terms of specific employment impact, the effect can be huge, both for the employee as well as for the employer. Stafford and Shoquist state:

> "Unfortunately, migraines cause children to miss school and adults to miss work. In fact, some employers grow so leery of migraine-ridden employees that they look askance at this kind of problem. To them,

> it translates to diminished attendance and low productivity. And, according to a study published in *Archives of Internal Medicine – April 1999* – employers have reason for their interpretation. The study cited migraine costs of $ 13 billion a year for American employers due to employees' missed work and lower productivity." (2003, p. 11)

One study found that the unemployment rate among individuals severely affected by migraines was two to four times higher than that of the general population (Von Korff, Ormel, & Keefe, 1992). Given these figures, one could estimate the high economic impact of migraines on the economy.

Wilper, Woolhandler, Himmelstein, and Nardin (2010) analyzed data from two federal surveys, the National Hospital Ambulatory Medical Care Survey and the National Ambulatory Medical Care Survey, in order to obtain a nationally representative sample of all U.S. visits to doctors, hospital clinics, and emergency rooms. They analyzed 6,814 visits for migraine between 1997 and 2007. This study found that migraines can cause people to lose an average of four to six days of work each year. (Wilper, Woolhandler, Himmelstein, & Nardin, 2010).

Causes. Migraine etiology involves an interaction between inherited characteristics, which predispose individuals to migraine, and exposure to specific internal factors and/or external environmental factors (Breslau and Rasmussen, 2001.) The neurologist Oliver Sacks makes the following statement in his now-classic work on migraines, about how individuals attribute the cause of their migraines:

> "Many patients consider their migraines to occur 'spontaneously' and without cause. Such a view leads, scientifically, to absurdity, emotionally, to fatalism, and therapeutically, to impotence. We must assume that all attacks of migraine have real and discoverable determinants, however difficult their elucidation may be. The determinants of migraine are almost infinite in number, and may present themselves in many different combinations." (1999, p. 117)

Symptoms. Migraines are not just 'a bad headache.' The key symptoms are a throbbing, one-sided, intense, severe head pain, of long duration, accompanied by nausea and vomiting and/or sensitivity to light and sound. Stafford and Shoquist provide the following list of possible symptoms of migraine, which they state is not an exhaustive list:

> "….a throbbing or hammering pain on one or both sides of your head…the pain ranges from moderate to severe to almost intolerable…you may experience an *aura*…you may feel lethargic and sad…along with the headache, you may experience nausea, vomiting, malaise, an extreme sensitivity to light, smells, and/or sounds." (2003, p. 12)

Migraines can cause significant distress, and are often characterized by excruciating headache and nausea (Wilper, Woolhandler, Himmelstein, & Nardin, 2010).

According to Stafford and Shoquist,

> "A migraine is essentially a headache and more. Because your central nervous system's normal state of functioning is disrupted during a migraine, all your body systems are affected. As a result, you may be bothered by sounds, smells, and lights…It's widely agreed that the symptoms of migraines can be different for each individual." (2003, p. 13)

Diagnosis. One study sought to examine whether people with migraine have been diagnosed (Lipton, Stewart, Celentano, & Reed, 1992). In a sample of the United States population, the researchers sought to determine the proportion of people with migraines diagnosed by a physician and to identify the headache characteristics and socio-demographic profiles associated with undiagnosed migraine. They used a mail questionnaire survey sent to 15,000 U.S. households, selected to be representative of the population. They found that diagnosis was more likely in females, in people with high income levels, and in individuals who reported migraine associated with vomiting, disability, or aura. An aura, which is experienced by a relatively small percentage of people with migraines, is "…typically, a visual disturbance that lasts from a few minutes to less than an hour, or numbness and tingling of the mouth area and arms…" (Stafford & Shoquist, 2003, p. 12) and may also include the following symptoms: "… speech problems, distortions of smells and sounds, numb hands, feet, and lips." (p. 15).

In a related study, Lipton, Stewart, and Simon (1998) sought to determine the proportion of people with migraines who ever consulted a doctor for headache and to identify the headache characteristics and socio-demographic factors associated with consulting. They sent a questionnaire to 2,479 people with migraines to assess headache characteristics, patterns of medical care use, medication use, and method of payment. They found that consultation was more likely with increasing age and married women. In females, several headache characteristics including pain intensity, number of migraine symptoms, duration, and disability were associated with consultation.

Although severely affected individuals tend to receive more medical care than those less affected (Lipton, Stewart, & Simon, 1998), over half of all people with migraines stated that they have not received a migraine diagnosis from a physician (Lipton, Stewart, & Simon, 1998; Richard, Massiou, & Herrmann, 1999; Stang and Von Korff, 1994), and of those patients who did receive an accurate diagnosis, many do not receive effective therapy (Lipton, Amatniek, & Ferrari, 1994) that provides them with the intended result.

Pain/ Classification/ Assessment. A number of measurements and scales have been used to classify migraine pain. Stewart, Lipton, and Dowson (2001) describe the Migraine Disability Assessment (MIDAS) questionnaire, a tool that exists to quantify headache-related disability for use in clinical practice. This tool uses a focused set of questions to capture the critical elements of the individual burden of migraine (Lipton, Stewart, & Goadsby, 2001.) Lipton, Stewart, and Goadsby (2001) concluded that an assessment of headache-related disability can improve health care delivery for people with migraines, and that the more disabled group of migraine sufferers have the most to gain from effective medical care.

Quality of Life. Holmes, MacGregor, and Dodick (2001) also demonstrate that increasing severity of migraine is accompanied by decreasing health-related quality of life. When a health-related quality of life questionnaire (the Medical Outcomes Study

Short Form 36, or SF-36) was used to compare migraine with other chronic diseases, it was found that people with migraine had more pain and restriction of their daily activities than patients with depression, osteoarthritis, diabetes, or hypertension, with especially poor function in mental health and social aspects of daily life (Osterhaus, Townsend, & Gandek, 1994). Migraine is therefore not an insignificant condition.

In attempting to assess health-related quality of life of people with migraine, Terwindt, Ferrari, Tijhuis, Groenen, Picavet, and Launer (2000) used a cross-sectional study and a semi-structured telephone interview, to compare health-related quality of life of people with migraine to those without migraine. Results showed that, compared to people without migraines, people with migraines reported diminished functioning and well-being. Compared to others with chronic conditions, people with migraines report lower physical, mental, and social functioning, particularly those with a high frequency of attack.

A survey recently released by the National Headache Foundation, found that three out of four people with migraines said that their current medication didn’t work fast enough (NHF Headlines, Summer 2010, page 11.) This survey, the National Migraine Treatment Survey, asked 500 clinically-diagnosed migraine sufferers between the ages of 25 and 45 about their migraine attacks, treatment satisfaction and experiences, and prescription medication. (NHF Headlines, Summer 2010, page 11.)

Relevance. According to Sacks, the study of migraine will always be relevant:

> “The chief features of migraine – its phenomena, and how these are experienced by the patient, its mode of occurrence, the triggers that may provoke it, the general ways in which one may live with it or combat

> it – none of these has changed in 2,000 years. Thus a vivid and detailed description of these matters is always relevant, and cannot become obsolete.” (1999, p. xv)

Readers who are unfamiliar with what a migraine ‘feels like’ may want to glance ahead at the section of Chapter 5 entitled ‘What a Migraine Feels Like’ before continuing below, to get a sense of the experience of migraine.

2. Theoretical Perspectives in Sociology

a. Social Construction

The social construction approach reflects that society – people and their actions – are involved in the ongoing process of becoming, and that society is in a constant negotiation of reality (Berger & Luckmann, 1966; Blumer 1969). The definition of something as a problem itself can involve social conflict between different groups (Brown, 1995). The history of medicine consists in large part of how disease has been defined and re-defined in society. The framing and reframing of the cause of and care for diseases were influenced by shifting scientific paradigms as well as changes in the structures of society (Brown, 1995; Rosenberg & Golden, 1992). Examining migraines through a social construction approach allows for a deeper understanding of migraines in the context of social forces.

“The social construction of diagnosis and illness is a central organizing theme in medical sociology. By studying how illness is socially constructed, we examine how social forces shape our understanding of actions towards health, illness, and healing”

(Brown, 1995, p. 92). Social construction involves a condition and a definition, and the condition is either generally accepted or not accepted, where the biomedical definition is applied or not applied, the presence or absence of a specific indication of the condition on the part of medical science (Brown, 1995, p.103).

Individuals can have the same condition, yet experience it very differently. Differences in perceptions of health problems often originate from race, class, sex, and ethnic and national differences, as found in Zola's research (1973) on patient help-seeking behavior in three clinics. In addition, for people with stigmatizing illnesses, some of the illness experience is concerned with avoiding public awareness.

Freund and McGuire provided the following explanation about social construction and health:

> "To construct is to make or build something. Because they are social constructions, our ideas about the body and its health and illness are influenced by both our culture and our social position, such as class or gender. Both cultural factors and social structural factors are important in understanding people's behavior regarding their health. People act as they do not only because of their beliefs about the cultural aspects of health, but also because of structural aspects, such as how power is distributed and relationships are organized." (Freund & and McGuire, 1999, p. 4)

The difference between 'disability' and 'impairment' (discussed further in an upcoming section) is one example of the use of social construction in the field of disability studies:

> “In a constructive mode first articulated by the late Irving Zola of Brandeis University, disability scholars make the distinction between impairment and disability. An impairment involves a loss or diminution of sight, hearing, mobility, mental ability, and so on. But an impairment only becomes a disability when the ambient society creates environments with barriers – affective, sensory, cognitive, or architectural. For example, a person using a wheelchair is only disabled if there are no ramps, a Deaf scholar is only disabled if there is no interpreter provided at a conference; a blind scholar is disabled in the absence of large-type or Braille texts, or a computer and scanner.” (Davis, 2002, p. 41)

b. Stigma

The self-perceptions of individuals with disabilities can be greatly influenced by the attitudes and expectations of others. In his classic work on sociology, *Stigma: notes on the management of spoiled identity*, Goffman (1963b) refers to "spoiled identity," a state of being discredited or stigmatized. He identifies "stigma" as an attribute that is deeply discrediting, and a stigmatized person as one who is thought to be “not quite human.” (1963b, p.5). Goffman (1963b) has asserted that interactions between individuals with physical impairments and persons without physical impairments will elicit discomfort and emotional arousal in the non-disabled individual. He calls this uneasiness the "pathology of interaction" (Goffman, 1963b). Goffman (1963b) used a theoretical framework to comprehensively analyze the issues facing an individual with a “spoiled identity.”

Stigma is not a simple concept, however. It is not experienced the same way for all people. Instead, it is a complex phenomenon that can be expressed subtly and/or overtly. The way stigma is experienced can depend partly on the nature of the stigmatizing condition, the specific situation, the social circumstances of the individual, and whether the condition is visible or invisible. Stigmatized individuals can be discounted and discredited – reduced in the minds of others from being whole and acceptable individuals to those whose identities are spoiled or tainted (Goffman, 1963b).

According to Mead (1934), the self arises through the process of interaction with others as the individual becomes an object to himself and takes the attitude of others toward himself. Cooley’s (1956) concept of the ‘looking glass self’, which is based on an individual’s perception of how others evaluate him/her, is consistent with this theory. In the case of the stigmatized persons, their opportunities in life are lessened, and they are set apart from others, which leads to social rejection and social isolation (Goffman, 1963b).

Illnesses can be stigmatizing because they represent potential or existing physical limitations; they are associated with negative images and myths, and therefore they can take on symbolic meaning (Sontag, 1978). The specific nature of stigma associated with a serious illness may be dependent on whether the individual can be blamed or held responsible for its occurrence, whether the illness has potentially serious consequences for others, whether there are outward manifestations of the illness, and/or whether it results in a decreased level of competence (Conrad, 1986). Some illnesses or medical conditions have additional cultural meanings attached to them (for example, AIDS) -- that result in a “spoiled identity” and the stigmatization of the affected individuals.

Once a stigma becomes known to others, individuals are sometimes labeled as ‘outsiders’, and expectations and assumptions are associated with the individual, and certain patterns of response from others emerge during interaction (Becker, 1963).

Goffman (1963b) described several progressive stages that stigmatized individuals experience in accommodating both self-identity changes and interpersonal transactions. One of these is learning the useful strategies such as what Goffman refers to as "passing" which is pretending to have a less stigmatic identity (Bowers, Clark-Mahoney, Forshee, Reiner, Schilling & Snyder, 1987).

This “passing” strategy that individuals use to avoid the potential stigma of a disability is concealing a discrediting social status or stigmatizing attributes (Goffman, 1963b). Another strategy is “selective telling” (Freund & McGuire, 1999, p. 160) which can act as a way to forestall a negative reaction from another person. For example, a person with epilepsy might weigh the stigma potential of their condition against the positive consequences of revealing: for example, having someone to help in case of seizure (Schneider & Conrad, 1983).

For many people with disabilities, interaction with an able-bodied person is often a struggle to manage the stigma, or to “disavow” (Davis, F., 1961) the deviant character of disability.

Fred Davis (1961), in *Deviance Disavowal*, wrote about a situation that happens during encounters, especially initial ones, between the able-bodied and disabled. The disability – paraplegia, blindness, or whatever it may be – is at center stage, in the forefront of the consciousness of both parties, and both must take steps to normalize the meeting, a process that Davis calls “deviance disavowal.” The participants try to conduct themselves as if nothing were amiss, as if there were no hidden agenda. Several different scenarios are possible, aside from avoidance. One technique is to make a brief reference to the disability at the outset, as if to put the able-bodied person at ease.

Goffman also described how some stigmatized people might use it to their advantage, such as procrastination, relief from unpleasant duties, escape from competition, protection from social responsibility. “The stigmatized individual is likely to use his stigma for ‘secondary gains,’ as an excuse for ill success that has come his way for other reasons.” (1963b, p. 10).

There are other concepts associated with Goffman’s (1963b) discussion of stigma, such as “sympathetic others”, and “the discreditable/the discredited”, and “information management” which are also relevant, but I explore them later.

c. Sick Role, Labeling, Deviance, Legitimacy

Sickness has historically been viewed by sociologists as a type of deviance, or departure from group-established norms. This view was formulated by Parsons (1951) and in his classic work in sociology, *The Social System,* he formulated his concept of “the sick role”: characteristic behaviors a sick person adopts in accordance with the situation. However, two people having the same condition (in the case of this dissertation, migraines) may behave quite differently. Becker (1963), one of the leaders in labeling theory, believed that deviance is created by social groups who make rules or norms. Freidson (1970) stated that illness as deviant behavior is relative. Freidson’s concept of legitimacy included a classification system: conditional legitimacy, unconditional legitimacy, illegitimacy. Freidson’s classification system implies that there are different consequences for the individual and that his or her treatment by other people depends on the label of the definition applied to the deviant’s health disorder by the social audience.

Labeling of an attribute or behavior as deviant is a social product (Becker, 1963). Labeling is not a form of social control, but may be sought by some individuals as a way to legitimate their condition (Brown, 1995), while others may avoid being “labeled” because of the negative associations that accompany that label. Therefore, the definition or label placed on a condition can have a profound effect on those who are labeled by others (or by themselves) as disabled or chronically ill.

Like other social roles, the sick role is primarily a description of social expectations. Parsons’ identification of the sick role (1951) entails certain responsibilities and privileges. Legitimate exemptions from work obligations, for example, vary enormously, typically according to social class. Even the meaning of the sick role itself varies considerably according to social class. The same sickness has different connotations according to class or gender of the individual (in this dissertation, this applies to both employer and employee) as well. Cultural expectations of the sick role also vary. “Cultures differ in the degree of legitimacy they accord various illnesses and their resulting claims to exemption from responsibilities” (Freund & McGuire, 1999, p. 123).

Parsons (1951) conceptualizes the "sick role" as a patterned, normal group of behaviors adopted by a sick person in order to meet the demands of the situation. Parsons (1951) states as part of his argument about the expectations of the sick role, that the sick person is exempt from normal social roles, is not responsible for his condition, should try to get well, should seek technically competent help and should cooperate with the physician.

Parsons states that society (via the institution of medicine) is responsible for returning the sick to their normal social functioning.

The sick role, however, is not an appropriate classification for individuals with disabilities. Many individuals with disabilities, while not considered "sick", do have altered mobility and body image, and are faced with medical, social, attitudinal, economic, and other difficulties. These individuals are not exempt from normal social and vocational roles and are not expected to behave in such a way as to "get well." The individual with a disability is expected to maintain normal behavior and make the most of his remaining capabilities, within the limits of his condition and the modification of his life situation (Lubkin, 1990).

Basically, a person’s ordinary roles in life all become temporarily suspended when that person gets sick (Murphy, 1987). The individual is relieved of some or all of his ordinary obligations (work, school, household duties), depending on how severe the sickness is. However, the sick person has the obligation of making every effort to get well (seek medical advice, take medicine, follow doctor’s orders.)

d. Health and Illness, Chronic Illness, Episodic Disabilities

Our culture derives many of its ideas about the body from the Western biomedical model. The medical model, as discussed later in this chapter in the subsection on models of disability, assumes a clear dichotomy between the mind and the body; physical diseases are presumed to be located solely within the body. As a result, the biomedical model tries to understand and treat the body in isolation from other aspects of the person. The sociological perspective on health and illness is different. It stresses the interactions of mind, body, and society, and the importance of subjective experience in understanding health and illness (Freund & McGuire, 1999). Following this perspective, illness is a socially constructed phenomenon.

Chronic illnesses and episodic disabilities result in a different experience than acute illnesses. Although some people with chronic illnesses are impaired and disabled, chronic illness does not inevitably lead to disability. For example, diabetes may only minimally interfere with some people's functioning and require no workplace accommodations or relatively minor accommodations. Migraine headaches interfere with people's functioning only when they occur, and the individual returns to ordinary functioning in between attacks. The sick role, discussed in the previous section, temporarily exempts people from normal activities, however.

> "Chronic illness often demands complex strategies for managing symptoms. Adhering to drug regimens must be balanced against the side effects of drugs; symptoms must be concealed from other people; life must be scheduled among symptom flare-ups or to avoid flare-ups. These strategies break up taken-for-granted rhythms and activities of daily life. Illness is especially damaging to the self when it is experienced as overwhelming, unpredictable, and uncontrollable because it paralyzes the person's ability to manage life, to plan, and to act." (Freund & McGuire, 1999, p. 140)

e. Identity: Social Identity, Self-Identity, Spoiled Identity

Throughout this research, many of the interviews explore the concept of identity, whether it is social identity, self-identity, perceived self-identity, or spoiled identity. Each of these concepts has its own body of literature. I have already touched on 'spoiled identity' in the sub-section on Stigma.

Because this dissertation focuses on migraines *in the workplace*, the individual's social identity and perceived self-identity are of special importance.

Michalko, in writing about blindness, disability, and identity formation, stated very eloquently:

> "There are many conventionally recognizable types that encompass the concept of social identity. They fall into categories of race, gender, ethnicity, profession, and so on. Now another type has been added to this list – disabled. Disability has existed as long as human life has existed but only recently has figured into human identity." (Michalko, 2002, p. 5)

The following are several quotes from Mead's classic work (1934) *Mind, Self, and Society* that are especially relevant to this dissertation in that they could be applicable to an individual's identity and/or behavior in the workplace. In Chapters 5 and 6, there are other quotes from Mead that I link to participant's experiences and insights in the analysis of the data within an explanatory framework.

> "….only in so far as he takes the attitudes of the organized social group to which he belongs…does he develop a complete self or possess the sort of complete self he has developed." (Mead, 1934, p. 155)
>
> "A person asserting his rights on a certain occasion has rehearsed the situation in his own mind; he has reacted toward the community and when the situation arises he arouses himself and says something already in his mind." (Mead, 1934, p. 197)
>
> "For instance, there is a group of individuals that have to work together. In a society, there must be a set of common organized habits of response found in all, but the way in which individuals act under specific circumstances gives rise to all of the individual differences which characterize the different persons." (Mead, 1934, p. 198)

Lennard Davis talks about how disability is different from other identities, and is a constructed identity:

> "Disability is an identity divorced from family, nation, ethnicity, or gender. It is not a discrete but rather a porous category. Anyone can become disabled, and it is also possible for a person with disabilities to be 'cured' and thus become 'normal.' Furthermore, race, nationality, and ethnicity have in effect been considered biological disabilities in eugenic culture. Because the category of disability is porous, its contingent nature is all the more challenging to identities that seem fixed. In some sense,

> disability is more like class, which is constructed but is not biologically determined.” (2002, p. 86).

“Choosing or reclaiming disability (Linton, 1998) begins with the attempt to understand the representations that our culture has ready-made for us and to grasp the relationship between them and our individual and collective identities.” (Michalko, 2002, p. 13).

Some spoiled identities are constructed in response to personal characteristics that are observable (such as race, gender) but others may be constructed around characteristics that are not evident at a glance, or possibly even through extended observation. Examples of these latter kinds of identities are hidden disability (mental illness, epilepsy, diabetes, migraine headaches) or transexuality (such as Garfinkel's Agnes, 1967) in which he discusses Agnes' management of disclosure of her change of sex status – discussed below). In these latter instances, it is often the case that the individual in question participates in the creation of 'spoiled identity' through disclosure of the particular characteristic at issue.

Agnes. In Chapter Five of his book, *Studies in Ethnomethodology,* entitled, “passing and the managed achievement of sex status in an ‘intersexed’ person part 1”, Garfinkel (1967), describes the case of ‘Agnes.’ Agnes was a 19-year-old girl born with “severe anatomical anomalies” (p. 117). She was raised as a boy, having a fully-developed penis and scrotum, yet she had the appearance by the age of 19 of that a female, with measurements of 38-25-38. “Agnes was born a boy with normal-appearing male genitals. A birth certificate was issued for a male and she was appropriately named.

Until the age of seventeen she was recognized by everyone to be a boy." (1967, p. 120). Agnes was referred to the Department of Psychiatry at University of California, Los Angeles, in 1958. At that time, she was a 19-year old, white, single girl, working as a typist. She appeared as a female, with a female shape, female measurements, long blonde hair, female features, dressed like a girl, with a soft voice and feminine manner. She had large breasts and the normal external genitalia of a male. As a result of abdominal laparatomy done two years earlier, it was revealed that she had no uterus or ovaries. She had high estrogen levels (female hormones). Although Agnes was raised as a boy (in the biography furnished), the male role was difficult for her, especially since feminine sex characteristics developed at puberty. The three years of high school were extremely stressful. Agnes was raised until she was 17 as a male. However, at the age of 17, she dropped out of high school and refused to return to complete her senior year. She left home, moved, changed to feminine attire, entered a hospital for examination and the exploratory laparatomy mentioned above, got a job, and met a man who became her boyfriend. In March 1959, a castration operation was performed, the penis and testes removed, and a man-made vagina constructed. The operation was performed primarily for psychological reasons. The medical staff felt that her identity was so strongly fixed in a female direction that no forms of treatment could ever make her masculine. (1967, p. 158)

During this period, Agnes was seen by psychiatrists and by Garfinkel; this chapter in his book is based on transcripts of conversations with her and materials collected by the psychiatrists.

Agnes' life consisted of the practical, day-to-day task of concealing her [true] identity and constructing lifestyle modifications in order to keep her secret. Disclosure of Agnes' sexual status would involve severe sanctions. Such is the case for persons who

> "… managed the achievement of their rights to live in the chosen sexual status while operating with the realistic conviction that disclosure of their secrets would bring swift and certain ruin in the form of status degradation, psychological trauma, and loss of material advantages." (Garfinkel, 1967, p. 117-118).

It is here that Garfinkel used the term 'passing' in connection with disclosure. "*The work of achieving and making secure their rights to live in the elected sex status while providing for the possibility of detection and ruin carried out within the socially structured conditions in which this work occurred I shall call 'passing.'*" (Garfinkel, 1967, p. 118). In her interactions with individuals, the secret of Agnes' sexual status was always a factor. "In almost every situation of interaction the relevance of the secret operated as background knowledge." (Garfinkel, 1967, p. 136). Garfinkel compared Agnes' 'passing' with the 'passing' that other groups face in other types of situations: "This kind of passing is entirely comparable to passing found in political undergrounds, secret societies, refugees from political persecution, or Negroes who become whites." (1967, p. 136).

> *"The work of achieving and making secure her rights to live as a normal, natural female while having continually to provide for the*

> *possibility of detection and ruin carried on within socially structured conditions I call Agnes' 'passing.'"* (Garfinkel, 1967, p. 137).

Agnes' desire to keep her secret was extremely important to her, as evidenced by the following three quotes from the text: "… accompanied by the feelings that she knew something that the other person did not know, the disclosure of which, she was convinced and feared, would ruin her." (1967, p. 136). "Punishment, degradation, loss of reputation, and loss of material advantages were the matters at risk should the change be detected." (1967, p. 136). "Her concern to escape detection had a value of highest priority." (1967, p. 136).

The following are the lengths that Agnes went through in order to 'pass':

> "Her situations of activity – a very large number of them – were chronically ones of 'structured strain.' We may think of them as socially structured situations of potential and actual crisis….Each of a great variety of structurally different instances required vigilance, resourcefulness, stamina, sustained motivation, preplanning that was accompanied continually by improvisation, and continually, sharpness, wit, knowledge, and very importantly her willingness to deal in 'good reasons' – i.e., to either furnish or be ready to furnish reasonable justifications (explanations) or to avoid situations where explanations would be required. Passing was not a matter of Agnes' desire. It was necessary for her. Agnes had to be a female. Whether she liked it or not she had to pass." (1967, p. 137)

"The 'real good situations' were those in which the work of passing permitted her the feelings of, and permitted her to treat others and be treated by others as, a 'normal, natural girl.' " (1967, p. 138-139). "…the situation to be managed can be described..as one in which the attainment of… goals…. Involved… a risk of exposure." (1967, p. 139). Her situation in passing was one in which she basically had to choose between accomplishing ordinary goals or maintaining a female identity.

The following example was provided, when Agnes had to take a pre-employment physical:

> "Before reporting for a physical examination for a job that she later obtained with a large insurance company, and because she had had similar previous physical examinations, Agnes decided that she would allow the physician's examination to proceed as far as her lower abdomen. If the physician then proceeded or gave any indication of examining the genital area she had decided to protest modesty and if this wasn't enough to put the physician off she would simply leave, perhaps feigning modesty, or if necessary giving no excuse. It was much to be preferred to forego the job than to risk disclosure, with one condition being dependent of course upon the other." (1967, p. 139).

Things that most people would take for granted were cause for concern and avoidance for Agnes because of their problematic potential due to the risk of disclosure – for example, she even felt as though she had to avoid using public restrooms and riding in cars. "Public baths and automobiles were to be avoided. If the necessary facilities were not available excuses were easy to make…She feared an accident, being rendered unconscious, and thereby risking exposure." (1967, p. 141). She wanted to have a job that was within walking distance of her home or where she could use public transportation.

"For the many situations where she knew enough, she would have mapped out possible alternative developments beforehand and would have decided the conditions of her choice of one course or another prior to her having to exercise those choices." (1967, p. 168). In fact, it got so bad that "…disclosure increasingly assumed the proportions of a major agony." (1967, p. 158).

When Agnes decided to legitimately change her sexual status and thereby disclose the secret [to some extent] that she had kept for so many years, "In seeking a change of birth certificate Agnes treated the change as the correction of an original error committed by persons who were ignorant of the 'true facts.'" (1967, p. 126).

> "Not only did Agnes directly express the claim 'I have always been a girl,' but it was advanced by the device of a remarkably idealized biography in which evidences of her original femininity were exaggerated while evidences of a mixture of characteristics, let alone clear-cut evidences of a male upbringing, were rigorously suppressed." (1967, p. 128).

"The sex status transfer involved the assumption of a legitimate status the disclosure of which involved great risks, status degradation, psychological trauma, and loss of material advantages." (1967, p. 136).

Even post-surgery, however, disclosure still remained an issue for Agnes. For example, she would find a way to back out of a physical exam should there be a possibility of the physician needing to examine her genitals, and she would adjust the truth when filling out job application forms.

> "Agnes summarized the case for herself: 'It is necessary for me to tell little white lies a lot of the time and I think there are those that…those are necessary and they have to be necessary to accomplish results.' Some of these little white lies were prefigured, many were improvised." (1967, p. 169)

For example, on employment applications, she would say that she had not had any major operations and did not have any physical defects. "She was particularly adept at furnishing information that would lead the other person away from entertaining the possibility that she was raised as a male" (1967, p. 169). She didn't want anyone checking into the part of her life she had when she was younger, so she avoided providing information on job application forms that might motivate employers to do so. She presented false information about her biography.

In summation about the case of Agnes, "… members of a society generally, and Agnes in a particularly dramatic way, are much concerned with the management of impressions." (1967, p. 174) "….lying provided for Agnes and her partners conservative effects for the stable features of their socially structured interaction." (1967, p. 174).

There are many parallels and similarities between the case of Agnes and the disclosure of people with migraine headaches in the workplace, especially in terms of 'stigma', 'passing', 'perceived self-identity', and 'information management', all topics that I research in this study.

f. Disclosure.

There is limited research on self-disclosure of hidden disability/illness in the workplace. Munir, Leka, and Griffiths (2005) describe the 'self-disclosure in the workplace' situation as follows: Since hidden illnesses are not perceptible to others, receiving appropriate support from managers and colleagues requires their knowledge and understanding of an employee's illness. Unless employees choose to inform others at work as to the nature of their illness, such support might be lacking. However, the choice to disclose a hidden illness is complex, and influenced by a host of factors such as stigma, type and severity of illness, and access to support. There are perceived risks to the employee in disclosing a hidden illness. These include potential rejection, discrimination, loss of social support, stigma, and loss of employment. Disclosure, however, may also confer benefits. The benefits to disclosure may include access to practical support (changes in work arrangements such as reduced hours, decreased pace, reduced workload, or adjustments to the physical work environment) and social support (increasing the understanding of supervisors and colleagues about effects of the illness), social integration, ensuring that the illness does not affect performance (providing explanation for frequent workplace absences), and re-affirming professional identity.

Individuals with hidden disabilities frequently do not disclose their disability for fear of subsequent negative attitudes and behaviors towards them. For example, students with psychiatric disabilities are especially reluctant to disclose because of the stigma associated with mental illness (Gordon & Keiser, 1998). Similar reluctance has been reported in terms of disclosure to employers (Friehe, Aune, & Leuenberger, 1996; Silver, Strehorn, & Bourke, 1997) in that a major reason for not disclosing was fear of discrimination.

There are several stages in the hiring process during which disclosure can take place. First, during the application process (pre-offer stage), second, once the individual has been offered a position (post-offer stage), third, if required to take a medical examination (O'Brien, 2004, p 112). There are difficulties associated with making decisions about whether to hide information about health. "Choosing not to release the information…is not without cost. Most important, no reasonable accommodations requests can be made. Employers have no obligation to provide reasonable accommodations for conditions of which they have no knowledge." (O'Brien, 2004, p. 113) "Not asking for accommodations until they become imperative puts [those] … who have invisible impairments in the position of possibly exacerbating their conditions." (O'Brien, 2004, p. 113)

Some people with migraines prefer to remain silent about their condition. Collins (2009) reports that Cindy McCain, wife of Senator John McCain, refers to her migraines as “a silent struggle…” that has burdened her through many political campaigns, her charitable work, and her day-to-day life.

g. Theoretical Perspective (General)

Researchers’ theoretical perspectives influence their choice of what to study, how to study it, and how they interpret their findings. This study is primarily descriptive in nature, and it has it been guided by several theoretical perspectives: The first is phenomenology. The phenomenological perspective can be described as follows:

> “The phenomenologist views human behavior, what people say and do, as a product of how people define their world. The task of the phenomenologist…is to capture how people construct their realities (Berger and Luckmann 1966). As we have emphasized, the phenomenologist attempts to see things from other people’s points of view. The phenomenological perspective is tied to a broad range of theoretical frameworks and schools of thought in the social sciences.”
> (Taylor & Bogdan, 1998, p 10-11)

I was also influenced by symbolic interactionism. Symbolic interactionism stems in part from the works of Charles Horton Cooley (1956) and George Herbert Mead (1934). Cooley’s (1956) discussion of the ‘looking glass self’ and Mead’s (1934) writings in *Mind, Self, and Society,* are two formulations of this perspective. Mead’s followers, including Howard Becker (1963) and Herbert Blumer (1969), have applied his insightful analyses of the processes of interaction to everyday life. The following is a brief summary of the symbolic interactionist perspective:

> “The symbolic interactionist places primary importance on the *social meanings* people attach to the world around them. Blumer (1969) states that symbolic interactionism rests on three basic premises. The first is that people act toward things, including other people, on the basis of the meanings these things have for them. Thus people do not simply respond to stimuli or act out cultural scripts. It is the meaning that determines action. Blumer’s second premise is that meanings are not inherent in objects, but are social products that arise during interaction…People learn how to see the world from other people. As social actors, we develop shared meanings of objects and people in our lives. The third fundamental premise of symbolic interactionism, according to Blumer, is that social actors attach meanings to situations, others, things, and themselves through a process of interpretation.” (Taylor & Bogdan, 1998, p. 11)

“People are constantly interpreting and defining things as they move through different situations. We can see why different people say and do different things. One reason is that people have had different experiences and have learned different social meanings.” (Taylor & Bogdan, 1998, p. 12).

Taylor and Bogdan (1998, pg. 12) provide the example of a student who breaks a window in a school cafeteria. The student defines the situation one way, but the principal, the counselor, the janitor, the nurse, and the parents all define the situation in different ways because of their own individual perspectives and experiences. In addition, the race, gender, or class, of any of these participants, may further influence how the participants view the situation. "The process of interpretation is a dynamic process…From a symbolic interactionist perspective, all organizations, cultures, and groups consist of actors who are involved in a constant process of interpreting the world around them." (Taylor & Bogdan, 1998, p. 12)

Other later theoretical perspectives influenced this research, also rooted in the phenomenological tradition, such as labeling theory (Becker, 1963), Garfinkel's ethnomethodology (1967), and Goffman's (1959a, 1959b, 1961, 1963a, 1963b) work, all of which I discuss within this study.

> "Ethnomethodology was developed by Harold Garfinkel and was first articulated in his widely read book *Studies in Ethnomethodology* (1967) … ethnomethodologists study the reality of everyday life …ethnomethodologists seek to understand how people… see, describe, and explain order in their world." (Taylor & Bogdan, 1998, p. 12-13)

Within phenomenological, symbolic interactionist, and ethnomethodological perspectives, it is taken for granted that reality is socially constructed. (Taylor & Bogdan, 1998, p 18-19).

> "In the field of disability studies generally and mental retardation specifically, for example, Becker's (1963) labeling theory of deviance and Goffman's (1961, 1963) analyses of total institutions and stigma not only

> have inspired research in these areas but have been extremely influential in the evolution of policy and practice. The trend of deinstitutionalization is due, in no small part, to an understanding of the social construction of disability, stereotyping, and the stigma of the disability label, and the devastating effects on the self of confinement in total institutions."
> (Taylor & Bogdan, 1998, p. 21)

3. Theoretical Perspectives in Disability

a. Models of Disability

The literature examining disability is divided into several major 'models' or perspectives, and their impact on the disability experience. Here I list and describe 9 of them: 1) the medical model, 2) the social model, 3) the administrative/bureaucratic model, 4) the moral model, 5) the minority model, 6) the personal tragedy model, 7) the political group model, 8) the feminist model, and 9) the charity model. I examine all of these models below. There is some overlap between some of these models; however, I present them separately.

I primarily discuss and compare two main alternative perspectives, the 'Medical Model', which is a clinical perspective focusing on abnormalities, and the 'Social Model', which is the perspective of the disability movement. The remaining seven models are only included in a brief discussion of various other movement approaches.

Medical model. The medical model is typically associated with pathology, impairment, clinical diagnoses, and medical intervention. It focuses on an individual's dysfunction and inabilities. The medical model is deficit-driven (Oliver, 1996).

The medical model of disability views the individual with a disability as a patient who is sick and in need of medical care. Disability is treated medically (Oliver, 1996; Wendell, 1998). There is a reliance on medical definitions of disability for eligibility for services such as rehabilitation, personal assistance, and social security benefits.

Michalko describes the medical model as follows:

> "The biomedical paradigm sees disability as something wrong with the biological body and thus constructs disability as a medical problem… Medical doctors likewise take over the problem of disability…The biomedical paradigm represents the dominant way of understanding the body and of defining what is normal and what is abnormal, particularly in Western cultures" (Michalko, 2002, p. 13).

O'Brien traces the history of the medical model: "From World War I until the 1970s, the medical model of disability reigned in the United States and other industrialized nations. This model gave physicians the discretion to diagnose a chronic illness or permanent injury. A medical model locates the source of disability in the individual's deficiency." (O'Brien, 2004, p. 168; 2005, p. 42). In the medical perspective, doctors and other professionals examine the cause, and how to prevent or cure, a disability. According to O'Brien,

> "In part because of the large number of veterans who became injured during World War I, and the even larger number during World

> War II, disability became medicalized. Offering a medical diagnosis and then treating him or her, the physicians helped turn the freak into a clinical version of the other. Today, despite mainstreaming and all the strides the disability rights movement has made, persons with disabilities are still seen as the other." (O'Brien, 2005, p. 136-137).

The medical model was used not only by doctors, but by others in the medical profession, as indicated by the following statement: "The medical model…was not restricted to doctors, however. Initially, it involved physicians…later developed into a whole rehabilitation empire…physical therapy, occupational therapy, vocational rehabilitation counseling, psychology, and social work." (O'Brien, 2005, p. 43).

Historically (in the traditional approach to disability), people with disabilities were viewed using this medical (functional limitations) model. Something is 'wrong' with the individual. However, modern ideas of disability are rooted in the rejection of deficiency models of disability, particularly of the medical paradigm.

The social model, also called social construction model (which will be described in the next sub-section) is a sharp contrast. In this model, the interaction between the individual and the environment determines whether a characteristic becomes a disability.

There are many criticisms of the medical model. Due to space considerations, I only provide some here. The medical model has become part of the discrimination and oppression experienced by individuals with disabilities (Lane, 1998; Linton, 1998).

Jung makes the following observation about the criticism regarding the medical model:

> “Disability rights activists have argued, since at least the 1960’s, that the biomedical model (which works in the interests of the medical system, health care professionals, social welfare workers, charitable fundraising associations, and so on), is a limited way of understanding and managing disability.” (2002, p. 181)

Lennard Davis presents a dramatic critique of the medical model:

> “…the medical and rehabilitation models – presume that disability is a universal constant. These models have been operating (literally) on disabled people for more than a hundred and fifty years. The medical model treats disability as a disease in need of a cure, while the rehabilitation model sees it as a body in need of repair, concealment, remediation, and supervision. The results of these two models are activities like implanting cochlear devices in the deaf…” (2002, p. 40-41).

The disability rights movement helped further a functional model of disability, which takes into account the individual person, not a medical diagnosis, and defines individuals by what they can do, not by what impairment or disease they have. (O’Brien, 2004, p 168).

Social model. The social model (the dominant paradigm for disability studies) takes into account the role of the social setting and the environment in shaping individuals’ experiences with disability. The social model of disability has served as one of the foundations of disability studies, and has been instrumental in advancing the rights of people with disabilities.

Disability is not easily defined separate from the social and cultural context of impairment. Under the terms of this model, the economic, political, and social structures of society are the major obstacles for people with disabilities. This model focuses on the relationship between disability and barriers.

O'Brien discusses how disability studies embraces the social model and rejects the medical model:

> "… one of the dominant models within disability studies argues for a social conception of disability, which emphasizes society's failure to adapt to persons with disabilities by alleviating environmental obstacles, like stairs…The social model rejects the personal-tragedy theory and argues that disabled people are held back not by their impairments, but by the obstructions that society places before them." (2004, p. 155-156).

Jung points out the differences between the medical model and the social model and draws upon the work of other disability scholars:

> "In contrast to the medical model, people with disabilities have argued for a social model of disability, a model that shifts the obligation for change from the body and activities of the person with a disability to the built environment and social arrangements that are organized around norms of able-bodiedness (Barnes, 1998; Davis, L., 1998; Oliver, 1996 a,b; Shakespeare, 1998)." (Jung, 2002, p. 181)

Lennard Davis speaks to the constructionist nature of the social model, in contrast to the medical model:

> "As opposed to the medical model, the constructionist model sees disability as a social process in which no inherent meanings attach to physical difference other than those assigned by a community. This model condemns the medical establishment for its single-minded reliance on technology, institutionalization, and remediation." (2002, p. 41)

Jung (2002, p. 181) states: "From the perspective of the social model, exclusion and marginalization are not consequences of an individual's impairment. Rather, they are the consequences of social discrimination (Davis, L., 1998; Oliver, 1996)."

O'Brien contrasts the social and medical models of disability in terms of society's impact:

> "On the one hand, the social model purports that societal bias, stigma, and prejudice, not the physical or mental impairment, is what debilitates disabled people. Train stations without elevators or ramps, for instance, reflect the able-bodied majority's bias, whether it is intentional or not, toward stairs. On the other hand, the medical model emphasizes how the person is limited by his physical or mental impairment and largely ignores the obstacles, like stairs, that society places in front of this person." (2004, p. 110).

O'Brien sums it up this way: "The disabling aspect of living with a physical or mental impairment, disability studies experts and activists argued, is totally environmental" (2005, p. 54).

Disability, in the social model, is not a bodily or mental attribute but results from the interaction between the person and the environment. Therefore, whether an impairment becomes a disability depends on the environment, the expected daily activities, and the attitudes of others. The sociological focus, therefore, is not on disabled people, but on disabling attitudes and environments.

The following is an excellent example (see Groce, 1985): Until the 1940's, a significant proportion of the inhabitants of Martha's Vineyard in Massachusetts were deaf. The entire community knew sign language, and even hearing people used it among themselves. Sign language became a natural and ordinary form of communication in this community. People who were deaf worked, got married, owned their own businesses, and were not thought of as separate, significantly different, or special.

Lennard Davis explains how in this community, disability is not relevant as a category: "One has only to think of Nora Groce's account of deafness on Martha's Vineyard, in which few contemporary informants could recall which citizens of the island in the past had been deaf since the entire community had learned sign language to accommodate extensive hereditary deafness." (2002, p 51).

In another example, this one more current, Lennard Davis explains how even in contemporary society, deafness is not seen as a disability among many people who are deaf:

> “Even within the disability rights movement itself, notions about who falls into the category of ‘disabled’ are unclear. For example, many Deaf activists do not consider themselves disabled. Rather, the Deaf think of themselves as a linguistic minority like Latinos or Asians, who are defined by their use of a language other than the dominant one in the United States…they have nothing in common with amputees, paraplegics, or people with mental retardation. Nor do they wish to be included in a group of people who are seen as ‘incapacitated.’…Deaf scholars argue that their ‘problem’ is not that they are deficient, but that the society at large does not know, nor does it care to know, how to speak American Sign Language.” (2002, p. 37).

The distinction between impairment and disability under the social model is explained by Lennard Davis:

> “….the social model, which saw disability as a constructed category, not one bred into the bone. This social model is in dialogue with what is often referred to as the British model, which sees a distinction between impairment and disability. Impairment is the physical fact of lacking an arm or leg. Disability is the social process that turns an impairment into a negative by creating barriers to access. The clearest example of this distinction is seen in the case of wheelchair users. They have impairments that limit mobility, but are not disabled unless they are in environments without ramps, lifts and automatic doors.” (2002, p. 12)

These concepts discussed above are explored further in Chapter 3, the Definitions of Disability.

Lennard Davis qualifies what is meant by disability, under the social model:

> "Disability is not so much the lack of a sense or the presence of a physical or mental impairment as it is the reception and construction of that difference. Contemporary theoreticians of disability distinguish between an impairment and a disability. An impairment is a physical fact, but a disability is a social construction. For example, lack of mobility is an impairment, but an environment without ramps turns that impairment into a disability. In other words, a disability must be socially constructed…" (2002, p. 50).

Lennard Davis sums it up this way: "In the social model, disability is presented as a social and political problem that turns an impairment into an oppression either by erecting barriers or by refusing to create barrier-free environments (where barrier is used in a very general and metaphoric sense)." (2002, p. 23).

Other Models. There are various other models of disability found in the literature, and I describe seven of them very briefly here as other movement approaches. I do not go into as much detail as I did with the medical and social models. The medical and social models are the two main alternative perspectives that I wish to contrast and those two models are the ones that I found to have the most relevance to this research with migraine headaches.

The administrative/bureaucratic model is associated with disability benefits eligibility and views disability as an administrative/bureaucratic entity. This model, either called administrative, bureaucratic, or a combination of the two, is usually used when discussing economics, insurance, social security, entitlements, looking at costs, or things of this nature. People with disabilities are seen in macro terms, in the aggregate. It is sometimes seen as a sub-unit of the medical model.

The moral model describes disability experiences as related to the quality of individual's moral character (Rosa, 2001); for example, disability as retribution for something that the individual did, or something one's ancestors did.

The minority model parallels that of other minority group models such as race, gender, etc., and is based on oppression, isolation, and control. People with disabilities are viewed as a minority group. The minority group paradigm focuses on issues of "alienation, marginalization, discrimination, and oppression" (Jones, 1996, p. 349). In this model, individuals with disabilities are understood using minority group status and privilege. An analogy can be made between the problems facing people with disabilities and those faced by women and racial minorities. A remedy is found in group solidarity, political action, and advocacy. Lennard Davis explains: "…a model of the disabled person as oppressed minority-group member …sees a capitalist, imperialist power structure as one that needs to create an exploited and exploitable minority…by casting out various minorities as abnormal---including minority ethnic groups and people with disabilities." (2002, p 41).

The personal tragedy model is close to what could be considered as a psychological viewpoint – the disability is seen as an individual, personal tragedy, and the person with disability is seen as a passive, dysfunctional individual. This model defines difference as a personal tragedy (Oliver, 1996). Personal tragedy definitions sometimes coexist with the medical model.

The political group model holds the view that activities such as political struggles, civil rights movements, political movements, protests, and other similar activities, laid the legal foundations for civil rights, and the activism of people with disabilities leads to legislation. This model is described in detail in Joseph Shapiro's book, *No Pity* (1993).

The feminist model - Feminist disability scholars push for analyses of disability that take into account consideration of other types of differences, such as gender, sexuality, age, level of ability, type of disability, race, and ethnicity (Jung, 2002; Thomson, 1998; Wendell, 1998). It is similar to the minority group model but focuses on feminist perspective. In the case of migraines, as stated previously, they predominantly affect women.

The charity model (or charitable model) is one that is used to view people with disabilities as objects of pity or victims in need of help. They are also seen as people who need to rely on other people (caregivers) for custodial care or personal assistance. Lennard Davis discusses how later models such as civil rights models were more progressive than charity models: "…In the earlier versions, people with disabilities were seen variously as poor, destitute creatures in need of the help of the church or as helpless victims of disease in need of the correction offered by modern medical procedures."

(2002, p. 12). Some disability groups use the charity model in their fund-raising efforts; for example, Jerry Lewis with the Muscular Dystrophy Association telethon (Rosa, 2001). Also, some European nations follow this model, for example:

> “The U.K, France, and Germany, for example, mandates that employers hire a certain percentage of persons with disabilities. This policy reflects a charitable model of disability. It asks employers to be charitable toward persons with disabilities… Charity-based public policies, many experts in disability studies have observed, help make members of the nondisabled society feel good about themselves.” (O’Brien, 2005, p. 8).

Migraines can be constructed using any one of these models.

b. The Americans with Disabilities Act

In the United States, the strength of the disability rights movement contributed to the passage of the Americans with Disabilities Act (ADA) in 1990, the first comprehensive civil rights legislation for people with disabilities (Shapiro, 1993). The ADA offers comprehensive protection against a wide variety of disability-based discrimination. It provides complex protection in various venues (public services, employment, transportation, etc.). It is the employment protections of the ADA that are most relevant to this dissertation.

The employment provisions of the ADA were considered revolutionary for several reasons. One is the way in which disability is defined:

> “By providing workplace accommodations, the ADA’s employment provisions make employers take into account the ongoing needs of their workers with traditional and nontraditional disabilities alike. The law defines a physical or mental impairment by virtue of what a person cannot do rather than in terms of a specific medical condition or disease.” (O’Brien, 2005, p. 1)

Another is that the ADA mandates reasonable accommodations, which is an obligation that the employer must adjust the workplace in certain circumstances and under certain conditions, in order to make it meet the needs of an individual employee who meets the criteria for a disability as defined by the ADA. Essentially, the ADA turned disability into something that was: “…socially constructed.” (O’Brien, 2005, p.1).

In addition, the ADA focuses on each person as an individual, not as a member of a particular group.

> “…the ADA … is a unique piece of civil rights legislation in that it recognizes a fluid identity. To be covered under the ADA, one must have a substantial impairment that rises to the level of a disability, and given how a person’s health can change, this identity is not based on a static or staid category. To qualify for this category, the person in question must be individually assessed. This person’s status is altered if his or her condition changes. The ADA is therefore similar to other civil rights laws in that it is based on someone’s identity. However, it departs

> from these laws because the identity of a person is fluid and individual rather than static and part of a group." (O'Brien, 2005, p.4)

However, the ADA has been interpreted narrowly in the courts, resulting in overwhelmingly pro-defendant outcomes, primarily in employment discrimination cases. These court interpretations have severely limited the potential impact of the ADA. I provide a more in-depth analysis of the Americans with Disabilities Act, the court interpretations of its language, and the impact of these decisions, in Chapter 3, the Definition of Disability.

CHAPTER THREE: THE DEFINITIONS OF DISABILITY

[emphasis on the ADA and Legal/Court Definition]

Chapter 3 contains material relating to various definitions of disability that are relevant to this study, in order to provide the reader with a broad perspective within the larger literature. This includes the difficulty inherent in defining disability, sociological definitions, the legal definition according to the Americans with Disabilities Act, specific cases presented before the Supreme Court, and analysis of the rulings and their implications.

Introduction

In the beginning of this chapter, I discuss the prevalence of disability. Several different figures are quoted because there are many ways to quantify disability, depending on the source (who’s doing the counting), the year, and the definition of disability used. The number of people who self-identify as having a disability, the number of people defined as disabled for the purpose of qualifying for various benefits and compensations, and the number of people who are classified as disabled according to health professionals, are just three possible different ways of quantifying disability. Definitions of disability also vary according to geographical location, religion, culture, socio-political policies, historical period, age, and many other factors.

I rely very heavily on the work of ADA scholar Ruth O’Brien (2004, 2005) and disability studies scholar Lennard Davis (2002) as valuable resources in the preparation of this chapter. This chapter concentrates on the legal aspects of disability; other definitions are explored in Chapter 2, the Review of the Literature.

Is “disability” a social distinction, socially constructed by a “difference” from the norm? If so, how much of a difference is significant enough to count as a disability? What disabilities are protected by law and which ones are not? How can we look at the disabilities that are not covered to determine if there is a violation of civil rights? When discussing “disability,” are we talking about a large population?

Prevalence Statistics: It is difficult to determine how many people have disabilities, especially since many disabilities are not visible. According to the 2000 United States Census, nearly 29% of American families include at least one person with a disability (United States Census 2000 Special Reports). It is estimated that there are 54 million people in the United States with disabilities (The National Organization on Disability, http://www.nod.org/, Accessed 8/13/2011). Disability prevalence varies depending on the survey used, questions asked, and ages covered. Estimates from the 2002 Survey of Income and Program Participation place the figure at 51.2 million, or 18.1% of the United States non-institutionalized population (United States Census Bureau, Current Population Reports, 2002).

The following quotations from the United States Census Bureau help illustrate how the definition of disability has changed over time:

> “During the past 30 years, the accepted definitions of disability have been changing. In the 1970s, the concept of a disability referred to an underlying physical or mental condition. A person with leg paralysis

would have been considered disabled based solely on their physical condition. Today, disability is seen as a complex interaction between a person and his or her environment. The same person with leg paralysis may be considered disabled due to their physical impairment as well as the barriers in the environment that prevent full social participation.…The development of the international classification of functioning, disability, and health (ICF) by the World Health Organization reflects this new perspective…The ICF views disability as an umbrella term and does not provide a single way to determine disability status." (United States Census Bureau, 8/31/09)

"…the US Census Bureau and other statistical bodies have attempted to capture the concept of disability for the purpose of measurement. The existing definitions present challenges in two areas. 1. The process of measuring a complex, multi-dimensional concept in a survey format is difficult. 2. The constantly evolving concept of disability requires survey professionals to continuously develop new measurement approaches to adapt to the newest definitions of disability. Since the definition of a disability varies, the collection of disability statistics depends on the purpose for which it is being used and the survey collecting the information. While the Census Bureau collects disability data from four household surveys, other agencies also collect disability data." (United States Census Bureau, 8/31/09)

Disability and Employment/Unemployment Rate: The available data shows a discrepancy in employment statistics between people with and without disabilities.

According to the United States Department of Labor, Bureau of Labor Statistics, "In July 2009, the unemployment rate of persons with a disability was 15.1 percent, compared with 9.5 percent for persons with no disability, not seasonally adjusted. The employment-population ratio for persons with a disability was 19.5 percent, compared with 65.0 percent for persons with no disability." (U.S. Dept of Labor, Bureau of Labor Statistics, Labor force statistics from the Current Population Survey, 9/3/09)

For the first time, in August 2010, the Bureau of Labor Statistics released a comprehensive overview on the employment of people with disabilities. The following data is taken from the Current Population Survey, a "monthly survey that provides statistics on employment and unemployment in the United States": "In 2009, the employment population ratio (the proportion of the population that is employed) was 19.2% for people with disabilities. Among the able-bodied, the ratio was much higher, 64.5%. For all age groups, people with disabilities were much less likely to be employed than those with no disability." (Paralyzed Veterans of America, Paraplegia News, Dec. 2010, p. 37)

Also using information provided by the Current Population Study, "a new monthly data series on the employment status of people with disabilities provided by the United States Department of Labor, Bureau of Labor Statistics": "…the rate of unemployment in the United States in October 2008 was 11.1% for people with disabilities compared with 5.9% for people without disabilities. In May 2009, unemployment was 13.7% for people with disabilities compared with 8.9% for people without disabilities." (Solovieva, Dowler, & Walls, 2011, p. 39).

According to an article in *Careers and the Disabled* Magazine, quoting data from the Kessler Foundation/NOD Survey of Americans with Disabilities, data was released in July 2010 from an earlier study, and showed that "…only 21% of people with disabilities, ages 18 to 64, reported that they are working either full or part time, compared to 59% of people without disabilities" ("Call to Employers", *Careers and the Disabled* Magazine, Fall 2010, p. 11.)

Defining Disability

The World Health Organization (1980) describes three classifications of disablement and makes the distinction between disabilities, impairments, and handicaps:

- <u>disability</u> focuses on the individual's inability to perform a task in the usual manner; it is any restriction or lack of ability (resulting from impairment) to perform an activity in the manner or within the range considered normal
- <u>impairment</u> focuses on how a condition affects the normal structure and function of the body; a loss or abnormality of psychological, physiological, or anatomical structure or function
- <u>handicap</u> focuses on the individual's inability to fulfill usual roles; it is a disadvantage for a given individual resulting from impairment or disability, that limits or prevents fulfillment of a normal role for that individual.

The definition of disability is difficult. Many people think they know a person with a disability when they see one, due to visual cues such as a wheelchair, a white cane, hearing aid, artificial limb, or a service dog. However, disability is a very complex concept, because of various levels of impairment and functional limitations. Disability also cannot be defined objectively and universally across time and place. To complicate matters even more, added to that are the spectrum of invisible/hidden disabilities and episodic conditions.

Another problem with the definition of disability is that even when people have the same disability, it may not have the same impact on some peoples' lives as it has on others. For example, some individuals with multiple sclerosis must use wheelchairs whereas others do not; some disabilities have exacerbations and flare-ups while others are predictable. Some people with upper body paralysis have family members to help them with grooming, eating, and other activities of daily living, whereas others do not and must hire outside help. The same diagnosis, even at the same severity level, can affect each individual differently. There can be differences due to socioeconomic status and cultural background. Some disabilities are progressive while others are stable.

There are medical, economic, and political definitions of disability (Kopfstein, 1999.) The medical definition of disability focuses on clinical aspects, such as what functions the individual can and cannot perform. It labels the person as having an illness or a deficit. The economic definition of disability focuses on the work limitations of the person, the level of economic independence, and whether or not the person must depend on society for financial assistance. The political definition of disability is based on a minority-group model in order to lobby for policy changes in state and federal law.

People with disabilities advocated for the Americans with Disabilities Act (ADA) and other related laws to change public policies affecting people with disabilities. A discussion of these three models of disability and various other models is provided in Chapter 2, the Review of the Relevant Literature.

In the general population, disability is often considered a physical problem and implies a role of helplessness, dependence, and passivity (Fine & Asch, 1988.) People with disabilities are often viewed with pity or ignored (Berkowitz, 1987; Gostin & Beyer, 1993). Many members of society who are ignorant about disability will view people with disabilities as different or worthless rather than seeing the individuals for who they are.

Physical limitations of an individual are often evaluated against a standard of normality. Many people studying or working in the areas of disability studies and activism contend that medically-oriented definitions of the impact of disability on life contain two incorrect assumptions (Asch, 1999) as follows: First, that the life of a person with a disability is forever disrupted, and second, that there are inevitable negative consequences of disability such as isolation, powerlessness, unemployment, poverty, or low social status (Asch, 1999).

It is only more recently that disability has been defined in terms of what people can do as opposed to what they cannot do. The following are quotes from two of Ruth O'Brien's books that illustrate this: "Defining disability as a condition that shapes how people do things instead of an identity that characterizes who they are, transforms it into an ever-evolving, nonessential, social construction that is nearly universal….Identities are fluid, and cannot be bound to static categories like race or gender." (O'Brien, 2005, p. 57). "Indeed, it was the EEOC that clarified the functional definition by suggesting that a disability is determined by what a worker or an employee can and cannot do in comparison with the average person in the general population." (O'Brien, 2004, p. 49).

Sociological Definitions

Irving Zola stated:

> "We delude ourselves into thinking there is some finite number of people who can be termed disabled…. In this way, in the defining, we try to make the reality of disability at least potentially someone else's problem. But any person may be able-bodied for the moment. But everyone will, at some point, suffer from at least one or more chronic diseases, and will be disabled, either temporarily or permanently" (as quoted in "Who's Disabled?", 1999).

Zola (1982) asserts that people with disabilities face not only medical problems, but also social, attitudinal, economic, access barriers, and other adjustments.

People with disabilities often encounter barriers to accessing basis resources and barriers to opportunities such as education and employment, which in turn result in larger problems that can impact their self-identity as well as their quality of life.

Wendell (1996), using her experiences with chronic fatigue syndrome, asked thought-provoking questions about what standard should be used to judge disability, such as, who defines disability, and for what purpose? Wendell believed that there is oppression and marginalization based on disability.

Within the field of sociology, ‘disability’ is often discussed within the context of deviance, labeling behavior, stigma, medical sociology, sociology of health and illness, and/or sociology of the body. The medical view of disability is one of deviance from a biological norm of health. In this view, the function of the physician in the treatment of disability involves diagnosis and care. In medical sociology, disability and disease are considered adverse physical states. The view of sickness as a form of deviant behavior was formulated by Parsons (1951) when he discussed “the sick role.” In very simple terms, the sick role was a set of behaviors a sick person adopts in order to meet the demands of the situation (as discussed in Chapter 2). Parsons viewed being sick as a deviation from “normal,” not just biologically, but also socially. The roots of describing disability as a type of deviant behavior come from the sociological definition of deviance as any socially-judged act or behavior that violates the social norms within a given social system (Cockerham, 1992). There is more to be said about deviance (Becker, 1963), the sick role, stigma, and labeling theory, but an extended discussion of these topics is beyond the scope of this Chapter, and I have already covered some of these in Chapter 2.

The Americans with Disabilities Act (1990)

There is no agreement regarding the definition of disability; however, a legal definition *was* provided by the Americans with Disabilities Act (ADA). The roots of the ADA came from the Rehabilitation Act of 1973 (Kopfstein, 1999). The ADA states that a person with a disability is someone who:

- has a physical or mental impairment that substantially limits that person in one or more major life activities; or

- has a record of such a physical or mental impairment; or
- is regarded as having a physical or mental impairment.

The ADA is considered an important piece of civil rights legislation for people with disabilities. It establishes both equal treatment and reasonable accommodations.

Lennard Davis discusses the specific nature of the ADA:

> “The Act defines a disability as a physical or mental impairment that substantially limits one or more of the major life activities, a record of such an impairment, or being regarded as having such an impairment. The ADA also bars discrimination against a person with a disability who can perform a job with reasonable accommodation. But the Act has not specified the range of definitions.” (Davis, 2002, p. 125-126).

I will discuss this point about the ADA not specifying the range of definitions briefly below, and return to it in a later section of this Chapter.

Congress enacted the ADA in 1990 to address unfair treatment towards people with disabilities, in attempt to secure equal opportunity, full participation, and equal access. When Congress ‘defined’ disability in the ADA, they used wording that was somewhat flexible and vague, to include people with physical or mental impairments that limit life activity, or a history of such, or are perceived to have such. Some believe the wording was intentionally left vague. By including those who are “regarded as having a disability,” the ADA definition reflects the recognition that disability is a social construct (Laspina, 1999).

> “If Congress wanted to limit coverage to ‘people in wheelchairs, the blind, the deaf’, then they certainly could have. Instead, Congress followed the advice of NCD and others and incorporated an inclusive definition of the protected class that would reach the many and varied ways that fears, myths, and stereotypes come into play to unfairly limit people” (Imparato, 1999).

This lack of a concrete definition of disability could be viewed as problematic. Davis states:

> “Further, it is hard if not impossible to make the case that the actual category of disability really has internal coherence. It includes, according to the Americans with Disabilities Act of 1990, conditions like obesity, attention deficit disorder, diabetes, back pain, carpal tunnel syndrome, severe facial scarring, chronic fatigue syndrome, skin conditions, and hundreds of other conditions. Further, the law specifies that if one is ‘regarded’ as having these impairments, one is part of the protected class.” (Davis, 2002, p. 23-24)

So did the writers of the ADA choose to be so vague on purpose? And should the ADA be amended? O’Brien discusses,

> “On the one hand, the ADA could have included a definition of disability that depends on physicians and experts. Indeed, some disability rights activists have called for the ADA to be amended so that it relies on

> a medical definition of a physical and mental impairment, because the federal courts have interpreted the functional definition so narrowly that few persons with disabilities are prevailing in Title I employment cases." (O'Brien, 2005, p. 8)

There are five "Titles" in the ADA. Title I prohibits employers from discriminating against qualified workers with disabilities, and requires reasonable accommodations. Title II prohibits state and local government from discriminating in employment, architectural access, public transit, and service delivery. Title III mandates accessibility when 'readily achievable' in public accommodations, including private transportation systems. Title IV requires access to telecommunications systems for people with disabilities. Title V provides information about how the previous titles are to be applied. Title I of the ADA, with its focus on protecting persons with disabilities from employment discrimination, and providing for reasonable accommodations, is the portion of the ADA that I am mainly concerned with in this Chapter.

The ADA is a civil rights act, not an entitlement program. That is an important distinction. The ADA was intended to protect individuals who were 'otherwise qualified' to perform the 'essential functions' of a job. The ADA guarantees that individuals who are otherwise qualified for jobs or educational programs will not be denied access simply because they have a disability. The intent of the law was to level the playing field, not to give special advantages or points to people with disabilities. The distinction is demonstrated below:

> “The drafters of the ADA, however, followed neither the medical nor the charity model. Instead, the legislative authors modeled Section 504, which created the blueprint for the ADA, after Title VI of the Civil Rights Act. The civil rights model, however, does not adequately describe the ADA provisions. Civil rights laws offer women and people of color negative rather than positive rights. That is, the legislation protects them from discrimination, but it does not mandate that an employer offer women and people of color anything substantive like a reasonable accommodation. By contrast, affirmative action policies do give people of color a positive right. These policies provide that if a person from an unprotected class and one from a protected class are equal, an employer should hire the latter.” (O’Brien, 2005, p. 9)

The ADA was intended to protect the rights of individuals with disabilities, as discussed in the sections above. However, the actual meaning of many key phrases (‘physical or mental impairment’, ‘major life activity’) was left open to interpretation. Lennard Davis emphasizes the potential impact of this vagueness on employers:

> “The ADA defines disability broadly as a substantial limitation in one or more life activities. In addition, people are considered to be in the protected class not only if they have a disability but also if they are ‘regarded as’ being a person with disabilities. The latitude of this definition has had employers, particularly, up in arms. They fear that they

> will be beset with requests from their employees for accommodations and will be sued for violations of the Act. This, they say, will reduce employers to poverty." (Davis, 2002, p.3)

Ruth O'Brien discusses the distinctiveness of the ADA in that it takes into consideration the needs of the individual:

> "The ADA is therefore a unique piece of legislation. It recognizes both the individual and the needs that this individual has, instead of categorically giving him or her an identity. It offers an expansive definition of disability in a way that few activists predicted would be opposed by the courts. The fact that these courts have not created their own medical definition – while not letting more persons with disabilities prevail – shows that the medical model path has been closed off. The ADA should therefore be viewed as an ideology that has had an effect on legal practices and discourses about persons with disabilities." (O'Brien, 2005, p. 9)

The legislation was not only unique, but also groundbreaking, for its view of a person's identity, the assessment of that identity, and the fact that this identity can change over time.

> "The ADA is the first federal statute that recognizes that someone's identity must be assessed individually and how this identity can

> change. This represents a significant departure from other civil rights laws, which are based on racial and gender binaries. Part of a vanguard, the ADA should be placed in context with the move away from such binaries as white and black, or male and female, toward the intersecting and dynamic identities that activists and other social movements have sought." (O'Brien, 2005, p. 9-10)

It also represents a huge paradigm shift away from defining the person by their medical condition or diagnosis:

> "The definition of a disability, which cuts across all the ADA's substantive provisions, has liberated persons with disabilities from what could be described as an identity box." …. "To be sure, lawyers might call upon physicians, psychiatrists, and rehabilitation experts to provide evidence of how a physical or mental impairment substantially limits the life of a person with a disability. Nonetheless, these experts have lost their monopoly power. The ADA does not make persons with disabilities solely dependent on diagnoses rendered by medical or rehabilitation experts…What this means for those people who are employed or are seeking employment is that employers must individually assess how a physical or mental impairment affects their substantial life activities. The person is no longer defined by his or her condition, illness, or injury." (O'Brien, 2005, p.10)

The ADA was groundbreaking in several ways. One of these was the inclusion of a functional definition of disability.   "The groundbreaking idea behind the functional definition of disability including in the ADA is that it affects persons with temporary or permanent disabilities." (O'Brien, 2005, p. 19)

> "… the ADA introduced the idea that identity is not staid and static… it has affected workplace dynamics. Employers must take into account the individuality of employees and employees must use this information to engage in an interactive process with employers that could alter the context of the workplace. Introducing a dynamic concept of need into the workplace, the ADA's employment provisions cover virtually every workplace, since any office, shop, or factory with over 15 employees must follow it. These employment provisions provide that an employee or prospective employee cannot be discriminated against because he or she has a physical or mental impairment. Because making a workplace accessible typically requires accommodations, this right is not a negative one. An employer must provide some *thing* – an accommodation – that transforms this right into a positive or substantive civil right. Employers must accommodate employees on the basis of their individual needs." (O'Brien, 2005, p. 21).

Accommodations

Another distinction between the ADA and civil rights legislation is its focus on individualized needs. “What makes the ADA not about disability per se, but about *needs*, stems from the fact that this statute insists on matching a person’s condition with his or her accommodations…the law does not use classifications or categories like other civil rights legislation does. Instead, the ADA’s employment provisions are based on an ‘individualized assessment’ of each person’s situation.” (O’Brien, 2005, p. 21)

However, the entire concept of accommodations is a negative, disruptive one in the eyes of many employers, management, and human resources. “Workers were not supposed to be involved in determining the labor process.” (O’Brien, 2005, p. 82). It goes against the principles and concepts of scientific management, Max Weber, capitalism, scientific rationality, Frederick Taylor, and it forces employers to have to negotiate with employees. “Employers benefit from employees not having a comprehensive understanding of how a factory or an office is run.” (O’Brien, 2005, p. 136).

. “The reasonable accommodations model impresses upon employers that their employees’ needs must be taken into account. This idea is radical in that it violates one of the fundamental principles within the classical concept of capitalism…” (O’Brien, 2005, p. 140). Under capitalism, profits are the driving factor in making decisions about work conditions. However, the ADA requires employers to take the needs of individuals with disabilities into consideration and make reasonable accommodations for them. In this respect, it also “undercuts the standardization of the workplace… and challenges what Max Weber described as rationalization” (O’Brien, 2005, p 3) by individualizing the workplace.

> "Most importantly, the ADA puts persons with disabilities in a unique position to negotiate with their employers. Reasonable accommodations requests could undercut managerial prerogative power, a power that does not foster a happy, productive, and efficient workplace. Persons with disabilities make these requests by engaging with their employers in what the ADA refers to as the interactive process….this means that employees or potential employees can negotiate with employers or prospective employers about what are the essential and nonessential tasks of a position to determine accommodations." (O'Brien, 2005, p. 112)

This is not as simple as it may sound, however, as this example shows:

> "Assessing what are essential and nonessential duties is an infinitely complex process. It involves not just the person seeking employment or the person working but the details of the office or company. The assessment process under the ADA mandates that an employee must perform the essential tasks of a specific job. The employee, in other words, must have the qualifications to perform all these tasks. This same employee, however, can be released from performing the nonessential tasks. What makes this complex is that there is no fixed rule about the difference between the two." (O'Brien, 2005, p. 112-113)

She provides a concrete example to illustrate her point:

> “There is no rule, for instance, that the job category of administrative assistant means that he or she must answer telephones. An essential duty can only be determined after locating one particular employee in a specific setting. If an administrative assistant with a severe neck injury works with three other assistants in an office, answering the telephones would not be essential. The other three assistants could do this. The employer could award the accommodation. By contrast, if there were no other staff members working with the administrative assistant, the employer would not be required to accommodate him or her.” (O’Brien, 2005, p. 112-113)

Reasonable accommodations can even include reassignment, under certain conditions.

> “Second, if a person with a disability can no longer perform the essential functions of a position, an employer must reassign him or her to a new position. As long as a reassignment does not mean that a disabled person receives a promotion or that a job was created specifically for him or her, an employer must retain this employee. It is then the employee’s decision whether or not to accept the new job. This reassignment could also involve a demotion in terms of pay or status.” (O’Brien, 2005, p. 23)

This all means that employers can no longer solely rely on an employee’s performance or profit-making potential; they have to consider employee’s needs as well.

"The ADA, as discussed earlier, presents an expansive definition of a disability because it is functional. It is about what people do, not who they are. Reasonable accommodations can be construed as workplace needs." (O'Brien, 2005, p. 118)

Sometimes the accommodations piece involves a shift in fundamental assumptions, interpretations, and/or workplace politics, not only between employers and employees, but also involving other employees.

> "No where is this better illustrated than with employers providing accommodations. The real question is: who loses? Who do these accommodations disadvantage? Is it able-bodied employees or employers? To answer this question without arousing the able-bodied employees' prejudice or biases, they must know how much the average accommodation costs. In fact, studies have shown that most accommodations are well within the budget of an office or a firm. Yet what these studies do not reveal is how much awarding accommodations undermines managerial prerogative power. Accommodations therefore threaten the interest of employers not only because of financial loss, but because of a managerial loss of control over their workplace. In making the zero-sum calculation, it is therefore vital for employees to know whether employers are more concerned with the dollar and cents cost of accommodations *or* with maintaining tight control over the entire workplace." (O'Brien, 2005, p. 119)

> "The Americans with Disabilities Act (ADA)'s…reasonable accommodations provisions are groundbreaking. They are not affirmative

> action provisions that compensate a group of individuals for past injustices; they are not antidiscrimination provisions that prevent employers from exercising any bias against people based on their group identity; nor are they a new form of collective bargaining. The reasonable accommodations provisions give affirmative or substantive rights to no identifiable group, but rather to individuals who have physical and mental needs that must be satisfied for these individuals to work. Put simply, these provisions create a model for interjecting a notion of workplace need that is based on our individuality rather than our group identity. Anyone can need anything at any time. Yet hearing one individual's voice could bring help to the collective. The accommodations offered to one individual can be passed on to a collection of individuals, albeit on a case-by-case basis." (O'Brien, 2005, p. 135)

The Supreme Court

It is impossible to discuss the various definitions of disability, at least in the context of this chapter and this dissertation, without discussing the legal definition of disability as interpreted by the Supreme Court. First, I provide a brief overview of the Supreme Court itself. The Supreme Court consists of nine justices who vote on a variety of important issues. "The Court functions as a collegial body of nine independent-minded judges who must by majority vote make the most basic judgments about the direction of our constitutional democracy" (Simon, 1995). Since there are nine justices on the Court, decisions with a vote of 9-0 and 8-1 are the strongest, whereas decisions where the splits are 5-4 or 6-3 are the weakest. When decisions are split, someone writes a ‘majority opinion’ while another justice writes what is called either a ‘minority opinion’ or a ‘dissenting opinion.’ The docket for the Supreme Court contains substantive cases that can have major impact on the lives of millions of people.

Next, I discuss the connection between the Supreme Court and the ADA. Since the ADA did not specifically provide a definition of disability, it became the job of the Supreme Court to provide the interpretation when cases involving the ADA were brought before the Court. “Interestingly enough, most of the Supreme Court’s ADA employment provisions cases involved persons not with traditional disabilities like paraplegia or blindness, but with carpal tunnel syndrome, breast cancer, and hypertension.” (O’Brien, 2005, p. 138)

O’Brien discusses the Court’s reaction to the ADA’s vague definition of disability:

> “When the ADA first became law in 1990, neither the business community nor the disability rights community realized its potential. The federal courts, however, recognized it immediately, and set out to dramatically decrease the number of persons eligible for protection under the law by rendering a narrow interpretation of the definition of a disability. Most importantly, the Supreme Court perceived the employment provisions in the ADA as an attack on managerial prerogative power, going so far as to hold that an employer can refuse to hire someone with limiting, but not substantially limiting, disabilities.” (O’Brien, 2005, p. 10)

Below, I provide four additional quotes from Ruth O'Brien and Lennard Davis which further illustrate the relationship between the Supreme Court and the ADA:

> "Instead of providing antidiscrimination protection, the Supreme Court and many lower federal courts have turned the employment provisions on their head, giving employers cause for letting someone go." (O'Brien, 2005, p. 11)
>
> "This stems in part from the fact that the ADA is based on a functional definition of disability. This means that someone has a disability by virtue of what he or she can or cannot do, not by what medical category the physical or mental condition falls into….Persons with similar disabilities do not all receive the same accommodations." (O'Brien, 2005, p. 11)
>
> "Ten years later, it has been estimated that 95 percent of the cases brought before the courts under the provisions of that act have been steadily hacking away at the provisions of the ADA, and the Court will hear cases whose outcomes could completely end the effectiveness of that legislation." (Davis, 2002, p. 2)
>
> "The perceived legal problem is that the protected class is too large, and that is one of the reasons there is a perceived backlash in the United States against the ADA. In response to initial concerns that too many people with minor conditions were qualifying as disabled, the federal courts have issued very narrow interpretations of disability. While

> we must deplore the fact that approximately 95 percent of cases brought before the courts are currently decided in favor of employers, we may also understand that some of this backlash is generated by a fear of creating a protected class that is too large. As with affirmative action, there is also a general resentment among the populace that certain minority groups have special rights and privileges with regard to college admissions, job hiring, and so on." (Davis, 2002, p. 24)

The courts have become active in defining what it means to be 'legally' disabled, in that a person is covered under the law only if the degree of impairment is substantial. In doing so, the courts have narrowed the definition of disability. The United States Supreme Court reviewed three cases in 1999 and 'constructed' their definition of disability. In those rulings, which I describe in the section below, the courts demonstrated their view that a disability exits only when an impairment substantially limits a major life activity, not when it 'could or would' be substantially limiting if corrective measures could not be taken.

Before I move ahead to the section in which I describe those three court cases, I include some information below about Sonia Sotomayor, her background, and her relationship to the Supreme Court.

Sonia Sotomayor is a fairly recent addition to the United States Supreme Court. The United States Senate confirmed her appointment in summer 2009 by a 68-31 Senate vote. The American Association of People with Disabilities (AAPD), along with two dozen national disability organizations, endorsed Sotomayor's candidacy for Supreme

Court Associate Justice and believes she will apply the law in a manner that safeguards the civil rights of all Americans (ABLE Newspaper, Sept 2009). Sotomayor has Type 1 diabetes, which is considered a disability (ABLE Newspaper, Sept 2009).

Andrew Imparato, who at the time was president and CEO of the American Association of People with Disabilities (AAPD) supported the confirmation, and was quoted as saying:

> "Today the United States Senate voted to confirm a true champion for equal justice under law... Associate Justice Sonia Sotomayor will follow in the tradition of Justices Thurgood Marshall and William Brennan and bring some balance to a court that has gone out of its way to undermine disability rights and civil rights more broadly. AAPD commends President Obama and all of the Senators who supported Justice Sotomayor's confirmation." (ABLE Newspaper, Sept 2009, p. 4)

The New Jersey Council of Developmental Disabilities also issued the following statement in support of Sotomayor and her position on disabilities:

> "… the 54-year-old daughter of Puerto Rican parents was raised in a Bronx housing project. She is the nation's first Hispanic justice and only the third woman to sit on the highest court. Over her history as a judge, some of Sotomayor's more prominent opinions on discrimination concern people with disabilities. In one case, Judge Sotomayor ruled that a law school graduate with a reading and learning disability was entitled to extra time in taking the bar exams. After the Supreme Court decided that

> people are not protected under the Americans with Disabilities Act if they can function normally by wearing glasses, taking medication or otherwise compensating for their disabilities, it told the Second Court to reconsider its decision in this case. Judge Sotomayor again found that the woman was disabled, and must be given accommodations, writing that test scores alone were not enough to diagnose a disability." (NJCDD, the Council, Sept 2009, page 1)

The three specific cases (1999)

I now turn to the discussion of the three specific Supreme Court cases from 1999. The United States Supreme Court reviewed three cases in 1999 and 'constructed' their definition of disability. In those rulings, which I describe in the section below, the courts demonstrated their view that a disability exits only when an impairment substantially limits a major life activity, not when it 'could or would' be substantially limiting if corrective measures could not be taken.

The three specific cases from 1999 are somewhat similar. The individuals seeking protection under the ADA were denied employment because they did not meet certain physical requirements. The three specific cases were:

- two women (twin sisters) with poor uncorrected vision (near-sightedness) denied employment as commercial pilots (*Sutton v. United Air Lines*) [1]
- a man with one-eyed (monocular) vision denied employment as a truck driver (*Murphy v. United Parcel Service*) [2]

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[1] Karen Sutton and Kimberly Hinton v. United Air Lines, Inc., 527 U.S. 471, 119 S. Ct. 2139 (1999)

- a man with hypertension (high blood pressure) denied employment as an auto mechanic (*Albertson's, Inc. v. Kirkingburg*) [3]

In all three cases, the individuals claimed that discriminatory employer policies had unfairly excluded them from employment based on their disabilities/impairments.

Karen Sutton and Kimberly Hinton, twin sisters with severe near-sightedness, applied for jobs as commercial pilots with United Air Lines. Their vision was corrected to 20/20 with eyeglasses. United Air Lines, using its own standard for pilots, denied the women jobs as pilots because their uncorrected vision was worse than 20/100. They did not meet the airlines' minimum requirement for uncorrected vision, even though eyeglasses provided them with 20/20 vision.

> "In 1999, the Supreme Court handed down three decisions that created this Catch-22 position for two pilots with vision problems, a truck driver with monocular vision, and a mechanic with high blood pressure. The lead case involved Karen Sutton and Kimberly Hinton, twin sisters who not only had the same career as regional airline pilots, but they shared a vision problem, a severe myopia that only 2 percent of people in the United States have. It was fully corrected by their glasses, but without their glasses, the twins' vision fell well below United Airlines' standard of 20/40, which is required of all pilots. Applying this rule to the twins, United Airlines claimed that while these women could fly regional airline

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[2] Vaughn L. Murphy v. United Parcel Service, Inc., 527 U.S. 516, 119 S. Ct. 2133 (1999)
[3] Albertson's, Inc. v. Kirkingburg, 527 U.S. 516, 119 S. Ct. 2162 (1999)

> routes, they could not be hired to fly global ones." (O'Brien, 2004, p. 100-101)

Justice Sandra Day O'Connor wrote the majority opinion in this case. She did not believe that the use of eyeglasses qualified someone as 'disabled' using the definition of impairment of a major life activity. She rationalized that there are many people in the general population who wear eyeglasses, and that Congress did not intend to protect all of them under the ADA.

"If the twins could mitigate their impairment by wearing glasses, they could enter the mainstream and should not qualify for statutory protection. The twins were 'normal,' the Court concluded….To the majority of justices, the ADA is not about protecting this type of person from employment discrimination." (O'Brien, 2004, p. 47)

This brings up the interesting question of whether people whose corrected vision is 20/20 (with eyeglasses) should be considered disabled if their uncorrected vision is worse than 20/100. Justice Ruth Ginsburg stated that a broad definition of 'the protected class' is inconsistent with legislative findings about people with disabilities as a "discrete and insular minority" (Johnson, 1999). In her view, the law should be reserved for a relatively small number of people, and Congress did not intend to cover a huge percentage of Americans.

The Supreme Court rendered this decision, which delineated how someone could 'mitigate' their impairment and therefore not be considered disabled and protected under the statute's employment provisions. Most important, the Supreme Court decided in *Sutton* that the twin sisters, who had severe myopia that was corrected by eyeglasses, were not “legally disabled.” While the twins had an impairment, it ‘did not rise to the level of a disability’ since it could be mitigated by eyeglasses (O’Brien, 2004, p. 46-47). The medical equipment – the eyeglasses – helped them compensate for their impairment. The eyeglasses corrected the poor eyesight. If the twins could mitigate their impairment by wearing eyeglasses, they should not qualify for statutory protection.

On the same day as the Sutton verdict, the Court released two other ADA-related decisions. In Murphy vs. United Parcel Service, a mechanic whose position required test-driving vehicles was fired for having high blood pressure. His doctor testified that his blood pressure, when medicated, was within normal ranges. The Court found Murphy to not be disabled because “an individual claiming a disability under the ADA should be assessed with regard to any mitigating or corrective measures.” (Weisman, 1999). The Court ruled that impairments should be assessed in their corrected or mitigated state in order to determine whether they are disabilities as defined in the employment provisions under Title I of the ADA.

Lennard Davis discusses that this is the similarity among these three cases from 1999:

> “For example, the Supreme Court in 1999 decided that a correctable disability is not a disability under the ADA in three cases which involve correctable vision in airline pilots and truck drivers and high blood pressure in a mechanic…A second area of ambiguity is the nature of reasonable accommodation, and a third is the very gray area which asks whether the impairment is such that it interferes with the employee’s ability to perform the job. This last issue is almost the litmus

> test for many of these cases because, if a person claims to have been discriminated against on the basis of disability, the accuser must establish that, although she is disabled, she is not so disabled as to warrant that the employer was correct in either not hiring her or in dismissing her. In all these instances, the claimant must rely on very fine distinctions. In other words, these are not cases in which the matters of fact are clear." (Davis, 2002, p. 125-126)

In the Sutton case, it was decided that the myopia, because it was correctable, did not constitute a disability under the ADA. In the Murphy case, it was decided that the high blood pressure, because it was controllable by medication, did not constitute a disability under the ADA. The Kirkingburg case was decided as "individuals with monocular vision are not per se 'disabled' within the meaning of the ADA, but must prove on a case-by-case basis that their conditions substantially limit a major life activity." (Davis, 2002, p. 125-126).

Not all of the justices of the Court agreed with the majority Court opinion. The vote was 7-2. Justice Stevens wrote the dissent, disagreeing with the Supreme Court's interpretation/construction of disability. "Realizing that the majority had created a new functional interpretation so that few people would qualify for protection under the ADA, Justice John Paul Stevens wrote a stinging dissent. The majority's functional definition was so broadly cast, he argued, that it penalized those who could compensate for their deficiencies more than those without them." (O'Brien, 2004, p. 47)

“More important, Stevens’ dissenting opinion explored how the Court’s action, in general, would affect disabled people in the future. Presenting such a narrow interpretation of what constitutes a disability, he maintained, made the Court a stern gatekeeper, which would exclude most persons with disabilities.” (O’Brien, 2004, p. 47-48)

> “The *Sutton* decision, as explained earlier, helped to define what constituted a disability. Writing for the seven-person majority, Justice Sandra Day O’Connor argued that the glasses mitigated the twins’ seeing problems, hence they could not be considered ‘legally’ disabled. Relying on the same logic about mitigating equipment and medicine, O’Connor wrote in *Vaughn L. Murphy v. United Parcel Service* that Murphy, a mechanic with very high blood pressure, could not be considered legally disabled. While the sisters put on glasses that ‘mitigated’ their vision problem, Murphy took medication that ‘mitigated’ his disease. None of these plaintiffs were therefore legally disabled and could therefore not protest any discriminatory treatment under the ADA’s Title I.” (O’Brien, 2004, p. 101)

Analysis and Impact of the Rulings

Until 1998, the U.S. Supreme Court had mentioned the ADA in passing, but never directly interpreted any of its positions (Sheldon, 2000). The Court had taken the position that the determination of substantial limitation in a major life activity -- the ADA’s definition of disabled -- was to be made without consideration for mitigating devices, such as through the use of medications, prosthetics, or eyeglasses (Sheldon, 2000). In their three rulings/decisions on June 22, 1999, however, the U.S. Supreme Court ruled that the employment discrimination protections of the ADA do not apply to people whose disabilities/impairments can be corrected or mitigated. The decision was applauded in the business community, but not in the disability community, where there was concern about the overall impact it would have. Many believed it created a no-win situation: The individuals with disabilities were not able-bodied enough to have the job, but they were not 'disabled enough' to have the protection of the law. Andrew Imparato, an attorney who promotes opportunities for the disabled, made the following statement in 1999 while he was director of policy at the National Council on Disability: "I am deeply concerned that the U.S. Supreme Court totally missed the mark recently in three cases construing the definition of disability…..The Supreme Court has left me and millions of other Americans with significant mental or physical impairments unprotected against egregious discrimination" (Imparato, 1999.)

Basically, the analysis and impact of the Court's decision in these three cases can be summed up by these four quotations:

> "In 1999, the Supreme Court handed down three rulings that upheld and extended the lower federal court decisions, curing the ADA's capacity to transform the workplace…by ensuring that few people fell under the ADA's jurisdiction." (O'Brien, 2005, p. 3)
>
> "Raising the threshold for this definition further, the Supreme Court ruled in a trio of employment decisions that an impairment that can be mitigated by medicine or equipment, like insulin for a diabetic, a

> hearing aid for a person with hearing problems, or a prosthesis for a person without an arm, is not a disability." (O'Brien, 2004, p. 100)
>
> "The Supreme Court…has also ruled that people with correctable disabilities, such as hypertension and myopia, are not protected under the law…The net effect of these decisions has been to continue a process of whittling away the protections designed by Congress for people with disabilities." (Davis, 2002, p. 3)
>
> "Essentially, the federal courts' rulings have put disabled people in a catch-22 position. Either you are not impaired enough to have a disability or your impairment impedes you from doing the job." (O'Brien, 2004, p. 100)

When reviewing these cases, the Supreme Court did not consider the question of physical standards in employment and did not give much consideration to the question of discrimination. Instead, the Court chose to focus on whether the individuals claiming discrimination were truly 'disabled' and thus qualified to use the ADA at all. The Court decided that, because their conditions do not substantially limit any life activity and /or are easily correctable, these individuals are not disabled according to the ADA. Why did the Supreme Court make this decision? Justice O'Connor wrote the majority opinion. She wrote: "The determination of whether an individual is disabled should be made with reference to measures that mitigate the individual's impairment," (Johnson, 1999). The Court decided that these three cases were not covered, that they fall outside of ADA's civil rights protections because the individuals' conditions are correctable. However, bear in mind that since the Supreme Court vote was 7-2, as mentioned in the previous section, there were two justices who disagreed with the majority opinion.

The Implications

Where is the distinction between disability and discrimination? When does a correctable condition become a disability? People with some limits on their capacity to function were being denied access to protection under the law. What are the implications for people with treatable/correctable conditions? People who function with disabilities were at risk of losing protection as a result of these Supreme Court decisions about the definition of disability. "In deciding that these people fall outside ADA's civil rights protections because their conditions are treatable, our highest court has left many people with treatable conditions – like epilepsy, diabetes, and in my case, bipolar disorder – outside the law's protection as well." (Imparato, 1999). What happens when a person believes that someone has a "disability" and the employer does not hire them because of it, but society does not label them as having a "disability"? The problem is that employers may say that a person is too disabled for a particular job but, under the law, that person is not disabled enough to be covered by the ADA. They may conclude that:

> "The applicant's condition was the reason they were not hired, however, it does not substantially impair their ability to engage in major life activities. It is not a disability as defined by the ADA and we are free to discriminate on the basis of an insubstantial impairment" (Weisman, 1999)

Some individuals with mental or physical impairments are as a result unprotected against employment discrimination.

> "Falling outside of the statute's coverage, moreover, O'Connor wrote in *Sutton*, meant that the twins could be dismissed for being people who have physical or mental impairments that an employer preferred not to have in the workplace…Employers, she maintained, can hire employees on the basis of them. As long as this impairment does not 'rise to the level' of a disability, an employer can exhibit her preference for able-bodied employees." (O'Brien, 2004, p. 101)

"On one hand, O'Connor ruled that the twins' eye problems could not be considered a disability because if all people with mitigating equipment like eyeglasses were taken into account, the definition would be too inclusive." (O'Brien, 2004, p. 101)

Now, moving ahead three years: In 2002, "the Supreme Court rendered three more decisions that limited the scope of the employment provisions." (O'Brien, 2005, p. 3). The result of these three decisions -- Toyota Motor Manufacturing, Kentucky, v. Ella Williams[4]; U.S. Airways v. Robert Barnett[5]; and Chevron v. Echazabal[6] -- was that the ADA continued to be largely unavailable to persons with disabilities.

The *Toyota v. Williams* case involves job-related repetitive motion injury (carpal tunnel syndrome), re-assignment, and the definition of disability. However, in this case, the Court was not looking at whether or not the disability could be corrected, but instead

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[4] Toyota Motor Manufacturing, Kentucky, v. Ella Williams, 534 U.S. 184, 122 S. Ct. 681 (2002)
[5] U.S. Airways v. Robert Barnett, 535 U.S. 391 (2002)
[6] Chevron v. Echazabal, 536 US. 391 (2002)

at the centrality of that disability to the person’s life. The decision of the Supreme Court opinion in *Toyota v Williams* in 2002 was unanimous. Below are several quotes that summarize the case and describe the implications of this decision:

> “… Williams had developed carpal tunnel syndrome and other repetitive motion impairments in a factory, and nothing could mitigate her condition…She could not take any medicine…to control her injury. When Williams used her arms and forearms in the same repetitive way that had caused her initial injury, she would reinjure herself…The manual tasks that caused this re-injury, the tasks that she had to perform to keep her position, the unanimous Court decided, however, were not central enough in her daily life to make her disabled.” (O’Brien, 2004, p. 48-49)
>
> “Here too, the Court, in effect, extended the Catch-22 that applied to the twin pilots. Williams was so disabled that she could not work without accommodations, but she was not sufficiently disabled to receive protection under the ADA. Writing for a unanimous Court, Justice Sandra Day O’Connor argued that people with impairments that restrict them from performing manual tasks at work but not at home may not be legally defined as disabled… Under the ADA, she wrote, an impairment must limit the ability to perform tasks that ‘are of *central* importance to people’s daily lives.’… It is the judiciary, moreover, that decides what is centrally important in someone’s daily life.” (O’Brien, 2004, p. 48-49)

"For two years, Toyota had honored the limitations that Williams's physician had imposed on the company so that she would not re-injure herself. Williams had sustained a myriad of repetitive motion injuries on the job. She then took medical leave, filed, and settled a workers' compensation case with Toyota. After filing an ADA case, Toyota put Williams on the Quality Control Inspections Operations Team…this team performed much lighter manual labor. Williams, moreover, only performed two of the four tasks assigned to the team…When Toyota's managers decided that members of the inspection team must perform all four tasks, Williams's injury flared up again...The Court ruled that the fact that Williams could not perform this last task was not tantamount to proving that she had a physical impairment that could be considered a disability. She was not given shelter under the ADA." (O'Brien, 2004, p 104)

"In *Toyota v. Williams*, the auto company argued that Congress has defined disability too broadly. In this case an employee of the company had carpal tunnel syndrome that limited the use of her hands. She was able to perform her job perfectly well until transferred to a different task, which she could not perform. Her employer claimed that she was not disabled because although she could not perform her new task, she could brush her teeth, pick up objects in her home, and so on. Toyota demanded that those claiming coverage under the ADA must demonstrate that they are "*severely restricted* from using their hands to perform a *broad range of*

> *basic functions* needed to meet the *essential demands of everyday life*." The Supreme Court decided in *Toyota v. Williams* that if a person could carry out tasks at home like tooth-brushing and general chores he or she could not be considered disabled." (Davis, 2002, p. 2-3)

Davis continues:

> "Despite the fact that Ella Williams, the plaintiff, had carpal tunnel syndrome and could not carry out her job assignment, she would not, for the purposes of the law, be considered a person with a disability. Therefore, her employer could fire her for not doing her job, and she will now have no recourse to legal redress." (Davis, 2002, p. 2-3)

The *Barnett v. U.S. Airways* case dealt with the issue of whether reassignment constitutes a reasonable accommodation. O'Brien writes:

> "… Robert Barnett, a cargo handler who sustained a serious back injury on the job, had been granted a reassignment to work in a mailroom. The Ninth Circuit Court of Appeals held that such a reassignment could be considered a reasonable accommodation as Barnett could no longer carry…his old position…As long as a reassignment does not mean that a disabled person receives an unwarranted promotion nor that a job was created specifically…an employer must retain this employee…it is up to the employee to decide whether to accept the new job…The Ninth Circuit majority ruled that Barnett had been given his reassignment…as a result of an interactive process in which he engaged with his employers…In 2002,

> the Supreme Court overturned the…ruling about Barnett's reassignment...by ruling in favor of U.S. Airways that an employee can not be reassigned to a position that violates a seniority system…"
> (O'Brien, 2004, p. 105-106)

The Court decided that U.S. Airways should not accommodate Barnett, even though he had been working in the mailroom for two years already. Two workers with more seniority put in bids for Barnett's mailroom position, he was bumped back to his cargo position, a position that he could not handle due to his back problem, and he was terminated. As a result of this case, 'reassignment' (one of the ways that a person with a disability could be accommodated) became more difficult to pursue. (O'Brien, 2004, p. 106.)

Conclusion (Definition of Disability)

Through their decisions in 1999, the Supreme Court decided that the ADA requires consideration of mitigating devices. By using eyeglasses (or other mitigating devices) – according to the Supreme Court – the plaintiffs were not substantially limited in any major life activity, therefore not disabled or protected by the ADA. While it is true that most people would not consider a person who wears eyeglasses as "disabled," the fact remains that these individuals were denied jobs because of this condition. The Court impaired the ability of people who were denied employment because of a treatable condition to use the ADA. Their decisions in 2002 further weakened the protections of the ADA. Employers could decide that a person is too disabled for a particular job, even though under the law they are not disabled enough to be covered by the ADA. The Court felt that corrective measures must be considered in determining whether or not a person is substantially impaired even if the employer’s decision not to hire was based on the disability without consideration of correction.

> “Disability should not be interpreted by the Supreme Court to exclude the many people whose conditions in their natural state result in significant impairments in functioning but who can function well with medication, assistive devices, or other mitigating measures….ADA is about equal opportunity, full participation, and equal access…..An inclusive definition of disability means extending a good thing – fairness – to more people.” (Imparato, 1999)

Sheldon (2000) points out the irony of the 1999 Court decisions.

> “Clearly, Sutton, Kirkingburg, and Murphy were each capable of performing the essentials of their jobs, but were excluded by a medical screening criterion imposed by an employer. The irony, of course, is that if they use the mitigating devices, they’re no longer ‘disabled’ under the statute; if they don’t use them, they’re unqualified for the job.”

Some believe that the Court ruled the way it did in order to manage the number of people who would be covered by its protections, and therefore, they decided conservatively.

> "What seems to concern the majority on the Supreme Court is that too many persons with disabilities, particularly those with nontraditional disabilities like carpal tunnel syndrome, will be able to use the ADA, and it will open the flood gates. The Court also recognizes how unique the ADA is in employment. Providing reasonable accommodations gives employees the power to undermine an employer's right to manage a workplace. Therefore, the majority on the Supreme Court has been very conservative in assessing who should qualify for this antidiscrimination protection and has ruled against all six employment plaintiffs." (O'Brien, 2004, p. 49)

The impact of the Supreme Court's decision was felt beyond the Supreme Court: "Given the *Sutton* decision, many lower federal courts had already adopted the Supreme Court's doctrine that someone can mitigate an impairment and therefore not be disabled in the workplace." (O'Brien, 2004, p. 49)

> "The employment provisions within the ADA should be interpreted as society's recognition that people with physical and mental needs belong in the work force and that it should not be considered entirely within the private domain. Employers, moreover, should shoulder the burden of providing reasonable accommodations. By rendering a functional definition of disability, the Supreme Court opened Pandora's box to all physical and mental needs. While it may not be in the short-

> term interests of capital, it is in capital’s long-term interest as well as in the interest of the government and society at large to accommodate persons with physical and mental needs in the workplace.” (O’Brien, 2005, p. 148)

CHAPTER FOUR: METHODOLOGY / RESEARCH DESIGN

In Chapter 2, Review of the Relevant Literature, I located this research study in existing literature and demonstrated my theoretical perspective. In this Methodology Chapter, I describe my general methodology and the specific procedures I use in this study. Also, I indicate the time and length of the study, the number and type of participants and settings, the research design, and my strategy for analysis.

I relied heavily on a text by Taylor and Bogdan (1998) as a valuable resource guide in the preparation of this chapter. I used this text for several years when I was an adjunct lecturer teaching Research Methods courses at the City University of New York, and I find it contains a good mix of theory and practice. I use this text here for several reasons: 1) its comprehensiveness as a qualitative research methods text; 2) its focus on open-ended interviewing, which is the same method I chose to use; 3) the authors' use of their own disability-related research experience; and 4) its inclusion of examples and discussions related to research with people with disabilities. In my opinion, this text is the definitive canon in Disability Studies research methods.

Overview / Choice of Method

"The term methodology refers to the way in which we approach problems and seek answers. In the social sciences, the term applies to how research is conducted. Our assumptions, interests, and purposes shape which methodology we choose." (Taylor & Bogdan, 1998, p. 3) Using a qualitative approach, this dissertation examines the retrospective self-reported experiences and perceptions of people with migraines in the workplace. By studying people's own accounts of their experiences in the workplace, this analysis seeks to reveal the subjective experience of illness. I use an exploratory, qualitative, phenomenological approach to concentrate on the substantive and methodological understanding of the individuals' experiences.   Phenomenology seeks to understand social phenomena from the actor's own perspective (Berger & Luckmann, 1966).   "When we reduce people's words and acts to statistical equations, we can lose sight of the human side of social life. When we study people qualitatively, we get to know them personally and experience what they experience in their daily struggles in society." (Taylor & Bogdan, 1998, p. 8)

I knew early on that I was not interested in doing standard survey-type research in which I would have the individuals rate their feelings along a scale, select the most appropriate answer from among forced-choice responses, or respond to a pre-determined set of answers. I knew that the qualitative method would allow me to obtain the type of information that I was seeking:

> "In stark contrast to structured interviewing, qualitative interviewing is flexible and dynamic. Qualitative interviewing has been referred to as nondirective, unstructured, nonstandardized, and open-ended interviewing. We use the phrase *in-depth interviewing* to refer to this qualitative research method….directed toward understanding informants' perspectives on their lives, experiences, or situations as expressed in their own words. The in-depth interview is modeled after a conversation between equals rather than a formal question-and-answer exchange."
> (Taylor & Bogdan, 1998, p. 88)

"In qualitative methodology….people, settings, or groups are not reduced to variables, but are viewed as a whole. The qualitative researcher studies people in the context of their pasts and the situations in which they find themselves." (Taylor & Bogdan, 1998, p. 8)

I used four qualitative methods texts (Esterberg, 2002; Flick, 2002; Glaser & Strauss, 1967; Taylor & Bogdan, 1998) as guides in the interviewing, data collection, coding, and analysis phases of the research.

I studied the experiences of people with migraines, in particular migraines at the workplace, by using narrative inquiry and speaking with individuals who get migraines. I was interested in ascertaining what having a migraine in the social situation of the workplace means to them and then to provide a sociological frame to interpret their accounts. "Qualitative researchers are concerned with how people think and act in their everyday lives." (Taylor & Bogdan, 1998, p. 8). I used a semi-structured, open-ended interview process, seeking the personal stories and experiences of the individuals who participated in this study through a series of focused, qualitative questions. I chose this method because I am interested in qualitative research and felt it was most appropriate for this type of study: listening to people talk about what is on their minds, collecting and producing descriptive data from their own spoken words. Phenomenologists strive for what Max Weber (1968) called *verstehen*, understanding the motives and beliefs behind people's actions. "Qualitative researchers are concerned with the meanings people attach to things in their lives. Central to the phenomenological perspective and hence qualitative research is understanding people from their own frames of reference and experiencing reality as they experience it." (Taylor & Bogdan, 1998, p. 7)

Qualitative research tries to understand social processes in context. In addition, qualitative researchers pay attention to the subjective nature of human life and try to understand the meaning of social events for those who are involved in them (Esterberg, 2002, p. 2). Social constructionist approaches share the notion that all social reality is constructed, or created, by social actors (Esterberg, 2002, p. 15). These approaches focus on interaction: How do humans act toward one another? What meanings do they attach to these actions? This analysis shows how people with migraines attach meaning to their migraine experiences in the context of the workplace.

To summarize, I chose a qualitative, social constructionist approach and believed the method of open-ended interviewing to be most appropriate for this study because it is designed to encourage people to talk about what is important to them, and because of its ability to provide rich descriptions and clear examples of participant's responses.

The following are some of the issues that I addressed:

- How frequently does the individual get migraines? Is he/she currently under a physician's care? What type of treatment is he/she receiving?
- Is he/she currently employed? What type of work does he/she do?
- What are his/her triggers for migraine? Which triggers are workplace-related and which are non-workplace related? (although there may be overlap)
- Has he/she disclosed to anyone in the workplace that he/she has migraines? If not, why not? (factors relating to disclosure) If yes, what was the reaction?

- Have accommodations been requested due to migraines? If so, what type of accommodations? What was the employer’s reaction/response to the request? Were the accommodations granted?
- Is stigma a concern to the individual?

Research Questions

Since I utilized a social constructionist approach, the processes and decision making that an employee uses to make the decision to disclose or not to disclose will likely be complex and somewhat varied from case to case. I assumed, from the outset, that there would be no straightforward answer for the individuals in this study and what would be interesting is the question of what factors went into their decisions about disclosure. I sought to describe the workplace experiences of those who did disclose. The second related question is what happened with those who did not disclose.

The interview schedule containing the actual questions that I asked during the interviews is located in the Appendix Section –Appendix E “Interview Guide.” As explained later in this Chapter, some interview questions were modified as the interviews progressed.

Prior to beginning the research, I had some [three] tentative hypotheses that I sought to validate.

One tentative hypothesis, prior to beginning the research, was that some of the employees who chose *not* to disclose (kept the migraines hidden) – chose to ‘pass.’ They felt as though they were seen as hard workers, they had a legitimate medical condition known only to the themselves; whereas others who chose not to disclose believed they were seen in a negative light as “slackers” for needing to take off from work when not feeling well. I believed that those who chose not to disclose in the workplace, made their decision based on a consideration of risks vs. benefits.

A second tentative hypothesis, prior to beginning the research, was regarding those employees who *did* disclose their migraine conditions. I believed that some of them encountered negative reactions, such as being seen as weak (stigmatizing), being seen as self-indulgent (when requesting accommodations), being viewed as not having a legitimate condition (feeling the need to justify or validate their condition); whereas some of them encountered positive reactions and felt legitimized.

My third tentative hypothesis was that the disclosure decisions were based on a complex weighing of the risks versus the benefits. My theory was that the employee’s decision about whether or not to disclose the existence of a migraine headache condition in the workplace would be based upon a number of factors, and that the decision would be made only after careful consideration of these factors. These include access to support, need for accommodation in the workplace, frequency and severity of the migraines, fear of potential rejection or discrimination, and gender bias.

I explored what the individuals had discovered about themselves through their migraine experiences. What knowledge does their experience reveal? How do their lived experiences influence their self-perception of workplace identity? By researching this topic, I was able to examine the relationship between migraines, self-perception of workplace identity, and stigma.

The dissertation also explores the relevance of stigma on the lived experiences of people with migraine, as their experiences are quite varied and somewhat unique, but under-researched. Goffman's (1963b) concept of stigma has been very influential and continually referenced within the disability and medical sociology literature. Additional information about stigma can be found in Chapter 2.

Participants (Selection and Recruitment, Number, Criteria)

I studied a convenience sample of individuals with migraines (**n = 40** individuals). It was a non–representative sample, since I was not seeking, in these initial interviews on this topic, to generalize the findings. I was instead interested in revealing patterns that may reflect, contradict, or prove the (in)adequacies of the tentative hypotheses presented. While this limited my ability to generalize the experiences of those interviewed as typical, it still allowed me to present a range of cases and perspectives in greater detail. In qualitative interviewing, it is more important to have the level of saturation of data rather than the higher number of participants. Having a higher number of participants could be one suggestion for a future study.

In order to incorporate the views of individuals across a wide spectrum of experience of migraine, the majority of the participants were recruited through the cooperation of the National Headache Foundation (NHF)'s membership. The National Headache Foundation is a large national membership association that represents the interests of people with various types of headaches. It provides support and information and a wide range of other services to individuals affected by migraine and also to professionals. This foundation provided a unique base for an opportunity to study individuals with migraines.

I had a general idea prior to beginning the research of approximately how many participants I wanted to interview, knowing that this would not be an absolute number. In their discussion of selecting informants, Taylor and Bogdan (1998, p. 92), state: "…qualitative interviewing calls for a flexible research design. Neither the number nor the type of informants needs to be specified beforehand. The researcher starts out with a general idea of which people to interview and how to find them, but is willing to change course after the initial interviews." The authors continue:

> "Those new to qualitative research usually want to know exactly how many people they need to interview to complete a study. This is a difficult if not impossible question to answer prior to conducting some research…The size of the sample in an interviewing study is something that should be determined toward the end of the research and not at the beginning.…you would have an idea that you had reached this point when interviews with additional people yield no genuinely new insights."
> (Taylor & Bogdan, 1998, p. 93)

I had originally planned to study approximately 25 individuals, via telephone interview only. My research proposal was reviewed by the City University of New York Faculty Membership Committee (FMC) in March 2008. Following this review, some of the members of Committee suggested that the research might be enriched if I expanded it to include in-person interviews as well. Therefore, I decided to include an additional component, in-person interviews, and I ended up interviewing a total of 40 individuals. The additional outreach to generate these participants was conducted during the month of

May 2008. Throughout the ensuing months, I continued to respond to emails and corresponded with potential participants via email to coordinate and schedule interviews. I created participant response logs to track responses and developed interview schedules. I corresponded with each individual at least two or three times prior to the interview, to give them more details about the study, to answer any questions that they had, to work out details about the date/time of the interview, and then to confirm the date/time chosen.

Taylor and Bogdan, (1998, p. 93), discuss the ways to find additional participants for a study:

> "One of the easiest ways to build a pool of informants is *snowballing* – getting to know some informants and having them introduce you to others. A potential drawback of the snowballing technique is that it can limit the diversity of your informants. Therefore you need to be prepared to use a range of different approaches to identifying people. You can locate potential informants through…checking with friends, relatives, and personal contacts; involving yourself with the community of people you want to study; approaching organizations and agencies; advertising in media sources; and announcements through the Internet."

My first recruitment effort was directed at NHF members who attend support groups. After consultation with the Executive Director of the NHF, I chose to target the support group membership, for two reasons: a) these individuals are more likely to be experiencing issues in general and be willing to talk about them; b) the entire membership list of NHF is in excess of 10,000 and therefore would be more appropriate for quantitative research or stratified sampling. The first wave letter was sent out in March 2008 and then again in April 2008, seeking to recruit individuals to participate in a qualitative study of their experiences.

To locate additional study participants, a second recruitment effort was directed at a variety of other non-NHF sources, such as the City University of New York adjuncts group list-serv, word-of-mouth (including but not limited to ‘snowballing’ referral technique as mentioned earlier), advertisements in the local newspaper, and the District Council 37 union newspaper.

This was done in an attempt to broaden the diversity of the sample, other than limiting it to NHF members only. I wanted to collect a variety of perspectives and to be able to examine different vantage points. I realized that NHF members might have access to information that others might not have or might have different demographic backgrounds.

The third and final recruitment effort was directed at NHF members who live in New York. This effort was undertaken in order to provide additional people for the in-person interviews. The in-person interviews were also supplemented by responses to the second recruitment effort who resided in New York.

The table below indicates the source from which each participant indicated that they heard about the study.

TABLE 1

Source of Referral to Study (n=40)

Source of Referral to Study	
▪ National Headache Foundation (30) ▪ CUNY adjuncts list-serv (2) ▪ DC 37 union newspaper (1) ▪ Word-of-mouth / referral (6)	▪ Other (0) ▪ Unknown (Don't know) (1)

Participants were thus self-selected. I maintained a participant tracking log throughout the recruitment and interview process. For each completed interview, I donated $10 to the National Headache Foundation, for a total of $ 400.

Participants represented a wide range of occupational titles, which was one of my goals in this project, because I wanted to hear perspectives from people in different occupations. The table below indicates the occupational titles each participant indicated that they currently held. In the case of individuals who held more than one title in their career, their most recent title is indicated. For those who are retired, on disability, or on leave, their previous title is listed in brackets.

TABLE 2

Occupational Titles of Participants* (n=40)

Titles (n=40)

- Retired [was Elementary School Teacher, 5th grade]
- Retired [was School Psychologist]
- On Disability [was Reporting Adverse Outcomes of Products for Pharmaceutical Company]
- Imports Inspector with the United States Department of Agriculture, Food Safety Inspection Service
- Office Manager
- On Disability [was Travel Agent]
- Social Worker, Hospital
- Retired [was Legal Secretary]
- Marketing Director
- Teacher, Elementary School
- Teacher, Elementary School
- Retired [was College Professor, Sociology]
- Retired [was Teacher, 8th grade Science]
- Chief Financial Officer, Special Events
- Self-Employed, Owner of design and remodel firm.
- Senior Clinical Trials Associate, Clinical Research, Pharmaceutical Company
- Retired [was owner of Pet Supply Business; before that, was Executive Vice President of Marketing and Sales]
- Vice President, Human Resources, children's outpatient mental health facility
- Ophthalmic Technician
- Foundation Director, Hospital
- Adjunct Teacher, English, College
- On extended leave [was Senior Vice President – Info Technology]
- Project Director/Psychologist, Hospital
- Director of Marketing and Communications for Admissions, College
- Retired [was Audiologist]
- Assistant Professor, Slavic Languages, College
- Assistant to President, International Sports Association
- Senior Editor and Financial Journalist, Web
- Assistant to Head of School, High School
- Attorney and Administrative Law Judge
- Marketing Manager, Magazines
- Senior Development Officer/Special Event Planner, non-profit
- Owner/Operator, Construction Co. and Crane Operator
- Psychotherapist /Social Worker, Hospital
- Sign Language Interpreter, Freelance
- Event Planner, Hotel
- Systems, Computer, and Adjunct Teacher, College
- Technical Writer, Freelance
- Meeting and Event Planner, Media Company
- Staff Assistant , Hospital Operating Room

*Note: Titles as reported by participant.

I have occupational title data on all 40 individuals. Although the table above lists the individual titles for all 40 participants, I did attempt to categorize the occupations of the participants in this study in order to ascertain which categories appeared more than once or twice. I compiled this categorization by first searching for each title in the on-line version of the “Dictionary of Occupational Titles” revised, fourth edition, and secondly, once the title was found, by searching the “Occupational Information Network Numerical Index O*Net OnLine.” For the most part, of the 40 titles of the individuals in this study, I found that 20 of them (half) appeared only once or twice. There were, however, six (6) titles that could be collapsed into a category, appearing three or four times, and those are listed below in the bullets, with the number of times they appeared in parentheses.

- Advertising and Promotions Managers (3)
- Executives (3)
- Teachers – Postsecondary (4)
- Owner (3)
- Meeting and Convention Planners (3)
- Teachers – Elementary School (4)

I collected demographic information on age, sex, race/ethnicity, employment status, and highest level of education completed. The participants in this study represented a wide range of ages; their ages ranged from 27-75. Highest level of education varied. Most participants were currently working; the others were retired, on disability, or on some type of leave from work.

34 participants were female, and 6 were male. Migraine is predominantly a female illness -- estimates of migraine prevalence are about 15-18% of women and 6% of men (International Headache Society, 2001) and the fact that the participants in this study were mostly women reflect this fact. Participant's gender is skewed but in relation to migraine as a whole is representative since more women than men report having migraine. For further discussion of migraine prevalence by gender, refer to Chapter 2, Review of the Relevant Literature.

The participants in this study were predominantly white. However, as mentioned in this Chapter, I wasn't trying to get a representative sample of all racial groups. It was more important for me to get a sample of different occupations regardless of race. This was an exploratory study. One suggestion for future study could be to make sure to get a larger representation from different races.   However, one study (Nicholson, Rooney, Vo, O'Laughlin, & Gordin, 2006), sought to determine whether Caucasians and African Americans with moderately to severely disabling migraines differed in regards to utilizing the health-care system for migraine care, migraine diagnosis, and treatment. Results showed that African Americans were less likely to utilize the health-care setting for migraine treatment, less likely to have been given a headache diagnosis, and less likely to have been prescribed acute migraine medication. For further discussion of migraine prevalence by race and/or ethnicity, refer to Chapter 2, Review of the Relevant Literature.

I provide a more thorough listing and discussion of the potential limitations of the demographic background of this study's participants in Chapter 7, Conclusions, Limitations, and Implications/Directions for Future Research.

The table below contains demographic information on the study participants, as described in the paragraphs above.

TABLE 3

Demographic Information about Participants (n=40)

Gender	
▪ Male (6)	▪ Female (34)
Age Range	
▪ 25 years or under (0) ▪ 26-35 (6) ▪ 36-45 (8)	▪ 46-55 (11) ▪ 56-65 (11) ▪ 66 years and older (4) ▪ Declined to answer (0)
Race / Ethnicity	
▪ White / Caucasian (36) ▪ Black / African-American (2) ▪ Latino-a / Hispanic (2)	▪ Asian / Pacific Islander (0) ▪ American Indian/Native Alaskan (0) ▪ Other (0) ▪ Declined to answer (0)
Employment Status	
▪ Currently Working: either for someone else or self-employed (30)	▪ Not currently working (10) ▪ Retired (7) ▪ Currently unemployed (0) ▪ On disability or ext leave (3)
Highest Level of Education Completed	
▪ Doctoral Degree (5) ▪ Masters Degree (11) ▪ Bachelors Degree (14) ▪ Associates Degree (4)	▪ Some college (3) ▪ High school grad. / No college (2) ▪ Declined to answer (1)

The sections above describe the selection of participants and the number of participants. At the time of interview, participants represented 13 different states, the majority from New York. New York was the area selected for the in-person interviews primarily because of my ability to access this population.

TABLE 4

State of Residence of Participants (n=40)

State of Residence	
▪ Arizona (2) ▪ California (1) ▪ Connecticut (1) ▪ Florida (2) ▪ Illinois (3) ▪ Kansas (1) ▪ New Jersey (3)	▪ New York (20) ▪ Ohio (1) ▪ Oregon (1) ▪ Texas (1) ▪ Washington (2) ▪ Wisconsin (2)

In terms of inclusion and exclusion criteria, there were four basic criteria: participants had to be 18 years or older, able to speak English, live in the United States, and be employed for money outside the home -- either past or present. Two individuals who did not meet these criteria were not included in the study.

Aside from that, inclusion criteria for this study also obviously required that participants self-identify as individuals who had been diagnosed with migraines by a physician. Participants were interviewed more or less in the order in which they volunteered, and recruitment continued until data saturation was reached. Basically, this means that interviews with additional people did not provide new insights.

Measurement

Some of the issues that I sought to measure were quantitative in nature, but most were qualitative. The issues that I measured included:

- Frequency of migraine
- Currently under treatment for migraine; type of medications tried
- How the migraines are treated / managed
- Type of work performed (past and present), type of employer(s), length of time at current employer
- Workplace triggers; Non-workplace triggers
- Disclosed or not disclosed? Factors relating to disclosure / non-disclosure.
- Response to disclosure
- If not disclosed, how that was managed
- Accommodations requested/granted; How the individual framed his/her accommodation request; Reactions/responses to request for accommodations – negative/positive
- Stigma at the workplace
- Absenteeism; Productivity
- Other workplace challenges related to migraine: (physical, psychological, and social problems that arose while at work); identity; work performance
- Best and worst experiences with bosses/supervisors, colleagues?

- Demographic information: gender, age, race/ethnicity, highest level of education, employment status

These items were measured by using specific questions on the interview guide. For example, I asked all individuals if they were currently under treatment for diagnosis of migraine. In order to ascertain migraine treatment, participants were then asked about the type of treatments they have tried in the past and what treatments they are currently using.

I collected some basic demographic information in order to explore whether the responses or experiences were different by gender, age, or by race/ethnicity, for the individuals in this study. I chose these categories because I believed that they are the ones that would have the biggest impact on the circumstances of the experience of migraine in the workplace. Collecting additional categories of demographic information would have been difficult to manage and unnecessary for this type of study.

As the interviews progressed, I added in a few new questions (measurement items) that I had not previously thought of, including for example: when were you initially diagnosed with migraine? This turned out to be a significant turning point for several individuals because it not only provided them with a label for their illness, but for some of them it also legitimized their condition in the workplace, and once I realized this after a few people mentioned it on their own, I decided to add it in to all subsequent interviews. This 'adding in of questions after the interviewing has started' is common for qualitative research. As Taylor and Bogdan (1998) state, "In qualitative studies, researchers follow a flexible research design. We begin our studies with only vaguely formulated research questions….As we learn about a setting and how participants view their experiences, we can make decisions regarding additional data to collect on the basis of what we have already learned." (p.8). I also decided to add in the question, 'Describe how it feels when you get a migraine?', because so many individuals were describing it to me on their own anyway, during the course of the interviews, and because the descriptions were so vivid and graphic that I believed that including them would help the study's readers to understand how it might feel when experienced in the workplace.

The interview consisted of six major sections: 1) a discussion of the employee's migraine condition itself; 2) a discussion of the workplace itself; 3) the effect of the illness at work; 4) disclosure and reactions; 5) work adjustments sought and received; and towards the end of the interview, 6) demographic and background information. As each of the six sections began, I introduced the subject of the section. The interviews allowed individuals to highlight specific issues that mattered to them, but every interview covered the same categories of information.

Data Collection and Study Procedures

I was interested in the experience of migraines in the workplace as revealed in the narratives provided during the interviews[7]. Copies of all invitation letters, all consent forms, and the interview guide, can be found in the Appendix section. I included a list of the Appendices below.

A / Recruitment Letter (Invitation) – Telephone – Feb. 2008
B / Oral Consent Form
C / Recruitment Letter (Invitation) – In Person – April 2008
D / In-Person Consent Form

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[7] In those instances when the discussion went beyond workplace, as I suspected it might, I allowed the individuals to finish their train of thought, and then I gently brought the conversation back to the discussion of the workplace. The exception was if we were already at the end of the interview, then I allowed them to just continue, because I knew I was going to include some additional material in the dissertation as well.

E / Interview Guide

I used the following process to collect data:

My research proposal received approval by the National Headache Foundation in early 2008. I composed an announcement (also called invitation letter or recruitment letter) about the research, and the National Headache Foundation (NHF) sent this out via email, first to their support group list-serv, and at a later date, to their members living in New York, asking any interested individuals to email me with contact information for interviews. E-mail correspondence ensued back and forth between me and potential participants, in order to introduce myself, answer their questions, and arrange for the interviews.

Not everyone who responded to the invitation letter was included in the study. Some were excluded because they were not available to be interviewed. Two people were excluded because they did not meet the inclusion criteria for the study, such as being employed either past or present for pay outside of the home. Others were excluded at a certain point in time because I had already interviewed a sufficient amount of individuals for saturation, based on the data I collected.

As stated above, in total, I interviewed 40 people, aged 27 to 75, about their perceptions and experiences related to migraines in the workplace. My main concern was exploring individuals from diverse occupations, and representing their beliefs and experiences.

I began conducting telephone interviews in March 2008. I conducted all interviews myself. 29 interviews were conducted by phone, and 11 interviews were conducted in person. On the day before each interview, in an attempt to try to avoid missed appointments (individuals failing to show or individuals not being available by phone, at the agreed-upon time), I sent an email to each individual reminding them about the upcoming interview.

Each day, I responded to the emails in my inbox, sending out information in response to questions, confirming appointments, and setting up new appointments. I created a participant tracking log and an interview date matrix. I printed out a supply of blank consent forms (see Appendix B, D). I followed up with individuals who expressed an initial interest, but who had not actually set up appointments.

All interviews were audiotape-recorded with the consent of the participant, so that I could record the details accurately. Taylor and Bogdan (1998, p. 112) confirm the following about tape recording, "A tape recorder allows the interviewer to capture more than he or she could by relying on memory." I purchased a recording device for this purpose, again, using the guidelines provided by Taylor and Bogdan (1998, p. 113): "…try to minimize the recorder's presence. Use a small recorder and place it out of sight. The microphone should be unobtrusive and sensitive enough to pick up voices without the participants having to speak into it." The actual interview times ranged from 16 minutes to 1 hour 15 minutes. All interviews were included for analysis, regardless of length, as they all provided valuable information. In general, the telephone interviews were shorter in length than the in-person interviews. The 16-minute interview, although shorter in length than many of the other interviews, yielded valuable information for analysis. The transcript of this interview may appear qualitatively different, in part because the interviewee was not forthcoming with details; however, she did answer all questions adequately.

I conducted exploratory qualitative interviews (open-ended, semi-structured) with 40 individuals who respond to the announcement. I explored the different accounts that the participants offered to make sense of their experiences with migraines in their workplace situations, based on the key measurement items and on the research questions. The general format of the interviews was that I asked the individuals to discuss their experiences based on a six-section interview guide (see Appendix E).

There are several guidelines on approaching informants suggested by Taylor and Bogdan (1998, p. 96). One guideline is to be clear about your motives and intentions. "Many people will wonder what you hope to get out of the project…your motivation will probably have something to do with contributing knowledge to your field and professional advancement…" I explained to each participant that this study was being done for my doctoral dissertation. Another guideline is anonymity. "It is usually wise to use pseudonyms for people and places in written studies. Although people might want to have their names published for a variety of reasons, you should resist doing so and explain this to informants." I used code names for all participants to protect their confidentiality. I allowed the individuals to choose their own code names if they wanted, but I also offered to pick one for them if they preferred.

I conducted the in-person interviews in places of the participant's choosing, usually in a location convenient to them. This resulted in a variety of locations and settings: cafes, the participant's home, my school, my office, the participant's workplace. Taylor and Bogdan (1998, p. 7) discuss the logistics of in-person interviewing:

> "You will have to settle on a rough schedule and a place to meet….You should find a private place where you can talk without

> interruption and where the informant will feel relaxed. Many people feel most comfortable in their own homes and offices. However, in many people's homes it is difficult to talk privately."

Refer to the table below for listing of method of interview (telephone vs. in-person) and, a further breakdown for the in-person interviews: the venue/location.

TABLE 5

Method of Interview (n=40)

Method of Interview	
▪ Telephone (29)	▪ In-Person (11) ▪ At the home of participant (3) ▪ At workplace of participant (2) ▪ At my workplace (1) ▪ At coffee shop or café (4) ▪ At my school (1)

Telephone interviews were held from March 2008 to May 2008, then from September 2008 to November 2008. In person interviews were held in May 2008, then from September 2008 to October 2008. [Note: All interviewing during June, July, and August of 2008 was suspended due to work-related obligations.] Individuals were interviewed once only.

"The interviewer strives to create an atmosphere in which people feel comfortable talking openly about themselves." advises Taylor and Bogdan (1998, p. 99). This is exactly what I strived to do. "In qualitative interviewing, researchers model their interviews after a normal conversation rather than a formal question-and-answer exchange." (Taylor & Bogdan, 1998, p. 8). I structured the interviews in such a way as to keep things both focused and yet open-ended. The interviews ended with some demographic questions for data collection purposes.

As I described in the measurement section of this Chapter, data collection consisted of several background questions (to gauge frequency, treatment, type of work, etc.) followed by key questions, with contingency probes relating to disclosure, accommodations, identity, reactions, etc. "*Tell me about your workplace experiences with…*". The interview guide covered a range of core issues relating to migraines and employment. Interviews were conducted around a guiding topic list (see: interview guide, Appendix E) that enabled participants to introduce and develop issues of particular significance to them. The use of this interview guide allowed me to explore all of the areas that I wanted to, but also allowed the individuals to introduce things during the interview that may not have been on the list of topics I had prepared. For example, as stated previously, "initial diagnosis" was one of the themes that emerged from talking with participants, rather than one of the issues from the initial list of topics.

In order to make sure key topics are explored, Taylor and Bogdan (1998, p. 105) discuss the use of an interview guide in multiple-informant studies: "The interview guide is not a structured schedule or protocol. Rather, it is a list of general areas to be covered with each informant. In the interview situation the researcher decides how to phrase questions and when to ask them. The interview guide serves solely to remind the interviewer to ask about certain things." Taylor and Bogdan also emphasize the flexibility of this interview guide (1998, p. 106): "The interview guide can also be expanded or revised as the researcher conducts additional interviews. As the researcher begins to identify themes in interview data, questions are added to the interview guide so that these areas can be covered with new informants." Other items that I added to the interview guide as I went along, aside from asking about the initial diagnosis, included: When did you experience your first migraine?; Describe what it feels like when you have a migraine?; and for those who did not disclose, Tell me about your passing/coping mechanisms? These are all topics that arose out of interviews, and I decided to add them into future interviews going forward.

The interviews followed a mostly conversational format. Taylor and Bodgan (1998, p. 99) state:

> "In qualitative interviewing, the researcher attempts to construct a situation that resembles those in which people naturally talk to each other about important things. The interview is relaxed and conversational, since this is how people normally interact… Certainly, there are differences between the interview situation and those in which people normally interact: interviewers sometimes hold back from expressing some of their views; the conversation is understood to be private and confidential; the flow of information is largely, although not exclusively, one-sided; and interviewers communicate a genuine interest in people's views and experiences and usually refrain from disagreeing with them."

It is also important during the interviewing process to pay attention, be nonjudgmental, allow participants to talk, and be sensitive to their feelings (Taylor & Bogdan, 1998). "In-depth interviewing sometimes requires a great deal of patience.

Informants can talk at length about things in which you have no great interest. Especially during initial interviews, you should try to force yourself not to interrupt an informant even though you are not interested in a topic." (Taylor & Bogdan, 1998, p 100).

The interview guide was initially informed by my literature review and evolved as interviews progressed. I pre-tested both the consent form as well as the interview guide (interview instrument) prior to their use, and I made refinements accordingly prior to beginning the actual interviews. As a result of the pre-testing, I realized that I had omitted asking for the participant's state, actual occupational (job) title, and source of referral to study, at the end of the interview, so I added those items into the instrument. Pre-testing is important, because no matter how carefully researchers design a data collection instrument such as a questionnaire or an interview guide, there is always the possibility of error, such as an ambiguous question or a question that respondents cannot answer (Babbie, 2004, p. 256). Therefore, when constructing a data collection instrument, the best protection against errors is to pre-test the questionnaire. Since it is not essential that the people who take the pre-tests comprise a representative sample, I asked two of my colleagues for whom the study would be relevant, to take the pre-test. As Babbie (2004) states, it is better to actually have individuals participate as pre-test study participants rather than have them simply read through the survey or interview guide looking for errors.

It was also important for me to strike a balance between getting people to talk about what is important to them and yet remain on target with the interview guide: "…researchers have some general questions to ask prior to starting the interviews. Yet they have to be careful not to push their own agendas too early in the interviewing." (Taylor & Bogdan, 1998, p. 102)

"By virtue of being interviewed, people develop new insights and understandings of their experiences. They may not have thought about or reflected on events in which the interviewer is interested, and even if they have, they interpret things a bit differently each time….By asking questions and probing for meanings, interviewers encourage people to articulate things that they have not articulated before." (Taylor & Bogdan, 1998, p. 98).

Probing was important too. "One of the keys to successful interviewing is knowing when and how to probe…Although the tone of qualitative interviewing is conversational, probing distinguishes this kind of interviewing from everyday conversations." (Taylor & Bogdan, 1998, p. 106). I found that I often had to probe for details and specifics in order to get clarification or specifics regarding the individual's responses.

Following the guidelines of Taylor and Bodgan, (1998, p. 115-116), I kept detailed notes about the interviews. These notes served several purposes. First, the notes listed any observations. I made note of any emerging themes, interpretations, ideas, and in the case of in-person interviews, non-verbal expressions that I thought were important. I also kept a record of conversations and emails with participants outside of the interview situation, as well as at other times when I thought of something important to record.

Although I did not offer interviewees any direct financial incentive for participating in the study (a $10 donation per individual went to NHF), many participants identified a desire to help others as the main reason for wanting to participate.

The fact that I am a person with migraines[8] too was helpful during the interviews. Aside from the fact that I was familiar with many of the experiences, terminology, and names of medications, associated with migraines, several participants who asked me about my status seemed relieved that they were being interviewed by a person who understood. One person said it was wonderful to talk to someone who could "speak the same language."

Protection of Subjects, Ethical Considerations

My research proposal was approved by the City University of New York Graduate School and University Center (CUNY GSUC) Institutional Review Board (IRB) on: December 17, 2007. All necessary steps were taken to ensure that this research did not harm any participants. This included following all Graduate School and University Center Institutional Review Board guidelines for research with human participants, such as obtaining informed consent, assuring and protecting participants' confidentiality, and using pseudonyms/code names. Individual responses were not made known to anyone except me. All identities attributed in the quoted excerpts in the data chapters and conclusions chapter (Chapters 5, 6, and 7) are pseudonyms.

The risks from participating in this study were no more than encountered in everyday life. The benefit of participation is that the participants' comments will add to the generalized body of knowledge about this topic. I was prepared in case any participant(s) seemed to show signs of stress, psychological discomfort, or anxiety, that I would refer them to a contact number at the National Headache Foundation. None of the

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[8] I did not mention this in any of the recruitment materials. I also did not volunteer this information during the interviews unless the participant asked me directly. In those cases, I replied that I was a person with migraines; any other questions were not answered until the interview had been completed.

participants showed any such signs. If a participant wanted a copy of the findings of the study, I advised him/her that I would send them a copy upon completion of the study. Participants were advised that even if they chose to participate but then decided to stop, they may do so with no penalty. Prior to the beginning of the actual interview, I reminded each participant that he/she did not need to respond to all of the questions.

Names of people, or any identifying characteristics, will not be used in any publications. When I conducted each interview, I therefore asked each subject to provide me with a “code name” that they would like me to use, and I also offered to assign a code name instead if the participant preferred. If a participant wanted a copy of their completed consent form, I copied it and mailed it to them.

The audiotapes of the interviews are available only to me and my GSUC advisor. All information gathered about or from participants was kept strictly confidential, and is stored in a locked file cabinet, to which only I, and my advisor, have access. The data will be kept for a period of three years following completion of the study, at which time all identifying information will be shredded/erased.

I was also prepared that should the research reveal the possibility of a medical or potentially troubling condition on the part of a participant, I would strongly encourage the participant to share this information with his/her personal physician. This did in fact happen with one participant. After I encouraged her to notify her physician, she thanked me for alerting her, and she later indicated that she had made an appointment to see her physician as a result.

The consent process was an oral one for the telephone interviews, and a written one for the in-person interviews. I printed the consent document for the in-person interviews on CUNY Graduate School and University Center Sociology department letterhead, but the consent document for the telephone interviews did not need to be printed on departmental letterhead. For the telephone interviews, a copy of the consent document was read aloud to the participant by me, via telephone. I wrote the participant's name on the oral consent form. I tape-recorded the reading of the oral consent form. I asked and recorded if it was acceptable to record that part of the conversation. Although the participant's real names appear on the consent forms, these are kept confidential and locked away.

Each participant was informed of his/her right to refuse to answer any questions or end the interview at any time. Each participant was informed of his/her right to listen to all or part of the audiotape if desired. Each participant was informed of his/her right to elect to have the tape erased should he/she wish to withdraw from the study.

Data Analysis and Interpretation, Coding

As I stated previously, my intent was not to conduct inferential or explanatory statistical analyses with this data. Instead, I planned to use the data to prepare a descriptive picture of migraines in the workplace, decisions to disclose, and the management of spoiled, hidden identity in the workplace.

"Qualitative research is inductive. Qualitative researchers develop concepts, insights, and understandings from patterns in the data rather than collecting data to assess preconceived models, hypotheses, or theories." (Taylor & Bogdan, 1998, p. 7)

All of the interviews were taped and fully transcribed for analysis. I listened to the audiotape recordings of each of the 40 interviews. I transcribed the audiotapes myself, a process which took much longer than I expected -- three months (November 2008 through February 2009). "…people sometimes underestimate the amount of time it takes to have taped interviews transcribed" (Taylor & Bogdan, 1998, p. 142), and this is exactly what happened in my case. Then I subsequently re-checked the recordings a second time against the transcripts. This was a necessary step prior to interpretation. The data consisted of verbatim transcripts of interview tapes and the additional observational notes that I had collected.

Taylor and Bogdan (1998, p. 142) state that "It is a good idea to begin coding as soon as possible after you have completed the fieldwork or collected the data." The authors (1998, p. 150) also explain about coding: "In qualitative research, coding is a way of developing and refining interpretations of the data."

The type of analysis that I conducted is qualitative, involving open coding of the data to determine categories, followed by focused coding to identify themes, and look for patterns in the data. The statements made by participants were analyzed by using this coding system to determine their impressions of their workplace experiences. Each comment was counted, coded, and analyzed. The purpose and logic of the analysis was to demonstrate and describe the experiences of the study participants in the workplace.

After much thought, I decided <u>against</u> using a computer assisted software program to facilitate qualitative coding and data analysis. I chose instead to read and ponder over what I had gathered, immerse myself in the data, with multiple readings and constant back and forth of themes that emerged as I read, and then to use a basic word processing program. As stated by Taylor and Bogdan (1998, p. 141): "Because qualitative data analysis is an intuitive and inductive process, most qualitative researchers analyze and code their own data…Data analysis is a dynamic and creative process." So I read over the interview transcripts from beginning to end – several times, along with the other notes that I made. I also listened to certain sections of the interview tapes several times.

As Esterberg (2002, p. 157-158) explains, the first step in making sense of one's data is coding. In qualitative analysis, the goal is to focus on the potential meanings of the data. A researcher doesn't want to limit potential insights by rigidly applying pre-established codes to the data. Esterberg states that most researchers use some version of grounded theory to work with their data and develop meanings. Esterberg (2002, p. 158) explains:

> "Essentially, this method involves a two-stage process of coding. In the initial stage, called *open coding,* you work intensively with your data, line by line, identifying themes and categories that seem of interest. In this early stage, you should remain open to whatever you see in the data….In open coding, you don't use someone else's pre-established codes, or even your own…..If you develop codes in advance, you will impose your own sense of what *ought* to be in the data and may very well miss what *is* there."

Esterberg states that after you have done open coding for a while, some recurring themes should begin to emerge, and some themes may seem especially relevant. Once you begin to identify several key recurring themes, you can do focused coding. Like open coding, focused coding entails going through your data line by line, but this time with a focus on the key themes.

I used two approaches in coding thematic content. First, I created codes for pre-identified concepts. I identified sections of the transcripts that addressed these pre-established codes by closely reading through the transcripts. Examples of these pre-established codes included items such as: disclosure, passing, fear, stigma, guilt, legitimacy, accommodations, anger, triggers, treatments, pain.   During this process, other patterns emerged from the data beyond those captured in the pre-established codes. Accordingly, I created additional codes to represent these emerging themes, and I went back and applied these codes in subsequent readings of the data. This latter technique approximates a modified grounded theory approach. In very simple terms, grounded theory refers to theory developed from qualitative data derived via specific process.

My approach could be considered a modified form of grounded theory (Glaser & Strauss, 1967). I read transcripts of each interview multiple times, allowing themes to emerge through this procedure. I looked for themes by examining my data (called ‘discovery’). I collected all my notes, transcripts, documents, and other materials and read through them carefully. I searched through the data for themes and patterns.

“Glaser and Straus (1967) coined the phrase ‘grounded theory’ to refer to the inductive theorizing process involved in qualitative research. A theory may be said to be grounded to the extent that it is derived from and based on the data themselves…” (Taylor & Bogdan, 1998, p. 7). A similar logic may be found in Flick (2002).

Theoretical coding is a procedure for analyzing data that was collected, in order to develop a grounded theory. This procedure was introduced by Glaser and Strauss (1967).

Flick describes the process of coding as:

> “Starting from the data, the process of coding leads to the development of theories through a process of abstraction. Concepts or codes are attached to the empirical material. They are formulated first as closely as possible to the text, and later more and more abstractly. Categorizing in this procedure refers to the summary of such concepts into *generic concepts* and to the elaboration of the relations between concepts and generic concepts or categories and superior concepts.” (Flick, 2002, p. 177)

Open coding attempts to express data in the form of concepts. Data is classified in order to attach concepts (codes) to them. Of the resulting codes, the next step is to categorize those codes, by grouping them around phenomena discovered in the data which are particularly relevant to the research question (Flick, 2002). Open coding may be applied line by line, sentence by sentence, paragraph by paragraph, or passage by passage. This depends on the research question, the material, or on the researcher’s personal style. The aim of coding is to break down and understand a text and to attach and develop categories and put them in order. Open coding is the analytic process by which concepts are identified and developed. The result of open coding is a list of codes and categories.

Flick, (2002, p. 181) describes axial coding:

> “The next step is to refine and differentiate the categories resulting from open coding. From the multitude of categories that were originated, those are selected that seem most promising for further elaboration. These

> axial categories are enriched by their fit with as many passages as possible. Finally, the relations between these and other categories are elaborated. The researcher moves back and forth between inductive thinking – developing concepts from the text, and deductive thinking – testing the concepts against the text. In axial coding, the categories most relevant to the research question are selected. Many different passages in the text are then sought as evidence of these relevant codes."

Flick, (2002, p. 182) goes on to describe selective coding, which is considered the third step. This continues the axial coding. The analysis and development of theory aim at discovering patterns in data and conditions under which they apply; grouping the data according to the coding paradigm. Finally, the theory is formulated in greater detail and again checked against the data. Flick (2002, p. 183) describes: "The procedure of interpreting data, like the integration of additional material, ends at the point where *theoretical saturation* has been reached, i.e. further coding, enrichment of categories, etc. no longer provides or promises new knowledge."

I content-analyzed each section using a coding system I developed to capture the most salient themes present, and this was then applied to the transcripts from all 40 participants. I recorded the presence of relevant themes in transcripts. One of my peers, who at the time was a colleague at the University where I am employed, coded a subset of the transcripts in order to establish inter-rater reliability.

There are certain guidelines involved in coding. Taylor and Bogdan (1998, p. 152) describe: "….The cardinal rule of coding in qualitative analysis is to make the codes fit the data and not vice versa. Record any refinements in your master list of coding of categories. You will notice that some pieces of data fit into two or more coding categories. These should be coded according to all relevant categories…Coding is intended to help you develop insights and generate theoretical understandings….” (1998, p. 154).

Analyzing qualitative data involves several stages besides coding. As I became increasingly familiar with the data, I began to generate themes and categories, and identify patterns in the data. As Esterberg (2002, p. 152) explains, in qualitative research, data analysis is a creative process of making meaning. My job was to actively create meaning out of the raw materials of interview transcripts and coding schemes. One of the difficulties in analyzing qualitative data is that there is no single method or rule for how to analyze it. Therefore, the sensitivities and activities of the researcher often govern what particular sense is made of what is said or seen.

The actual mechanics of managing data was also a concern during this process. I had to find some way to physically manage and organize all of the material I had accumulated. I used Esterberg (2002, p. 151-153) as a guide throughout this process. At this point, I had two three-ring looseleaf binders, many paper file folders, interview transcripts on the computer, and index cards. As part of the process of analyzing qualitative data, one task is to organize data in order to make sense of it. I had to make sure that all of the taped interviews were transcribed and that my notes were together and complete. I labeled the audiotapes so that I knew what was contained on each. I made a list of all the materials I had gathered. This was a fairly mechanical process of gathering all the materials and creating a filing system for organizing everything for easy access and retrieval. I placed a copy of each transcript in a three-ring looseleaf binder, in chronological order. I stored all correspondence, notes, documents, and any other materials relating to the interviews in file folders. I kept my notes in chronological order. During the course of the research, I collected a number of miscellaneous documents and articles. I kept a list of everything I gathered, all interviews, with date conducted and date transcribed. I kept multiple copies of all the transcripts, one printed copy, kept one file on my computer at home and one at work, plus a back up copy of the interview transcripts and dissertation drafts on a flash drive. All physical materials were kept in the locked file cabinet.

The concept of building theory from data was discussed by Taylor and Bogdan, (1998, p. 136-137):

> "Qualitative researchers have discussed whether the purpose of theoretical studies should be to *develop* or *verify* social theory, or both. Glaser and Strauss argue that qualitative and other social science researchers should direct their attention to developing or generating social theory and concepts (1967). Their *grounded theory approach* is designed to enable researchers to do just that. Other researchers, writing from a more positivistic stance, take the position that qualitative research, just like quantitative studies, can and should be used to develop and verify or test propositions about the nature of social life…..Although we question whether qualitative methods lend themselves to verification and testing, we find the logic behind…grounded theory…useful in analyzing qualitative data."

Taylor and Bogdan (1998, p. 137) continue:

> "The grounded theory approach is a method for discovering theories, concepts, hypotheses, and propositions, directly from data rather than from a priori assumptions, other research, or existing theoretical frameworks. According to Glaser and Strauss (1967), social scientists have overemphasized testing and verifying theories and have neglected the more important activity of generating social theory…Glaser and Strauss propose two major strategies for developing grounded theory. The first is the *constant comparative method*, in which the researcher simultaneously codes and analyzes data in order to develop concepts. By continually comparing specific incidents in the data, the researcher refines these concepts, identifies their properties, explores their relationships to one another, and integrates them into a coherent theory."

This is not as simple as it may sound. Taylor and Bogdan (1998, p. 140-141) describe the difficulty of making sense of data gathered through qualitative research methods:

> "Data analysis is probably the most difficult aspect of qualitative research to teach…Most people who are new to the methodology are capable of establishing rapport…, asking questions, and recording data, but get stuck when it comes to analyzing their data… It is not fundamentally a mechanical or technical process; it is a process of

> inductive reasoning, thinking, and theorizing…Data analysis…entails certain distinct activities. The first and most important one is ongoing discovery – identifying themes and developing concepts …data analysis is an ongoing process in qualitative research…In qualitative research, data collection and analysis go hand in hand. Throughout…qualitative research, researchers are constantly theorizing and trying to make sense of their data. They keep track of emerging themes, read through their field notes or transcripts, and develop concepts and propositions to begin to interpret their data…The second activity, which typically occurs after the data have been collected, entails coding the data ….”

To summarize the process of data collection and analysis, I asked each of the participants a core set of questions, but each interview was modified somewhat and tailored to each person, depending on their occupation or something they told me. I asked about their present and past jobs, how the migraines affect their work, the problems and challenges they faced at their jobs, and what it feels like to have a migraine. My process for coding and analyzing was based on a modified version of the grounded theory approach (Glaser & Strauss, 1967.) I read and re-read transcripts of the interviews, looked for themes, and coded interview data. I categorized the interview material into broad themes, and then I developed more refined codes to target the analysis. I then went with those target codes and compared back to the interviews to generate themes and ideas from the data.

A very profound conclusion is made by Taylor and Bogdan (1998, p 156):

> "By comparing different pieces of data you refine and tighten up your ideas and gradually move to a higher level of conceptualization…..Since this is an inductive and intuitive process, there are no simple procedures or techniques for this kind of analysis….There are no guidelines in qualitative research for determining how many instances are necessary to support a conclusion or interpretation. This is always a judgment call…."

In terms of validity and reliability, qualitative research is systematic and demanding, but does not necessarily follow standardized, structured procedures the way quantitative research does (Taylor & Bogdan, 1998); but checks can still be placed by researchers on their data recording and interpretations. "Qualitative research is a craft… The researcher is a craftsperson." (Taylor & Bogdan, 1998, p 10)

CHAPTER FIVE: THE DATA – [ISSUES AT THE WORKPLACE] - THE RELATIONSHIP BETWEEN MIGRAINES AND WORK; WORKPLACE ACCOMMODATIONS; AND CAREER IMPACT

Outline of this Chapter

1. Effects of the Workplace on Person: Workplace Environment; Stress
2. Effects of the Workplace on the Person: Work-Related Triggers
3. Workplace Challenges: Lack of Understanding and Bad Experiences
4. What a Migraine Feels Like
5. Consequences of Migraines on Work: Attendance/Absenteeism, Productivity/ Work Performance, and Other Consequences
6. Workplace Accommodations – and Disability/ADA
7. Career Impact: Missed Opportunities and Career Choices

In Chapter 5, I concentrate on the portion of the workplace data relating to three areas: 1) the relationship between migraines and work, including effects, experiences, and consequences, 2) workplace accommodations, and 3) career impact. Within these three broad areas, I focus on the following seven topics: 1) effects of the workplace on the person, such as workplace environment or stress, 2) effects of the workplace on the person, with a focus on work-related triggers, 3) workplace challenges, such as lack of understanding and bad experiences, 4) what a migraine feels like, 5) consequences of migraines on work, including attendance/absenteeism, productivity/work performance, and other consequences, 6) workplace accommodations, and 7) career impact, such as missed opportunities and career choices.

One epistemological note for Chapters 5 and 6: Since my choice of method was to interview individuals about their experiences (see Chapter 4, Methodology), I am not able to speak about actual behaviors in the workplace, only the study participants' perceptions of them. Therefore, when I discuss behaviors (e.g., responses to disclosure, etc.), I am actually discussing the perceptions of those behaviors as described by the study participants rather than the behaviors observed by me.

1. Effects of the Workplace on Person: Workplace Environment; Stress

Different types of workplace environments can have specific effects on each individual who works in that environment. I asked participants in this study to describe the effect of their workplace on their migraines (how their job affects their migraines). The environment can have a variety of effects, in particular, on individuals who are prone to migraines:

> "Migraineurs can be bothered by allergens such as dust, mold, and pollen; by changes in the weather or temperature; by glaring or fluorescent lights; and by strong odors and high altitudes – and even computer screens. People who have migraines have a set threshold that, if exceeded, will result in a migraine." (Stafford & Shoquist, 2003, p. 170)

Many individuals in this study cited stressful or hectic work environments, or other factors in the workplace environment, as contributing to migraines. Below are some examples:

Tori, a sign language interpreter for individuals who are deaf, described the enormous amount of pressure on an interpreter for accuracy in conveying information. She gave the following example of how important it is to get the correct message across and the significance of what it is that interpreters must do:

> "…if I'm interpreting something, somebody can receive the wrong medication because I interpreted something incorrectly. Or go to jail. Or be set free. Or have their child sent home to them when their child should go to foster care instead. Of course, that added pressure doesn't help."
> [Tori, sign language interpreter, female, 44]

She told me that interpreters can get sued by college students who didn't pass a class, or by medical patients who later claim that they didn't understand something, for example, and then blame the interpreter.

When one has a stressful job, the unpredictability of migraines adds to the stress. Adrienne explained that this:

> "It's a lot of stress. And that doesn't make it any easier, since you're supposed to relax. How can you relax when you can't do your job? And then what are your options? You can't predict when you are going to get your next migraine. You might be lucky and not get one for a month. Yey, that's great! Then you get like what happened to me…I had it for a full 30 days." [Adrienne, assistant to president, female, 39]

Naomi, who works in a hospital operating room, provided another example of a stressful work environment and how that contributed to getting a migraine and making it worse:

> "…working in the operating room in the hospital environment, there are a lot of stressors, and it does not help the situation, plus the bright lights… Bright lights…being one of the physical stressors for me because when I usually get it, it has to be quiet, it has to be dark…and obviously when you are at work…you can't really…get the environment that you want to help it to stop, and then I am dealing with a lot of patients and doctors…too much noise and bright lights and just a fever pitch, and you have to be this

> multitask person, and all of the stuff that I have to deal with in that environment is what makes the migraine worse. It is a living hell." [Naomi, staff assistant in hospital operating room, female, 41]

Eleanor, currently a psychologist in a schizophrenia clinic, describes the time she worked in a psychiatric emergency room and what it was like when she had a migraine there:

> "Working in the psychiatric emergency room when I had a migraine, that was very hard. Because the smell. People smell terrible in the psychiatric emergency room. It's all the people. You must know from having migraines, that you're smell-sensitive. And so I think I was more inclined to nausea down there anyway, because of the smell, when I got migraines, which is a killer." [Eleanor, project director/psychologist, female, 36]

Eleanor's description, above, is an example of how her sense of smell was affected by a migraine. Sacks (1999) described how migraines often affect one's sense of smell:

> "Very characteristic of this state is an exaggeration, and often a perversion of the sense of smell; delicate perfumes appear to stink, and may elicit an overwhelming reaction of nausea." (Sacks, 1999, p. 25)

Candrine, who has been a marketing manager for special interest magazines for the past 22 years, described why her job is stressful:

> "…I do all of the marketing promotions for our direct mail…I've done renewals, billings, a whole bunch of things within marketing. It's stress-related…I am on the computer 24/7 … it's very tense…because you have a budget to make, and you have to meet those goals, whether they are revenue dollars they want you to make, or they want to make their rate base of the number of subscribers that they have, you have a target…so you are under intense pressure to make sure you meet those targets, and…you have to say why you don't. Not if you did, but why if you don't. So that pressure alone is enough." [Candrine, marketing manager, female, 37]

Liza, who works as a financial journalist and senior editor for a financial website designed to summarize and analyze financial news, described the stress level inherent in the fast-paced financial industry at certain times:

> "…there are times during earnings period…where it's going to be crazy…So I get to work at about 5:35 in the morning. I work until 2 usually, except during earnings periods. And then I will either stay through until about 5, so almost 12 hours. And then I will go and work at home for an hour or two…" [Liza, financial journalist and senior editor, female, 27]

Allison, who works in clinical research for a large pharmaceutical company, describes the integrated relationship of stress and migraines and her job:

> "…it feeds on itself a little bit…if my job is stressful, for example…if I'm reaching a deadline and it's pretty tight, and then I have a migraine, and then I miss work, and then I'm further behind…it can kind of make things much worse." [Allison, senior clinical trials associate, female, 35]

Lainy has worked in the special events industry for 12 years. Her company produces a lot of outdoor events, such as charity runs, community fairs, festivals, and outdoor concerts. Therefore, there is a seasonal aspect to her workload and stress level:

> "…my job is very stressful, and it's also 7 days a week, May through October, so there's definitely a lot of pressure and a lot of work during those months…" [Lainy, chief financial officer, female, 32]

Vita, an adjunct college teacher of English for almost 40 years, described how she was preparing for a certificate of continuous employment (CCE), which she described as kind of tenure for adjuncts, and the pressure of providing the documents required:

> "When I first really started having severe frequent migraines was when I was up for the C.C.E….it was just like being up for tenure, the requirements were the same, the pressure was the same, they all wanted the same proofs of everything I had done, all my…publications, every job I ever had… and…the pressure was so tremendous…It was after that, that's when I really had to really get help, because they were so bad." [Vita, adjunct teacher English, female, 71]

Several individuals in this study reported changing jobs in order to reduce stress levels and therefore reduce the frequency or severity of their migraines. Allison, who has worked in clinical research for the past seven years, has been at her current job for about one year. She talks about changing jobs:

> "…my last job…it was a very, very stressful environment, and my migraines had gotten really bad. In fact…I had week-long migraines…So, it's pretty much as soon as I switched jobs, the frequency and the intensity dropped off a lot." [Allison, senior clinical trials associate, female, 35]

For some individuals, although workplace stress was a contributor to or trigger for migraines, stress was an issue for them in general:

> "My triggers are stress. I'm a great worrier. I anticipate things six months in advance." [Londoner, assistant to head of school, female, 63]

Adrienne, who works in an international, high-pressure job, describes her industry as very dynamic and high stress. She works with an international professional sport, helping to organize tournaments throughout the world at a professional level. She and her colleagues prepare for tournaments and attend tournaments and meetings around the world. Below are two excerpts from Adrienne's interview which demonstrate the results of this high-stress, fast-paced, frequent-travel job:

> “So it’s busy year round, and travelling year round, where out of a given month, I used to average being home maybe 3 to 4 days. So you’re basically living out of a suitcase, you’re spending a lot of hours on an airplane, where you’re uncomfortable, you’re not sleeping, so you’re sleeping let’s say 13 hours on a flight, to arrive where it’s daylight… somewhere else, different climate, and you’re going straight into a meeting, you’ll stay there 2 days, and then once you’re there, because of etiquette and protocol, you’re being wined, dined, and entertained, so you can’t just politely go to the hotel room and sleep.” [Adrienne, assistant to president, female, 39]

> “There’s a lot of stress, because you have responsibilities with fans, and security, you have VIPs and celebrities… so it’s on you to make sure that everything is okay... You’re looking at security, you’re taking care of your VIPs, making sure they’re fine…that the paparazzi is not out there ready to stalk them, that…someone’s not going to attack one of the…players just because they didn’t like how they played, or a crazy fan is not trying to break into the locker room, and this is around the clock….that’s like the norms….there’s like very little time for you to relax…And obviously, someone with my history, a lot of time to get migraines.” [Adrienne, assistant to president, female, 39]

As Stafford and Shoquist (2003, p. 173) indicate, “Just by virtue of being a migraine sufferer, you’re probably ultrasensitive to your surroundings.” So many factors within the workplace environment can affect an individual and trigger a migraine. In the next section, I examine workplace triggers in more detail.

2. Effects of the Workplace on the Person: Work-Related Triggers

As indicated in Chapter 2, Review of the Relevant Literature, migraine etiology involves an interaction between inherited characteristics, which predispose individuals to migraine, and exposure to specific internal factors and/or external environmental factors (Breslau & Rasmussen, 2001.)

“Triggers” are the stimuli that set off a migraine attack. They aren’t the *cause* of the migraine, since the actual cause of migraines can be very complicated and is still the subject of some controversy (i.e., genetics, chemical changes, etc.) During the interviews, I had prepared a uniform definition for “triggers” to have available (see last page of Appendix E) when I asked the interview questions pertaining to triggers, in case anyone asked me what I meant by “triggers.” But no one asked for it, so all of the individuals in this study must have understood the use of this term in the context of migraines.

In general, specific triggers for migraine vary for each individual. I asked each participant in this study to tell me about their overall migraine triggers. Many individuals have triggers that are not related to work. Common ones in this study were: certain foods or drinks, weather patterns (e.g. heat or humidity, barometric pressure, when it’s going to rain, drastic changes in weather), certain odors, anxiety, sleep patterns (fatigue, going to bed and waking up at different times, sleeping varied amounts of hours), and for women, their menstrual cycles and hormonal changes. I didn’t calculate or analyze the triggers that were not related to work, since that is outside the scope of this study.

Although the majority of people in this study knew exactly what their triggers were, five people did not know what their triggers were. Those individuals have tried more of this, less of this, eliminating that, and none of it worked. As a result, these individuals didn’t know what their triggers were. Unfortunately, “There will remain a large and severely-afflicted group of patients who suffer very frequent attacks without easily-defined antecedents…” (Sacks, 1999, p. 231)

Engrid, who remembered having migraines since she was 5 years old, describes trying very hard to find out what her triggers were, without success:

> “I stopped eating certain foods…I have stopped caffeine, I have started caffeine…And I’ve kept records of what I ate… And I will admit, I am going to be 65 in April and I have had a lot of years to think about this, and I have never come up with anything.” [Engrid, attorney and administrative law judge, female, 64]

Next, I also asked each person specifically if there were any particular triggers for migraine that were related to his/her workplace (past or present). The questions about triggers were open-ended questions. Some individuals did not have triggers related to the workplace; however, the majority of people who participated in this study did have work-related triggers.

Some workplace triggers can be changed or avoided; others can’t. I discuss this further in the accommodations section of this chapter.

Below is a chart that summarizes the responses of the 40 participants in this study regarding their work-related triggers. Note that the numbers add up to more than 40 because almost half of the participants named more than one work-related trigger, and also because some individuals discussed more than one workplace.

TABLE 6

Participants' Work-Related Triggers

Participants' Work-Related Triggers

- Stress / Work Pressure (20)
- Workplace Lighting (14), especially fluorescent lighting or bright lighting
- Workplace odors/smells/scents (6)
- Not getting enough sleep or not getting a good night's sleep, as a result of working late or working a long event (5)
- An office that was dark, hot, and far away from a window; or had no windows and clogged vents; or was stuffy and hot (3)
- Temperature extremes between hot and cold (1)
- Computer monitors and/or use of computers; spending too much time on computers (7)
- Business travel: i.e., on airplanes or long bus rides (2)
- Workplace noise / loud noise (3)
- Working all day without taking a break; or can't stop to eat, i.e. skip eating and no break, working straight through without meals or breaks, not having regular meals (2)
- Long meetings - over one hour (1)
- Extra long work day (1)
- Doesn't know what his/her triggers are (5)
- Has triggers, but None are work-related triggers (6)

Note: Total adds up to more than 40 because many participants named more than one work-related trigger, and also because some individuals discussed more than one workplace

The triggers questions were open-ended. I combined/collapsed, and grouped them into the categories in the table above.

One of the reasons I asked about *workplace* triggers was that I thought that people in different occupations would report different triggers due to the circumstances of their workplace and job requirements. Also, some triggers can be changed, while some can't be changed. I knew this would be an important piece of information to study.

Sacks (1999) used the term 'arousal migraine' (p. 140) to denote the occurrence of migraines in circumstances that activate or arouse. It is a type of 'circumstantial migraine' (p. 140) that tend to provoke attacks of migraine in predisposed individuals. Lights, noise, and smells, were some of the triggers for arousal migraines. Sacks stated the following about light, noise, and smells:

> "There are many patients who insist that glaring light and blaring noise are liable to give them a migraine…A number of patients in this class enter one's consulting room wearing dark glasses…the question of *flickering light* as a highly-specific provocative circumstance must be considered…We have noticed the occasional occurrence of olfactory hallucinations in migraine aura…a specific sensitivity to certain smells…" (Sacks, 1999, p. 141)

Below are descriptions from some individuals in this study who had workplace triggers of lights, noise, or smell:

Kellie, who has been self-employed for the past 16 years, describes flickering workplace lights and flickering computer monitors:

> "One of my worst triggers is computer monitors that flicker…the other bad one for me is flickering lights. Fluorescent lights and some halogen lights tend to flicker. And that will trigger a migraine for me within seconds. Those are probably the worst two work factors…" [Kellie, self-employed owner of design and remodel firm, female, age 54]

Donna also described how flickering workplace lighting was a migraine trigger for her:

> "…harsh, fluorescent lights that some older offices have, are really hard…a big trigger. Certain kind of lights, any flickering lights, a huge trigger for me…bright fluorescent lighting in an office is not a good thing

> for migraine people day after day after day." [Donna, marketing director, female, 52]

Sacks (1999) had a specific name for the flickering light migraines: 'resonance migraine' (p. 149) which he described as "…Flickering light from any source -- emitted from a fluorescent or television-tube…" (1999, p. 149). However, he noted that it was "…only *particular frequencies* of flashing light…" (1999, p. 151).

Liza, a financial journalist, stated that the loud noise at her workplace was a migraine trigger for her:

> "…we have televisions on all the time, and they're very loud, and…a lot of analysts yelling at each other. We watch either CNBC or Bloomberg TV and everybody's yelling at each other…and then there's always one person who's saying, 'Can you make it a little bit louder?'…" [Liza, financial journalist and senior editor, female, 27]

Then, once she had the migraine, Liza said the loud noise only made it worse. "During a migraine, you may find that all kinds of sounds are unbearable." (Stafford & Shoquist, 2003, p. 22)

Aside from lights, smells, and sounds, some of the other triggers listed in Table 6 have also been noted in the literature: travelling by bus or airplane (Sacks, 1999, p. 146), emotional stress (Sacks, 1999, p. 164), computer screens (Stafford & Shoquist, 2003, p. 170), sleep deprivation (Stafford & Shoquist, p. 170), the features of the individual's personality (Sacks, 1999, p. 164).

At various points in his book, Sacks (1999) points out that it is frequently stated that migraines are 'peculiar to a specific migraine personality.' This personality is portrayed in his book as: "ambitious, successful, perfectionistic, rigid, orderly, cautious…” (Sacks, 1999, p. 166), “impatient…living in a chronic anxiety state…” (Sacks, 1999, p. 167), “obsessive, rigid, driving, perfectionistic….” (Sacks, 1999, p. 124), “a hypertensive perfectionist…obsessional, brilliant” (Sacks, 1999, p. 129).

Below are examples of two individuals in this study who attributed to their migraines at the workplace as being triggered by things they did that they perceived were due in part to their ‘migraine personality’. Both of them talked about putting pressure on themselves.

Linda, a director of marketing and communications, was getting migraines almost daily at one point in her career. Linda explained that one of her triggers, working straight through the day without taking a break, came from within her own personality/nature:

> “…I tend to be... a task master towards myself so …I will just keep working and working and working, and then I will realize that it’s 3:00 and I haven’t even taken a break, which…definitely doesn’t help. And I would find…my headaches, when I was getting them on a regular basis, would often come in the late afternoon... I think there was a part of me that felt like I just had to keep pounding away at it. You know, and just work, work, work…and I put a lot of pressure on myself that way.” [Linda, director of marketing and communications, female, 53]

Maria currently takes three prescription medications in combination to prevent migraines. Maria, like Linda above, also talks about her personality/nature:

> “…I am always involved in, not just school, I am a perfectionist, and I have to have things done. I’m very organized, like things done in a certain way, and I was always very involved in outside of school activities…I’m always doing a lot of things…It was usually the pressure I put on myself…I always did more than my share.” [Maria, retired teacher, female, 60]

Ted reports having had severe migraines for 30 years. He worked in the corporate world for 20 years, first in various managerial positions in sales and marketing, and then later, executive positions. He describes working through meals (as a result of the demanding jobs) as triggering his migraines:

> "And then… probably some of the other things in the work environment, like working some of these jobs were demanding, so we might end up working through meals or working without meals. And that would key things too. Not having regular meal times." [Ted, retired owner of pet supply business, male, 61]

Linette, who currently works as an imports inspector in food safety inspection, tells about the numerous workplace triggers at a previous job:

> "…prior to that, I was working as a slaughter inspector in a chicken plant and beef plant. And what I noticed as triggers…there were the smells in the plant, and there's temperature extremes between hot and cold, the loud noises, bright lights, it was just a horrible place to be with migraines…" [Linette, imports inspector, female, age 39]

Donna, who worked in New York in magazine and newspaper publishing, an industry that she describes as "very stressful," describes an important decision that she made:

> "…I actually moved out of New York, because I thought that whole lifestyle was too much for me, after a lot of… soul-searching. And the profession I was in was very intense. So I thought I really had to downgrade my whole lifestyle…I really couldn't keep going at that pace and hope to get my headaches under control at all." [Donna, marketing director, female, 52]

3. Workplace Challenges: Lack of Understanding and Bad Experiences

I asked each participant to describe the effect of their migraines on their work situations and to tell me about their experiences. These included questions such as: Can you describe any workplace challenges related to your migraines such as physical, psychological, or social issues that arose while at work? Were there any best and worst experiences with bosses/supervisors or colleagues when dealing with your migraines at work? People in different occupations are faced with different challenges. During the course of conducting the interviews, I heard about many bad experiences and workplace challenges that individuals encountered in the workplace.

By far, the theme that I heard most often, regardless of occupation, was about the lack of understanding in the workplace regarding what migraines really are and how they are completely different from a ‘regular headache’. A related theme was that of people at work (both colleagues and supervisors) not taking migraines seriously. I discuss this also in Chapter 6 as it related to disclosure and stigma. As I state in Chapter 6, some of the mixed reactions or negative reactions to workplace migraines most likely originate from not being believed or from being misunderstood. People who are not familiar with migraine may think that the individual is exaggerating (i.e., perceptions that migraine is ‘just a headache’.)

These types of situations are supported to some extent by Conrad and Barker’s statement:

> “In the case of contested illnesses, the fact that sufferers’ symptoms are not readily associated with a discernable biomedical abnormality often makes it difficult for them to have their symptoms acknowledged… and often raises suspicions that their problems are ‘all in their heads’.” (Conrad & Barker, 2010, p. S70)

There were many individuals in this study who _did_ report having understanding workplaces. Below are some examples:

> “…one day, I just had to go home. Somebody called a car service for me, and I went home…I just felt so faint and dizzy and people were nice about it…it’s very nice where I work…and my boss is wonderful and it’s a good atmosphere, so if somebody’s not feeling well, they will be taken care of…” [Hillary, technical writer, female, 62]

Morgan, an events planner in a hotel, takes medication every day to prevent the almost-daily migraines that she gets without the medication:

> “I’ve always had compassionate bosses…I’m a hard worker…I think I’ve gone home for migraines maybe once or twice in my life. Other times I just sat there and suffered through it, went to the bathroom and threw up, and then came back out and tried to work for the rest of the day…When you are a worker that works really hard, then they know that when you are in pain you just can’t do it…Because I don’t call in sick, I never do. I’ll go to work sick, then work through the day.” [Morgan, event planner, female, 48]

Eleanor also had understanding bosses and colleagues throughout her career:

> “I think that for the most part in my life…partly because I’m not much of a complainer to begin with, about it, people have generally been very understanding…” [Eleanor, project director/psychologist, female, 36]

Maria, who says she has “probably tried every type of preventative medication and every type of abortive medication there is” is thankful for her supportive workplace:

> “I know that I had wonderful administrators…And I remember one administrator …he had to drive me home, because I couldn’t drive my own car…They were very, very good to me, and very concerned about me…” [Maria, retired teacher, female, 60]

Madelin, who has worked in human resources at her current place of employment for over 20 years, describes her attendance and her supervisor’s attitude:

> “…I could do my job, not the best…but I would be able to go in to work, so I would work through…I would have missed a whole lot of work if I

> didn't do that. I couldn't afford to. I needed to be at work…I would definitely lose a couple of days a month, for quite a while. Fortunately, at that point, the CEO that I have right now who is my immediate supervisor, and has been my immediate supervisor for 20-something years, has been fine with me…" [Madelin, vice president of human resources, female, 65]

Linda told me about her boss, who she describes as understanding, but a 'no-nonsense' person:

> "She's got this sign in her office… 'No whining'…she's a great person, but she's a very no-nonsense, not particularly sympathetic, so I would probably not go into a lot of detail with her…" [Linda, director of marketing and communications, female, 53]

Then there are those individuals who were faced with a *lack of understanding*. I heard from so many people about how a migraine is different from a headache. Many of the individuals who encountered lack of understanding, five of whom are quoted below, believe that part of the problem is that people in the workplace don't understand because they think a migraine is like a regular headache:

> "…it's starting to be a problem…because of the frequency that I get the migraines and because it's basically something that you have to take someone's word for it. It's not something that that they can physically see for themselves, so it's becoming an issue again, like oh there goes [name] again, stating that she has a migraine, but what's the big deal about a headache, how can a headache affect you like that?" [Naomi, staff assistant in hospital operating room, female, 41]
>
> "Some people don't really understand how bad migraines can really be, so they think, oh you just have a headache. But it's not just a headache. It's way beyond that…" [Anita, meeting and event planner, female, 32]
>
> "…when you say you have a migraine, people assume that it's just a really bad headache. But that's really not what it is at all...That's what's so hard for people to understand." [Jen, senior development officer, female, 30]
>
> "…It's one of those ailments, where…'take two aspirins and see me in the morning.' People don't take it seriously." [Engrid, attorney and administrative law judge, female, 64]

> “And people in work…I find the majority…do not understand the visual disturbances aspect. They think it’s just a severe headache. They don’t understand that it’s a complete breakdown of …your whole system. And you just have to go into a dark room and especially trying to explain to someone that you have visual ocular migraines…people just look at you as though you’re crazy when you mention something like that. And they just equate a migraine with a bad headache. Take two aspirin and come back in a couple of hours.” [Londoner, assistant to head of school, female, 63]

Adrienne described understanding in the workplace up to a point, but not when it interfered with the job itself:

> “…people can be sympathetic with you in the beginning…but not when it’s all the time and it’s persistent…it’s not your fault you have one [a migraine], but…their sympathy is limited, and if there is a big conference, and guess what you have a migraine…it makes it very difficult…you find some people that are sympathetic, and some people that are rolling their eyes, because nonetheless, the job needs to be done…if you can’t do the work, they gotta get someone else to fill in for you.” [Adrienne, assistant to president, female, 39]

Donna, whose migraines often lasted between three to five days, described something similar to what Adrienne said:

> “And people get very exasperated very quickly…if they’re sympathetic the first few couple of times, after that, they’re just not. Sympathy goes very quickly, and, ‘Why are you having another headache?’ and ‘Why are you leaving work again?’ and ‘Why…did you have to cancel that meeting again?’ It just doesn’t fly.” [Donna, marketing director, female, 52]

And so did Margate:

> “…But, you know, how much could you be out sick if you want to keep your job? You know, maybe…a day every 2 or 3 months, I would call in with a migraine, but not more than that. I couldn’t… I was embarrassed to be calling in sick too much, and I also felt that I had a job to do, so I would just take medication and come in and just try to get through the day…if I was out sick… 5-6 days a month, they would look at me cross-eyed, but I really wasn’t out that much…” [Margate, retired legal secretary, female, 65]

Then, I heard about the boss who doesn’t understand, not because of unfamiliarity with migraines, but because he/she is ‘the boss who never gets sick’. Liza described this:

> “…That’s not to say that he’s an awful person, he just doesn’t understand…illness, uh-uh. He doesn’t get sick. So nobody else gets sick. What he does…when he starts not to feel well, is he takes a lot of Vitamin C and Echinacea, and that’s it…He never gets sick. And therefore nobody else does. You never ever see it. I’ve never seen him sneeze or cough.” [Liza, financial journalist and senior editor, female, 27]

In terms of ***bad experiences***, I heard about many. Some of these very bad experiences serve to illustrate what a serious problem migraines really are. Almost everyone in this study had at least one story that they remembered right away, for one reason or another, and they remembered it very vividly, even if it happened a long time ago. Very few people said that nothing came to mind when I asked. Although my intent was to concentrate on work-related experiences, I did listen to personal experiences as well. I summarize some of the bad *personal* experiences here below in bullet format, just as examples of the depth and breadth of these experiences. However, I focus on the work-related experiences for the remainder of this section of the Chapter.

- Morgan told me about the time that she was vomiting from a severe migraine at a friend’s house, but couldn’t take any medication because she was pregnant.
- Tori told me a powerful story about a case of vertigo that accompanied a migraine when she was home alone in bed watching

her 10-month-old daughter, and her fear of not being able to get up to move to help her daughter while the baby was running around.

- Russel remembered very clearly about how he cried in pain when he was young and had migraines, and how much it bothered him when his father told him: ‘you’ll be fine, just sleep it off’, because his father didn’t understand the extreme pain he was in.
- Madelin had a similar story of having horrible headaches and vomiting as a child, but her parents thought she was making it all up.
- Jen remembered being a bridesmaid at her friend’s wedding and being so sick with a migraine that she was not able to be there for her friend.
- Candrine told me about a bad stretch of migraines so severe that she had to be put on sedatives. As a result, her two year old twin daughters had to be moved out of her home for awhile, since she couldn’t take care of them because of the sedatives.
- Engrid still vividly remembers what she calls a ‘mortifying’ experience, over 40 years ago, when she was on the London Underground [similar to New York subway]. She became nauseous from a migraine, but couldn’t find a ladies room in time and had to vomit in a garbage can.
- Engrid also recalled another time from 10 years ago when she broke her ankle, had surgery, and was ‘in agony’ from a migraine after the surgery. She insisted at the hospital that she needed a painkiller for her ankle, which really wasn’t bothering her at all, because she knew

if she told them that she had a migraine, they would give her two aspirin. She needed the painkiller for her migraine, not her ankle.

- Lainy, who is now divorced and living alone, told me about having a very bad migraine and contemplating calling 911 at 4:00 a.m., a scary situation for a person trying to get through on her own.
- Julia had a migraine during the weekend of her son's college graduation, and remembers the car ride there and being "in agony", but she doesn't "remember much of what happened" that entire weekend because the pain was so excruciating. "I basically don't remember my son's graduation."

Now I shift focus to the <u>*work-related bad experiences*</u>. Tori, the sign language interpreter, described one time when she had a migraine during what she called a "high-profile interpreting job" and how the man who would later become her husband helped her through it:

> "I had a migraine and I had a really important job to do…I had a suit and everything on…and I could not keep my head above my heart level…Then when it was time for me to get myself together, I took some deep breaths, stood up, did what I had to do, and put my head back down when I was finished. And 'J' actually would take me, he picked me up one time and carried me into the women's bathroom, in this very fancy hotel, walked into the bathroom with me, held my hair up while I threw up, washed my face, re-applied my lipstick, and took me back out. And I was like, okay, I have to marry this man." [Tori, sign language interpreter, female, 44]

Engrid told of a bad experience from when she took the bar exam:

> "…when I took the bar exam, which was in 1969…I had a horrible headache. It was when there were very few women taking the exam.

> They assigned a specific proctor to walk me to the ladies room to throw up…I have no idea how I passed because I have no idea what happened. I have no idea how I got home that day.” [Engrid, attorney and administrative law judge, female, 64]

Liza described staying home from work after waking up with what she considered “the worst headache ever”:

> “…I had my sunglasses on, the lights were off, I had my earplugs in, and all day long my boss kept sending me IMs and saying ‘Are you sure you can’t come in? You sure? We really need you here.’” [Liza, financial journalist and senior editor, female, 27]

Ted’s bad experience had to do with strobe lighting, which was popular in the 1970’s. I discussed lighting as a trigger earlier in this chapter. Several study participants remembered strobe lighting because it was problematic for them.

> “I remember there was an era in the 1970s where people used strobe lights a lot. And I remember being in one sales meeting where the strobe lights just caused an instant migraine. And I ended up I had to get out and leave it. I had to leave the place, and I couldn’t find my way out, and I walked right into a pillar. I was trying to get out. The strobe set it off. …The worst day of my life with the migraine all I remember was that meeting with the strobes…That was probably one of the worst migraines I’d ever had...” [Ted, retired owner of pet supply business, male, 61]

Vita told me the following story about a bad experience from an earlier job, when she felt a migraine coming on:

> “When I was working as a reporter, I was interviewing somebody one time.   And I had to run out of the room in the middle of the interview to go throw up.” [Vita, adjunct teacher English, female, 71]

Lainy described what happened when she got a really bad migraine “that came out of nowhere” during a special event at work:

> “…my same co-worker who’s been with me through all of this, because he was the one who had to drive me home that evening, because I couldn’t even drive, obviously I couldn’t drive my car. I think he carried me up to my apartment…that night.” [Lainy, chief financial officer, female, 32]

Adrienne, the woman who works for the international professional sport, and has the hectic job, describes the following experience -- a migraine that did not go away:

> "I had a scary experience…where I had a migraine that just wouldn't go away, and it lasted about a whole month, and it was a trying period where I travelled for the first time with the organization, for three months back to back. So I was away from home, and …I travelled to the Caribbean, from the Caribbean to Miami, from Miami to France, so…maybe because of the time zones, and so on, everything, it was just a combination, but the point was, when I got back, I couldn't get rid of this f***ing headache…" [Adrienne, assistant to president, female, 39]

4. What a Migraine Feels Like

"Migraine headache is traditionally described as a violent throbbing pain in one temple..." (Sacks, 1999, p. 14). However, 1) since symptoms, duration, sequence, and intensity of migraine can vary from person to person, and 2) each person describes the feelings and experience of migraines in their own way, especially in a qualitative study, and 3) because lack of understanding in terms of what a migraine was all about, was a problem in the workplace for so many people, I decided to devote a section of this chapter to discussing 'what a migraine feels like' for the participants in this study.

As I discussed in Chapter 1, Introduction, the symptoms of migraine vary but commonly include headache, and nausea. In Chapter 2, Review of the Relevant Literature, I presented a list of common migraine symptoms: a throbbing, one-sided, intense, severe head pain, of long duration, accompanied by nausea and vomiting and/or sensitivity to light and sound. Stafford and Shoquist provide the following non-exhaustive list of possible symptoms of migraine, which they state can be different for each individual:

> "….a throbbing or hammering pain on one or both sides of your head…the pain ranges from moderate to severe to almost intolerable…you may experience an *aura*…you may feel lethargic…with the headache, you may experience nausea, vomiting, malaise, an extreme sensitivity to light, smells, and/or sounds." (Stafford & Shoquist, 2003, p. 12)

Towards the beginning of each interview, I sought to get background information about the migraines that each participant experienced. I asked questions about the frequency of their migraines, the length of time that they had been having migraines, the types of treatments they had tried for migraines, current treatments, and how long ago they had been diagnosed. The answers to these questions were wide-ranging, helped me establish rapport with the individuals, and provided me with additional background information for subsequent questions. However, those topics are not included in this analysis, other than some that may be mentioned briefly, since they are beyond the scope of this study.

Another question that I asked each person was what to describe what it feels like when they get a migraine. Everybody experiences a migraine differently, and one of the reasons that I asked this question was to try to raise awareness, especially for those people who would be reading the report of this study who don't have migraines or don't know anyone who experiences migraines.

Using study participants' own words, I try to capture these descriptions as best as I can, on paper, so that it will make sense to people who don't get migraines: migraines are not a condition like a regular headache in which you can take two aspirin and it will go away.

Jen feels strongly that other people need to understand about migraines, even though it is difficult for them, and that it is the responsibility of people with migraines to explain it to them:

> "…it's hard to make people understand what a migraine really is, people that don't understand it. And I think it's important…that people that do deal with it, that they have to explain it, because I've had plenty…who say, well you just have a headache, just take some Tylenol…And they don't understand… I think it's important to understand…and unfortunately it lays on the shoulder of the person who gets them [migraines], to be able to explain it to them so that they do understand." [Jen, senior development officer, female, 30]

Many people in this study said that the pain from migraine is the worst pain they had ever experienced. Some compared it to childbirth or passing a kidney stone and said that the pain from migraines was worse. Here are examples from six individuals, who wanted to describe the *severity of the pain:*

> "There are times that it's been so bad where I just want a lobotomy…it's so bad that I just want…to cut my head off." [Hillary, technical writer, female, 62]
>
> "I would take brain surgery. I would have someone work on my brain and open it up if they had to and fix it." [Morgan, event planner, female, 48]
>
> "…I was in the hospital two years ago, for two weeks because the headaches were so bad that…I couldn't go out of my apartment because it's on the fourth floor and I couldn't walk up the stairs because it would make the pain so bad." [Karen, assistant professor, female, 39]

> "…nothing hurts as much as that…And I've had childbirth and that doesn't hurt as much as those migraine headaches." [Morgan, event planner, female, 48]
>
> "The worst experience in the world…It's very excruciating. It's the worst pain I've ever experienced." [Susanna, social worker, female, 34]
>
> "I would definitely rather have children than have [migraines]. I have two kids…" [Julia, retired elementary school teacher, female, 67]

Below are other graphic illustrations of what a migraine feels like:

Darlene, who has had migraines for about 40 years, said that when she gets a migraine, it feels like:

> "…my head is my worst enemy. That I have been slaughtered. That there's something ripping open on the top of my head…and you just have to go as deep into the ground as possible, in a kind of hibernation because you can't come out…This is the most wretched thing I've ever felt in my life…I can barely keep my eyes open at that moment." [Darlene, psychotherapist/social worker, female, 57]

Russel, who has had migraines since his early teens, says that he usually gets warning signs before a migraine starts, such as a dull aching at the base of his neck and the back of his head, that then works its way up to his ears or into his eyes:

> "…And then what happens is I'll start getting a droopy eye or a bloodshot eye, it almost looks like I was drinking or something. And then the headache starts…And that's I would say 5 or 10 minutes before the onset of true agony. It is agony. I've been maxxed-out in pain. I'm a pretty tough guy, I'm not a wimp. And I've been maxxed-out on my hands and knees. It's just all I can handle." [Russel, owner of construction company and crane operator, male, 42]

Adrienne said her migraines feel like:

> "Hell. It's a throbbing, an endless throb that doesn't go away…even closing your eyes doesn't take it away, you just want to bury your head under some sort of…something cool, quiet, hurts in and around your eyes, you're nauseous, everything smells, lights bother you, people bother you,

> voices, everything…I see lights, it's stars and stripes forever, it's horrible." [Adrienne, assistant to president, female, 39]

Being irritated by light and smell, as Adrienne describes above, and that others described in the earlier section on workplace triggers, is consistent with what Stafford and Shoquist (2003) describe as the sensitivity to light and smell that often accompany a migraine:

> "Light sensitivity is such a common migraine symptom that it's in the top tier of symptoms and is usually part of a migraine…Smells may bother you before or during a migraine….Finding perfumes and cigarette smoke very obnoxious isn't at all unusual…" (Stafford & Shoquist, 2003, p. 21)

Lainy, who has struggled with medications and has "gone through every migraine medication on the market," gave an extremely graphic description:

> "I would prefer a steamroller to come roll over my head and push my eyeballs out and stomp on them. That would be much better. Sometimes that's the only way I can explain it to people who don't have them. They don't understand. I have a lot of piercing pain…And you know that's probably at the worst point when they're sitting behind the eye sockets, because again you just want to rip out your eyeballs and stop the pierce. That would feel much better…The steamroller, that's my description…" [Lainy, chief financial officer, female, 32]

The description provided by Lainy, above, and many of the others in this study, some of whose descriptions follow, demonstrate that often individuals with migraines have symptoms relating to the eyes. Sacks (1999) characterized them as ocular symptoms: "Tenderness or pain in an eyeball or other, almost uncategorizable, sensations in the eye…" (Sacks, 1999, p. 18).

Liza, who remembers having migraines since childhood, experiences several changes with migraines:

> "…it starts usually over one eye…then…my hearing gets, I call it 'sonic boom hearing', where all of a sudden everything is amplified about a gazillion times, and so somebody will whisper something, and I think they're screaming at me…then I get really light sensitive, so the tiniest bit of light will set me off. And it's horrible, I get nauseated, and I start to see all these weird colors and things that aren't there….And the only thing I can do is lay in a really cool, dark room, under all the blankets, with an ice pack on my head, ear plugs in…The sonic boom hearing is probably the biggest thing for me. It feels like I am in a tunnel and everything is amplified…I have to cover my ears if I don't have my earplugs with me. The light, the colors, I get nauseous, sometimes I vomit…" [Liza, financial journalist and senior editor, female, 27]

What Liza described in terms of her hearing sounds like what Sacks (1999) discussed as part of his review of the variety of migraine symptoms:

> "An exaggeration and intolerance of sounds – phonophobia – is equally characteristic of the severe attack; distant sounds, the noise of traffic, or the dripping of a tap, may appear unbearably loud and provoke the patient to fury. " (Sacks, 1999, p. 25)

Madelin, who works in human resources at a children's outpatient mental health facility, has migraines that affect many bodily systems:

> "Most of my migraines are generally over one eye or the other…like the top of my head is really going to explode. And I will definitely be nauseous at the same time…my vision is impaired. I'm very sick to my stomach. I get cold and clammy. And a lot of times, my speech is impaired, where I can't…form a sentence, can't speak a full sentence, I can't get out what I want to say. But…I need to get someplace, I need to lay down, before I fall down. And it needs to be dark, and it needs to be cold, and I just need, I need really to be left alone…the pain in my head…if I could open up the top of my head and let the pressure out, it's just so hard to describe….it's so different…it's such a sharp

> penetrating…through your brain, into your eyes…it's like so deep inside..." [Madelin, vice president of human resources, female, 65]

Brown, who was "written up" in her current job for not being able to come to work because of migraines, describes her migraines as:

> "I get no warning of any kind. They're just…there. Like this morning. I usually wake up with them, or have been woken up by one. And I feel dizzy, I feel pain in my eye…I have swollen face, and… I cannot stop throwing up. I have intense pain to the point that I see triple, and I have, I become evil. My husband will confirm to that. Because I have no patience, no nothing. It changes you. And I become white. I become very, very white…" [Brown, office manager, female, 49]

Brown's description of becoming 'white' is consistent with Sacks' (1999) use of the term of 'white migraine' to describe the facial appearance of some people with migraines:

> "Much more familiar is the picture of white migraine, in which the face is pale, or even ashen, thin, drawn and haggard, while the eyes appear small, sunken, and ringed. These changes may be so marked as to suggest the picture of surgical shock. Intense pallor is always seen if there is severe nausea." (Sacks, 1999, p. 18)

One similarity/pattern I found is that fifteen (15) times in this study, participants described the pain of migraines by using 'tool'-type words. The following 'tool' words were used by participants, followed in parenthesis by the number of unique times participants used this word: sledgehammer (1), vise (2), knife (4), chisel (1), ice pick (4), skewer (1), hammer (2). These are some examples of participants who described their migraines using tool words:

> "Feels like a sledgehammer on my head. It feels like if I could take my head off and throw it, I would. It's like a pounding sensation in the

temporal artery, then…like a pressure right above my eye and a pain by the lower part of my brain…it's excruciating…I can barely keep my eyes open..." [Naomi, staff assistant in hospital operating room, female, 41]

"It sort of feels like my head is in a vise. There's just this unbelievable pressure that anything touching it just feels like just my hair hurts. It's really very intense…" [Anita, meeting and event planner, female, 32]

"…and then the worst kind is when it feels like there's a knife in my eye or a vise in my head." [Hillary, technical writer, female, 62]

"…to put a knife into your brain. It's turning the knife that hurts, not just having the knife in your head, because you feel the pain is killing you. But it just keeps turning and turning…like an excruciating pain in your head…I feel it like a knife in my skull, and just feel like it's grinding into my head." [Morgan, event planner, female, 48]

"…for me it's my left eye. It's a pulling sensation. If feels as though the optic nerve in the back, there's a string and my eye starts to pull…it almost feels as though there's a wire from the back of my neck going around my ear up into my temple…having chisels, and just chop chop in your head…you just want to rip your eye out….you have this throbbing pain, and you just want to take your eyeball out…" [Tori, sign language interpreter, female, 44]

"…it's like somebody's got a knife and is digging out my eye, and I become totally non-functional, the pain is so severe. Like the light, the noise, everything, it's just I want to chop my head off…then I end up puking. You getting sick over the degree of how intense it is." [Candrine, marketing manager, female, 37]

"…a lot of pain in…my left eye, behind my eye. And I used to describe it as like a skewer going through my temple. From one temple through the other…" [Linda, director of marketing and communications, female, 53]

"It's sort of like there's somebody stabbing an ice pick up through that side of my head and then coming out through my eye, and it will spread to the entire head, and light is painful to me…sounds are painful, and I'm very tired and fatigued." [Linette, imports inspector, female, age 39]

"…I'd get a headache, right at the base of my skull…an ice pick headache. That's really what they feel like, feels like somebody's jabbing an ice pick in the base of your skull." [JP, retired school psychologist, male, 65]

"For me, it is an ice pick through my left temple and down into my eye. Not always the eye, just sometimes it stays above the eye. Sometimes it

> goes from the top of my head to the eye. But it is a sharp pain…it's just very, very sharp, and extremely painful…." [Julia, retired elementary school teacher, female, 67]

Nausea and/or vomiting was very common among participants in this study, as indicated in many of the previous quotes, plus this one from Lainy:

> "…I had a migraine last week. I think I was in the bathroom for 4 hours throwing up with it…I was drinking water just to throw up something at that point. So the nausea will last…somewhere between 8 or 10 hours. Then the effects linger for a few days when you've had a really bad one." [Lainy, chief financial officer, female, 32]

It was interesting to hear Lainy's description about drinking water in order to vomit something, because once you have vomited so much, your stomach is empty, dry heaves can irritate your throat.

According to Stafford and Shoquist (2003), who discuss nausea and vomiting during a migraine: "These stomach problems sometimes result from chemicals your brain releases during a migraine." (Stafford & Shoquist, 2003, p. 21)

Several participants described to me about how they had difficulty driving when they had a migraine, or were unable to drive at all. Ted, who has had severe migraines for 30 to 35 years, describes:

> "…sometimes, I'd be driving and…luckily I never got into any accidents or anything, but I might forget where I was actually going and go past it. I have been…5 miles away and realize that oh, that I was supposed to turn there or something." [Ted, retired owner of pet supply business, male, 61]

> "…when I start to get the headache, I start to lose my peripheral vision…I cannot tell you how many times I drove into the side of the garage, or a wall, the back of the wall…that's something very bad that I have a lot of trouble with, because at the beginning of it's coming, I just can't see out the sides as well, and I'm not driving safely, I know it…" [Julia, retired elementary school teacher, female, 67]

To illustrate how painful his migraines are, Russel told me about an incident when he was taken by ambulance to the hospital with a migraine, and he was given Morphine, a very powerful painkiller, at the hospital, but it didn't help his migraine at all:

> "I've had broken bones and had stitches, and there's nothing, believe it or not, there's nothing…I can't tolerate, no problem, but the headaches, they take me down…even though I'm a very strong person…" [Russel, owner of construction company and crane operator, male, 42]

Auras are a particular feature of migraines that some people experience. According to Stafford and Shoquist (2003),

> "Visual and perceptual disturbances can accompany a migraine headache…about 20 percent of the time. Typically, an aura starts about an hour before a migraine headache begins. You may hear or smell things that aren't really there….Some theories on the causes of auras are: excitation of brain cells and decreased blood flow to the brain. With different types of auras, you can experience visual anomalies such as white or colored squares, circles, or triangles that appear to be moving; zigzag lines…diminished field of vision..." (Stafford & Shoquist, 2003, p. 20)

Sacks (1999) describes the history of the term 'aura' and discusses why it is so difficult to describe an aura:

> "The aura itself is far from uncommon…good descriptions are hard to obtain, because many aura phenomena are exceedingly strange – so strange as to transcend the powers of language…The term aura has

> been used for nearly two thousand years to denote the sensory hallucinations immediately preceding certain epileptic seizures. The term has been employed, for somewhat over a century, to denote analogous symptoms which inaugurate certain attacks – the so-called classical migraine…" (Sacks, 1999, p. 52)

At least 9 participants in this study described getting auras in conjunction with their migraines. Below are some of those descriptions:

Londoner described the pre-migraine visual disturbances in graphic detail:

> "Well, for perhaps anywhere from 48 to 24 hours beforehand, I have what I call Haley's Comet. I have lights flashing across my vision…So I have a little inkling of what's going to come. I also have dizzy spells. And once the actual migraine attack is starting, I'll get in just one particular field of vision, and it can be on the right or the left, it starts off as a small zig-zag, and it progresses across my field of vision but still really on one side and it's like July 4th, it turns out to be like a fireworks display, in silver and gold. And the visual has never changed in the 53 years that I've suffered with migraines." [Londoner, assistant to head of school, female, 63]

For Maria, the aura was more debilitating than the actual headache:

> "…the aura for me always came first, so for me it was always the vision that was interrupted first. And it was either the flashing lights…the lights flashing, my vision is gone, a whole or blocked vision, numbness, speech impairment, just a sense of not knowing where you are…I remember on several occasions, trying to remember my name…that is why the aura is always the worst part. Because it's that total sense of helplessness….And then sometime after that, sometimes a half hour, sometimes an hour later, the headache would come…And the headache was unlike any other headache…For me, the key was…to find a way to deal with the aura. I've always said, I can put up with the pain…The aura is not like anything else…it is the aura that always was the most debilitating." [Maria, retired teacher, female, 60]

Here are three more quotes from participants that illustrate auras:

> "I'll go through periods when it's coming on, of a yellow flashing light in one of my eyes, so I'll like go blind temporarily in my eye, and I have to keep blinking to bring the vision back." [Tori, sign language interpreter, female, 44]

> "…the aura…for me as a teacher, was always the hardest part. The headache I could put up with, but not knowing what I was doing, was always the harder part." [Maria, retired teacher, female, 60]

> "They first started with mild visual disturbances…my vision was affected, and at that time I would vomit and just feel very, very ill…As I've gotten older, the visual effects have always affected me more than the headache. I find them very scary…I get severe visual problems…" [Londoner, assistant to head of school, female, 63]

These five descriptions of auras, above, are consistent with Sacks' (1999) statements:

> "The manifestation of migraine aura are exceedingly various, and include not only simple and complex sensory hallucinations, but intense affective states, deficits and disturbances of speech and ideation, dislocations of space-and time-perception, and a variety of dreamy, delirious, and trance-like states." (Sacks, 1999, p. 53)

Sacks (1999) also specifically described the visual hallucinations:

> "A remarkable variety of visual hallucinations may be experienced during the course of a migraine aura. The simplest hallucination takes the form of a dance of brilliant stars, sparks, flashes or simple geometric forms across the visual field." (Sacks, 1999, p. 55)

The presence of auras that is found in some individuals serves to reinforce how neurological in nature a migraine is.

As a final thought to this section of the chapter, I include something that Tori said while describing her migraines; it reminded me of the moral model of disability, discussed in Chapter 2, Review of the Relevant Literature. In the moral model, disability is related to the quality of an individual's moral character, e.g., disability may be seen as retribution for something that person did.

> "There's been times when I've actually crawled across the floor to get to the bathroom and the wet porcelain of the bathroom toilet, and just put your head on it and hold it. And those are the times when…you're like asking God, 'I'm sorry, I'm sorry for what I did. I won't do it again. Just take this pain away from me.'" [Tori, sign language interpreter, female, 44]

Participants' descriptions of what their migraines felt like were very graphic, for the most part. Individuals described how their migraines felt, in their own words, the experiences, and how it affected them. Although each person described it differently, some words or phrases appeared repeatedly. I heard about excruciating pain, auras, nausea and vomiting, sensitivity to light and sound. These descriptions underscore the fact that migraines are not 'just a headache.'

5. Consequences of Migraines on Work: Attendance/Absenteeism, Productivity/ Work Performance, and Other Consequences

In terms of the specific effects of migraines on employment, I sought to examine the consequences of migraines at work in the areas of attendance, productivity, and work performance. I asked individuals in this study if migraines caused them to be absent from work and if so, were they concerned about absenteeism? I asked if migraines had an impact on work performance or productivity and if there were concerns about that. I also wanted to know about any other consequences. I discuss the consequences of migraine in the workplace in terms of stigma and identity, in Chapter 6, Disclosure, Stigma, and Identity.

People with migraines often fear that they may lose their jobs because of taking too much sick leave, or feel that they miss opportunities for promotion due to absence and reduced productivity (Clarke, MacMillan, & Sondhi, 1996). Therefore, these are important areas to investigate.

In this section, I begin by briefly describing some other consequences at the workplace that participants experienced, followed by the section's focus on consequences on attendance and work performance/productivity.

Other Consequences at work

Adrienne, whose occupation requires her to be very visible, described what she called a 'vicious cycle' of migraines and overcompensation:

> "So you try to overcompensate, which again affects you, and stresses you out. Because instead, for example if I had a migraine let's say yesterday, then tomorrow I'm going to work twice as hard, which is then maybe the third day that I'm going to end up with a migraine because now I've overexerted myself. And you end up in a vicious cycle that's not healthy, just to try to preserve an image, just so that at least the higher-ups can see, wow this person is making an effort. And it's very frustrating…And…if you're with the press, and you got cameras shooting in your face…and it's like…I want to throw up right now, and I can't, and all the cameras are on me… " [Adrienne, assistant to president, female, 39]

Karen teaches college in the field of Slavic languages and literatures, and experiences chronic daily migraines that she described as debilitating. She told me that she had tried over 50 different types of medications to combat them, but many either didn’t work or made her feel tired all the time. She experienced a different type of vicious cycle at work:

> “…And I also had depression, because I guess well partly because I couldn’t do anything and I was in pain, and I guess that they’re related. The migraines give you depression, and depression gives you more migraines…And then I start feeling guilty and I think that contributes to depression.” [Karen, assistant professor, female, 39]

Sacks (1999) discussed the depression, like Karen’s, that sometimes accompanies migraines:

> “Feelings of depression will be associated with feelings of anger and resentment, and in the severest migraines there may exist a very ugly mixture of despair, fury and loathing of everything and everyone, not excluding the self. Such states of enraged helplessness may be intolerable both for the patient and his family…” (Sacks, 1999, p. 27)

When I asked Russel, the crane operator and owner of a construction company, what has happened when he gets a migraine at work, he said:

> “Pretty much I would crawl under a truck…and just wait it out...If I’m at work with a headache, I’m done, you can’t do nothing…My vision gets blurry…I feel nauseous, I get sick to my stomach…I’ve crawled underneath…construction trailers, just hid away from everybody, to try to get away from the noise, and the light, and the sound, and…that’s happened hundreds of times.” [Russel, owner of construction company and crane operator, male, 42]

Engrid described handling the necessary business entertaining aspect of her work, while she had a migraine, which she described as an ‘excruciating’ combination:

> "…Because there is nothing like sitting through a very fancy dinner with 10 people you don't really like, where you were going to pick up the tab, and you were in pain." [Engrid, attorney and administrative law judge, female, 64]

Like Engrid, Ted experienced the challenge of business entertaining with a migraine during his time in the corporate world working in sales and marketing:

> "And some of the other problems occurred…where you are expected to go out for meals and drinking, and stuff like that. And that I learned how to go past too. I probably ordered more drinks that I didn't have, than anybody anywhere in the country. In the workplace…when you're out with salesmen…you were expected… in the beginning days, they were really aware of the 3-martini lunches, 2 drinks before lunch and a bottle of wine during lunch, and learn how…order drinks that, you had to order…like stuff on the rocks, and then just let it melt. It was fairly easy to fake it. Just get fresh ones." [Ted, retired owner of pet supply business, male, 61]

Another problem for Ted was not being able to do work when he had the migraine and then having to squeeze it into a smaller timeframe once the migraine subsided. Here he describes this scenario from his time in the corporate world:

> "…sometimes like I was supposed to have written a paper over 3 or 4 days…presentations and things, and then as soon as the headache was over, just staying up all night and doing it. Doing it straight through." [Ted, retired owner of pet supply business, male, 61]

There are unique challenges when you are a sign language interpreter with a migraine, and Tori described her experiences when she had migraines and was trying to interpret. She told me that she has interpreted in all types of settings, and she gave examples of Madison Square Garden concerts, Broadway shows, educational settings, medical settings, prisons and courts, and for politicians. She explained the nuances of being an interpreter:

> "…because American Sign Language is not just your hands, but your body language, your facial expressions, which we call the non-verbal communication, non-manual cues, it affects everything. So it's not like a hearing person, who when a presenter is speaking, they may look down and they're writing their notes, they can tell that the person still has a positive affect based upon the intonations in their voice. Deaf people are looking at me, and they are waiting to know what the intonations of the voice are from my facial expression. So I'm hurting like hell, but I can't let them know that. I still need to…give them as close to the affect of the hearing people who are there…So I can't allow my facial expressions to impede upon it, otherwise I am not deemed a good interpreter." [Tori, sign language interpreter, female, 44]

Karen, the college assistant professor, prepares her lessons ahead of time, just in case:

> "…I also try to prepare things early, because…I can't think, 'well, tomorrow I'll wake up in the morning and prepare for class', which is what my husband does because he's also a professor, but I can't do that, so…I try to prepare at least several days in advance, and certainly not wait until the same day." [Karen, assistant professor, female, 39]

Fenno, like Karen, also had a strategy to be prepared; his was for when migraines occurred, so that he as a college professor could still deliver lectures:

> "…I'd have to stay pretty close to my notes, and I always tried to go to class over-prepared so that if, usually I used my notes as main points and then elaborate on them, but if I'm feeling really bad, elaboration got pretty short, so I wanted to have enough notes so that if I was going to do nothing but essentially regurgitate my notes, that it would be enough substance to make the class worthwhile for students to come." [Fenno, retired college professor, male, 68]

Leo, who has worked in technology for his whole career, most recently as Senior Vice President, describes one of the effects of his migraines on work as changing his desire to be with people when a migraine occurred:

> "…I was at less than 50% functional. And the way it would manifest itself is…in my career, I've always enjoyed interfacing with people, and that's been a very key element of it, whether it's employees, whether it's

> part of the team, whether it’s customers, I’ve always enjoyed interfacing with folks and solving problems…And either if I had a migraine, or if I had to take something for the migraine, I would want to completely avoid having any interface with people. Obviously, that’s a key element of my job…you really don’t enjoy going to work because you’re miserable. …with a headache, I would try to avoid meetings, I would try to avoid meeting with people. I could spend time alone working, but I would try to do it alone. I guess that’s the best way to describe it. It’s a significant impact on my work.” [Leo, on extended leave from senior vice president, male, 56]

Leo’s personality and mood changes during his migraines, described above, are an example of “…profound affective changes may occur during, and only during, a migraine attack, changes which are particularly startling in patients of normally equable temperament.” (Sacks, 1999, p. 26). Stafford and Shoquist (2003) discuss symptoms of migraine that some individuals experience, such as a personality change, “…feeling irritable and absolutely miserable…turn into a nasty creature who wants people out of his way…” (Stafford & Shoquist, 2003, p. 21-22).

Attendance/Absenteeism

For some people in this study, their attendance was not affected; they took little or no time off from work. They basically bear it and deal with it if they are at work, try to make the best of it, not functioning at 100%, but just get through the day, usually by taking medication. These people used expressions such as “I worked through the pain,” or “You just have to get through it,” or “I had to tough it out,” or “You do the best that you can,” or “I pushed through it.” For some individuals, whether or not they had to leave work to go home depended on the pain level of the migraine, when it struck, or what was planned at work for that day.

People with private offices had an advantage in terms of attendance, because they were able to lower the lighting, put heads down on desks, etc., for a while rather than leave work when they got a migraine. People who work in cubicles or public areas do not have that opportunity. Below are some examples:

> "…I was always in a very private kind of office…so if I needed to put my head down, it was very private. It makes a big difference. Because when we moved…to a different location…we were put into cubicles, and I really couldn't ever put my head down…Sometimes all it takes is to put your head down for 20 minutes, sometimes half hour, and you can get up and you can function, even if the headache isn't gone. And in a cubicle, you can't." [Benny, retired audiologist, female, 61]
>
> "…in my previous position, I had the kind of office…my door was a glass door, but it had a shade on it. So I could close my door and close my window shade and just lay on the floor if I had to, and try to get rid of it. In this job…I have a glass window, and they don't believe in shades. We're like fish in a bowl in our offices. I don't feel like I can really…lay on the floor. Not too professional. So I don't do that…" [Linda, director of marketing and communications, female, 53]
>
> "When I was doing therapy or when I was a supervisor for programs, I had my own office, so I would make sure all the fluorescent lights were turned off. I'd make sure that I would just use lamps…which is kind of a soft light…At the hospital, I don't have that luxury right now…I can't turn off the lights in my office because I work on the main…med-surg floor…" [Susanna, social worker, female, 34]

Also, the individuals in the teaching professions had somewhat of an advantage in terms of their autonomy and flexibility to switch gears and change plans when they got a migraine:

> "…in education, you have at least the autonomy to decide and make your own decisions…in terms of what you do within your day, that is your decision…" [Maria, retired teacher, female, 60]
>
> "…I was a college teacher in the sociology department…and the fortunate thing about the job was I had a lot of discretion in the way I met my responsibilities. So if I went in the morning and I had an uncontrolled headache coming on in the morning, then as soon as I got done with my

> last class, I could go home and go to bed." [Fenno, retired college professor, male, 68]

Darlene's attendance wasn't affected much by migraines; she described a workplace where taking off from work was 'frowned on':

> "You just don't…take time off… People are encouraged to work through walking pneumonia….So I think…in the year that I've worked there, I think I've called in twice because I've had a migraine and…I just couldn't sit in the light on those two occasions." [Darlene, psychotherapist/social worker, female, 57]

Similarly, Adrienne felt that if she took off from work, she would not be seen as reliable and she would "look bad," something she did not want to do in the current economy:

> "And there's always someone, an eager beaver, willing to do better than you…and will be there. And bottom line, when someone hires somebody, it's because you expect them to be there. And…you really don't want someone that's going to be sick and you can't even predict it…and it's not productive and you know it." [Adrienne, assistant to president, female, 39]

Allison stated that she only needed to stay home from work for a migraine once or twice in the past year. However, she was concerned about her migraines having an impact on her attendance, because of the time that she would lose from work due to migraine-related doctor visits:

> "…I'm sometimes concerned because I have to go to the doctor quite a bit, to keep up my meds and that kind of thing, and…no one has ever said it to me, but I sometimes wonder if people aren't thinking, 'God, how many times is she going to go see the doctor?'…" [Allison, senior clinical trials associate, female, 35]

Lainy, a chief financial officer, also doubles as human resources because she works for a small company. She perceives that this adds an extra layer of meaning to her absenteeism:

> "…when their HR person is out all the time, they kind of like look at, 'well…you're only given 5 sick days a year, and…how many has she taken?', and I don't know if they say that or not, but that's what I think they do. Because obviously no one would say that to my face. But…I know they talk, and again…the regular employees don't know, they may know I have migraines, I have not specifically told them, it's none of their business to me…I feel, I guess guilty, which I shouldn't, but I definitely do…for having off…XYZ days, yeah, I definitely do, even though I know I work 7 days a week in the summer." [Lainy, chief financial officer, female, 32]

Some participants perceived that their bosses had no problem with migraine-related absences and/or latenesses:

> "…I have the big boss who I said to him once, 'oh I got a doctor's appointment, I'm going to be coming in late, is that going to be a problem?' And he said, 'no, no, just let me know, yeah, if you gotta be late, you gotta be late', he said, 'there's no problem with that, you work your hours, you do your thing'. So that's one of the nice things that he was like that." [Bill, computer systems, male, 50]
>
> "I've called in sick. I've said 'I can't come in because I have a migraine', and they're perfectly fine with it." [Candrine, marketing manager, female, 37]

Anita stated that she was not concerned about her absenteeism, because she communicated openly with her boss. The fact that she communicated ahead of time to make sure her boss was aware, resulted in her not feeling like it was an issue. Similarly, Candrine had an agreement with her boss, to do as much as she possibly could, and as long as she showed that she would try, they were understanding about her coming in late or leaving early. She would tell them what was going on, and try to work with them, and they in turn would work with her.

Julia, a retired elementary school teacher, talked about how no one was inconvenienced when she called in sick; in fact, her absences made some other people (the substitute teachers) happy and they "loved" her when she was out sick:

> "No other teacher is inconvenienced…we are in a different type of workplace. So a sub had to come in, so what? They didn't care. A sub came in…I think, if somebody else had to cover your desk or handle your clients or something, they weren't going to be happy. But like I said, it didn't, mine didn't inconvenience anybody…." [Julia, retired elementary school teacher, female, 67]

Note that Julia contrasts the impact of her absenteeism on her occupation/workplace with other types of occupations/workplaces.

About 75% of the participants in this study *did have concerns* about their attendance/absenteeism being a problem. Here are some examples from individuals who were concerned about absenteeism/attendance:

> "…it was usually three days, when I had the headache…which is really when it was most disabling…And… I hated taking off. I have guilt thing, even if I'm entitled to it…It's like it would be really hard for me to take time off. First of all, it was because I worked with this other person who I knew couldn't necessarily handle, and also because, the way the whole thing was situated…they would never cancel clients, it would always be that the person who was there had to do double. So that was terrible…So yeah, I felt bad, I never wanted anyone else to have to do double-work." [Benny, retired audiologist, female, 61]
>
> "I am always concerned about my absenteeism. I'm a Type A person, I give 110% of myself to everything I get myself involved in, and so, yeah. That's my personality." [Lee, foundation director, female, 52]
>
> "…at my last job, yeah…there was a time when I missed a whole week, and…by the end of the week, I was…wondering, was I even going to be able to go in on Monday? I was a little concerned about how much time can I take here? You know, a day, that's not too much of a big deal, but

> when you get to weeks?" [Allison, senior clinical trials associate, female, 35]

Bill rationalized the amount of time that he had to be absent due to migraines, by comparing it to people in the office who were absent due to their drinking:

> "…I lost less time to migraines than a lot of people lost to drinking. And I'm not even talking about people who were alcoholics, I'm just talking about your average drinking beer on the weekend, going out Friday night, guys who were single going out Wednesday nights, Thursday nights, drinking, and I probably lost a lot less time than they have." [Bill, computer systems, male, 50]

Jen rationalized her attendance in a similar way as Bill, by telling me about her boss, who has children:

> "…she's got kids, so there are sometimes that she can't come in because she's got to pick up her kids. Well, I don't have kids, but this is something that where if I get a migraine, I can't come in." [Jen, senior development officer, female, 30]

Ted, who believed that it was perceived as unacceptable for a man to have migraines and therefore did not disclose them (discussed further in Chapter 6), told me that when his migraines caused him to miss work, he was concerned:

> "…And that's why if it was really bad, and I had to [miss work], I'd tell them I had the flu. Otherwise, I'd just, even if I wasn't doing anything, I'd be there. And I probably worked every time I did have the flu, to save it. The migraine was so much worse than having the flu." [Ted, retired owner of pet supply business, male, 61]

Allison, one of those individuals who did disclose her migraines, said basically the opposite from Ted:

> "…I've needed to stay home from work…there's nothing really that they can do. I mean, I've never like, tried to make out like, oh I have the flu or something. I have a migraine, I can't come in." [Allison, senior clinical trials associate, female, 35]

Russel stated that his droopy and bloodshot eyes when he had a migraine made him look like he was drunk. Migraines interfered with his attendance:

> "I can say honestly this, you can't keep a normal 8 to 4:30 job every day, no I don't think you can do it. There's not enough understanding out there…" [Russel, owner of construction company and crane operator, male, 42]

Kellie has been self-employed for the past 16 years, but prior to that, she worked as a faculty researcher in a university. Although she is concerned about migraine-related absences, she explained why it is somewhat less difficult, now that she is a business owner:

> "Well, when I was at the university, it's a little harder there…the expectations are higher than when you own your own company. You know, I can take days off a little more easily sometimes. At the university, it was harder to just say, 'I'm going home now. I have a migraine.' Well…'These samples are running through the machine. So what do you want us to do with them?'…a little harder to just walk away. So that was difficult. That made it really hard. Owning my own business, it was easier most of the time, to have to say, 'I gotta go now,'…" [Kellie, self-employed owner of design and remodel firm, female, age 54]

About 25% of the participants in this study said that their migraines *did not* affect their attendance. Tori, the sign language interpreter, is one of the people whose migraines did *not* affect her attendance. She explained why her attendance was not affected by migraines:

> "…I've never called into an agency that's hired me…and cancelled a job because I've had a migraine…I try to work at least one month to two months in advance. So by me leaving this job or not going to this assignment, it's not just affecting my payroll, but it's affecting at least two other people in that room, if not more. So there is a lot riding on me being there. And sometimes schedules have been made based upon my availability…" [Tori, sign language interpreter, female, 44]

Londoner, who describes herself as a ‘Type A’ personality (like several others in this study), stated:

> “…I have a very good attendance record in work, and that’s why I try not to go home unless I absolutely have to.” [Londoner, assistant to head of school, female, 63]

Susanna, a social worker at a hospital, doesn’t feel that migraines are accepted in the workplace, no matter what profession you are in, and feels that nobody understands when you call in sick with a migraine. As a result:

> “…I go to work with migraines. I never miss work. I probably missed 2 days of work in the past 3 years with a migraine…” [Susanna, social worker, female, 34]

Adrienne, who describes herself as a ‘career woman’, feels guilty when her migraines affect her attendance, and states:

> “…I have a responsibility…I can’t just vanish and leave all my stuff on my desk and think that everyone’s going to know what everything is. They’re going to go through my stuff, and…that’s not what I want to leave an impression. Let alone if I get replaced, because let’s face it, we gotta be realistic. And I’m a single mother….” [Adrienne, assistant to president, female, 39]

Lacey tried to keep her migraine-related absences to a minimum because of her concern that she might need her sick time for something else:

> “…I really hate calling in sick with a migraine, because then, what if I really do get sick with the flu or something else. So I don’t take off unless I have to, with a migraine.” [Lacey, ophthalmic technician, female, 49]

Lee, a foundation director for a medical center for the past 14 years, said that how she handled her migraines in terms of attendance depended on when they struck. If the migraine came on in the afternoon, which was more typical for her, she would take her medication and cope for the rest of the day until it was time to go home. She hasn't had to leave work too many days for migraines. However, morning headaches were different:

> "Once in a while, I will wake up in the morning with a migraine, and if I wake up with it, I know I will have that pretty much all day, so I do not even attempt to go into work, because in the times that I have tried to do that, the following day when I go back, I see errors in my work, and I am very emotional, I cry easily, and it's embarrassing, and so I've learned not to go into work if I wake up with a migraine." [Lee, foundation director, female, 52]

Lacey described something similar:

> "I've gotten them both at work, and I've gotten them before I have to go to work. If I wake up early in the morning or during the night with one, I'll take one type of medication and put ice on my neck and try to go back to sleep, and hopefully they'll go away. If they don't…I can …call work and say I'm not coming in. That's when it gets to the point that I'm throwing up, the pain is so bad. I can't do anything. I drive an hour each way to work, so for me to get one at work, to try to drive home with it, sometimes is worse…" [Lacey, ophthalmic technician, female, 49]

And so does Madelin:

> "I've had…one or two instances since…being on this medication, where I woke up with something in the morning, and then I can't function at all and I have to call in that I can't go in to work, at that point if I wake up with one." [Madelin, vice president of human resources, female, 65]

This was a common theme that I heard. Waking up with the migraine meant staying home, while getting the migraine later in the day, while at work, meant trying to stay at work. Sacks (1999) described the migraines that occur while sleeping as 'nocturnal migraine' (p. 148) and said:

> "It is often a matter of astonishment to patients that they should sometimes be woken from sleep by a migraine, and their astonishment may only be increased when they are assured that an association between sleep and migraine is not merely common, but to be expected…there are

> attacks which come at the dead of night, jerking patients from the deepest sleep; there are attacks which tend to come at dawn…" (Sacks, 1999, p. 148)

Productivity/Work Performance

I looked for patterns and themes in what people in this study said about how having migraines affected their productivity and/or work performance.

For Karen, as an assistant professor in a college, she prioritizes in order to put teaching at the top of her list so that teaching would not be affected, but her migraines affect her ability to research, write, and publish:

> "And what it affects most therefore is my scholarship, because sometimes I want to write, I have to write articles, and I'm supposed to publish, do research, and sometimes I just can't do it because my head is hurting too much, so I lose a lot of time on that." [Karen, assistant professor, female, 39]

For those people who stated that their work performance or productivity was affected by migraines, I most commonly heard things such as: it would take me longer to do something (or not as quick, I needed more time), it took extra hours to get the work done (or slowed down), it took me longer to focus (or might not be as sharp), I work a lot slower (or talked slower), I took breaks more often, I might have missed things (or not as attentive to detail), not being able to think clearly (or hard to think), I tried to do less-challenging work. Below are some examples of these:

> "…on bad days, I didn't do any work that day, but when the headache went away, I just had to work harder because I wouldn't miss the deadline because of it. I wouldn't miss a deadline because of anything." [Hillary, technical writer, female, 62]

> "…now I conduct the hearings, and I write them up. And I…might be a little slower, and I might be less anxious to pick up the next case or the next hearing…Ideally, I would prefer on a day when I have a migraine, to do paperwork. But you can't always arrange to do that…I try and get things done when I am fine, so that I didn't have to worry on days when I wasn't feeling well. You know, bank a little something." [Engrid, attorney and administrative law judge, female, 64]

> "…Because if I'm in slow motion…if I force myself to stay when I have a migraine, I'm not really being productive. Let's say that I'm here 8 hours, and I have a migraine the entire day, maybe I've really done 2 hours worth of work. So I'm not producing at the level that I should be, even though I have a migraine and I'm here." [Adrienne, assistant to president, female, 39]

For Lainy, who has had migraines for 15 years, most of her migraines occur at night. However, here she describes what happens when she gets a migraine at work. She works in the special events industry:

> "…when you're doing that once or twice a week…for some of the major ones…it adds up, I mean, you do miss a lot of work, and… you're still dealing with the neck pain the next day or whatever…I've definitely gotten them at our events as well, which is absolutely awful. I do a lot of the accounting and stuff like that for our charity events and things like that. So…I'm usually in a room where I'm lucky enough that I can kind of sit in a quiet corner for a while but I still have to continue my work. It doesn't stop just because you have a migraine. Only I can do it…With my job, it's crucial that I…get something done in a timely fashion. And I am…out quite often." [Lainy, chief financial officer, female, 32]

The above is a good example of the difference between certain occupations. In some occupations or job situations, the work can stop and wait for the person with the migraine to come back to it, or someone else can fill in and do the work for that employee. However, in other professions or job situations, only that particular employee can do that work. Lainy (above), Maria, Margate, and JP (all below) are examples of the latter.

Maria taught elementary school (6th grade) and then science in middle school (8th grade) for 34 years before retiring.

> "…when I taught elementary school, it was the most difficult…because I had 8 classrooms, I had 25-30 kids who were totally dependent on me for the entire day, and no one could come in and take them for me. And when the aura was occurring, there wasn't much I could do…I couldn't call the office, I would have to have somebody watch my class so that I could get to a phone, because those were the days when you didn't have phones in the room…but just to try to get somebody to stay in the classroom long enough to get somebody…to come in. For me….when it would happen, I was scared and panicky…I panicked. As soon as the aura came, I panicked…At any rate, I would have to try and find a way to let someone in the office know that I needed somebody to come in and cover my class. And they had to get a sub for me." [Maria, retired teacher, female, 60]

Margate, who has worked for about 43 years, told me that when she got a migraine, she:

> "…had to keep a happy face, because I had a job to do. And being a legal secretary for the past 22 years of my life, I worked in a one-person office, myself, so I couldn't be out sick a lot. Nobody else would get the work done. I took a lot of medications, try to get through the day." [Margate, retired legal secretary, female, 65]

Also, JP, as a school psychologist, faced a similar situation. He told me that school psychologists "are always in demand" and since there "was not an abundance" of them, it wasn't like they could call for a replacement when he was out sick. Even if they did get a replacement, "they would be stretched thin in terms of how much time they could give. It was difficult to get any extra help." When JP reduced his work hours due to the migraines, then if he missed a day, he would come in on another day to do the work, since there was no one else who could do his work:

> "…if I missed a day, I would go back and work, make up that day on another day, so, that gave me some flexibility, because if I didn't…there's nobody to do the work. I mean, if I didn't make up the work, it would just be a mess...It's not like somebody was going to come in and do part of my work when I was gone, so…it's a matter of the more work that piles up,

> the more complicated my job would have been when I came back…" [JP, retired school psychologist, male, 65]

Adrienne told me that it was very frustrating when she got a migraine at work because:

> "I'm very detail-oriented, and I don't like feeling restricted, and having a migraine is going to restrict you because you can't really concentrate, and you want to lay down, because you don't have a choice. And then yet here you have these responsibilities…where everyone is expecting you to handle professionally and now here goes another migraine." [Adrienne, assistant to president, female, 39]

Lacey, whose job performance was to some extent measured by quantity, explained the effects of the migraines on her productivity at work, which resulted in her being fearful when she got a migraine:

> "We're supposed to work up so many patients in a session, which a session is like the morning, or the afternoon, and I am always fearful that I am not working up that number of patients. When I get a headache, I'm slower, can't comprehend things, and it's taking me longer." [Lacey, ophthalmic technician, female, 49]

Jen described her boss as being supportive in allowing her to take days off when she had a migraine. Similar to Hillary, quoted earlier, she attributed this in part, to not letting her migraines affect her work.

> "..she knows that I get my work done, she knows that she can trust me that if I miss a day, I might stay a half hour extra the next day if I'm feeling well, to get done whatever needs to get done. So I think it's also…because I show her that if I have to miss a day, if I am sick, it's not going to impact my work." [Jen, senior development officer, female, 30]

Candrine, like Hillary and Jen, also talked about making up for lost work and not missing deadlines:

> "…I try to pick up the slack on the other end. I get home, if I feel better later on, I work from home on my computer…I work long hours, so I think in most cases because of my way of team dedication to my job and doing a really good job, I think that's how they compensate me for understanding that there are times that I cannot do it because of this situation…I've never really missed any deadlines because I pick up the slack the other way…I would have to work harder to make sure that I made those dates if I actually was out of the office for a day or had to leave…I pride on my job performance so I work out my hours and difference at home or stay late the next few days to make up the difference. Which is probably key as to why companies can work with you." [Candrine, marketing manager, female, 37]

And Ted did also. He admitted that he was concerned about the impact that migraines had on his work performance, and as a result he worked extra hours to make up work:

> "Yeah, I was, but I was usually able to fake it and make it up. I probably worked an average of 60 or 70 hour weeks sometimes just to get over that. You know, I'd work, if I had to, I'd go in on Saturdays and Sundays." [Ted, retired owner of pet supply business, male, 61]

Several people described a 'hangover'-type feeling once the migraine had subsided, and that this also had an impact on work performance:

> "…after the migraine is gone, whether it's later the same day or the next day, I get what I call a 'pain hangover' and I just feel like I've been dragged through a hedge backwards. And…trying to go to work and answering difficult questions and walking clients through things, it's hard…when I feel that tired and dragged out. And so, not only the migraine, but also the aftermath of the migraine, made it difficult." [Kellie, self-employed owner of design and remodel firm, female, age 54]

This is consistent with what Stafford and Shoquist (2003) describe: "After a headache, you may experience a *pain hangover* – you're tired, you don't feel hungry, and your thinking process seems slower." (p. 13)

Bill, who works in computer systems, stated that he becomes concerned about his productivity and performance only when he has a bad string of days, which happens to him occasionally, where for an entire week he has a migraine almost every single day, despite trying various types of medications. This is especially problematic if there is a big project that needs to get done. But then he thinks about it this way:

> "But then on the other hand, there are people who are in bad moods over the course of days. So it's all on how you want to look at it and judge it… And then there's the normal stuff that will affect productivity…if somebody's married and they're having a problem in the marriage that affects them, and then of course anyone who has to deal with anybody else who is going through some traumatic event, that affects them no matter who they are, and even if your kid is sick…this person is not going to be right on their job, because they're concerned about something else really." [Bill, computer systems, male, 50]

When Bill initially told me that he works in 'computer systems,' I asked him to describe what he meant by that. Bill describes 'computer systems' as diagnosing system-wide problems, designing systems, and putting in upgrades. But when he has a migraine, he said that:

> "…I definitely stay off the production systems…certain kinds of work are going to make it worse. So I'll do less detailed work, less numerically oriented work." [Bill, computer systems, male, 50]

Morgan also describes how she cannot do work that takes "thinking" when she has a migraine or is about to get one:

> "…I try to slow down…try to do jobs tasks that are not as intricate…I certainly can't do a tough task if I feel a headache coming on. I… put sales kits together and things like that, quiet things… I'm a manager so I kind of can do my own thing if I have to." [Morgan, event planner, female, 48]

Some of the individuals quoted above, plus the people quoted below, have difficulty with what Sacks (1999) called– "Alterations of highest integrative function" (p. 72). During a migraine, they may feel strange or confused. Sacks gives the example of someone writing a letter, but later when checking it, had written words other than the ones the person thought were writing.

Lacey, an ophthalmic technician for the past 22 years, describes the cognitive difficulty that she has in 'working up' patients for the ophthalmologist when she has a migraine:

> "…no matter what you tell me, I can't comprehend it. And it's very hard when I'm in that predicament, trying to work up a patient, asking them…how their eyes bother them, how to check their vision, do any kind of testing, because I have to ask them 3 or 4 times again, 'well how many times are you putting the drops in?' or 'when did your symptoms start?', that type of thing, because I'm not comprehending it to be able to write it down." [Lacey, ophthalmic technician, female, 49]

JP, who spent over 30 years as school psychologist for grades K-12, also had performance issues when he had migraines at work. He describes problems with concentration and forgetfulness:

> "And of course it affects your concentration at work. It's very difficult, it was hard for me to concentrate sometimes, and sometimes forget appointments… that's that really caused some problems with meetings that I…forgot about, aren't always very forgiving about things like that, they don't understand… that I am not the average guy on the block. I've got these damn migraines, and…that has an impact on my ability to recall things sometimes. I'm doing my best…" [JP, retired school psychologist, male, 65]

Susanna, as a social worker, spends a portion of her work time in counseling sessions with clients. When she has had a migraine, she remembers:

> "…sitting in a therapy session and being so nauseated and having a migraine so bad that you can't concentrate on what the client is saying. I've had a couple of those, and… you feel like you're short-changing the client." [Susanna, social worker, female, 34]

Leo, a business executive, would usually try to ‘work through’ his migraines, rather than calling in sick or if he got a migraine while at work. However, it did affect his work performance in a way that is specific to executives or those whose responsibilities include leadership and creativity:

> “…I would try to work through it. And again, if I was able to dull the pain enough with the pain medication…I could get through the day. But it was really literally just getting through the day. Part of my value to an organization was beyond just doing tasks. It was…being creative, it was coming up with ideas, leadership, things that you just don’t do very well if you’re under a migraine.” [Leo, on extended leave from senior vice president, male, 56]

Similarly, Lee, a hospital foundation director whose work involves fundraising and public relations, describes her concerns about the effect of her migraines on her work performance on the days that she had to be at work.

> “…if I go into work and I have the migraine…there are times that you have to be at work and it’s unavoidable to stay home….On those days, if I have to get through it, an important meeting or a presentation, I will try to get through it, and then the rest of the day, I will either go home…because like I said, I have gone back the next day and said, ‘oh my gosh, look what I did.’ It’s not really good to try to perform at your best.” [Lee, foundation director, female, 52]

Donna tries very hard not to miss a full day of work because of migraines, and as a result she will come in late or leave a little early and spend the rest of the day working with the migraine, but there was definitely an impact on her performance:

> “But then I’m sitting there, I’m like, 50% at best…just trying to do something, and…this could go on for 3 or 4 days…I’m not at my full capacity… it’s hard to try and focus on what you’re supposed to be doing. And of course, now you’re doing everything on the computer, which is very hard, when…your head is pounding, and you’re sensitive to light, and I find that very hard to try and focus on the computer so much of the day…and it’s hard to think straight…really focus and think straight and organize…it’s been a real struggle... I’m not working at my best. I’m not

> as effective as I want to be, or as effective as I can be, but…what are you going to do?" [Donna, marketing director, female, 52]

Shilo described how working as a travel agent at a commercial travel agency was difficult when she had a migraine:

> "…working in the travel business…you gotta be very particular on what you did…when they say you want to go here, and…if you put it someplace else…so I would double check my work, and double…talking to them and making sure I put them in the same place that they want to go…" [Shilo, on disability, was travel agent, female, 55]

Londoner expressed concern about her migraines affecting her productivity and she explained why by describing her personality:

> "Well, I'm the type of person who takes their job very seriously and I need to be on top of everything. And that's just part of my personality. Type 'A' personality, I guess. And it bothers me because prior to a migraine, I'll be a little forgetful. Words get transformed; I'll say the wrong thing. Knowing very well I've just said the wrong thing, and I'll correct myself, but it bothers me that people think I'm 'losing it'…" [Londoner, assistant to head of school, female, 63]

Lacey, a chief financial officer in the special events industry, described the impact that migraines had on her work performance. She considers herself to be a "successful person":

> "…dealing with numbers, I…deal with other clients, I deal with other people's money per se, and so especially at the event sites when you get a migraine, you definitely feel…incompetent to do your job, because number one, you don't want to screw up, so unfortunately no matter how successful these events are, the bottom line is the numbers and the finances, and so when they look at that and…all of a sudden you're not counting their money and they have no updates, because you can't keep up with it, it definitely makes…the company look bad…as well as myself…" [Lainy, chief financial officer, female, 32]

Tori, the sign language interpreter, described to me how sign language interpreters work with partners, and they switch with each other every 20 minutes. Tori described her job as mentally and physically exhausting when she has a migraine. During the 20 minutes that she is actively interpreting, she is concentrating, hearing, comprehending, changing it into another language, and still trying to keep up with what the speaker is saying, so she has to remain very focused and very fast. Then, during the 20 minutes that she is not actively interpreting, she goes to the bathroom and throws up. She gave me an example of times that she was on stage interpreting for Broadway and off-Broadway shows with a migraine:

> "…I've even done Broadway and off Broadway shows, and during intermission, ran off, threw up, came back…keep on going, and nobody knew it. I just did that recently in a show I was in. And I was able, I timed it out where I knew what was going on, and I was on the stage, so when my character left the stage, even though I was supposed to stay there, I just walked off the stage, ran down three flights of steps, ran underneath the building, to a bathroom, threw up, and ran back…and hit the mark when my next character spoke. That's what you have to do." [Tori, sign language interpreter, female, 44]

Candrine described how one of the prescription medications that she took for migraines affected her productivity:

> "…it made you feel like you had a hangover the next day…I would take that and come in the next day and feel like I was out drinking all night. And so you couldn't focus all day long, it was like a tunnel, like get me out of it, so I can focus. I hated taking that prescription medicine, but it did help the migraines. So that was something I had to struggle with the next day…I think that I would lose hours at that time sometimes, just trying to get myself going again…" [Candrine, marketing manager, female, 37]

Karen also experienced a serious problem due to medications:

> "…I had to go through detox because I was taking too much [migraine prescription] all the time, partly so that I could get through the teaching,

> and so I had to go through the detox…" [Karen, assistant professor, female, 39]

Shilo also had a bad experience in the workplace due to medications:

> "…I went ahead and kept working, but one day I didn't even know I was in the restroom and I was passed out…I was on really strong medication when I was working…" [Shilo, on disability, was travel agent, female, 55]

JP also had side effects in the workplace due to medications. Like Karen, he ended up spending two weeks in the hospital for withdrawal from pain medication. Below, he describes the side effects of the medications:

> "…some of the medications I was on, for a while there I was on so damn many medications that were sedating, that it would be hard for me to stay awake at a meeting…if I didn't, if I wasn't talking a lot…you'd have this tendency to doze off, but people were wondering…what was going on with me. I was fine as long as I was able to talk…but God forbid, I didn't have…an active part to play, I'd have a hard time staying awake…there were times where people were wondering, 'What the heck?'…" [JP, retired school psychologist, male, 65]

Julia, an elementary school teacher for over 30 years (mostly 5th grade), described personality changes that happened when she got migraines and their effect on her work: Her migraines were mostly estrogen-related, occurring once per month for several days.

> "…And it made me grouchy. I tried not to take it out on the kids, really, but…you're angry. You're angry and the serotonin levels drops so low that you just aren't in a good mood…It had an effect on my work. I definitely couldn't, I didn't have the patience to go over something with a child, over and over, like I usually could, I would just, like…if you didn't get it then, I would say, 'Go sit down' or something. I just couldn't. I couldn't deal with it. But yeah… I didn't want to take it out on them. It wasn't their fault…I think I would have been a more, even a more efficient teacher…" [Julia, retired elementary school teacher, female, 67]

According to Sacks (1999), organic irritability is "exceedingly common in the course of migraine attacks." (p. 24).

As I was writing this section (Consequences of Migraine) of the Chapter, I realized that several people's comments reminded me of two of Mead's thoughts. Mead wrote:

> "Intelligence is essentially the ability to solve the problems of present behavior in terms of its possible future consequences as implicated on the basis of past experience – the ability, that is, to solve the problems of present behavior in light of, or by reference to, both the past and the future…" (Mead, 1934, p.100).

Karen, Lee, and JP, all quoted earlier in this section, provide examples of this.

- Karen, the college assistant professor, prepared her lecture notes early because she knew she couldn't prepare for class on the same morning of class. She tried to prepare several days in advance because she knew from past experience that she could not say: tomorrow, I will wake up and prepare.
- Lee, the foundation director, knew that when she wakes up in the morning with a migraine, that she will have it all day, so she does not try to go to work. She knew from past experience in the times she tried to go to work with a morning migraine, the next day when she goes back, she sees errors in her work, so she learned not to go into work if she wakes up with a migraine.
- JP, the retired school psychologist, knew that if he missed work, he would go back and make up the lost time on another day, because there was nobody to

> come in and do the work while he was gone. He learned from past experience that if he didn't make up the time, the work would pile up, and the more complicated his job would be when he gets back.

Mead also wrote:

> "The behavior of an individual can be understood only in terms of the behavior of the whole social group of which he is a member, since his individual acts are involved in larger, social acts which go beyond himself and which implicate other members of the group" (Mead, 1934, p. 6-7).

Benny, Tori, and Leo, all quoted earlier in this section, provide examples of this.

- Benny, the audiologist, talked about how she hated calling in sick because the other person she worked with would have to do double-work. It was hard for her to take time off because she did not want anyone else to have to do double-work.
- Tori, the sign language interpreter, talked about why she never called in sick because it would affect so many other people due to the teamwork nature of her job with her interpreting colleague, and the fact that so many people were depending on her.
- Leo, the senior vice president, talked about how migraines affected his work by changing his desire to 'interface' with people, to the extent that he changed from enjoying that part of his job to trying to avoiding it completely when he had a migraine.

6. Workplace Accommodations – and Disability/ADA

As I explained in Chapter 2, Review of the Relevant Literature, and Chapter 3, Definitions of Disability, employment provisions of the Americans with Disabilities Act (ADA) mandate reasonable accommodations -- an obligation that employers must adjust the workplace in certain circumstances and under certain conditions, in order to make it meet the needs of an individual employee who meets the criteria for a disability as defined by the ADA.

Although not a central focus of this research study, it was important and relevant to find out about workplace accommodations and work adjustments. I asked participants in this study if they felt that they needed accommodations or adjustments in their workplace in order to perform their work, due to their migraine condition. If they answered yes to this question, I asked them what type of accommodation(s) they felt they needed, and did they request them, and if no then why not. If they did ask for accommodation(s), I asked how was the request for accommodation(s) received (i.e., what was the employer’s reaction to the request – positive, negative?), and was the requested accommodation(s) granted? I asked if they had made any adjustments other than formal workplace accommodations. There were a wide variety of responses to each of these questions.

As I state in Chapter 6, The Decision to Disclose or Not Disclose, several individuals disclosed their migraines because they needed some type of accommodation in the workplace in order to perform their jobs or remain employed. Once a request for accommodations has been made, the individual usually has expectations that the request will be seriously considered.

In this study, my interest in accommodations was to learn more about how people with migraines used accommodations at the workplace to enable them to cope with migraines and to improve their performance, productivity, and/or attendance. I also wanted to uncover the wide range of workplace accommodations that employees with migraines used.

Shift in Accommodations Approach

According to a recent study by Solovieva, Dowler, and Walls (2011), the accommodations approach in the contemporary United States has gradually shifted from that of a charitable ‘hire the handicap’ model to a more careful matching between employer needs and employee competencies:

> “Implementing job accommodations for individuals with disabilities is a vital tool for increasing workplace productivity. Workplace accommodations are individualized solutions that enable people with disabilities to achieve and maintain employment, and considering an accommodation is a necessary step for employers who wish to attract and retain workers with disabilities.” (Solovieva, Dowler, & Walls, 2011, p.40).

This would seem to be in line with the vision of the ADA, as discussed in Chapter 3, Definitions of Disability.

Thinking of traditional accommodations for people with physical disabilities, one may picture physical things such as ramps to get into buildings that have stairs, for people with mobility impairments, or alternate format documents for someone with a visual disability. However, as noted by the two quotes below, that is a very limited picture of accommodations:

> "Accommodations take many forms. They can be goods or products, such as a special keyboard for someone with carpal tunnel syndrome or a scanner that reads text for an employee with vision problems. They can also be specially modified work conditions. A worker who has suffered a head trauma may need a day shift because he cannot drive and the bus system does not run at night. Since the human body itself is variable, accommodations can vary and take different forms as someone's needs can change over time." (O'Brien, 2005, p. 21)

> "Reasonable accommodations are not merely tangible goods like a chair or a ramp. They are also work conditions like offering flextime or job sharing, the feasibility of which can only be understood if an employee has a full understanding of a company's routine operations." (O'Brien, 2005, p. 135)

Accommodations – General Findings

I found that there was a wide range of workplace accommodations used by individuals in this study. In general, accommodations did not vary by job, with the exception of certain accommodations that were specific to a particular occupation, e.g., teachers canceling a class when they had a migraine. Ten people reported that they did not request any special accommodations. More than half of the people in this study named more than one accommodation.

Responses to Request for Accommodations

There were a range of responses to the request for accommodations, from positive, to mixed reactions, to negative. On the *positive* end of the spectrum were the supportive work situations, in which the employers were willing to work with the employees and their needs, and the requests were granted. In this study, the majority of participants reported positive responses *in terms of requests for accommodations.*

Findings for Type of Accommodation

Below is a table that summarizes the responses of the 40 participants in this study regarding their workplace accommodations for migraines. Note that the numbers add up to more than 40 because over half of the participants named more than one migraine-related accommodation and some discussed more than one workplace. The table includes both accommodations *requested* as well as accommodations that were *used* without actually having to make formal requests (e.g., if self-employed, if have high level of autonomy, or if they are things able to do on one's own due to their occupation or work setting - "I never specifically asked for them, I just set them up myself.") Fenno provides an example of this:

> "… the flexibility in how the role is played, I think, made it a lot easier to give myself the accommodations I needed, as opposed to if I had been an office manager, or some other setting which required 8-5 attention." [Fenno, retired college professor, male, 68]

Note how Fenno contrasts the ease of his ability to provide accommodations for himself due to his occupation, as compared with other types of occupations/workplaces.

TABLE 7

Participants' Workplace Accommodations

Participants' Workplace Accommodations

- No Special Accommodations Requested (10)
- Change Workplace Lighting (18) – 7 with regard to the overall fixtures, bulbs, and/or type of light, and 11 with the ability when a migraine occurs to keep the lights lowered or turn them off, or to shut the blinds, making room dark
- Flexibility of time in conjunction with a migraine, e.g., ability to come into work late, leave work early, and/or not come to work at all, when migraine occurs (19)
- Ability to do different type of work during a migraine (3)
- Stop using substance (odor) that triggered migraine (1)
- Shut down the job when migraine occurs (1)
- Take leave of absence (2)
- Cancel a class, get someone else to cover my class (3) [teachers only]
- A laptop to do work at home (1)
- Reduce work hours (1)
- Relocate to a different re-designed office (1)
- Go to nurses office, infirmary, sick room, sofa, or other designated location to lie down (6)
- Ability to close door to the office and/or put head down on desk or sit in a corner with head against wall when migraine occurs (6)
- Ability to work from home sometimes when migraine occurs (5)
- Ability to cancel meetings and reschedule for another day (2)
- Adjustment to work schedule, not in conjunction with migraine, e.g., start work in afternoons instead of mornings; leave work early once a week to several times a week for physical therapy or doctor appointments; re-do schedule to come to work early to work 40 hours (4)
- Change type of computer used (1)
- Unknown (1)

Note: Total adds up to more than 40 because many participants named more than one migraine-related accommodation, and also because some individuals discussed more than one workplace

The questions about type of accommodations were open-ended. I combined/collapsed, and grouped them into the categories in the table above.

Accommodations – those who did not request and why

Ten people in this study stated that they did *not* request any accommodations. When I asked why not, some of the people who did *not* request accommodations told me that they did not request them because what they needed would not be possible in their workplace setting. For example:

> "…no, because…the simple fact is that what helps with my migraines is quiet and peace and darkness, no bright lights, no sounds, no noise, and that's not something you can do obviously in a hospital setting…so that's not something…that I can really request." [Naomi, staff assistant in hospital operating room, female, 41]
>
> "… it's extremely difficult in a large office building to get them to change the lights for you." [Engrid, attorney and administrative law judge, female, 64]

However, Ted did not ask for accommodations when he was in the corporate environment, for a different reason: because he perceived an extremely negative reaction if he had asked for any accommodations:

> "…And [company name] would have fired me if I had asked for anything. And … since I was at an Executive level, probably wouldn't have gotten the jobs, if I needed accommodations." [Ted, retired owner of pet supply business, male, 61]

Accommodations – most common type

As indicated in the table above, the most common accommodation for individuals in this study was a flexible schedule (time flexibility in conjunction with a migraine), with 19 people naming that accommodation. This was defined as the ability to come into work late, leave work early, and/or not come to work at all, when a migraine occurs. This type of accommodation is effective for a variety of disabilities or medical conditions, not just migraines. In fact, a flexible schedule was cited in a recent study as an example of a type of accommodation that works for multiple types of impairments:

> “Some accommodations are effective with a particular disability (e.g., a fragrance-free area for a person with chemical sensitivity), and some accommodations are effective with a variety of impairments (e.g., a flexible schedule.)” (Solovieva, Dowler, & Walls, 2011, p. 40).

Accommodation – other Types

Workplace lighting was frequently cited as an accommodation in this study, with seven people reporting changing workplace lighting and 11 people wanting to keep lights lowered or turn them off, or shut the blinds, making the room dark when a migraine occurs. This totals 18 people who stated accommodations relating to workplace lighting, either different types, different intensity levels, or absence of lights. Some people needed brighter, more intense lights, whereas some people wanted lower, less intense lights.

Anita, a meeting and event planner, requested that workplace lighting be changed, and her bosses were supportive.

> "I moved from one location from another and the lights gave me a migraine the first day. So I reported it, and there's I guess these special light bulbs that they have for people that have migraines. They're more expensive, so they don't have them everywhere, but they had to put them above where I sat." [Anita, meeting and event planner, female, 32]

Kellie, a self-employed woman who stated that flickering fluorescent lights was one of her triggers, told me:

> "… my husband, bless his heart, he's my business partner, also went through and changed all the ballasts in the fluorescent lights in our building, through electronic ballasts, so they wouldn't flicker, which was amazingly wonderful." [Kellie, self-employed owner of design and remodel firm, female, age 54]

Londoner also requested a change in workplace lighting, but for her it was not as simple:

> "One thing that I finally very recently achieved at work with the help of my neurologist, I had the lighting changed in my office. It wasn't easy. I fought for it. I had a dimmer put in my lights…But it did take a letter from my neurologist stating that, studies have proven, etcetera, etcetera…" [Londoner, assistant to head of school, female, 63]

Helen, an elementary school teacher who was getting migraines almost every day during the school year, also attributed her migraines to the fluorescent lighting in the classrooms. She experienced a positive/supportive reaction. She describes how the administration was willing to work with her:

> "…I told them right out, '…I have a problem with the lights.' And they said, 'Well…your room is scheduled to get all new fluorescent lights… with new ballasts that don't flicker,' … and they said, '…we'll make sure your room is…first.' They really tried very hard to… make it work for me. So they…right away, changed all the lights in my room. I said… 'Can I get blue covers on the lights?' because I've heard that that helps, and they said 'Sure no problem.'…They really were very good about trying to accommodate." [Helen, elementary school teacher, female, 43]

Below are two more examples regarding fluorescent lighting:

> "…And we have just recently moved offices again, and he [the owner] actually did remember because he said, 'She can't have fluorescent lighting in her office.' … I was very thankful for that…they put… non-fluorescent lighting in my office before I moved in." [Lainy, chief financial officer, female, 32]

> "Now, once you're up at a certain level, you could do things…Once I was a VP, …I could turn off the fluorescents in my offices… just have regular incandescent lights. And that might be a little eccentric, but it was okay. Spend $500 on expensive light and get rid of the fluorescent. And you could buy those on your own, and…people didn't see that as accommodating. Now, for somebody…in a cubicle, and all the cubicles have these fluorescent lights, it would be a lot harder. Luckily…I always had a private office, except for my first job. So, thinking back on that now, that was fairly easy for me to do…" [Ted, retired owner of pet supply business, male, 61]

Sacks (1999) described the sensitivity that people with migraines generally have with light, both as a trigger for migraines, as well as dealing with light once a migraine occurs. "In particular, migraine patients are prone to photophobia, an intense discomfort, both local and general, provoked by light, and an avoidance of light which may become the most obvious external characteristic of the entire attack." (Sacks, 1999, p. 25)

Four individuals cited adjustments to work schedule. This is a more permanent adjustment, not on an as-needed basis when a migraine occurs. Karen adjusted her college teaching schedule around anticipated migraines, so that she could teach in the afternoon:

> "…the other thing I do is try to teach as much as possible in the afternoon, when I have a choice. Usually, I can choose when I'm teaching, and the migraines are at their worst in the morning when I wake up, so several times they've asked if I could teach at 9:00, and I say I'm sorry but I'd rather teach in the afternoon if possible." [Karen, assistant professor, female, 39]

Some individuals who owned their own business spoke of the ease of making accommodations because the accommodations were for themselves, and they had control over their own schedules and workflow. One example was Kellie, mentioned in the section on lighting, whose husband changed the ballasts in the fluorescent lights in the building. Another example was for those who required flexible schedules, because they could take a day off or come in late if needed, since ‘it was my schedule’ or they had more autonomy over the work. Eleanor, who previously was working in her own business, but then went back to school, and who has been at her current job for 10 months at the time of the interview, described this:

> Past job: “…it’s a very autonomous, self-driven, so…I could take a day if I needed to…”
>
> Current job: “You know, after, after having your own business, you’re so used to it. It’s very hard to…be on someone else’s schedule.” [Eleanor, project director/psychologist, female, 36]

Kellie, who I will discuss further in the section on computers, was able to replace the computers in her office, since she owned her own business.

As a business owner and crane operator, Russel had the ability to shut down jobs when he had a migraine, until he felt better.

> “We’ll just shut down. If I can walk away and have things keep going, we will, but we’ve also had to shut down jobs for…a couple of hours at a time…You know, as a leader of what’s going on, I have to be there. Is there somebody to take my place and do what I do? No …To find a qualified crane operator to take your place is not the easiest thing in the world to do…Luckily I’m the boss…” [Russel, owner of construction company and crane operator, male, 42]

Six people spoke of an accommodation relating to the presence of a designated location (whether it be a nurse's office, infirmary, or sick room) and the ability to go there to lie down during a migraine, and another six stated an ability relating to putting their head down on their desk or against a wall. This was helpful because then they could be in the dark, possibly wait for medication to take effect and/or migraine to go away, and they might be somewhat productive when they went back to work. This totals 12 individuals. These individuals may have been affected by the following cluster of symptom of migraines: "…Lethargy and drowsiness – a degree of listlessness and a desire for rest. Many patients feel weak. Many are dejected, and seek seclusion and passivity. Many are drowsy." (Sacks, 1999, p. 20)

Linda, who at one time was getting migraines on almost a daily basis, told me:

> "…we had what they called the 'sick room'. It just had…a settee in there, and you could just shut off the light and just go in there…it's always best to go someplace where it's kind of dark and quiet…noises just really bother me and the light really bothers me." [Linda, director of marketing and communications, female, 53]

In Adrienne's workplace, this was called a 'green room':

> "What helps me is the kind of set-up that we have in our office…we have a room they call the green room, all the way in the back, and that has helped, because if I'm at work, and I get a migraine, I can go lay there." [Adrienne, assistant to president, female, 39]

I asked Adrienne what was in that room.

> "It's just a couch, it's dark, the walls are dark, everything's like a dark green, and you can just lay there, no one disturbs you. And that helps, because not too many people have a place where they can…relax or rest when they have a migraine…you can't do it at your desk where you have

> bright lights and everybody's walking back and forth." [Adrienne, assistant to president, female, 39]

Jen found her workplace to be very supportive. Following a promotion, she was moved into a tiny office that was dark, hot, and far away from a window. Her migraines got extremely bad afterwards, and she ended up having to take migraine medication every day for a month. So she talked to her department, and:

> "They moved us into a different office, re-designed it so that I could be close to a window. They installed all these extra lights for me, so the space that I'm working in is much lighter, much airier, much quieter…they have been very open to helping and making whatever changes I need them to make…they are in general just very amenable…." [Jen, senior development officer, female, 30]

Computers were a problem for many people. For most of them, it was the actual computer monitors that were the problem. But for Londoner, it was a specific software program:

> "…I'm having problems with our tech department, because they just don't get it. And there are things that I just cannot do the way they want me to on a computer. I cannot do Excel. It's instant migraine if I look at the way an Excel spreadsheet is, and that bothers me…there's a guilt, and they don't understand it…when… I can't do something because of the migraine." [Londoner, assistant to head of school, female, 63]

For Kellie, the computer monitors themselves were the trigger because of the flickering. She talked about a time before LCD monitors were available, when the older CRT monitors had a 'refresh rate', and no matter how fast she set it, she could still see the flicker. The newer LCD monitors helped. And because she and her husband own their own business, they decided to buy LCD monitors for all the employees.

> "…as soon as the LCD monitors came out and I checked them out… my husband and I bought one for me immediately, and that did help a lot. You don't have the refresh rate…And now we have them for the entire company. Mostly just…for everybody else, because they're really good-looking monitors, but also because they also do reduce eyestrain. And for me, it's absolutely necessary. It helps everybody." [Kellie, self-employed owner of design and remodel firm, female, age 54]

This is an example of how accommodations can help not only the individual employee who requests them, but also can impact the entire group of co-workers.

> "Although a physical or mental impairment is individual, organic, and socially constructed, accommodations made for one person can benefit others….While the ADA rests on the idea of an employer and an employee understanding needs after an individualized assessment, nothing prevents the accommodations devised from helping the entire workforce." (O'Brien, 2005, p. 22)

Lee described her accommodation of being able to work from home sometimes when she had a migraine and why she thought this worked out well:

> "…there were a few times I would call in sick in the morning with a migraine, and then be feeling better in the afternoon, and so I would ask to be able to work from home, so I guess that would be considered a special accommodation. You know, not every time, but if I'm able to…that's my way of showing that I'm committed to my job. At least I could put in a half day's worth of work, and it would just be better to do it from home rather than go into the office." [Lee, foundation director, female, 52]

When I asked Lee how her request was received, she replied:

> "They were receptive. I didn't ask for it very often. And I think based on my track record as a good worker, that was probably why it was received favorably. No, I didn't make a blanket statement by saying, 'Well, every

> time I have a migraine, I'm going to stay home and I want you to pay me.' It was…on an as-needed basis." [Lee, foundation director, female, 52]

Accommodations - Denied

From the Table on workplace accommodations (Table 7), 5 requests were denied. 3 were denied outright (stop using the substance that caused an odor that triggered migraine; a laptop to do work at home; adjustment to work schedule/leave work early for medical appointments) and 2 were sometimes denied (ability to work from home sometimes when a migraine occurs; adjustment to work schedule/leave work early for medical appointments). Reasons for denial ranged from a flat-out 'can't do it' with no real explanation given, to budgetary considerations, to staffing situations (short-staffed).

Liza told of an accommodation that she requested that was denied:

> "…I came in, and it was 6:00 in the morning…it was in the middle of the winter. I come in, and I already have this horrible headache, and I have no idea how I made it to work. I barely got myself dressed. I barely washed my face and brushed my teeth, because everything hurt. But I had asked my boss if I could please work at home that day, and he said, 'No. We need you to come in.'…" [Liza, financial journalist and senior editor, female, 27]

Liza (above) told me that another woman in the office frequently calls in and is allowed to stay home, whereas Liza was not. She attributed that to the fact that she (Liza) was seen as extremely dependable and responsible, whereas the other woman was not. Liza called this a "blessing and a curse." She also perceived that the different treatment was due to favoritism, since the other woman was a friend of her boss. What Liza thought was most interesting was that the other woman claimed to have migraines also.

Donna described a similar situation. Like Liza, she also asked for an accommodation that was denied, in her case a laptop. She told me that other people had received laptops. This accommodation would have allowed her to remain productive even when she had migraines:

> "…my home computer at that point was significantly outdated. I asked for a laptop, so I could…do some work at home, which would have been very feasible, given the work I was doing…and times when I…was not coming into the office, but certainly could do the work. They refused. Even though other company people had laptops…I was the most senior woman at the company, and they weren't so great with women. No, they refused that. So that would have been helpful…they…just… said, 'Well we don't have it in the budget right now.'" [Donna, marketing director, female, 52]

Linette also experienced negative reactions from her supervisors when she needed to leave work early from time to time due to migraines:

> "Well, sometimes he would try to talk me out of it…one of the supervisors, his reaction was, 'Well, just take some aspirin.'…One of the other supervisors that I worked with one day said, 'You know, this is sure happening a lot. You need to get this under control.' And I explained to him… 'I am trying to get this under control. I've been to the doctor. I'm taking medication. It's a hit and miss kind of thing. Sometimes it helps and sometimes it doesn't.' And after that, I felt like I had to stay at work, no matter how bad I felt…" [Linette, imports inspector, female, age 39]

Accommodations and Disability/ADA: Opinions

"…the Americans with Disabilities Act (ADA) affirms the essences of social constructionist claims – namely, an individual's impairment need not be disabling when society makes reasonable accommodations…" (Conrad & Barker, 2010, p. S71)

As I indicated in Chapter 3, Definitions of Disability, the definition of disability is difficult, and disability is a very complex concept, partly because of various levels of impairment and functional limitations. To complicate matters even more, added to that are the spectrum of invisible/hidden disabilities and episodic conditions: something like migraines, in which people with migraines don't necessarily "look" disabled ("invisible"), and aren't disabled all the time ("episodic").

I did not ask any questions in this study specifically about disability or the ADA. However, several individuals brought it up on their own during discussions that occurred over the course of the interview.

Bill discussed how he perceives the general corporate world views the hiring of people with disabilities, and why this puzzles him:

> "…it's so bizarre that anybody would be like, 'oh this person has diabetes, they're not going to be showing up at the office too often, we can't have them.' Well what about this sh** over here? He yells at everybody and they quit and they leave, and don't you think they affect the work environment much more?...I feel that the corporate environment is still highly discriminatory…" [Bill, computer systems, male, 50]

Below are some other examples of participants' views on migraines, disability, the ADA, discrimination, and accommodations:

> "I think there were years when technically I might have really considered it a disability. And indeed at one point had taken out disability insurance…this is a disability." [Engrid, attorney and administrative law judge, female, 64]
>
> "…and so having migraines is not in the same category as being in a corporate office and being black, or being a woman and trying to get ahead, they are not in the same ballpark, but they are certainly in the same kind of vein…if somebody is in a wheelchair, they get the sympathy that they need, or they tend not to get a hard time, and they make the accommodations and usually that works out fairly well." [Bill, computer systems, male, 50]
>
> "…it is a handicap. This is a handicap." [Russel, owner of construction company and crane operator, male, 42]
>
> "…I would say you know, I think this really is a disability. But it's not a visible disability. And I think people deal with it like they deal with a lot

> of other things…if you've ever known anybody who had Crohn's syndrome… It's the same kind of thing…" [Engrid, attorney and administrative law judge, female, 64]
>
> "It's disabling. I mean, it really is." [Kellie, self-employed owner of design and remodel firm, female, age 54]

Bill has an interesting viewpoint about accommodations in the corporate environment, and about accommodations for migraines:

> "…certain people have to make more accommodations for people's personality flukes and problems, than I've had to make for my migraines…My thing is an occasional thing…There are people who have things that they don't have syndromes for…So in my mind, having a migraine is one of the less things that have to be dealt with…Usually personality quirks require much more time and energy to deal with…I've worked in corporations and there are tons of people that have to be dealt with in certain ways and special ways." [Bill, computer systems, male, 50]

Recall two earlier similar quotations from participants who rationalized taking time off due to migraines. One person compared it to time other employees lose due to drinking, or distraction due to family problems, and the other individual compared it to time lost when an employee has to take care of her children.

Workplace experiences relating to ADA/disability

At least four individuals– Brown, Donna, Mina, and Adrienne – had migraine-related workplace experiences that were also somewhat related to either disability or the ADA.

Brown, an office manager, told me that she had many different office jobs in her life, and each of those workplaces was supportive about her migraines. However, when she moved to California in an attempt to lessen the migraines, she started working for a company that was not supportive, even though she provided medical documentation. She described her new employer this way:

> "… 'too bad, you have to come to work'...they don't care that you're sick. You're there to do a job, get the job done…if you don't have time off, then you work. And being I'm new, I have no time off. So this situation is not working out. So I am trying to find new employment. I did tell them…before they even hired me that I get migraines and that I may have to leave, and they said oh that would not be a problem. Well apparently it is…they just said … if you take too many days off, you could be fired. That's their way of dealing with it…but anyway, wherever else I've worked, and I've had many jobs…I've been able to keep them for many years, they've all worked with me except this last one…" [Brown, office manager, female, 49]

Donna, who at the time was on a "very fast track" in a magazine publishing career in New York, told me about the following experience in which she was fired from her job:

> "And then finally, in the job I had right before I left New York, the biggest job, where I was travelling nationally and had a national staff, when my headaches were the worst, I was really ill…I was really, really, ill…I kept trying to catch up. Then I was fired…because of it. Now I know today, that that was probably illegal. But it was too soon after the ADA was passed…I hadn't heard much about it…I didn't know it applied to migraines. I couldn't think of myself as disabled…" [Donna, marketing director, female, 52]

Adrienne described an encounter at work during a discussion about a raise, where her migraines were used as a factor against her:

> "…I ended up having problems where…it…worked against me, in a discussion that had to do with a raise….I'm here basically being told, 'Yeah, you've been loyal, but you really haven't been on the ball because you have your disability, and as a result of your disability, you're not giving me the best of you...Do you think you merit a raise? You know, when face it, out of a given month…you were only able to function and give me X amount of you? You weren't able to come in in the morning on

> time because you ended up with a migraine at home?...And what about me? What about my day? It's disruptive because of your disability'…" [Adrienne, assistant to president, female, 39]

Mina encountered a legal situation at her job. As she describes it, she worked for 18 years for a pharmaceutical company, keeping track of and reporting adverse reactions with products, reading medical records to find out what drug the patient was taking when they had a reaction, and writing reports for the FDA. Mina said that she had worked for three or four other managers during the time she worked there, and they all were "fine with" her migraine situation and "they understood everything." Then she started working for a new manager, for four years, and he was the only one who was "not understanding." He took a lot of responsibilities away from her, even though she "begged" him not to do that, and in Mina's opinion, he was "trying to do whatever he could to get me to leave." She was providing notes to Occupational Health from her doctors, and both her supervisor and manager knew she was having migraines. She states she was treated differently from other people, and she provided some examples:

> "… any time they had a meeting with me, they had legal department there. Any time I missed work, I had to go down to the Occupational Health Department, which nobody else had to do, to get the okay to come back to work. They put a lot of restrictions… on me, compared to other people who were allowed to take breaks, who were allowed to go smoke. If I wasn't at my desk, they would try to deduct that from my time." [Mina, on disability, was reporting adverse reactions of products for pharmaceutical company, 47]
>
> "…they…took the majority of work away from me, so the majority of the time for about 2-3 years, I just basically sat there and had nothing to do. And I'd come in early like they asked me to do, and…I'd be just sitting there in front of the computer…" [Mina, on disability, was reporting adverse reactions of products for pharmaceutical company, 47]

Mina said that they told her they took the work away because they didn’t think she could handle it anymore because it was giving her migraines. She told me that she kept trying to make them understand her migraines had nothing to do with work. This manager, according to Mina, was “not well-liked in the company” and “not a people person” and within the first year that he started, three or four people left because of him, in a small department of about seven. Mina didn’t leave because she liked her job. But she was afraid she was going to lose her job.

> “… I did find an attorney…that was helping me too, on what I could do. He dealt with people with disabilities in the workplace. But I ended up having back surgery, and I was out on short-term disability. And when I… called to my supervisor, to say I was ready to come back, he calls me back and says, ‘Your position has been eliminated.’ …And there was no other job vacant in the company for me….The way I look at it, they found a way of doing it…” [Mina, on disability, was reporting adverse reactions of products for pharmaceutical company, 47]

In the end, the company closed. Mina is still getting disability and medical benefits from the company, for over 10 years.

7. Career Impact: Missed opportunities and Career choices

Perhaps the most dramatic are the stories that I heard of *long-term career impact*. These are stories of individuals who decided to open their own business, take leaves of absence or early retirements, or who had to change entire industries or career paths, just to get the kind of control over their lives that they needed, because of their migraines. They are also stories of missed opportunities and changed career choices. In terms of this, the impact was *huge* for some individuals.

I did not specifically ask any questions of each individual in this study about long-term career impact or career choices. However, I did hear many stories of missed opportunities and life changes because of migraines during the natural course of the interviews. When individuals brought it up during discussions that occurred over the course of the interview, I did ask questions about this.

As I described in the accommodations section (section 6) of this chapter, Adrienne's migraines interfered with her getting a raise, Donna and Mina lost their jobs due to migraines, and Brown was in danger of losing her job.   I described in the workplace challenges section (section 3) of this chapter many bad experiences that the study participants had been through.

In this final section of the Chapter, I concentrate on individuals whose career was impacted by migraines, or who made life-changing decisions, or who had similar long-term opportunities that were affected by migraines. Most of these individuals were disappointed and/or frustrated, because they originally wanted to do one thing but then because of the migraines, they couldn't stay with the career that they had chosen, and had to switch and do something else.

Here I discuss individuals who I believe fit these criteria.

Morgan, who works in the hotel industry, and takes medication to prevent almost-daily migraines, describes how migraines affected her career and her life:

> "…I always thought to myself, without these migraines, I would be bigger and better than what I am…they pulled me back so much…I'm just talking about taking on more tasks in life, because I'm afraid to take them on because they might give me a headache." [Morgan, event planner, female, 48]

Russel, the construction company owner, describes his migraines as “torture.” Because he was unable to find a decent frontline medication that works for him, he has paid up to $700 per week on medication and has had about 30 nerve block treatments at $800 per treatment. He told me about the impact of migraines on his life and his business:

> “…It affects me an unbelievable amount. I’m probably one third of what I should be if I didn’t have this issue going on in my life. My business is restrained that much…especially in my early days of being in business, when I exhausted my finances. And I’m not everything I could be.” [Russel, owner of construction company and crane operator, male, 42]

Ted told me how he changed his mind about his first choice for branch of military service during the Vietnam era due to his migraines:

> “…I was accepted for Air Force Pilot school… and I knew that flying as an air force pilot was not going to be a good idea. And so I ended up … making sure I got into the Navy instead. So even early on, I was coping, because I knew in the Navy, it would be a lot easier to work with a migraine than it would be flying a plane…” [Ted, retired owner of pet supply business, male, 61]

Londoner, the woman who gets the severe visual disturbances immediately prior to her migraines, works on the administrative staff of a private school. Years ago, as part of her job there, she used to do advising with groups of students, which she told me she enjoyed very much. However, when the migraines got really bad, she decided she could no longer do that. She states:

> “…I felt that I should give that up, because there would be times that I would be in front of a class, and when my vision goes, I just panic...” [Londoner, assistant to head of school, female, 63]

Engrid, an attorney who has been working as an Administrative Law Judge for the past 12 years, also made a career change due to migraines. In her current job, she works only 4 days a week, basically 9 to 5, and does not take any work home with her. But:

> "I started off doing litigation, and that was out of the question, because I could not do that with a bad headache. And you don't have the option of not doing it. And I really felt I was not doing my best job that way….I was afraid I was going to end up not being able to work because they'd become so overwhelming…I think my career choices would have been different without the headaches…I had started off litigating, and it was very clear to me that I just could not do that… It was just not an option." [Engrid, attorney and administrative law judge, female, 64]

Karen turned down an offer at her college, twice, to teach in the Intensive Russian language summer program:

> "I really wanted to take the job on both occasions, for the money and experience, and also because I thought it would look good in the department if I did it, but I said no first because it starts every day at 9 AM, and secondly, because it is so intensive – 9 to 1, five days a week for four weeks, plus grading homework and tests – and I was quite sure I wouldn't be able to do it given my condition…I did specify the reason why I declined the job offer, though it is considered a compliment and almost an honor to get the job, as competition is high." [Karen, assistant professor, female, 39]

Leo, who had been an executive in the business world, decided to take an extended leave of absence from his job, even though he enjoyed his work. At the time of my interview with him, he had been on leave of absence for one year and three months. Prior to that, he had taken two six-week leave of absences for the migraines, both to find out if the migraines were work/stress-related (they weren't) and to try out a variety of different medications.

> "… it's something that I reflect on, and …at age 55, I took a leave, and potentially retired, depending on what happens with my headaches. And fortunately, I am financially able to do that, because of the success I had in the business world in the 30 prior years…and… 55 to 60 are some very productive years, for 'an executive', and I was unable to take advantage of that…It has forced me to change my life's direction, pretty significantly." [Leo, on extended leave from senior vice president, male, 56]

Similarly, Vita, an adjunct teacher of English, also had to leave work for a while. This happened when a neurologist who she calls a 'horrible doctor' told her she was taking too much prescription migraine medication and gave her strong painkillers instead. Like Adrienne (mentioned earlier in this Chapter), she had developed a month-long migraine:

> "But at the worst, there was one period when I had to take a semester off from work…for that whole month, I had… an ongoing migraine…I thought I was going to die…it took the whole semester for that to finally ease off…" [Vita, adjunct teacher English, female, 71]

Like Vita and Leo, Donna, the woman I described earlier in this Chapter who discussed getting fired, also had to leave work for a while. Donna talks about the severe impact on her career:

> "…Over the years, I probably have tried…100 different pharmacological things, combinations of medications, every category you could possibly think of. None of which were particularly successful… And they just kept getting worse. And really impacted everything, my entire life…to the point where I lost my job. I didn't work for…more than two years…I don't really have a career anymore." [Donna, marketing director, female, 52]

Londoner, who has been getting migraines for over 50 years, told this dramatic story, not of career impact, but of life impact:

> "When I became pregnant, I had always been told that when you are pregnant, the migraines abate. Well, mine got ten times worse. And in my second trimester, I had a migraine every single day. And going through that with no medication, I would never tell my son this, but that was the reason I only had one child. Because I could not go through a second pregnancy." [Londoner, assistant to head of school, female, 63]

Ted talked about how switching from a high-pressure corporate executive career to a self-employed business owner, and then finally his retirement, gave him more control over his life, and therefore helped with his migraines:

> "Now that I am retired, I am able to avoid my triggers…I can totally avoid fluorescent lights…It's a lot easier to just stop and get something to eat, or … plan meetings and things…And actually, working for myself helped too. Because I was able to set more of my own hours and then just stop… when you're your own boss, then if you feel hungry, you can stop and get lunch. There's nobody to say, 'No you can't, we've got an important meeting'…" [Ted, retired owner of pet supply business, male, 61]

Fenno took early retirement, and like Ted above, noticed a decrease in migraines after he left his job; they began to get less severe and less frequent. He reports that as of the time that I interviewed him, he is not having migraines any longer and has not had to take medication in 18 months. Fenno attributes the change in migraines to his retirement, since he states that he didn't make any other changes in lifestyle or diet.

> "…I took an early retirement… it was hard to keep going…" [Fenno, retired college professor, male, 68]

Kellie switched from being a faculty researcher at a university to a self-employed business owner 16 years ago. The flicker of computer monitors is one of her triggers. Migraines have had a big impact on her professional life:

> "But the computers got to be a problem to the point where I had to quit work. I couldn't work anymore…That was about 10 years ago. So the migraines, for a while, ended my professional life. I really could do very, very little…And now I can work part-time. I can't work full-time, I'm not reliable enough…I can't say, 'yes, I'll be there from 10 every morning until 6 every night', that's not going to happen. I still get migraines. And too much computer work will still trigger one. I really have to push my limits for it to do that. So yeah, the migraines have had a huge impact on my professional life." [Kellie, self-employed owner of design and remodel firm, female, age 54]

Helen, the elementary school teacher who had the lighting changed in her classroom and was experiencing daily migraines during the school year, has been teaching for 12 years. She told me that she plans to quit at the end of the year:

> "… when I tell them that I'm not coming back to work next year, they are not going to be so happy. But I am really not going back to work. Because my doctor is very unhappy about the amount of medicine I'm taking. And that I can't go to work without taking this [medicine], but it's really not good for my body... But I'm not happy that I'm actually going to quit my job because of it… it's definitely life-affecting." [Helen, elementary school teacher, female, 43]

Martha, also an elementary school teacher, was experiencing week-long migraines before they were brought under control with proper medications. She told me how she might have had a different career altogether if not for the migraines:

> "In the '70's, I was accepted in law school, and then realized that I just couldn't. I didn't want to take something and just fail at it. So I bowed out there. And then it was disappointing. I mean it wasn't tragic, but it was disappointing." [Martha, elementary school teacher, female, 75]

Shilo, a travel agent, has been unable to work for 3 years due to migraines. She gets migraines every day that don't go away:

> "…I can't seem to get it to stop. If I can, then I'm in bed most of the day, and that's no life. And I'm having to take all this medication…I have to try this one to see if that one works…and then my nausea comes up and I have to take nausea pills…and now I'm on disability because no job wants me, because I call in." [Shilo, on disability, was travel agent, female, 55]

JP, who was losing a lot of sick time to migraines and was taking many medications for migraines including painkillers, discusses the impact of migraines on his career:

> "…I finally reduced my work days from 4 days a week one year, and then the following year to 3 days, and then I finally retired a year earlier than I had planned because I just couldn't handle it." [JP, retired school psychologist, male, 65]

This was not the first time that migraines had impacted JP's career. JP, who has a master's degree, was working on a doctorate at one time, but because of migraines, he dropped out one year beyond his masters.

Perhaps Donna sums it up most dramatically:

> "…I was very ambitious when I was a younger person… I was going to set the world on fire…I was going to accomplish something professionally, and I haven't. And it really is because of my headaches. I have to say that. I'm not making excuses. But sometimes I…wonder what things would have been like otherwise." [Donna, marketing director, female, 52]

The stories of long-term career impact were not all bad, although the vast majority of them were. There were some that turned out well in the long run, mostly from people who opened up their own businesses or left the workforce a little earlier than they planned. I found similarities in the stories of people with migraines who, after working for other people, opened up their own businesses. This provided them with the autonomy and the ability to make their own schedules, in order to deal with the migraines without having to be judged or second guessed. Eleanor and Kellie were two of the individuals who talked about this. A couple of individuals took leaves or early retirements due to migraines and then opened up their own businesses, and reported now being very happy with that choice.

Others who are not working pointed out that they look at the benefit of their circumstances. Leo, the 56-year-old Senior VP who is on extended leave, told me that he has a 4-year-old grandson that his wife takes care of because his daughter is in school. Leo has developed a relationship with the grandson, since he is on leave and is able to spend a lot of time with him, which he never would have been able to do if he had been working. Ted, the 61-year old former corporate executive, who opened up his own business, and is now retired, talks about all three phases. One of the benefits of retirement is that he can now completely avoid certain triggers that he didn’t have control over when working, like avoiding fluorescent lights and skipping meals. But even owning his own business was much better than when he was a corporate executive, because he made his own schedule, stopped work when he needed to, and ate when he was hungry. Also, once he retired from the Vice President position to open up a pet supply company business, there was an added bonus:

> “They wouldn’t let me get dogs until I had a job where I didn’t have to travel. Because we started stores and we kept them all in New Jersey, then we could have a dog… [Opening a pet supply company] …is a lot of fun, because everybody that comes in to see you, wants to be there. Perfect business…it’s a lot of fun.”

This chapter served as an extensive background of the workplace data relating to three areas: 1) the relationship between migraines and work, including effects, triggers, experiences, and consequences, 2) workplace accommodations, and 3) career impact. With this background in mind, individual decisions regarding disclosure (the main topic of the next Chapter) may be placed in a social/political/economic context.

CHAPTER SIX: THE DATA – [ISSUES AT THE WORKPLACE] - THE DECISION TO DISCLOSE OR NOT DISCLOSE, PERCEPTIONS OF STIGMA, AND PERCEIVED SELF-IDENTITY

Outline of this Chapter

1. Disclosure vs. Non-Disclosure
2. Disclosure – Factors
3. Disclosure - Reactions/Responses
4. Non Disclosure – Factors
5. Non Disclosure – Coping Mechanisms, Hiding Behaviors, Passing Strategies
6. Perceptions of Stigma
7. Perceived Self-Identity

In Chapter 6, I concentrate on the portion of the workplace data relating to three main areas: 1) disclosure, 2) stigma, and 3) self-identity. Within these three broad areas, I focus on the following seven topics: 1) the decision to disclose or not to disclose, 2) factors involved in disclosure, 3) reactions and responses to disclosure, 4) factors involved in non-disclosure, 5) 'passing' strategies and hiding/coping mechanisms employed in non-disclosure, 6) perceptions of stigma (if any), and 7) perceived self-identity.

1. Disclosure vs. Non Disclosure

Since migraines are, for the most part, a hidden condition (not visible to others), in order for the employee to receive support from supervisors and/or co-workers, it requires that those individuals know about the employee's condition. However, if the employee chooses not to tell those at work about his/her migraines, the employee might not receive this support.

The decision whether or not to disclose a chronic illness is complex, and influenced by many factors such as stigma, type and severity of illness, and access to support (Munir, Leka, and Griffths, 2005). Mead described how "The process of intelligent conduct is essentially a process of selection from among <u>various alternatives</u>" (1934, p. 99).

I asked the individuals in this study if they had disclosed their migraine condition to someone at work at some point. There were a variety of different responses to this question. Responses demonstrated the full range of the spectrum.

For some participants, disclosure wasn't even an issue because it never occurred to them <u>*NOT TO*</u> disclose. Benny and Allison are examples of this. When I asked them about disclosure:

> "It never dawned on me, not to." [Benny, retired audiologist, female, 61]
>
> "I think, and maybe it's because I've always had them all my life, that it never occurred to me, to not disclose." [Allison, senior clinical trials associate, female, 35]

At the opposite end of the spectrum, were those individuals for whom it never occurred to them <u>*TO*</u> disclose:

> "… it never occurred to me to tell anybody, when I took my job, not that I could remember, that I get migraines…" [Vita, adjunct teacher English, female, 71]

The factors involved in those decisions and the reactions/responses will be examined in later sections of this Chapter.

Of the **40** participants in this study, I found the following regarding disclosure: **24** disclosed their migraine conditions at work, and **8** did not disclose. **3** disclosed in some situations but did not disclose in others; these individuals decided whether to tell only after assessing each individual situation. I also encountered **5** individuals who described a process wherein their migraines became known, or that they were 'found out', rather than a conscious choice to disclose. I will refer to this last group as being 'discovered' or 'discovery'.

The table below, Table 8, summarizes the study data regarding the decision to disclose or not disclose.

TABLE 8

Disclosure vs. Non Disclosure (n=40)

Disclosure vs. Non Disclosure
▪ Disclosed (24) ▪ Did not disclose (8) ▪ Discovered (5) ▪ Disclosed in some situations but did not disclose in others (3)

Below, I include a brief discussion of people whose migraines became known but not by choice, in order to differentiate between those whose migraines were known by choice.

The following are two examples of ‘discovery’. Naomi experienced discovery because of the number of times she had to be absent from work due to the frequency of her migraines and because of the difference in her level of functioning.

> “They know because before I took so much time off from work because of it. Plus they know by now how I function when I am at optimum level and they know when they see me when I am walking around.” [Naomi, staff assistant in hospital operating room, female, 41]

Madelin experienced discovery because her physical appearance changed when she had a migraine.

> “So, people were aware at work…they just were aware of it simply because sometimes I would just get hit with them at work, and there’s actually no way of hiding the way I would be at work, because I get very pale and I get very sick-looking, and there really is no way of hiding the way I am when I get a migraine…the disclosure comes when something happens. It’s not something like I went in and announced it. It’s like when something happens, then… it would come out…” [Madelin, vice president of human resources, female, 65]

Since not all migraines in the workplace are disclosed in the same way, this has an impact on the circumstances as well. As demonstrated in the examples above, while some people make a conscious decision to disclose, for others, there are events at work where the migraine becomes evident or causes absences that need to be explained. In those cases, the individuals did not necessarily want to disclose but were ‘discovered.’ Therefore, while the migraines are known in both cases, they did not become known in similar ways. Discovery and disclosure are not exactly the same processes. However, a comparison of discovery and disclosure is beyond the scope of this study.

As an example of how biased some individuals expected potential employers to be, a couple of individuals specifically mentioned the job interview process itself, very emphatically:

> "I certainly would not disclose it in a job interview. For sure!" [Engrid, attorney and administrative law judge, female, 64]
>
> "Certainly never mention it in a job interview or anything!" [Ted, retired owner of pet supply business, male, 61]

For some individuals, their decision to disclose depended on an assessment of each specific situation. Several people stated that in the workplace, they would tell some people but not others. Goffman (1963b) referred to the different layers of people within an organization, and how an individual could make a decision to tell some people but not others, depending upon the location of those people within the organizational structure. Tori, a sign language interpreter, described the reasons why she would *not* tell her employer, but she felt it was critical to tell her interpreting partner since interpreters work as a team:

> "I would probably be more apt to tell in an interpreting situation… I would tell my partner, not necessarily the people who hired me. Because the person who hired me or the company would assume that I'm not giving them top quality. But I would tell my partner because of the fact that as interpreters, when we're working, we're working as a team, and sometimes they will look at me in order to confirm that the information that they're giving out is correct, you know, just as reinforcement. And I don't want them to look at my face, and I might have a frown on my face, and them thinking that the message that they're delivering is incorrect. So I need to let them know, no, don't read into my face that there's something wrong, I'm just not feeling well right now. And also, as I said, I do that because if I'm not able to stay up there the 20 minutes and I need for them to relieve me for the 20 minutes, then we could set up some kind of signal for each other, like come up here, I need you now, I need to leave. So I will tell my partner." [Tori, sign language interpreter, female, 44]

A condition such as chronic migraines requires a strategy on the part of each individual for managing the various symptoms that accompany migraines. Depending on whether or not the condition was disclosed in the workplace, the symptoms and/or the treatments may need to be concealed from supervisors and/or co-workers. Medications or other treatments for the migraines sometimes have side effects that may affect the individual in the workplace, and this needs to be managed as well. As if this weren't complicated enough, for many people, migraines often strike without warning, which makes them even more difficult to manage in the workplace.

The following six sections will discuss the study data in terms of the factors involved in disclosure, reactions and responses to disclosure, factors involved in non-disclosure, the strategies employed in non-disclosure, perceptions of stigma (if any), and perceived self-identity.

2. Disclosure – Factors

I asked each individual what factors went into his/her decision to disclose or not disclose. I found that there were a range of different factors that went into the decision to disclose or not to disclose, to whom to disclose, and even how much to disclose.

I sought to examine the factors that each individual took into consideration in order to make what I refer to as the 'disclosure decision'. For most (but not all) participants, it was not a straightforward decision. I found that the factors included: desire for access to support, need for accommodation in the workplace, frequency and severity of the migraines, fear of potential discrimination, and gender bias.

This section will cover those individuals whose migraines were *disclosed*. (Another section will cover those who chose not to disclose.) I asked about factors that went into the decision *to disclose*. Some participants took many factors into consideration, weighing risks vs. benefits, before deciding to disclose the existence of a migraine condition; whereas for others it was more of a 'natural' decision. Examples of the latter would be Allison and Benny, quoted in the previous section, for whom it never occurred *not to* disclose. There are also those who disclosed, not necessarily by choice, but as a result of 'discovery', also discussed in the previous section.

Factors leading to the decision *to disclose* included: need for accommodations, legitimizing the illness (attempting to explain that the reasons for absence were based on a medical condition and to ensure that performance was not affected), and to explain to others about the condition.

Some people described a need to let their boss/supervisor, or co-workers, know that they get migraines in order to get the support or understanding that they needed. Individuals with migraines sometimes need help in handling work situations, from maintaining a good reputation to dealing with an unsympathetic co-worker. JP, quoted below, talked about how he was fortunate in that he perceived that his decision to disclose helped his administrator to understand his situation and work with him, which he believed would not have happened if he had not shared that information:

> "…I never kept that a secret. I didn't see any purpose in keeping it a secret…I was fortunate. I did have some difficulty at the beginning of my assignments this last year, but then after…I really kind of, talked to the administrator and shared, you know, disclosed more information, then she worked with me, but initially…that was a little difficult. But, fortunately … she was understanding once she understood my situation. But if I

> hadn’t shared that information, I could have had a tough time of it.” [JP, retired school psychologist, male, 65]

Candrine talked about how she decided to disclose because she felt that hiding migraines would be more stressful than disclosing, and she didn’t want to put any additional stress on herself, adding another layer to an already stressful situation. However, she realizes that this might not work for everyone:

> “I mean, it’s sometimes you can’t avoid not telling them, because they ask you right up, ‘are you alright? Is something wrong?’…I feel like if you hide it, it makes it even more stressful for when you do have that migraine, and it makes it even harder for you to get over it, because you’ve already put more stress on it by trying to hide it. So I feel the best way is probably to be as open as possible with it. Fortunately for me, it has worked out, but in some cases, it might not…And to get stressed out does not help at all. I think it’s for me, because I know that stress is one of the triggers for me, you know, that works for me, because then it’s not stressful.” [Candrine, marketing manager, female, 37]

Many individuals decided to disclose in order to provide a reason for either their migraine-related absences or the effects of their migraines. This was done either to preserve their reputations (they didn’t want to be viewed as ‘slackers’), or to protect their jobs, or simply out of consideration for their supervisors and employees:

> “I’ve told them. I didn’t want to and it took a while, but there are some times when it was unavoidable. Because I didn’t want them to think that I’m flaking out on work. Because I don’t flake out.” [Liza, financial journalist and senior editor, female, 27]
>
> “I feel that it’s important for my supervisor to know…for both of the jobs that I had, probably within a few weeks after I was hired, I told them that I do suffer from migraines, and that I am otherwise pretty healthy, just to kind of warn them that if I am out of work, it would probably be because of the migraines.” [Lee, foundation director, female, 52]
>
> “Yes, I did… because I was missing work…I would have to leave work early some days because I was getting so sick.” [Linette, imports inspector, female, age 39]

Several people seemed to stress the importance of honesty in the workplace, with statements like “I’m open and honest” and “I’ve never lied…” and “Being up front is better.” Maria described how she felt compelled to disclose:

> “My gut told me I have to tell them, because I certainly can’t fool them into believing that I’m okay.” [Maria, retired teacher, female, 60]

As I suspected, many individuals disclosed their migraines because they needed some type of accommodation in the workplace in order to perform their jobs or remain employed. Many participants, when they have a migraine, experience considerable physical effects, cognitive limitations, and/or have attendance issues that interfere with their employment. I discussed the types of accommodations requested and the reactions to those requests in Chapter 5.

3. Disclosure – Reactions/Responses

For those individuals who indicated that they did disclose, I asked them about the responses and reactions to their disclosure.

I found that the responses to individuals’ disclosure varied widely in the workplaces. There were a range of responses, from positive, to mixed reactions, to negative. I expected that individuals would have different experiences with disclosure in the workplace, which is why I asked about this issue.

Once a medical condition such as migraines has been disclosed, the individual often has expectations for how the disclosure will be received. There are also unexpected consequences of disclosure that the individual may encounter.

Some of the mixed reactions or negative reactions most likely originate from not being believed or from being misunderstood. People who are not familiar with migraine may be skeptical and think that the individual is exaggerating (i.e., perceptions that migraine is 'just a headache'.)

On the *positive* end of the spectrum were the supportive work situations. These were characterized by words like 'supportive', 'compassionate,' 'sympathetic,' 'helpful', 'empathy,' and 'understanding.' The employers were willing to work with the employees and their needs:

> "I get a lot of compassion in my job, and I've always had that in every job." [Morgan, event planner, female, 48]
>
> "So I have had the same boss for pretty much the last five years, and she is extremely understanding, which makes it very easy for me. And she won't question if I have to call in sick for a migraine. Because she knows that I know how to take care of them when she really needs me, and if there's a 12 hour event, and if I am not feeling well, I know that I have to take the medicine." [Jen, senior development officer, female, 30]
>
> "…my boss actually…came up to me and said, 'Go home.' You know, I was trying to work through it, and said, 'No. You look terrible. You're obviously sick. Go home.' So…of course, I really wasn't too worried, that she thought I was… malingering or anything." [Allison, senior clinical trials associate, female, 35]

In addition, some of these individuals talked about 'being believed', or not thought to be faking/exaggerating, as a factor in understanding and compassionate workplaces:

> "… it has never been something that people think I'm making it up…And I've never, never, experienced anybody making out like I'm not really sick, I don't really need to stay home…" [Allison, senior clinical trials associate, female, 35]
>
> "… No one ever thought that I was taking advantage of a situation, or blowing up a situation. No one ever, ever, in 34 years, ever said anything that was negative. If anything, I got, 'Don't you think you ought to go home now?' when it got to the point that I would, that I wasn't going home, when I was staying." [Maria, retired teacher, female, 60]

A couple of individuals stated that having a workplace where there was a culture of supporting taking off when one was sick, regardless of the reason, was helpful:

> "…I had a different boss, and she was also very understanding…that if somebody's sick they should be staying home and they should be able to take a day off. Which is also interesting about our office too, there is always something to do, but no one ever looks down on you if you call in sick. If you're really sick, no matter what the reason is, nobody ever says, 'God I wish you were here today because we really needed you.' … that's why they give you sick days. So I think that in general, in our office, it's helpful to have that outlook." [Jen, senior development officer, female, 30]

For several of the participants in this study, they perceived that two additional factors contributed to positive reactions: the presence of a high number of women in the workplace, and the presence of those who were familiar with migraine:

> "Well, at the last two places that I was at, I was fortunate, because both places, the person who was overseeing me…they both suffered from migraines…My boss is like, 'Oh, take the day off, you know, if you need to.'… I work mostly with women, because I'm a psychologist, so a lot of women know. " [Eleanor, project director/psychologist, female, 36]

> "It may be too that the industry I work in…it's very heavily female-dominated. So, you know, because more women than men get migraines, it may be that just statistically, I'm more likely to be working with people who get them." [Allison, senior clinical trials associate, female, 35]

However, due to the methodology of this study, these factors cannot be generalized to the population at large. A full examination of the factors leading to positive and negative reactions is beyond the scope of this study. I sought to examine the reactions themselves, rather than the factors leading to those reactions.

Toward the *middle* of the range, were those situations that I describe as 'mixed.' These situations were characterized by understanding to a certain extent, or a covert understanding but a latent level of something not as positive, such as the individual believing that there were some feelings or comments showing a lack of understanding about migraine. Below are some examples of this:

> "People I had worked for, no. I won't say not no, period, but no, there's not a true understanding of what's going on." [Russel, owner of construction company and crane operator, male, 42]
>
> "My boss sort of understands. If I get an attack in work, and he knows about it…he's pretty tolerant, but…I think his reaction is, 'Oh not again, where is she going to disappear to now? Is she going home?' And… there's a level of stress involved with that." [Londoner, assistant to head of school, female, 63]
>
> "… he's not very understanding about it. I think because he's never experienced one…He's very tough. And he doesn't get anything but headaches. And so he assumes that everybody else's are the exact same way. And so when I say 'I have a migraine,' I think he means that… I have a small headache. I have no problem coming to work if I have a small headache! But if I can't see straight, it's a little more." [Liza, financial journalist and senior editor, female, 27]
>
> "For the two females that I worked with, I would say that it was favorable, because at that time, my migraines were triggered by my menstrual cycle, and so they understood that…being a female. My current boss…I'm not really sure how he feels, because he doesn't express any compassion to me. I guess indifferent would be how I would describe him..." [Lee, foundation director, female, 52]
>
> "I don't know how to describe it, but I don't think they… believe you… … I'm in a smaller company where he does understand, but you know at some point, I don't think he really does… yeah, just to satisfy the moment, and then there's truly understanding, which I definitely don't think they really understand." [Lainy, chief financial officer, female, 32]

Because some individuals with migraines may not exhibit outward signs during a migraine episode, this may arouse suspicion from managers and co-workers. Stone (1995) states that some people have difficulty imagining that someone who looks able-bodied may have a disability; and as a result, they tend to believe that the person's condition is not 'real'. Lee describes this situation with her new boss:

> "I've also been lucky, because my two bosses have been female, and so that's easier to explain. I currently, as of just a year or so ago, have a new boss who is a man, and I don't know if he quite understands about it, because he says when he looks at me that he doesn't see that I have one…" [Lee, foundation director, female, 52]

Some co-workers and supervisors doubted the reality or severity of the migraines. Often in workplaces, one will find supervisors and co-workers who don't understand why migraine 'headache' pain sometimes makes a person stay home from work, leave work early, or come in to work late.

At the *negative* end of the spectrum, were those situations of negative reactions and responses. These were characterized by a complete lack of understanding, negative comments, not being believed at all, and even at a stronger negative level, retaliations and punishments, or responding with anger at cancellations, inconveniences, or absences.

Aside from the situations of missing work (calling in sick, leaving early, arriving late) mentioned earlier, there are other behaviors that a person with migraines may exhibit that may arouse suspicion among co-workers and supervisors. These include things like running repeatedly to the bathroom during a migraine to vomit; needing to go to a dark, quiet place; mood changes (irritability); or sensitivity to lights and sounds.

The most common comments I heard were related to not understanding the severity of migraine, e.g., how it is neurological in nature and can affect the entire body, or urging the individual to take aspirin. Below are some examples.

> "I don't think the stereotype of calling it generally a headache, a migraine, or any other type of headache…generally you're working with people or coworkers or bosses…and you say you have a migraine… there's a stereotype that is involved – 'you'll be fine, take an aspirin.' …It's debilitating. Period." [Russel, owner of construction company and crane operator, male, 42]
>
> "Every now and then, I come across someone who kind of has the, 'Oh take an aspirin and come do this anyway' attitude." [Kellie, self-employed owner of design and remodel firm, female, age 54]
>
> "But yeah, I ended up telling them, and again, the reaction was first, 'Oh, it's just you know a headache. I don't understand what the big deal is…'…" [Lainy, chief financial officer, female, 32]
>
> "I would have to leave work early some days because I was getting so sick. And one of the supervisors, his reaction was, 'Well, just take some aspirin.' I just wanted to hit him…a lot of people just do not understand, that it's not just a headache." [Linette, imports inspector, female, age 39]

However, some negative reactions went far beyond this. One individual, Ted, who has had migraines for over 40 years and is now retired, had made a decision to no longer disclose his migraine headaches at the workplace. However, earlier in his career, he <u>did</u> disclose his migraines. Before retiring from owning his own pet supply business, he was an executive vice president of marketing and sales. He describes an encounter when he was a general manager, with his immediate supervisor:

> "I had once mentioned something about migraine headache to him, because I had been diagnosed at that time, and his thing, well his basic answer was, 'Nobody who gets migraines is going to work for me!'…But so, I worked for that guy for four and a half years, and you knew, never to mention you had a headache. Because he just didn't believe it, that you got them." [Ted, retired owner of pet supply business, male, 61]

Then there is Mina, who is currently on disability after 18 years of work with a pharmaceutical company. She describes what happened after a new manager started at her company:

> "Well, they took work away from me because I was missing work. So they took a lot of responsibilities away from me. Even though I begged them not to do it, and I begged to work, you know, at home and stuff. But they took work away from me. I have to say, everybody that I worked with there was really good, it was just the manager I had for the last four years. He was the only one that was not understanding. He's the one that took the responsibilities away from me, and I know that he was trying to do whatever he could to get me to leave." [Mina, on disability, was reporting adverse reactions of products for pharmaceutical company, 47]

4. Non Disclosure – Factors

Another question I investigated was, what about the individuals who decided not to disclose all the time, or decided not to disclose in some workplace situations? For those individuals who responded that they decided not to disclose, I asked why not? I wanted to know what factors went into their decision not to disclose. There are perceived risks to the employee in disclosing a chronic illness. These include potential rejection, discrimination, loss of social support, loss of employment, and stigma (Munir, Leka, & Griffiths, 2005). Many individuals in this study expressed fear of subsequent negative attitudes and behaviors.

Individuals may perceive that if they do not disclose, they have more job opportunities. However, if they do not disclose their condition, it means that they cannot receive the protections of the ADA (O'Brien, 2004, p. 96) that they may be entitled to, such as workplace accommodations or protection against discrimination. Therefore, the individuals who choose not to disclose are either a) unaware of such protections, b) do not think it applies to them, c) work in a workplace that is not covered by ADA such as an employer with too few employees, or d) they are aware but have decided that it is best to hide their condition, thereby giving up any possible right to accommodations in order to avoid revealing their migraines.

Some individuals in this study were concerned that disclosing would label them negatively in some way. I describe these concerns briefly in this section, but I will examine this further in the section on Perceptions of Stigma. Reactions of colleagues and employers vary in terms of this.

Unlike those with a visible physical disability, most people with migraines have a choice about disclosure because their migraines are not visible. Goffman (1963b, p.3) makes the distinction between a discreditable and a discredited individual. With the discredited individual, it is assumed that his differentness is already known; whereas with the discreditable individual, it is assumed that his differentness is neither known about nor immediately perceivable (Goffman,1963b, p. 3). Garfinkel's Agnes (1967), discussed in the Identity section of Chapter 2, Review of the Relevant Literature, is an example of a discreditable individual.

Therefore, the discreditable individual has to make decisions about how much information to reveal and to whom to reveal it. Goffman refers to this as 'managing information' and discusses this in a chapter on information control and personal identity:

> "However, when his differentness is not immediately apparent, and is not known beforehand (or at least known by him to be known to the others), when in fact his is a discreditable, not a discredited, person, then the second main possibility in his life is to be found. The issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display; to tell

> or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where." (Goffman, 1963b, p. 42)

As I found with the decision to disclose in an earlier section, the data for the decision *not* to disclose showed that there was a range of factors. When deciding whether or not to disclose, most individuals made their decision based on weighing of the risks vs. benefits.

At one end of the spectrum, were the individuals for whom it simply seemed natural *not to* disclose: One example is Vita, the adjunct teacher whom I quoted at the beginning of this chapter, for whom 'it never occurred to me to tell anybody.' Another example of this is Leo:

> "…I wouldn't…if I was in the middle of a headache, at work, I just wouldn't tell anybody. I just…didn't feel it was appropriate." [Leo, on extended leave from senior vice president, male, 56]

Recall Tori, the sign language interpreter whom I discussed earlier in this chapter, who stated that she would not necessarily tell the people who hired her because she was concerned that they would assume that she was not giving them top quality.

However, the majority of people who chose *not to* disclose, did so for reasons relating to stigma, although only one or two of them used that actual term to answer the question, and their specific reasons may have differed. (I asked the questions about disclosure chronologically before asking the questions about stigma.) When reviewing their responses, I found that they were concerned about shame, disgrace, being seen as less than acceptable, and/or their workplace reputations/identities.

Jen described a general feeling of embarrassment in front of her co-workers when she had to leave a work-related event early, yet she was more concerned about hiding her migraines and leading people to believe that she was sick with something else:

> "Well, I think at the time…I couldn't feel anything else because I was so sick, I was just in my head determined to hide it as much as possible until I got home. And then it was afterwards that night and the next day that it was the embarrassment. I hid it pretty well, and I've learned to do that…I was so concerned about just hiding it as much as possible, so people just thought I was sick." [Jen, senior development officer, female, 30]

Karen and Donna both described concerns that disclosure about migraine could make them be seen as unreliable and less effective in the eyes of others, and they were worried about how that would impact their future at their jobs. Karen, an assistant college professor, was concerned about tenure and promotion, and Donna, who worked for a publishing company, had a national staff and did a lot of corporate travelling, was concerned about being removed from the 'fast track' that she was on. For these individuals, their perception was that revealing their medical condition would have left them vulnerable to obstacles for job advancement.

> "It's more that I'm afraid of what they might think when they are considering me for a position or when they are writing a letter of recommendation. I'm just worried that they might take it into consideration and see it as a disadvantage…I would be afraid that they would think that I'm not entirely competent or not reliable…" [Karen, assistant professor, female, 39]

> "I was always trying to keep the headache information from the people that I worked for, as long as possible. I didn't really want people to know, that I had headaches as often as I did…Because …people…first of all, they don't understand them. They don't understand what a migraine is like. They think it's like the kind of headache… that they get rid of with two aspirin…And then they start to look at you as a less effective worker, and I was certainly, I was on a very fast track, so looking less effective and less reliable and less…as someone who could be counted on, was not,

> it was not a good thing. It wasn't a good thing at all." [Donna, marketing director, female, 52]

Some of the comments above illustrate how disclosure could cause insecurity, as Goffman also describes: "The fear that others can disrespect a person because of something he shows means that he is always insecure in his contact with other people…" (1963b, p. 13)

In some cases, discrimination was mentioned as an additional factor, aside from concerns about reputation: One of these was Donna, whom I quoted above in her comments about the fast track. She had some additional thoughts about discrimination:

> "Pure discrimination, actually, and I'm going to use that word…they still have an attitude about people who seem to have any sort of chronic condition. Most employers do. So I just didn't let them know." [Donna, marketing director, female, 52]

And so did Bill:

> "…I tend not to do anything because yeah I think there is a huge stigma with it. And I do think that there's plenty of people that they're gonna view it how they're gonna want to view it and you're just better off keeping your mouth shut… in most typical offices you are just better off keeping your mouth shut…A lot of people are still very, very discriminatory, very prejudiced, they would never admit it, they would say of course I'm not, but based on what they say and everything they absolutely are no question about it…. Because I've seen that…if they know that they have some kind of condition, that just puts getting rid of them even faster." [Bill, computer systems, male, 50]

There were a couple of individuals who referred to their sex when discussing their non-disclosure about migraines, which is very interesting sociologically, since one was male and one was female.

> "You know how women used to be seen as hysterical. A hysterical woman." [Vita, adjunct teacher English, female, 71]
>
> "…a migraine just wasn't an acceptable thing for a man to have. You could occasionally say you had a bad headache." [Ted, retired owner of pet supply business, male, 61]

Martha, who is 75 years old, discusses the difference in the way migraine etiology was understood in the past:

> "…I tried not to tell anyone … today people have much more knowledge about it, but at that time, people who were nervous…would get migraines, or it wasn't considered a real disease…It was more like, 'Oh the person is nervous' or that kind of thing." [Martha, elementary school teacher, female, 75]

Susanna's comments demonstrate that many factors can be taken into account in the decision not to disclose. Susanna talks about the nature of her profession, the appearance of weakness, the lack of understanding, and the perception of non-acceptance:

> "First of all, I never disclosed to an employer that I have a migraine. As a social worker, I feel like I should be the helping person. And I, and logically I know it's not the case, but I feel like migraines are almost a weakness, they're very isolating, it's hard to say that you can't come to work or you can't perform your job because you've got a migraine or a headache, nobody understands that…I don't feel like migraines are accepted in the workplace, no matter what profession you do." [Susanna, social worker, female, 34]

Finally, in addition to what the study participants actually *said* about the factors involved in their decision not to disclose, I reviewed the demographics of those who did not disclose. I found the following three patterns: With only one exception, all of the people who did not disclose were aged 50 or older. In addition, a high percentage of males, relative to total number of males in the study, did not disclose. Finally, those who did not disclose tended to have a higher level of education. As a reminder, these findings apply only to this study and cannot be generalized.

This section has identified the factors involved in the decision *not to* disclose. Since the majority of the factors related to stigma, I have sections on Perceptions of Stigma and on Perceived Self-Identity later in this chapter. The next section will examine the strategies that were used by individuals who did not disclose.

5. Non Disclosure – Coping Mechanisms, Hiding Behaviors, Passing Strategies

Once I knew the factors that led an individual to not disclose his/her migraines in the workplace (either all the time or some of the time), a second related question is what happened with those who did not disclose.

I was interested in hearing about the mechanisms, behaviors, and strategies used by the people who did not disclose in order to assist them in their goal of keeping their migraines hidden. I found that there were a variety of strategies. Some individuals who chose not to disclose took specific steps to ‘pass’ (Goffman, 1963b) in the workplace as a person without migraines.

Goffman (1963b) describes a useful strategy that he refers to as “passing” that individuals use to avoid a potential stigma; passing is concealing a discrediting social status or stigmatizing attribute. When Garfinkel (1967) discusses Agnes, and the' management of disclosure of her change of sex status, which I described in the Identity section of Chapter 2, Review of the Relevant Literature, this is an example of 'passing' behavior.

Sometimes efforts to pass may obtain the desired result, even though the passing may interfere with actual job performance. Hauk (2010), a multi-grade elementary school classroom teacher who stutters, describes how she attempted to hide her stuttering during classroom observations. She would employ various techniques during observations in order to score well, even though these techniques were not desirable and affected her actual teaching. She concluded, "Because of these efforts to pass resulted in what I think was less effective teaching, I obtained a good referral." (Hauk, 2010, p. 15).

However, as explained by Goffman, " Because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent." (1963b, p. 74)

Below, I summarize some of the strategies and behaviors used by the participants in this study to avoid disclosing their migraines at work.

Hillary and Susanna describe how they just kept working through the migraines, despite the pain and/or migraine-related effects:

> "For the longest time, up until very recently, I've never told anyone at work. I mean, I fake it really well…I've worked through and gone to meetings and did work through very painful migraines, and I don't know if that's good or bad but I've done that." [Hillary, technical writer, female, 62]

> "I go to work with migraines, I work through them…I kind of slow down, it's hard to think, I probably talk a little slower, I need a little bit more time…" [Susanna, social worker, female, 34]

For Engrid, an attorney and administrative law judge, the flexibility provided by the type of jobs that she has held in her career has been a big help in helping her to cover her migraines. She describes this:

> "I can tell you that for most of my life, people who dealt with me had no idea. Unless I told them…Well, for the most part, I've usually had enough flexibility…And I could usually work around to take advantage of the flexibility when I needed, and those were the years when the headaches were really terrible…So that was important. I could always find a place to hide out for a half an hour… Because you try very hard to cover it up, you know?" [Engrid, attorney and administrative law judge, female, 64]

Donna, described earlier in this chapter, who was concerned about being removed from the 'fast track', also talked about the type of job she had. Like Engrid, the characteristics of Donna's job allowed her to sometimes keep her migraines hidden:

> " I had a situation where I was in and out of the office with clients and things like that, so I could keep some of it hidden…And I was always trying to… not let people know what was really going on…" [Donna, marketing director, female, 52]

While some took more passive steps of working through migraines and using the job's flexibility to cover, there were also those who actively took steps and told false stories when they had migraines. This range from passive to active is illustrated by Goffman's statement regarding managing information: "….the extent of passing can vary, from momentary and unintended at one extreme to the classic kind of deliberate total passing." (1963b, p. 80).

Ted falls into the active, deliberate, total category. I discussed Ted earlier in this chapter. He was the individual who once was told: 'Nobody who gets migraines is going to work for me!', and he is also the person who told me of his perception that others thought 'a migraine just wasn't an acceptable thing for a man to have.' As I mentioned earlier, before retiring from owning his own pet supply business, he was an executive vice president of marketing and sales. Ted was very vocal in describing to me the elaborate steps that he took to cover his migraines. Since he thought that it was perceived that migraines were not an acceptable for men, as a result when he needed to call in sick with a migraine, he pretended to have something else:

> "And what I'd do at work is, if I really couldn't take it at all, I'd call in sick and tell them I had the flu. Because they'd believe that, and they wouldn't believe a headache…I remember telling somebody at one point, I said, 'Look, I've just got too bad a headache, I can't come in,' you know, and that just didn't fly at all. You know, it wasn't a legitimate excuse. Then after that, I said, okay, you don't use *that* next time. Tell them you got the flu. They believe that." [Ted, retired owner of pet supply business, male, 61]
>
> "And what you do is say you drank too much, and that was perfect. You know, you could have gone home the night before and put an ice pack on your head at 6:00 and slept through, and but if you told them the next morning you had a wicked hangover, that would be fine. That would be very acceptable, if you didn't use it too often." [Ted, retired owner of pet supply business, male, 61]

He perceived that it was more acceptable to tell his workplace that he couldn't come to work because he had been drunk the night before and had a hangover, than to say that he had a migraine!

When he was at meetings and was unable to pay attention, Ted had strategies for passing at those as well:

> "Well, thinking back now, it's amazing how…you have to actually hide the fact that… you have a migraine…I know a bunch of times… I had to figure out what had really gone on in a conference, the next day… I had to kind of fake the fact that whatever was said, it went totally past me. And I was usually able to fake that pretty good. How to make the right noises as if you're observing. And then…putting an 'X'…on the papers that you're really supposed to check. And luckily, I think that I have fairly high

> intelligence, and I was able to fake a lot of things…I remember being able to do that a lot." [Ted, retired owner of pet supply business, male, 61]

Since concentrating on numbers was difficult during migraines, Ted also had a strategy for that:

> "And then the other thing I was able to, when I had a headache, I'd concentrate on the non-numbers things. Numbers seemed to be a problem…But I learned how to…always have a little calculator with me. And I also had a fairly decent mathematical mind, so I was able to… always get kind of in the range if I had to do mathematical things." [Ted, retired owner of pet supply business, male, 61]

Perhaps the most dramatic is Ted's account of how he would handle business travel, and his strategy for how to hide a migraine while on a business trip. This strategy was acceptable in Ted's mind, whereas disclosing that he had a migraine to his work colleagues would not have been acceptable:

> "At work, if you really had a bad meeting and a rough day, and were travelling, you could say you were going out to jog, and then instead just go up and put ice on your head for an hour. That would cover your not meeting people for cocktails. As I think of it, you think of more and more things that you did to cope, to basically hide it, because it just wasn't acceptable." [Ted, retired owner of pet supply business, male, 61]

Many participants in this study who did not disclose worked constantly to hide their migraines. For some individuals, these strategies required creativity and proved to be very time-consuming.

However, despite its perceived advantages, 'passing' is not without its price: "The phenomenon of passing has always raised issues regarding the psychic state of the passer. First, it is assumed that he must necessarily pay a great psychological price, a very high level of anxiety, in living a life that can be collapsed at any moment." (Goffman, 1963b, p. 87). In effect, individuals who do not disclose and who ‘pass’ are pretending to have a different identity.

This concludes the four sections on disclosure management; I discuss Stigma and Identity in the next two sections.

6. Perceptions of Stigma

I asked the individuals in this study about stigma: -- whether they were concerned about stigma at the workplace and if it was a factor in their decision making about disclosure. I wanted to find out about the relevance of stigma and the impact of stigma on migraines in the workplace. I found that there was an almost equal division among the responses.

Of the **40** participants in this study, I found the following: **21** responded that they *were* concerned about stigma, and **19** responded that they *were not*.

The table below, Table 9, summarizes the study data regarding the concerns about stigma.

TABLE 9

Concerned about Stigma? (n=40)

Concerned about Stigma ?
▪ Yes (21) ▪ No (19)

I reviewed the demographics of those who answered affirmatively about stigma concerns and compared them against the demographics of those who answered negatively about stigma concerns, to check for any difference between the two groups. I could not find any difference in terms of age, race, or educational status, between the two groups. The only difference I found was in terms of sex: There were twice as many males in the "yes-stigma" group as there were in the "no-stigma" group. However, due to the low number of males in the overall sample, this result should be interpreted with caution. Again, these findings apply only to this study and cannot be generalized.

Stigma is a complex concept. The circumstances surrounding stigma can depend partly on the nature of the stigmatizing condition, the specific situation, factors relating to the individual, and whether the condition is visible or invisible.

In addition, according to Conrad (1986), the stigma associated with an illness may be dependent on whether the individual can be blamed or held responsible for its occurrence, whether the illness has potentially serious consequences for others, and/or whether it results in a decreased level of competence. All of these have important implications for the workplace and for this study.

"The lesson from a constructionist standpoint is that there is nothing inherent about a condition that makes it stigmatizing; rather it is the social response to the condition and some of its manifestations, or the type of individuals who suffer from it, that make a condition stigmatized." (Conrad & Barker, 2010, p. S69)

As was the case with disclosure, responses about stigma in this study demonstrated both ends of the spectrum. There were those who gave stigma no thought at all, and yet there were those who thought about it quite a lot.

One on end of the range, were those individuals who perceived no stigma with migraines at all:

> "No, no, I don't think so. I don't see it. I don't think it ever crossed my mind, to be really honest with you." [Madelin, vice president of human resources, female, 65]
>
> "No, I didn't even think about it." [Allison, senior clinical trials associate, female, 35]
>
> "No…I've never felt a stigma or that I was weaker…Because I feel like I'm stronger than most people, because to go through that pain…But no, I never felt any stigma, that I was weaker or inferior to other people because I was getting severe migraines." [Morgan, event planner, female, 48]

Not surprisingly, there were many individuals who *were* concerned about stigma due other people's lack of understanding about the condition, and it being seen as 'just a headache':

> "…a lot of my friends have migraines…I pick friends similar to me and we tell each other when we have migraines, there's no stigma. But with people who don't have them I just I think there's probably a stigma." [Hillary, technical writer, female, 62]

As Hillary indicated above, this lack of understanding was not present during contact with other people who also had migraines, because those people presumably understood. Goffman (1963b) describes these other people as 'sympathetic others'.

> "In some cases, he may feel like he is the only one of his kind and all the world is against him…In most cases, however, he will find that there are

> sympathetic others who are ready to adopt his standpoint in the world and to share with him the feeling that he is human…The first set of sympathetic others is of course those who share his stigma.” (1963b, p. 19-20)

After I reviewed the individual responses, it became clear to me that some people perceived that there were different types, or levels, of stigma: one for physical conditions, and one for mental or emotional illnesses. Fenno and Helen talked about the migraine stigma and the stigma associated with mental illness:

> “I wouldn’t say concern about stigma in the same sense that maybe a mental illness would cause concern for stigma. I’d put it more in the category of ulcers or some other chronic condition than as more of a physical rather than an emotional or mental.” [Fenno, retired college professor, male, 68]
>
> “Yes, definitely. Yeah, because people have the attitude that it’s all in your head, or that if you get migraines, it’s some emotional problem rather than a physical problem…People who never get a migraine, just can’t understand. I really think people think it’s an emotional problem, a stress-related problem, ‘you’ve got to relax,’ that kind of thing…” [Helen, elementary school teacher, female, 43]

Helen’s comments are similar to those of Martha, also an elementary school teacher, quoted in an earlier section. For Martha, the stigma was about migraines not being a real disease and being labeled as nervous.

As I demonstrated in the section on factors involved in non-disclosure, many individuals do not disclose because of fear of subsequent negative attitudes and behaviors towards them. For some, the stigma was in the fact that migraines can’t be proven (credibility) and that there is something ‘wrong’ with people who have them:

> “Absolutely. If you say you’ve got migraines, you’re going to be the hypochondriac, because the next thing you’re going to have something else wrong with you…Because you can’t prove that you have a headache,

> unlike diabetes, some of the more physical ailments…" [Susanna, social worker, female, 34]
>
> "…there is a certain amount of stigma involved…I find that people feel that if you react to stress in this manner, there is something wrong with you…It's just a feeling that I'm not living up to what I should be doing, or what I am capable of doing, and there definitely is some stigma involved." [Londoner, assistant to head of school, female, 63]
>
> "… yeah I think there is a huge stigma with it…You're better off not letting whatever's happening…make it to the workplace." [Bill, computer systems, male, 50]

When I asked about the reason for the stigma, I found that a common theme was concerns about not being seen as reliable. Adrienne, the assistant to the president of an international sport association, was one of these. In fact, she was pregnant at the time I interviewed her, and she talked about a constant struggle between needing to take care of herself but also wanting be seen as reliable and competent. This concern was also shared by Donna (the publishing executive on the 'fast track') and Karen (the assistant professor up for tenure), who I discussed earlier in this chapter regarding their reasons for non-disclosure. Lainy, a chief financial officer, said that she didn't want people looking at her 'differently.'

However, Engrid had a bit of a different spin as to what the stigma actually is:

> "Well, I think the stigma is, I don't think it's the fact that you have a migraine that's the stigma. I think the stigma is that you are in some way incapacitated by something that everybody thinks is nothing and doesn't take seriously…and somebody looks and says but it's just a headache, it's nothing ….that's where the problem is. I think it's the disconnect..." [Engrid, attorney and administrative law judge, female, 64]

Vita was the adjunct teacher who didn't disclose because 'it never occurred to tell anybody' and who referenced the stereotype of the 'hysterical woman'. When asked about stigma, both Vita and Martha did not want to be blamed for causing their own migraines:

> "Well, yeah, that's been a concern my whole life. Because people think …you're doing it to yourself. They think that it's your own doing. You know, just pull up your bootstraps and get over it." [Vita, adjunct teacher English, female, 71]
>
> "Because the question was, 'What did you do to bring that on?' [Martha, elementary school teacher, female, 75]

Ted, whom I discussed in the last section regarding his extensive passing strategies, discussed stigma in terms of his sex and the time period:

> "Definitely…actually, until I was working for myself, it was pretty much something you…weren't open about. And in some cases, had to really hide it…I didn't *have* migraines, because men didn't get migraines. Back in the late 1960's almost to 1980, that's why this study is interesting, you couldn't tell anybody you had migraines." [Ted, retired owner of pet supply business, male, 61]

Two individuals mentioned having other medical conditions besides migraines, and they contrasted the stigma of both conditions. However, interestingly enough, they had different viewpoints regarding the contrast:

> "That's ironic that you bring that question up, because when you say stigma, I wear a hearing aid, I have about a 90% loss in one ear, and about an 80% loss in the other ear. I feel no stigma in telling people that I have migraines, but I do feel a stigma in telling people that I'm almost deaf." [Maria, retired teacher, female, 60]
>
> "I had breast cancer about six years ago. And I told almost no one. I worked through it, although I cut my hours…except for two or three people, nobody that I worked with knew…I dealt with it the same way I dealt with my headaches." [Engrid, attorney and administrative law judge, female, 64]

The above discussion about Perceptions of Stigma contains some overlap with the next section, Perceived Self-Identity, since the two topics are closely intertwined.

7. Perceived Self Identity

Although identity is not a central concept of this study, I read through the transcripts to examine what themes and issues emerged regarding identity. Unlike with disclosure, stigma, and accommodations, I did not ask any questions specifically on the topic of identity, although the concept was explored through conversations on the many other topics we discussed. Identity is an extremely complex topic and is closely intertwined with other concepts such as, but not limited to, culture, location, gender, social and political factors, historical time period, stigma, and guilt.

An individual's sense of self is connected to how others react to him/her. The self-perceptions of an individual can be influenced by the attitudes and expectations of others. Because this dissertation focuses on migraines *in the workplace*, the individual's social identity and perceived self-identity are of special importance. Because this study concerns stigma and disclosure, the management of spoiled identity is also of importance.

In his classic work, *Mind, Self, and Society,* Mead stated:

> "The individual experiences himself as such, not directly, but only indirectly, from the particular standpoints of other individual members of the same social group, or from the generalized standpoint of the social group as a whole to which he belongs…..and he becomes an object to himself only by taking the attitudes of other individuals toward himself within a social environment or context of experience and behavior in which both he and they are involved" (Mead, 1934, p. 138).

It is often the case that the individuals participate in the creation of 'spoiled identity' through disclosure of the particular characteristic at issue, in this case, migraines. People with migraines, in particular, when they experience migraines in the workplace, are often stigmatized. I wanted to see how the lived experiences of the individuals in this study (both the ones who disclosed and the ones who did not disclose) influenced their self-perception of workplace identity. By using content analysis, I examined the relationship between migraines and self-perception of workplace identity and thereby the management of spoiled, hidden identity in the workplace. I identified seven identity-related themes in the transcripts.

THEME: Migraines as Contested Illness (or not Legitimate)

Many participants spoke of their perception of a fear of migraines not being viewed in the workplace as a legitimate condition. I already discussed this in several sections earlier in this Chapter.

Conrad and Barker describe a category of illnesses called "contested illnesses" in which "Physicians, the public, and sometimes even sufferers themselves question the authenticity of the symptoms and the mental stability of the sufferer." (Conrad & Barker, 2010, p. S70). They continue:

> "Contested illnesses are a category of disorders that, by definition, have a very particular cultural meaning. These are illnesses where sufferers claim to have a specific disease that many physicians do not recognize or acknowledge as distinctly medical. Contested illnesses…are

> medically suspect because they are not associated with any known abnormality." (Conrad & Barker, 2010, p S70)

Migraines fall into the category of "contestable complaints," according to Segal, (2007, p. 229) which denote complaints that are not objectively verifiable and rely on some form of argument to be taken seriously. However, Segal makes the distinction between "contestable illnesses" (illnesses such as fibromyalgia, or chronic fatigue syndrome, whose actual existence is contestable) and an illness like migraine, wherein the illness itself is not "contested" but whose sufferers are sometimes understood to make contestable claims. (Segal, 2007, p. 229).

For this reason, the actual diagnosis of 'migraine' is very valuable to many individuals, according to Brown (1995): it provides a narrative for previously unexplained events and experiences, rendering the world and one's place within it more predictable. Therefore, labeling is sought by some individuals as a way to legitimize their condition (Brown, 1995.)

Some individuals perceived that their migraines and their bodies were viewed as medically suspect; they often felt as though they were expected to just 'overcome' their migraines (since it's not perceived as a legitimate condition) and get to work.

> "And being stigmatized as just being a headache, it shouldn't be like that. In general, in the workplace…everybody still thinks it's just a headache."
> [Russel, owner of construction company and crane operator, male, 42]

THEME : Making Sense of Illness, Illness Identity

This was categorized by individuals who attempted to form a kinship with people at work who either ‘understood’ (perhaps knew someone with migraines), or else with colleagues who had migraines themselves.

Conrad and Barker discuss how individuals with medical conditions can form an illness identity:

> “Chronic illness can prompt an evaluation of one’s former life and identity, and in some cases, the creation of a new illness identity (e.g., cancer survivor). Finally, medical sociologists have documented how laypeople sometimes create and join illness-based social movements…and forge new communities based on illness identities” (Conrad & Barker, 2010, p. S72)

Goffman also describes that individuals who feel stigma can find moral support in a group of others with the same stigma:

> “Knowing from their own experience what it is like to have this particular stigma, some of them can provide the individual with instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support…” (Goffman, 1963b, p. 20)

Many participants in this study belonged to migraine support groups, since that was one of my original recruitment sources. This would seem to support Conrad and Barker’s and Goffman's assertions above. However, a discussion of the role of support groups is beyond the scope of this study.

> "…people struggle to make sense of their illness and reclaim a sense of self. People endeavor to endow their illness with meaning within their context of their personal and social relationships, employment status, health insurance coverage, religious and cultural beliefs, and the like."
>
> (Conrad & Barker, 2010, p. S72)

Lainy and Susanna discuss the importance of finding an ally in the workplace who understands:

> " I have one good friend I work with, who understands, and when I have one [a migraine], he'll try to jump in and I always feel like he's covering for me, and unfortunately, that's hard you know, because I don't want to feel…that I'm being covered for…but unfortunately I have no options." [Lainy, chief financial officer, female, 32]
>
> "I think you'll find that… if you find somebody that has migraines in the workplace, you tend to feel kind of a kinship with them, I guess, you tend to talk to them a little bit more…." [Susanna, social worker, female, 34]

THEME : Effect of Episodic Illness on Self (Sometimes Sick, Sometimes Well)

People with migraines move back and forth, repeatedly, between times when they are healthy and times when they are having periods of disabling illness. This seems to have an effect on their perceived self-identity, including their identity at the workplace. They are never always well nor always sick. This can be very disconcerting because sometimes they are healthy and able to work as usual, but sometimes they are sick and cannot work effectively or cannot work at all.

To complicate matters even more, many individuals spoke about the unpredictable nature of migraines, the back-and-forth between ‘migraine’ and ‘non-migraine’ time periods that can change on a daily basis and affect their ability to function in the workplace.

Lainy recalled her frustration when, at a fairly new job, a severe migraine occurred at a work-related special event. Part of her frustration was due to the fact that her migraines were so unpredictable:

> “The first time was probably when I had it when it happened at an event and… unfortunately it was one of those really bad ones that kind of come out of nowhere, and slam you… at that point …” [Lainy, chief financial officer, female, 32]

THEME : Strong Emotions Felt (i.e., Guilt, Depression).

Individuals in this study reported or expressed a wide range of emotions, including guilt, depression, self-loathing, embarrassment, fear, shame, failure.

I already discussed feelings of fear, shame, embarrassment, in earlier sections of this Chapter. A couple of individuals expressed feelings of failure, such as “I feel like a failure,” or self-loathing, “I hate myself every time I have to miss work.” It seems as though, for some, the migraines had the impact of decreasing one’s sense of worth at the workplace. However, this varied from person to person, and may be dependent on other factors. Again, that is beyond the scope of this study.

Many individuals gave examples of staying at work while sick, rather than giving the ‘wrong’ impression by leaving early because of an illness that is not well understood by others. Feelings of guilt and depression were most common with many of the people in the study, when talking about whether the migraines affected their work life.

> [Guilt] “Even at work, I’ll feel guilty if I can’t perform to 100%. …I feel really bad about that. I’ll go home feeling I didn’t give 100% at work…I feel bad my headaches stopped me from doing that…Yeah, I feel guilty when…it got the better of me and I can’t do…what I have to do for the day.” [Morgan, event planner, female, 48]
>
> [Guilt] “So I always had feelings of guilt when I had to leave work, pretty much on a regular basis…every month, to go home with a migraine. And that was hard. And feeling guilty is not something that a migraine person should have to deal with anyway…” [then described how difficult it was trying to get through migraines, especially for a Type A person, to not perform at your best, but the migraines were beyond her control..She struggled to learn to accept that over 40 years of migraines.] “..I’ve learned to accept that over the years. I don’t feel guilty anymore…” [Lee, foundation director, female, 52]
>
> [Guilt] “…there’s a lot of guilt that goes with that for some unknown reason, at least in my world. You know, I feel guilty that yeah, I have these, and …I can’t function properly.” [Lainy, chief financial officer, female, 32]
>
> [Guilt] “I would feel guilty, and they would kind of make me feel guilty, about leaving or calling in sick. Because they were so short-handed and they needed me there. And so that was a very tough situation….” [Linette, imports inspector, female, age 39]

Even though many people know what their triggers are for migraines, as mentioned previously, some people in this study didn’t know the reasons for their migraines. Morgan described how she would get very depressed, out of frustration wondering why the migraines kept happening:

> [Depressed] “I think you can get depressed from them. Very depressed. It’s very depressing…Like why am I getting these? Why do I have to keep suffering like this?” [Morgan, event planner, female, 48]
>
> [Depressed] “It wears at your emotions, and it wears at your psyche too. Now I’ve gone through after several bouts two or three a day, for any

> length of time, I start getting depressed… I can say that I have gotten deeply depressed over it.” [Russel, owner of construction company and crane operator, male, 42]

Jen described her feelings of embarrassment while working a new job. She was at a work-related special event and when she didn’t take her migraine medication in time to abort the migraine, she became sick:

> [Embarrassed] “When I first started there… we had an event and I had started to feel the migraine come on, and didn’t know at that time that I had to take, that it was very important to take the medication right away, and I thought, well maybe if I just wait until the event is over, and sure enough, the event ended, and I was completely sick. I was sick in the car ride home, and it was embarrassing for me to have my co-workers see me that way…” [Jen, senior development officer, female, 30]

<u>THEME: Concern regarding other’s perceptions of being seen as unreliable</u>: or weak, inferior, incompetent, etc.

There were many participants who expressed concerns regarding *other’s* perceptions in terms of variations on a theme of competence: being viewed as unreliable, weak, inferior, incompetent, less effective, etc. I discussed this to some extent, in the section on Non-Disclosure Factors and the section on Stigma.

“The capitalist workplace culture is ultimately a ‘macho’ culture in that it denies any weakness or dependence. Everyone is supposed to be independent, effective, and productive.” (O’Brien, 2005, p. 31)

Individuals talked about their professional identity and reputation and images of being strong. They didn’t want their public identity to be one of someone who has disabling migraines or is sick. This deviation from the norm affected their self- image.

> “…you know, you try and keep it private, you try and keep it so other people do not judge you based on that. Professionally, you sure as hell don’t want to admit it because it’s first of all, it’s a weakness, and second of all, it might be used against you in some way. And third of all, it’s because nobody takes it seriously.” [Engrid, attorney and administrative law judge, female, 64]

> “…I tried to…as much as possible to teach even if my head is killing me because I don’t want them to think that it’s a disadvantage that I have these headaches because they write my letters of recommendation, and I’d like to get a tenure track position. And I don’t want them thinking that I missed classes, that I’m not reliable or something, or that migraines might be affecting my work, so I’ve taught with like really bad headaches, and I’ve taught with having taken lots of medications and feeling kind of out of it.” [Karen, assistant professor, female, 39]

> “…I don’t want people looking at me differently just because I have migraines. Because…I am successful and I can do the things I can do, even with them…but I’m concerned I don’t want them again talking about it or using it against me…” [Lainy, chief financial officer, female, 32]

Having migraines or other people’s knowledge that one takes medication for migraines can also lead to being labeled as disabled or sick, and even ridicule. Fenno and Adrienne talked about this:

> “I didn’t want to be seen as a complainer. And I didn’t want people to treat me as if I was in the sick role or a patient…Nobody wants to get written off because of some infirmity that may have little to do with their overall performance.” [Fenno, retired college professor, male, 68]

> “I mean, thank God for pills and so on, but ... it just makes you feel incompetent, and you want to produce more, so then you end up pushing yourself even more, sometimes working with a migraine, because you’re fearing that you’re going to be seen as this disabled, this handicapped…because they do make jokes about it… it’s like a joke to them. ‘Oh take your magic blue pill’ ...Then how can you be seen as reliable?...and then you end up pushing yourself because you don’t want to look bad, because face it…the way things are in this economy, anyone can be replaced.” [Adrienne, assistant to president, female, 39]

THEME : Stigma's affect on Self Identity, Spoiled Identity, Social Identity

Another factor that contributes to the self-identity of an individual with migraines is whether they believe there is a stigma attached to migraines, and if so, how they handle that in the workplace.

I already discussed issues related to disclosure and stigma in the majority of this Chapter. Some individuals who disclosed their migraines had feelings of self-acceptance. For those who felt a stigma with migraines and chose not to disclose, they engaged in stigma management.

Goffman observed that keeping the stigma hidden, which is one strategy for managing discrediting knowledge to the public about the self, may partially explain the coping strategies that people use in response to stigma (Goffman, 1963b). The following three quotes from Goffman (1963b) illustrate the relationship between stigma and identity:

This illustrates how disclosure can show pride in the acceptance of self: "I want to suggest now that the stigmatized individual can come to feel that he should be above passing, that if he accepts himself and respects himself he will feel no need to conceal his failing." (Goffman, 1963b, p. 101)

This illustrates how when someone hides information about their real identity, they are treated based on that false identity: "By intention or in effect the ex-mental patient conceals information about his real social identity, receiving and accepting treatment based on false suppositions concerning himself." (Goffman, 1963b, p. 42)

This illustrates how the hiding of stigma becomes part of one's identity: "The stigma and the effort to conceal it or remedy it become 'fixed' as part of personal identity." (Goffman, 1963b, p. 65)

> "Having a migraine, saying I'm having a migraine…I wouldn't want people to start associating me with that." [Hillary, technical writer, female, 62]
>
> "Until I had my own company, never really said migraines to anybody, unless I really knew what the score was." [Ted, retired owner of pet supply business, male, 61]

THEME: Concerns that they are accused of faking or lying or malingering, because they do not look sick (invisible or hidden condition)

People with migraines do not always exhibit physical signs when they have a migraine. Therefore, since the condition may not be visible, it may arouse suspicion from others at the workplace during a migraine episode.

A few individuals told me about workplace colleagues thinking that their migraines were an excuse to get out of work, 'people think you're making it up' or that they were exaggerating. Goffman (1963b) described how people with stigma might use it to their advantage, such as procrastination, relief from unpleasant duties, escape from competition, protection from social responsibility. "The stigmatized individual is likely to use his stigma for 'secondary gains,' as an excuse for ill success that has come his way for other reasons." (Goffman, 1963b, p. 10)

According to Stafford and Shoquist, "the people skills involved in migraine management are extremely important because people who don't have migraines usually have trouble understanding them or relating to the sometimes-debilitating nature of headaches…" (2003, p. 17) I heard this over and over again; co-workers and employers who either didn't understand, thought the employee was making it up, or malingering/exaggerating.

Segal made the following statements about malingerers, which help demonstrate why individuals with migraines are not always taken seriously:

> "Malingerers malinger for a variety of reasons. They may seek as adults the attention for being ill that they came, as children, to expect (Ehrlich, 1980); they may feign distress not for attention but for financial reward…. The existence of feigners of any description, however, complicates things for people who are indeed ill, but who have illnesses that exist at the borders of sickness." (Segal, 2007, p. 232-233)

Some individuals explained how their migraines do not make them look sick in ways the employer expects a sick person to look, and therefore, how it is difficult to prove. Lee described why the invisible nature of migraines caused problems for her.

> "…if I got a migraine, I would have to go home and leave work. And that was always difficult, because I pride myself on being healthy. I would never leave work if I had a cold, or I mean, I never got sick in any other way except for the migraines, and it's hard because people don't see that you're sick, in looking at you they may not perceive that you have a headache, and whereas if you're coughing and sneezing and blowing your nose and that kind of thing, it's just more noticeable." [Lee, foundation director, female, 52]

Liza described how she doesn't like when people think that she's faking.

> "I don't like that people think that I'm faking it…You say you have a migraine, and they say, 'oh you're fine, do what you're going to do.' And that's not true." [Liza, financial journalist and senior editor, female, 27]

And Bill wondered why anyone would suspect him of lying:

> "…when you think about it, it's like why would somebody lie about that? …I suppose if it's somebody who is an individual who is manipulative might do something like that, but if you don't suspect that the person is like that, why would they make up a story about having a migraine?" [Bill, computer systems, male, 50]

Adrienne told me why she preferred when her migraines happened at work, because then her colleagues knew for sure that she was telling the truth:

> "So to me…I'm happy if the migraine happens while I'm at work, because they look at my face and they see it coming. And they see me still trying to struggle and work…and they're like, 'Please stop and go lay down.' And that makes me feel better. As opposed to me being home and saying, 'I woke up with a migraine' and it sounds like…when you're a kid, 'my dog ate my homework.' [Adrienne, assistant to president, female, 39]

Donna, the publishing executive who kept her migraines hidden in order to stay on the fast track, described how keeping the migraines secret was not in her nature:

> "I don't like to be deceptive. I'm not by nature deceptive, at all." [Donna, marketing director, female, 52]

And Russell described to me what his co-workers thought he was doing, rather than having migraines:

> "Actually I've been accused of…you're stoned or you're drunk… because of the look in my eyes and my face. I can't really think clearly when they're going and I kind of am short…I have clearly been accused of being on drugs." [Russel, owner of construction company and crane operator, male, 42]

These examples in this subsection on Perceived Self-Identity reflect the basic connection between migraines and identity. The impact that the 1) individual's feelings about *having* migraines (e.g., guilt, depression, stigma, etc), and 2) the individual's feelings about the *nature* of migraines (e.g., episodic, invisible, contested), and 3) the individual's feelings about other's perceptions (i.e., reputation as reliable, faking/malingering) can all have an impact on the individual's perceived self-identity in the workplace.

This concludes the chapter on data analysis regarding the following issues in the workplace: disclosure, stigma, and identity.

This excerpt from Lainy's interview demonstrates the many difficult decisions Lainy faced regarding disclosure:

> "…I felt that the people that I told, you know, number one the boss, you know the owner, had to know and then again everybody else is almost pretty much underneath me and… I didn't think it was any of their business…sometimes I wish I would tell them because maybe they would understand. But then I'm concerned I don't want them talking about it or using it against me or feeling sorry for me or whatever the case may be…"
> [Lainy, chief financial officer, female, 32]

Lainy also talked about how hard it was to weigh whether giving various people information would be beneficial or not beneficial, and she asked that at the conclusion of my research, "When you find out, let me know."

Unfortunately, there is no simple 'one-size-fits-all' answer to the *disclosure dilemma*, as I have shown throughout this Chapter. This Chapter also illustrates how the topics of disclosure of migraines, stigma, and perceived identity are closely related in the workplace. I expand on this in the next chapter by providing findings and conclusions, recent developments, and then discuss the implications of this study and directions for future research.

CHAPTER SEVEN: FINDINGS/CONCLUSIONS, LIMITATIONS, AND IMPLICATIONS/DIRECTIONS FOR FUTURE RESEARCH

Outline of this Chapter:

1. Summary of the Research and Data
2. Findings/Conclusions
3. Recent Developments
4. Limitations
5. Implications; Directions for Future Research
6. Closing/ Final Thoughts

In Chapter 7, the final chapter, I present: 1) a summary of the research and demographic data, 2) the findings/conclusions of the research, 3) a brief discussion of recent developments: in migraine treatments, and in legislation pertaining to the Americans with Disabilities Act (ADA), 4) the limitations of this project, and 5) the implications of the findings, along with an identification of possible directions for future research. I then provide my closing thoughts.

"Disability" is often understood by the general public as being blind, deaf, developmentally disabled, or using a wheelchair. However, "disabled" is no longer defined only as persons with visible physical disabilities, but also more broadly includes "hidden" or "invisible" disabilities and "episodic" disabilities/conditions. Unfortunately, many individuals with hidden disabilities never become involved with disability community or culture. In addition, given the fact that having a disability or being perceived as a person with a disability could be considered to be a stigma, some people who have chronic medical conditions or invisible disabilities do not think of themselves as disabled. Even among those individuals who *do* consider themselves disabled, many are reluctant to disclose their disability, especially in the workplace.

The workplace is different from the community-at-large, since at work there are people who have authority over others, and therefore, an imbalance of power exists. Also, people at work do not usually have the freedom to leave that they would in other situations, and often have to work in an assigned area, with other people, under specific conditions over which they may have little or no control.

The benefit of employment, aside from supplying income, should not be underestimated. The following two quotes illustrate this: "Gainful employment is important. It enhances an individual's self-worth and sense of independence…" (Solovieva, Dowler, & Walls, 2011, p. 40). "Employment generates income, but it also provides opportunities for social participation which leads to increased psychological well-being and improved life satisfaction of employees." (Naami & Hayashi, 2011, p. 40).

1. Summary of the Research and Data

Description of The Study

This dissertation examined the social construction of migraine headaches in the workplace. This is a research study of people's experiences with migraine headaches as they relate to the workplace. The study explores people's perceptions of workplace attitudes and factors surrounding employee disclosure of migraines at the workplace.

Specifically, this study examined the workplace experiences and perceptions of people who experience migraine headaches, using a qualitative interview methodology.

This study investigated the impact of migraines on the individual's work experiences, the processes involved in disclosure, and explored perceived self-identity and stigma in the workplace.

I asked questions about participants' migraines, their employment situation, the effects of their migraines on their employment (past or present), the effect of the workplace on their migraines, whether or not they have disclosed their condition to their employers, the factors that contributed to their decision whether or not to disclose, reactions to disclosure, any special accommodations that they requested, the reactions to that request, and their perceptions of workplace identity and stigma.

In the process of studying various aspects of migraines as they relate to the workplace, this project placed this topic within a range of different theoretical and methodological approaches to the study of hidden disability, chronic illness and medical sociology. The sociological study of migraine must be understood within this context.

I explored various issues and topics in this research, including: how migraines affect the individual in the workplace, disclosure management, stigma, how a chronic condition such as migraine affects one's workplace identity, and related issues surrounding workplace accommodations, and the definition of disability.

Migraines are often not viewed as the legitimate neurological disorder that they are. Migraines, while typically not a visible condition, are an intermittently disabling illness. People who experience migraines in the workplace may be stigmatized if they take time off from work or if they request other accommodations, because of the invisible nature of migraines and lack of knowledge about the nature of the condition.

"Many patients with migraine have a positive family history of migraine in a first-degree relative. Migraine is known as a neurovascular disease, meaning that both the nervous system and vascular (blood vessel) system play a role. A number of external factors can trigger a migraine in some patients...." (National Headache Foundation, NHF Headlines, Winter 2011b, Number 177, p.13)

<u>Data on Disability and Employment:</u> The available data shows a discrepancy in employment statistics between people with and without disabilities in the United States. The percentage of the population that is employed is three times higher for people without disabilities than for people with disabilities. (Paralyzed Veterans of America, Paraplegia News, Dec. 2010, p. 37).   The unemployment rate for people with disabilities is twice as high for people with disabilities as for people without disabilities. (Solovieva, Dowler, & Walls, 2011, p. 39).   Almost three times as many people without disabilities reported that they are working, as compared to people with disabilities.   ("Call to Employers", *Careers and the Disabled* Magazine, Fall 2010, p. 11.)

<u>Data on Migraine:</u> "According to the American Migraine Foundation, 36 million Americans suffer from migraines…with women being affected three times more often than men…" (North Shore Long Island Jewish Health Network, Vitality, Spring 2011, p. 10).   The National Headache Foundation estimates that there are about 30 million people with migraines in the United States (National Headache Foundation, NHF Headlines, Summer 2010, p. 11). "Approximately 12% of the US population suffers from migraine,

and up to 18% of women between the ages of 16 and 40 have migraine." (National Headache Foundation, NHF Headlines, Winter 2011b, Number 177, p.13)

Lipton, Stewart, Diamond, Diamond, and Reed (2001) found that 51% of individuals with migraine reported that work productivity was reduced by at least 50%. One study found that migraines can cause people to lose an average of four to six days' work annually (Wilper, Woolhandler, Himmelstein, & Nardin, 2010). Given these figures, one could estimate the high economic impact of migraines and its effect on the economy.

Information about the Study:

I conducted qualitative interviews with **40** individuals who get migraines, working in different occupations across the United States, as an exploratory analysis. I used telephone and in-person interviews to study a non-representative sample of individuals, the majority of whom were recruited from the membership of the National Headache Foundation. Participants were self-selected and represented a range of occupational titles.

I explored the different accounts that participants offered to make sense of their experiences with migraines in their workplace situations, based on key measurement items and on a series of research questions.

My goal was to interview people in different types of occupations and workplace settings, to find out about the migraines they get, the type of work they do, how migraines affect work, how work affects migraines, and the ways that they dealt with it. I was interested in hearing about their experiences with migraines in the workplace, and the issues and challenges that they faced at work. I wanted to know about the effects of the workplace on their migraines, but looking at it from the other side, also about the effects of their migraines on work. What happened when they got a migraine while working?

This dissertation examined the self-reported experiences and perceptions of people with migraines in the workplace. By studying people's own accounts of their experiences in the workplace, this analysis revealed the subjective experience of illness. I used an exploratory approach to concentrate on the substantive and methodological understanding of the individuals' experiences.

Disclosure

The main topic that I was interested in researching was disclosure of migraine headaches in the workplace. Many factors are involved in the decision to disclose and how much to disclose. This dissertation examined what is behind the decision whether or not to disclose, the underlying factors that go into this decision, as well as the reactions to disclosure.

This dissertation analyzed how disclosure is structured or patterned, the paths workers took through this decision, and the perceived reactions of co-workers and supervisors to these individuals.

As a person with migraines, I've had both good and bad experiences in the workplace. Therefore, when I initially sought to develop a dissertation topic, I tried to locate sociological research about migraines in the workplace.

During my literature review, I discovered that there was extremely little scholarly research in this area. Although volumes of books and journal articles were available to explain various aspects of migraines, mostly from a medical, neurological, psychological, or economic standpoint, there was limited scholarly research in the highly significant area of *sociology that pertains to migraines in the workplace*. When s*ociological* literature on migraine was found, it pertained mostly to interpersonal issues, such as: spousal relations, or physician-patient relationship. Nothing on the sociology of migraine and employment (with the exception of economic burden/impact) appeared to be available. I knew that I had found a topic about which I could make a contribution to the literature.

Because this topic has not been researched before, this dissertation is a pilot study that uses interview data from study participants to examine how individuals with this condition have managed the issue of disclosing their disability in the workplace. The particular example of migraine headaches was chosen because of the relatively high incidence of this condition, lack of data about the experience of this population, the suspected high social and economic costs that are associated with this condition, and my personal interest in migraines.

There is limited research on self-disclosure of hidden disability in the workplace. Munir, Leka, and Griffiths (2005) describe the ‘self-disclosure in the workplace’ situation as follows: Since hidden conditions are not perceptible to others, receiving appropriate support from managers and colleagues requires their knowledge and understanding of an employee’s illness. Unless employees choose to inform others at work as to the nature of their illness, such support might be lacking. However, the choice to disclose a hidden illness is complex, and influenced by many factors such as stigma, type and severity of illness, and access to support. There are perceived risks to the employee in disclosing a hidden illness. These include potential rejection, discrimination, loss of social support, stigma, and loss of employment. Disclosure, however, may also confer benefits. The benefits to disclosure may include access to practical support (changes in work arrangements such as reduced hours, decreased pace, reduced workload, or adjustments to the physical work environment) and social support (increasing the understanding of supervisors and colleagues about effects of the illness), social integration, ensuring that the illness does not affect performance (providing explanation for frequent workplace absences), and re-affirming professional identity.

Individuals with hidden disabilities frequently do not disclose their disability for fear of subsequent negative attitudes and behaviors towards them. A major reason reported for reluctance in terms of disclosing/disclosure to employers has been fear of discrimination (Friehe, Aune, & Leuenberger, 1996; Silver, Strehorn, & Bourke, 1997). However, "Choosing not to release the information…is not without cost. Most important, no reasonable accommodations requests can be made. Employers have no obligation to provide reasonable accommodations for conditions of which they have no knowledge." (O'Brien, 2004, p. 113)

Qualitative Research

I studied the experiences of people who get migraines by using qualitative methods for data collection and analysis. I was interested in ascertaining what having a migraine in the social situation of the workplace meant to them and then to provide a sociological frame to interpret their accounts. "Qualitative researchers are concerned with how people think and act in their everyday lives." (Taylor & Bogdan, 1998, p. 8) I used qualitative inquiry and a semi-structured, open-ended interview process, seeking the personal stories and experiences of the individuals who participated in this study, through a series of focused questions. Phenomenologists strive for what Max Weber (1968) called *verstehen*, understanding the motives and beliefs behind people's actions. "Qualitative researchers are concerned with the meanings people attach to things in their lives. Central to the phenomenological perspective and hence qualitative research is understanding people from their own frames of reference…." (Taylor & Bogdan, 1998, p. 7)

Qualitative research tries to understand social processes in context. In addition, qualitative researchers pay attention to the subjective nature of human life and try to understand the meaning of social events for those who are involved in them (Esterberg, 2002, p. 2). My analysis illustrates how people with migraines attach/assign meaning to their migraine experiences and interactions in the context of the workplace. I chose this method because I believed it to be the most appropriate for this type of study.

Social Construction

There are many social constructionist approaches, but they share the idea that all social reality is constructed (created) by social actors (Esterberg, 2002, p. 15). These approaches also focus on interaction: how people act toward each other, and what meanings they attach to these interactions.

"Social constructionism is a conceptual framework …The emphasis is on how meanings of phenomena are not necessarily inherent in the phenomena themselves but develop through interaction in a social context." (Conrad & Barker, 2010, p. S67)

A constructionist approach *to illness* takes the subjective experience of illness seriously, examining the personal and social meanings of illness, and exploring how illness is managed in the social context. (Conrad & Barker, 2010, p. S73) In other words, social constructionists examine how the meaning and experience of illness is shaped by social systems and experienced within the context of daily social interaction.

The sociological perspective on health and illness stresses the interactions of mind, body, and society, and the importance of subjective experience in understanding health and illness (Freund & McGuire, 1999). According to this perspective, illness is a *socially constructed* phenomenon.

Chronic illnesses and episodic disabilities result in a different experience than acute illnesses, just as people with visible disabilities have different experiences than those of individuals with invisible disabilities.

Individuals who have the same condition, can still experience it very differently. Differences in perceptions of health problems often originate from race, class, sex, and ethnic and national differences, as found in Zola’s research (1973) on patient help-seeking behavior in three clinics. In addition, for people with stigmatizing illnesses, some of the illness experience is concerned with avoiding public awareness.

Examining migraines through a social construction approach allows for a deeper understanding of migraines in the context of social forces.

Since I utilized a *social constructionist* approach, I assumed that the processes and decision making that an employee uses to make the decision to disclose or not to disclose would likely be complex and somewhat varied from case to case. I assumed, from the outset, that there would be no straightforward answer for the individuals in this study and what would be interesting is the question of what factors went into their decisions about disclosure. I sought to describe the workplace experiences, for those who did disclose, and discover what happened with those who did not disclose.

To summarize, I chose a qualitative, social constructionist approach and believed the method of open-ended interviewing to be most appropriate for this study, because it is designed to encourage people to talk about what is important to them, and because of its ability to provide rich, clear descriptions of participant's responses. Through the examination of everyday human interaction in specific workplace contexts, I sought to answer my research questions (see Chapter 4, Methodology) in a way that revealed the meanings that participants attributed to their own actions (Becker, 1963; Blumer, 1969). I used theories of social construction to examine how disclosure (and related concepts) is incorporated into the workplace order, and to engage with sociological concerns and fields such as medical sociology, workplace studies (including occupational sociology), and disability studies.

Stigma and Identity

The self-perceptions of individuals with disabilities can be greatly influenced by the attitudes and expectations of others. According to Mead (1934), the self arises through the process of interaction with others as the individual becomes an object to himself and takes the attitude of others toward himself. In Goffman's (1963b) classic work on sociology, *Stigma: notes on the management of spoiled identity,* he refers to "spoiled identity," a state of being discredited or stigmatized. The way stigma is experienced can depend partly on the nature of the stigmatizing condition, the specific situation, the social circumstances of the individual, and whether the condition is visible or invisible. Illnesses can be stigmatizing because they represent potential or current physical limitations; they are associated with negative images and myths, and therefore they can take on symbolic meaning (Sontag, 1978). The specific nature of stigma associated with a serious illness may be dependent on whether the individual can be blamed or held responsible for its occurrence, whether the illness has potentially serious consequences for others, whether there are outward manifestations of the illness, and/or whether it results in a decreased level of competence (Conrad, 1986).

This dissertation also explored the relevance/impact of stigma on the lived experiences of people with migraine. Goffman's (1963b) concept of stigma has been very influential within the disability and medical sociology literature.

One strategy that individuals use to avoid the potential stigma of a disability, called "passing," is described as concealing a discrediting social status or stigmatizing attribute (Goffman, 1963b). I examined 'passing' strategies used by individuals who did not disclose.

I also explored what the individuals discovered about themselves through their migraine experiences. How did their lived experiences influence their self-perception of workplace identity? By researching this topic, I was able to examine the relationship between migraines and self-perception of workplace identity.

Because this dissertation focuses on migraines *in the workplace,* the individual's social identity and perceived self-identity are of special importance.

Americans with Disabilities Act

The (workplace discrimination) employment provisions of the Americans with Disabilities Act (ADA), which became law in 1990, were considered revolutionary for several reasons. One is the way disability is defined: "…The law defines a physical or mental impairment by virtue of what a person cannot do rather than in terms of a specific medical condition or disease." (O'Brien, 2005, p. 1). In addition, the ADA focuses on each person as an individual, not as a member of a particular group: "…To be covered under the ADA, one must have a substantial impairment that rises to the level of a disability…. The identity of a person is fluid and individual rather than static and part of a group." (O'Brien, 2005, p. 4).

Another is that the ADA mandates reasonable accommodations, which is an obligation that the employer must adjust the workplace in certain circumstances and under certain conditions, in order to make it meet the needs of an individual employee who meets the criteria for a disability as defined by the ADA. "By providing workplace accommodations, the ADA's employment provisions make employers take into account the ongoing needs of their workers with traditional and nontraditional disabilities alike." (O'Brien, 2005, p. 1).

The ADA focuses on individualized needs: "… this statute insists on matching a person's condition with his or her accommodations…the law does not use classifications or categories like other civil rights legislation does. Instead, the ADA's employment provisions are based on an 'individualized assessment' of each person's situation." (O'Brien, 2005, p. 21).

Therefore, in this study, I also examined the topic of workplace accommodations in order to learn about how people with migraines used accommodations at the workplace to enable them to cope with migraines in various facets of their employment, e.g., attendance, performance.

Conrad and Barker view the ADA from a social construction framework by stating that the ADA "…affirms the essence of social constructionist claims –namely, an individual's impairment need not be disabling when society makes reasonable accommodations, such as ramps to allow wheelchair access into buildings…" (2010, p. S71)

However, there have been restrictions to the actual application of the ADA as a result of court decisions (as I described in Chapter 3, Definitions of Disability), although recent revisions to this law should help to remedy this situation (see section on Recent Developments, later in this Chapter.)

Demographic Data of Study Participants: sex, race/ethnicity, age, employment, education

I collected demographic information on sex, race/ethnicity, age, employment status, and highest level of education completed (see Table 3, Demographic Information about Participants, in Chapter 4).

The participants in this study reflected a wide range of ages: from age 27 to 75. 15 members (37.5 percent) of my sample are over age 55.

Highest level of education also varied, from high school level to doctoral level[9], with 75 percent having received either a bachelor’s degree or higher. No one reported having less than a high school education.

Most participants were currently working (75 percent); the others were either retired, on disability, or on some type of leave of absence from work.

My sample is not equally distributed by sex: of the participants, there were 6 men (15 percent) and 34 women (85 percent). However, migraine is predominantly a female illness: estimates of migraine prevalence are about 15-18% of women and 6% of men (International Headache Society, 2001), and the fact that the participants in this study were mostly women reflect this. The American Migraine Foundation (as cited in North Shore Long Island Jewish Health Network, Vitality, Spring 2011, p. 10), states that women are affected by migraine roughly three times more often than men. Lipton, Stewart, Diamond, Diamond, and Reed (2001) found the prevalence of migraine was 18.2% among females and 6.5% among males. In my study, participants’ sex is skewed towards females, but in relation to migraine as a whole it is somewhat representative, since more women than men report having migraine.

The participants in this study were predominantly white. However, as mentioned earlier, I wasn’t trying to get a representative sample of all racial groups. It was more important for me to get a sample of different occupations regardless of race. One suggestion for future study (see section on future study, later in this Chapter) would be to get a larger representation from different races, since my sample is not an accurate reflection of the racial/ethnic composition of the United States. In my study, 36 people

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[9] One person declined to answer this question.

were white (90 percent), 2 were black (5 percent), 2 were Hispanic/Latino (5 percent), and there were no Asian/Pacific Islander, or American Indian/Native Alaskan (see Table 3, Demographic Information about Participants, in Chapter 4).

Participants represented a range of occupational titles, since I wanted to hear perspectives from people working in different titles. See Table 2 in Chapter 4 for the complete list of Occupational Titles as reported by participants.

At the time of interview, participants reported residing in 13 different states[10] (See Table 4, State of Residence, in Chapter 4). I selected New York for the in-person interviews primarily because of my ability to access this population in person. Therefore, the sample has a high percentage of people who live in the Northeast portion of the United States. There are 20 individuals from New York (50 percent); and a total of 25 people altogether (62.5 percent) from the Northeast. The remaining individuals lived in other states. Although the following information was not included in the data analysis, some participants had lived in other countries or non-U.S. regions at various times in their lives, including England, the Caribbean, France, the Czech Republic, Moscow, Kiev, and Prague.

I collected this basic demographic information in order to explore whether the responses differed for the individuals in this study. I chose these categories because I believed that they were the ones that would have the biggest impact on the circumstances of the migraine in the workplace experience. Collecting additional categories of demographic information would have been difficult to manage and unnecessary for this

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[10] I recorded primary residence at time of interview, since several interviewees had more than one current residence and/or had lived in different states.

particular study, but may be interesting possibilities for future study. My chief concern in this study was exploring diverse occupations and workplaces.

In terms of inclusion and exclusion criteria, there were four *basic* criteria: participants had to be 18 years or older, able to speak English, live in the United States, and be employed for money outside the home – either past or present. Inclusion criteria for this study also obviously required that participants self-identify as individuals who had been diagnosed with migraines by a physician.

2. Findings/Conclusions

As described in the previous section, I used a social constructionist approach and a medical sociology background, to study migraines in the workplace from the individual's perspective, in order to explore many different topics. I summarize the findings of the research in this section. Chapters 5 and 6, the two data chapters, contain the *full* description of the data, along with excerpts from the interviews.

Findings: Effects of the Workplace on the Individual

Different types of workplace environments can have specific effects on the individual who works in that environment. I asked participants in this study to describe the effect of their workplace on their migraines (how their job affects their migraines). The majority of individuals in this study cited stressful or hectic work environments, or other factors in the workplace environment, as contributing to migraines. Several participants provided examples of stressful work environments and described how that contributed to getting a migraine and/or making it worse. Many individuals discussed the integrated relationship of stress and migraines and their jobs, and some even reported changing jobs in order to reduce stress levels and therefore reduce the frequency and/or severity of their migraines.

Findings: Triggers

In general, specific triggers for migraine vary for each individual. I asked each participant in this study to tell me about their overall migraine triggers. Many people have triggers that are not related to work, such as certain foods or drinks, weather patterns, sleep patterns, and for women, their menstrual cycles. Although the majority of people in this study knew what their triggers were, five people did not know what their triggers were.

Next, I also asked each person specifically if there were any particular triggers for migraine that were related to his/her workplace (past or present). Six individuals did not have triggers related to the workplace; however, the majority of people who participated in this study (72.5 percent) did report having work-related triggers. Table 6 (Work-Related Triggers) in Chapter 5 summarizes the responses of the 40 participants in this study regarding their work-related triggers. The four most common work-related triggers in this study were: stress/workplace pressure, followed by workplace lighting, computer-related triggers, then workplace odors. Chapter 5 contains examples of individual’s experiences with workplace triggers.

Effects of Migraines on the Work Situation; Lack of Understanding in the Workplace

I asked participants to describe the effect of their migraines on their work situations and to tell me about their experiences. People in different occupations are faced with different challenges, and I heard about many workplace challenges that individuals encountered.

There were many individuals in this study who *did* report having understanding and supportive workplaces. However, many of the individuals who encountered a *lack of understanding* in the workplace believed that part of the problem was that people in general don't understand because they think a migraine is like a regular headache.

Most Common Theme

Overwhelmingly, the theme that I heard most often, regardless of occupation, and regardless of the specific topic being discussed, was the lack of understanding in the workplace regarding what migraines really are and how migraines are different from a 'regular headache'. A related theme was that of people at work (both colleagues and supervisors) not taking migraines seriously. I discuss this in both Chapters 5 and 6, and I provide numerous examples from the interviews. As I state in Chapters 5 and 6, some of the mixed reactions and/or negative reactions to workplace migraines most likely originate from not being believed or from lack of knowledge. People who are not familiar with migraines may think that the individual is exaggerating (i.e., perceptions that 'migraine is just a headache'.)

These types of situations are supported to some extent by Conrad and Barker's statement: "In the case of contested illnesses, the fact that sufferers' symptoms are not readily associated with a discernable biomedical abnormality often makes it difficult for them to have their symptoms acknowledged… and often raises suspicions that their problems are 'all in their heads'." (2010, p. S70) Although migraines would not be considered a contested illness by Conrad's definition[11], there are similarities in the workplace experiences of the participants of this study and those with contested conditions.

Bad Experiences

I heard about many "bad experiences." Some of these bad experiences served to illustrate how really serious a problem migraines are. Almost everyone in this study had at least one story (either personal or professional) that they vividly remembered right away, even if it happened a long time ago. Some of them were important, one-of-a-kind events that individuals had to miss or things that had happened that truly upset them. In Chapter 5, I provide numerous examples of these. Here are three examples of *personal* experiences: Candrine's two year old twins were moved out of her home because she could not take care of them, Jen attended her friend's wedding as a bridesmaid but was not really able to participate, and Julia did not remember anything about her son's college graduation, all because of migraine pain or effects. The *work-related* experiences included: uncontrolled vomiting (Engrid during the bar exam, Vita having to run out of the room during the middle of an interview), Ted having to leave a meeting due to a migraine and walking straight into a pillar because of the pain, Lainy's co-worker having to drive her home and carry her up to her apartment, Adrienne experiencing a one-month-long migraine after three months of non-stop business travel across time zones, and many others.

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[11] Migraines would not be a 'contested' illness, using the definition provided by Conrad and Barker (2010, S70). They define contested illnesses as "…illnesses where sufferers claim to have a specific disease that many physicians do not recognize or acknowledge as distinctly medical." They provide the following as some examples: chronic fatigue syndrome, fibromyalgia syndrome, irritable bowel syndrome, and multiple chemical sensitivity. These "…are medically suspect because they are not associated with any known physical abnormality." (Conrad & Barker, 2010, S70.) However, I am repeating his quote in the section above because of the parallel with the way many *employers and work colleagues* may feel about migraines.

What a Migraine Feels Like / Migraine Pain

"Migraine headache is traditionally described as a violent throbbing pain in one temple..." (Sacks, 1999, p. 14). Everybody experiences a migraine differently, so I asked each person to describe, in their own words, what it feels like when they get a migraine. I knew from background reading that 1) symptoms, duration, sequence, and intensity of migraine can vary from person to person, and 2) in a qualitative study, each person would describe the experience in their own way. Some individuals in this study said that the pain from migraine is the worst pain they had ever experienced. Participants' descriptions of what their migraines felt like were very graphic, for the most part; I provide many examples and participants' descriptions in Chapter 5. One example: To illustrate how painful his migraines are, Russel told me about an incident when he had a migraine, and he was taken by ambulance to the hospital. He was given the very powerful painkiller Morphine, but it didn't help his migraine at all. Although each person described migraines differently, some words or phrases appeared repeatedly. I heard about excruciating pain, auras, nausea and vomiting, sensitivity to light and sound. These descriptions again underscore the fact that migraines are not 'just a headache.'

Findings: Consequences on Employment

In terms of the specific effects of migraines at work, I examined the consequences, focusing on the areas of attendance, productivity, and work performance. I asked participants if migraines caused them to be absent from work, or if migraines had an impact on work performance or productivity, or any other consequences, and what their concerns were.

People with migraines often fear that they may lose their jobs because of taking too much sick leave, or feel that they miss opportunities for promotion due to absence and reduced productivity (Clarke, MacMillan, & Sondhi, 1996).

Individuals in this study did report some consequences *other than* attendance or work performance, including: depression, overcompensation, avoiding contact with other people, staying up all night to finish a project (squeezing it into a smaller timeframe), preparing work ahead of time, being over-prepared, and personality changes.

Personality and mood changes during migraines are an example of "…profound affective changes may occur during, and only during, a migraine attack, changes which are particularly startling in patients of normally equable temperament." (Sacks, 1999, p. 26). An example of personality and mood changes during migraines was described by Leo, a former senior vice president, who discussed how he ordinarily enjoyed going to work and interacting with employees and customers, but when he had a migraine, he was miserable, tried to avoid people and meetings, and preferred to work alone.

Findings: Effects on Attendance

For some people in this study, their attendance was not affected; they took little or no time off from work due to migraines. They coped with migraines by basically dealing with it if they were at work, tried to make the best of it, not functioning at full power, but just getting through the day, usually by taking medication.

About 25% of the participants in this study said that their migraines *did not* affect their attendance. Reasons *why* attendance was not affected by migraines varied, for example: the sign language interpreter who knew other people were depending on her and had a lot riding on her being there, people who reported having Type A personalities, fear of migraines not being accepted in the workplace, feelings of guilt and responsibility. Many feared that if they took time off from work, they would not be seen as reliable and they would “look bad”, something they did not want to do.

People with private offices had an advantage in terms of attendance, because they were able to lower the lighting, put heads down on desks, etc., for a while rather than leave work when they got a migraine. People who work in public areas do not have that opportunity. Also, the teachers had somewhat of an advantage in terms of their autonomy and flexibility to change plans when they got a migraine.

About 75% of the participants in this study *did have concerns* about their attendance/absenteeism being a problem. Business owners were still concerned about migraine-related absences, but they explained that it is somewhat less of a concern, because they operate their own businesses.

Findings: Effects on Performance/Productivity

I looked for patterns and themes in what people said about how migraines affected their productivity or work performance.

For those people who stated that their work performance or productivity was affected by migraines, I heard comments about taking longer to get the work done, needing to take breaks, having difficulty with challenging work or details, or having trouble concentrating/focusing.

There are differences among certain occupations. In some occupations or job situations, the work can stop and wait for the person with the migraine to come back to work. In other jobs, someone else can fill in and do the work for that employee when he/she is out sick or cannot work. However, the third possibility is that in some occupations or job situations, only that single person (the one who has the migraine) can do that particular work and it is time-sensitive and obviously does not go away. Examples of the latter, in this study, included: the chief financial officer, the school psychologist, and the legal secretary in the one-secretary office.

Several people also talked about making sure not to miss any deadlines in order to not let migraines affect their work. Some told me that they were so concerned about the impact that migraines could have on work performance, that they worked extra hours to make up for lost work.

Some individuals described cognitive impairments. For example, Morgan described how she cannot do work that takes “thinking” when she has a migraine or is about to get one. Luckily, she has the type of job where she has control over how her workday is organized; in other types of occupations, the individual can’t choose to do different types of tasks when they are not feeling well. Lacey, an ophthalmic technician for the past 22 years, described the cognitive difficulty that she has in ‘working up’ patients when she has a migraine: problems with concentration, forgetfulness. Sacks called these “Alterations of highest integrative function” (1999, p. 72).

Leo, a business executive, would usually try to ‘work through’ migraines, rather than calling in sick or going home if he got a migraine while at work. However, it did affect his performance in a way that is specific to executives or those whose responsibilities include leadership and creativity. As Leo described it: “…Part of my value to an organization was …being creative, it was coming up with ideas, leadership, things that you just don't do very well if you're under a migraine."

Others also described how difficult it was to perform their jobs when they had a migraine in connection with their specific job, for example, the travel agent, the special events person, the individual who did fundraising and public relations, the chief financial officer, all described the impact that migraines had on work performance. Examples include dealing with numbers, dealing with other clients, feeling incompetent to do the job, being irritable. I also heard about side effects from strong migraine medications (hangover feeling, heavily sedating).

Accommodations

As I explained in Chapters 2 and 3, employment provisions of the Americans with Disabilities Act (ADA) mandate reasonable accommodations: an obligation that employers must adjust the workplace in certain circumstances and under certain conditions, in order to make it meet the needs of an individual employee who meets the criteria for a disability as defined by the ADA.

Although not a central focus of this research study, I wanted to find out about workplace accommodations and work adjustments. I asked participants in this study if they felt that they needed accommodations or adjustments in their workplace in order to perform their work, due to their migraine condition. If they answered yes to this question, I asked them what type of accommodation(s) they felt they needed, did they request them, and if no, then why not. If they did ask for accommodation(s), I asked how was the request for accommodation(s) received (i.e., what was the employer's reaction to the request) and was the requested accommodation(s) granted? I also asked if they had made any adjustments other than formal workplace accommodations. There were a wide variety of responses to each of these questions.

Accommodations is closely related to the central topic of this study, ‘disclosure’, because, as I discuss in Chapters 5 and 6, several individuals disclosed their migraines because they needed some type of accommodation in the workplace in order to perform their jobs or remain employed. Others did not necessarily request a formal accommodation, but set up something on their own in order to manage working with migraines.

In this study, my interest in accommodations was to learn more about people with migraines’ experiences with them at the workplace. I also wanted to uncover the different types of workplace accommodations that employees with migraines used. Accommodations are individualized solutions that allow people with disabilities to obtain and keep employment. They include both material items – products, like a special desk or a ramp, but can also be modified work conditions like a flexible schedule.

As O’Brien explains, “Work conditions are created for each individual on a case-by-case basis. For instance, flextime could help someone with diabetes who took medication that prevented him or her from arriving at work early in the morning.” (2005, p.141)

Accommodations – General Findings

Individuals in this study used a wide range of workplace accommodations. In general, accommodations did not vary by job, with the exception of certain accommodations that were specific to a particular occupation, e.g., cancelling a class (for teachers). Ten people (25 percent) reported that they did not request any special accommodations. More than half of the people in this study named more than one accommodation.

Responses to Request for Accommodations

There were a range of responses to the request for accommodations, from positive, to mixed reactions, to negative. On the *positive* end were the supportive work situations, in which the employers were willing to work with the employees and their needs, and the requests were granted. In this study, the majority of participants reported positive responses *in terms of requests for accommodations.*

Findings: Type of Accommodation

Table 7 (Workplace Accommodations) in Chapter 5 summarizes the responses of the 40 participants regarding the type of workplace accommodations for migraines. Note that the numbers add up to more than 40 because over half of the participants named more than one accommodation. The table includes both accommodations *requested* as well as accommodations that were *used* without actually having to make formal requests for them (e.g., if self-employed, if had high level of autonomy, or if they are things the individual was able to do on one's own: "I never specifically asked for them, I just set them up myself.") As shown in Table 7, there were a variety of accommodation types.

Accommodations – those who did not request and why

Of the ten people in this study who stated that they did *not* request any accommodations, I asked them why they did not. Some of the people who did *not* request accommodations told me that they did not request them because what they needed would not be possible in their workplace setting. An example of this is Naomi, who works in a hospital operating room, and said: "… what helps with my migraines is quiet and peace and darkness, no bright lights, no sounds, no noise, and that's not something you can do obviously in a hospital setting…so that's not something…that I can really request."

Some others did not ask for accommodations because they perceived that there would be a negative reaction if they asked for anything. An example of this is Ted, who did not ask for accommodations when he was at an Executive level in the corporate environment, because he perceived an extreme reaction if he had asked for any accommodations; he thought that he wouldn't have gotten the jobs or he would have gotten fired.

Findings: Accommodations –most common type

As shown in Table 7 (Workplace Accommodations) in Chapter 5, the most frequently-mentioned accommodation for individuals in this study was a flexible schedule (time flexibility in conjunction with a migraine), with 19 people naming that accommodation. This was defined as the ability to arrive to work late, leave work early, and/or not come to work at all, *when a migraine occurs*. This type of accommodation is effective for a variety of disabilities or medical conditions, not just migraines. In fact, a flexible schedule was cited in a recent study as a type of accommodation that works for multiple types of impairments (Solovieva, Dowler, & Walls, 2011, p. 40).

Findings: Accommodation – other Types

Workplace lighting was the second-most frequently cited accommodation in this study, with seven people reporting changing workplace lighting (in general) and 11 people wanting to keep lights lowered or turn them off, or shut the blinds, making the room dark when a migraine occurs. This totaled 18 people naming accommodations related to workplace lighting, whether it was different types of lighting (i.e. not fluorescent), different intensity levels, or absence of lights. Some people wanted brighter, more intense lights, whereas some people wanted lower, less intense lights.

Four individuals cited adjustments to work schedule (in general, not just when a migraine occurs.) For example, Karen adjusted her college teaching schedule around anticipated migraines, so that she could teach in the afternoon.

Some individuals who owned their own business spoke of the ease of making accommodations because they were their own boss. One example was Kellie, whose husband changed the ballasts in the fluorescent lights in the building, and she was also able to replace the computers in her office. Another example with business owners was for those requiring flexible schedules, because they could take a day off or come in late if needed, since ‘it was my schedule’ or they had more autonomy over the work. For example: As a business owner and crane operator, Russel had the ability to shut down jobs when he had a migraine, until he felt better.

Six people spoke of an accommodation related to the presence of a designated location (such as a nurse’s office or sick room) and the ability to go there to lie down during a migraine, and another six stated an ability relating to putting their head down on their desk or against a wall. This was helpful because then they could be in the dark, possibly wait for medication to take effect and/or migraine to go away, and then go back to work. This totaled 12 individuals.

Computers were a problem for many people. For most of them, it was the actual computer monitors that were a trigger because of the flickering. In one situation, when everyone’s computers were changed as a result of one person’s accommodation needs, this is an example of how accommodations can help not only the one employee who requests it, but can also impact the entire group of colleagues. O’Brien talks about how the accommodations model is unique because: “… nothing prevents the accommodations devised from helping the entire workforce.” (O’Brien, 2005, p. 22)

Findings: Accommodations – Denied

Five requests for accommodations were denied. With these individuals, I asked a follow-up question to find out if they were provided with a reason why the decision to accommodate was denied. Three were denied outright (stop using the substance that caused an odor that triggered migraine; a laptop to do work at home; adjustment to work schedule/leave work early for medical appointments) and 2 were sometimes denied (ability to work from home sometimes when a migraine occurs; adjustment to work schedule/leave work early for medical appointments). Reasons for denial ranged from a flat-out ‘can’t do it’, to budgetary considerations, to staffing situations (short-staffed).

According to O’Brien, “employers often play the cost card – maintaining that their firm or company cannot afford an accommodation…” (2005, p. 140). O’Brien provides another possible reason why supervisors might want to deny accommodations: “Providing reasonable accommodations for disabled people undermines the authority of a supervisor…” (2005, p. 30)

As I indicate in Chapter 3, Definitions of Disability, disability is a complex concept, partly because of various definitions of disability and the multiple levels of impairment and functional limitations. When one also considers all the different types of invisible/hidden disabilities and episodic conditions that exist, a condition such as migraines in which people with migraines don’t “look” disabled and aren’t always sick, and as a result, some employers may not take requests for accommodations seriously.

Long Term Career Impact

During the natural course of the interviews, I heard stories from individuals about how they became so disabled by migraines that they could no longer work at the same type of job; those who had to resign or were fired because they could not continue to work or complete job responsibilities; and those whose symptoms interfered with their career plans.

In Chapter 5, I included interview excerpts that illustrated dramatic stories of *long-term career impact*. I provided many examples of individuals whose careers were impacted by migraines, or who made life-changing decisions, or who had other long-term opportunities that were affected by migraines.

These stories are of individuals who decided to open their own businesses, take leaves of absence or early retirements, or had to change entire industries or career paths, just to get the kind of control over their lives that they needed, because of their migraines. I heard many stories of missed opportunities and life changes because of migraines. I summarize some of these below, as reported by participants and described more fully in Chapter 5.

Adrienne described an encounter at work during a discussion about a raise, in which her migraines were used as a factor against her and interfered with her getting a raise.

Morgan, a 48-year old event planner who works in the hotel industry, and takes medication to prevent almost-daily migraines, described how migraines affected her career and her life. She believed that without migraines, she would be bigger and better than what she currently is.

Russel, a 42-year-old construction company owner and crane operator, described his migraines as “torture.”   Because he was unable to find a medication that works for him, he has paid up to $700 per week on medication and has had about 30 nerve block treatments at $800 per treatment. He told me about the impact of migraines on his life and his business by stating that he is not everything he could be; he described himself as being probably only one-third of what he should be if he didn’t have migraines.

Engrid, a 64-year-old attorney who has been working as an Administrative Law Judge for the past 12 years, made a career change due to migraines. In her current job, she works only 4 days a week, basically 9 to 5, and does not take any work home with her. However, she started out doing litigation, and found that she couldn’t continue in that career path, due to migraines.

Karen, a 39-year-old assistant professor, turned down an offer at her college, twice, to teach in the Intensive Russian language summer program, even though she wanted the job and it was prestigious. She declined because of the early start time and the intensive nature of the job, and her concern that she would not be able to do it, because of the migraines.

Leo, a 56-year-old former senior vice president, decided to take an extended leave of absence from his job at age 55, even though he enjoyed his work. He believes that he has potentially retired, depending on what happens with his headaches, and as a result, he will be unable to take advantage of what could have been very productive years as an executive. He stated: "…It has forced me to change my life's direction, pretty significantly."

Like Leo (above), Donna also had to leave work for a while, in her case for more than two years. A 52-year-old marketing director, she stated that she has probably tried 100 different medications but her migraines kept getting worse. Donna talked about the severe impact on her career: "… impacted…my entire life…I don't really have a career anymore." Donna, who at the time was on a "very fast track" in a magazine publishing career in New York, told me about how she was fired from that job due to migraines.

Londoner, a 63-year-old assistant to head of school, who has been getting migraines for over 50 years, told me that her headaches got ten times worse when she became pregnant. She said that she had a migraine every day in her second trimester of pregnancy, and could not take migraine medication. As a result: "… that was the reason I only had one child…" Although this story doesn't demonstrate career impact, it struck me as being such a life-altering decision that I decided to include it.

Ted talked about how switching from a high-pressure corporate executive career to a self-employed business owner, and then finally retirement, gave him more control over his life, and therefore helped with his migraines.

Fenno, a 68-year-old college professor, took early retirement, and like Ted (above), noticed a decrease in migraines after he left his job; they began to get less severe and less frequent. Fenno attributed the change in migraines to his retirement.

Kellie, a 54-year-old self-employed owner of design and remodel firm, switched from being a faculty researcher at a university to a part-time self-employed business owner 16 years ago. Migraines had a huge impact on her professional life when she was a faculty researcher, to the point where she had to leave that job.

Helen, a 43-year-old elementary school teacher who was experiencing daily migraines during the school year, has been teaching for 12 years. She told me that she plans to quit her job at the end of the year because her doctor is very unhappy about the amount of medication she is taking for migraines. She is upset about not going back to work, but she can't work without taking the medication.

Martha, also an elementary school teacher, age 75, was experiencing week-long migraines before they were brought under control with proper medications. She told me how she might have had a different career altogether if not for the migraines: She was accepted into law school, but then realized that she couldn't do that, due to the migraines.

Shilo (female), age 55, a former travel agent, has been unable to work for 3 years due to migraines, and is on disability. She gets migraines every day that don't go away and sometimes spends most of the day in bed.

JP (male), a 65-year-old psychologist who was losing a lot of sick time to migraines, and was taking a lot of medications for migraines including painkillers, discussed the impact of migraines on his career. He reduced his work schedule and finally retired a year earlier than he planned.

Donna, the 52-year-old marketing director discussed earlier in this section, summed up her situation as follows: "…I was very ambitious when I was a younger person… …I was going to accomplish something professionally, and I haven't. And it really is because of my headaches. …."

There were others who either lost their jobs or were in danger of losing their jobs, due to migraines.

As some of the above summaries indicate, migraines impacted not only people's careers, but also their daily lives, finances, outlooks, and interfered with goals and plans that individuals had set.

Disclosure vs. Non Disclosure

Since migraines are, for the most part, a hidden condition (not visible to others), in order for the employee to receive support from supervisors and/or co-workers, it requires that those people know about the employee's condition. However, if the employee chooses not to tell those at work about his/her migraines, the employee might not receive this support. Some employees choose their privacy over disclosure/receiving accommodations.

The decision whether or not to disclose a chronic illness is complex, and influenced by many factors such as stigma, type and severity of illness, and access to support (Munir, Leka, & Griffiths, 2005).

In Chapter 6, I report and discuss the data relating to workplace disclosure. I summarize the data here; discussed more fully in Chapter 6. I asked all of the individuals in this study if they had disclosed their migraine condition to someone at work at some point. There were a variety of different responses to this question, demonstrating the full range of the spectrum.

For some participants, disclosure wasn't even an issue because it never occurred to them *not to* disclose in the workplace. Benny and Allison are examples of this. When I asked them about disclosure, responses were: "It never dawned on me, not to." [Benny, retired audiologist, female, 61]; "... maybe it's because I've always had them all my life that it never occurred to me, to not disclose." [Allison, senior clinical trials associate, female, 35]

At the opposite end of the spectrum, were those individuals for whom it never occurred to them *to* disclose in the workplace: "… it never occurred to me to tell anybody… that I get migraines…" [Vita, adjunct teacher English, female, 71]

Findings: Disclosure vs. Non-Disclosure

The findings of disclosure vs. non-disclosure in this study are shown on Table 8, Disclosure vs. Non-Disclosure, in Chapter 6. Of the **40** participants in this study, I found the following regarding disclosure: **24** disclosed their migraine conditions at work, and **8** did not disclose. **3** disclosed in some situations but did not disclose in others; these individuals decided whether to disclose only after assessing each individual situation. I also encountered **5** individuals who described a process wherein their migraines became known, or that they were 'found out', rather than a conscious choice to disclose. I refer to this last group as being 'discovered' or 'discovery'.

Since not all migraines in the workplace are disclosed in the same way, this has an impact on the circumstances as well. While some people make a conscious decision to disclose, for others, there are events at work where the migraine becomes evident or causes absences (or other actions) that need to be explained. In those cases, the individuals did not necessarily want to disclose but were 'discovered.' Therefore, while the migraines are known in both cases, they did not become known in similar ways. However, a comparison of discovery and disclosure was beyond the scope of this study.

Decisions involved in Disclosure

For some individuals, their decision to disclose also involved deciding which people to tell. Goffman (1963b, p. 94) referred to the different layers of people within an organization, such as the employer, the personnel officer, and workmates, and he explained why an individual could make a decision to tell some people but not others, depending upon the location of those people within the organizational structure. Several people in this study stated that they would selectively tell only some people in the workplace. For example, Tori, a sign language interpreter, would *not* tell her employer (the person who contracted or paid for her services), but she felt it was critical to tell her interpreting partner since interpreters work as a team on each assignment.

Goffman describes: “A very widely employed strategy of the discreditable person is to handle his risks by dividing the world into a large group to whom he tells nothing, and a small group to whom he tells all…” (1963b, p. 95). However, Goffman also describes the stress from partial disclosure *in the workplace* as the risk of being discovered at any time. “… this could involve a certain amount of insecurity because it would not be known for sure who ‘knew’ and who didn’t, and how long-lasting would be the ignorance of those who didn’t know.” (1963b, p. 94).

A condition such as chronic migraines requires a strategy on the part of each individual for managing the various symptoms that accompany migraines. Depending on whether or not the condition was disclosed in the workplace, the symptoms and/or the treatments may need to be concealed from supervisors and/or co-workers. Medications or other treatments for the migraines sometimes have side effects that may affect the individual in the workplace, and this needs to be managed as well. As if this weren't complicated enough, for many people migraines often strike without warning, which makes them even more difficult to manage in the workplace.

Findings: Disclosure – Factors

I asked each individual what the factors were that went into his/her decision to disclose or not disclose. I found that there were a range of different factors that went into the decision to disclose or not to disclose, to whom to disclose, and even how much to disclose.

I sought to examine the factors that each individual took into consideration in order to make what I refer to as the '*disclosure decision*'. For most (but not all) participants, it was *not* a straightforward decision. I found that the factors included: desire for access to support, need for accommodation(s), frequency and severity of the migraines, fear of potential discrimination, and gender bias.

Findings: Those who Disclosed – Factors

For those individuals who *disclosed* their migraines, I asked about factors that went into the decision *to disclose*. Some participants took many factors into consideration, weighing risks vs. benefits, before deciding to disclose the existence of a migraine condition; for others it was more of a 'natural' decision. Examples of the latter would be Allison and Benny, quoted in the previous section, to whom it never occurred *not to* disclose. As I mentioned in the previous section, there are also those whose migraines were disclosed, not necessarily by choice, but as a result of 'discovery'.

Factors leading to the decision *to disclose* included: need for accommodation(s), legitimizing the illness (attempting to explain reasons for absence and ensure that performance was not affected), and to explain to others about the condition.

Some people described the need to let their boss/supervisor or co-workers know that they get migraines in order to get the support or understanding that they needed. Individuals with migraines sometimes need help in handling work situations. Candrine talked about how she decided to disclose because she felt that hiding migraines would be more stressful than disclosing, and she didn't want to put any additional stress on herself.

Many individuals decided to disclose in order to provide a reason for either their migraine-related absences or the effects of their migraines. This was done either to preserve/maintain a good reputation (they didn't want to be viewed as lazy, unprofessional, or unreliable), or to protect their jobs, or out of consideration for their supervisors and co-workers. Several people stressed the importance of honesty in the workplace, with statements like "I'm open and honest" or "I've never lied…" or "Being up front is better." I was surprised by how many individuals emphatically referred to themselves as either "hard workers" or "Type A personalities" or "reliable workers", as if to convince me that the migraines themselves were not part of their work ethic.

As I suspected, many individuals disclosed their migraines because they needed some type of accommodation in the workplace in order to perform their jobs or remain employed without repercussions. Many people, when they have a migraine, experience physical problems, cognitive limitations, and/or have attendance issues that interfere with their employment, if accommodations are not provided.

Findings: Disclosure – Reactions/Responses

For those individuals who indicated that they ***did disclose***, I asked them about the responses and reactions to their disclosure. I found that the responses to individuals' disclosure varied widely in the workplaces. There were a range of responses, from positive, to mixed reactions, to negative. I asked about this because I expected that individuals would have different experiences with disclosure.

Some of the mixed reactions or negative reactions most likely originate from not being believed or from being misunderstood. Employers (like members of the general public) who were not familiar with migraine may be skeptical and think that the individual is exaggerating (i.e., the perception that 'migraine is just a headache'.)

On the *positive* end of the spectrum were the supportive work situations. These were characterized by words like 'supportive', 'compassionate,' 'sympathetic,' 'helpful', 'empathy,' and 'understanding.' The employers were willing to work with the employees and their needs. In addition, some of these individuals talked about 'being believed', as opposed to their perception of being thought to be faking/exaggerating, as a factor in understanding and compassionate workplaces. A couple of individuals stated that having a workplace where there was a culture of supporting taking off when one was sick, regardless of the reason, was helpful. For several of the participants in this study, they perceived that two additional factors contributed to positive reactions: the presence of a high number of women in the workplace, and the presence of those who were familiar with migraine. However, due to the methodology of this study, these factors cannot be generalized to the population at large. A full examination of the factors leading to positive and negative reactions was beyond the scope of this study. I sought to examine the reactions themselves rather than the factors leading to those reactions.

Toward the *middle* of the range, were those situations that I described as ‘mixed.’ These situations were characterized by understanding to a certain extent, or a covert understanding but a latent level of the individual perceiving that there were some feelings or comments showing a lack of understanding or suspicion about migraine.

Because some individuals with migraines may not exhibit outward signs during a migraine episode, this may arouse suspicion from supervisors and co-workers. Stone (1995) stated that some people have difficulty imagining that someone who looks able-bodied may have a disability, and as a result, may believe that their condition is not ‘real’. Many individuals in this study reported that co-workers and supervisors doubted the reality or severity of their migraines. They didn’t understand why “a headache” would make someone stay home from work, leave work early, or come in to work late.

At the *negative* end of the spectrum, were those situations of negative reactions and responses. These were characterized by a complete lack of understanding, negative comments, not being believed at all, and at even a more negative level, responding with anger, retaliations or punishments, at migraine-related cancellations, inconveniences, absences, or mistakes.

Findings: Non Disclosure – Factors

Another question I wanted to investigate was, what about the individuals who decided not to disclose all the time, or decided not to disclose in some workplace situations? For those individuals who responded that they decided not to disclose, I asked why not? I wanted to know what factors went into their decision not to disclose.

There are perceived risks to the employee in disclosing a chronic illness or hidden/invisible disability. These include potential rejection, discrimination, loss of social support, stigma, and loss of employment. (Munir, Leka, & Griffiths, 2005.) Many individuals in this study expressed fear of subsequent negative attitudes and behaviors.

Individuals may perceive that if they do not disclose, they have more job opportunities. However, if they do not disclose their condition, it means that they cannot receive the protections of the ADA (O'Brien, 2004, p. 96) such as workplace accommodations or protection against discrimination. Therefore, the individuals who choose not to disclose were either a) unaware of such protections, b) did not think it applied to them, c) work in a workplace that was not covered by ADA such as an employer with too few employees, or d) they were aware but have decided that it is best to hide their condition, thereby giving up any possible right to accommodations in order to avoid revealing their migraines.

Some individuals in this study were concerned that disclosing would label them negatively in some way. Unlike those with a visible physical disability, most people with migraines have a choice about disclosure because their migraines are not visible.

Goffman (1963b, p.3) makes the distinction between a discreditable and a discredited individual. With a discredited individual, it is assumed that the person's differentness is already known; whereas with a discreditable individual, it is assumed that the person's differentness is neither known about nor immediately perceivable (Goffman, 1963b, p. 3). Therefore, the discreditable individual has to make decisions about how much information to reveal. Goffman refers to this as 'managing information' and discusses this in a chapter on information control and personal identity:

> “However, when his differentness is not immediately apparent, and is not known beforehand … then…The issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where.” (Goffman, 1963b, p. 42)

As I found with the decision *to* disclose, the data for the decision *not to* disclose showed that there was a range of factors. When deciding not to disclose, most individuals (but not all) made their decision based on weighing of the risks vs. benefits.

At one end of the spectrum, were the individuals for whom it simply seemed natural *not to* disclose: One example is Vita, the adjunct teacher who I discussed earlier, for whom ‘it never occurred to me to tell anybody.’

However, the majority of people in this study who chose *not to* disclose, did so for reasons relating to stigma, although only one or two of them used that actual term[12] to answer that question, and their specific reasons may have differed. When reviewing their responses, I found that they were concerned about shame, disgrace, being seen as unworthy, and/or their workplace reputations/identities.

Goffman describes how reputations and images can change, not only in the present but also in the future, upon disclosure/revealing a stigma: “Discovery prejudices not only the current social situation, but established relationships as well; not only the current image others present have of him, but also the one they will have in the future; not only appearances, but also reputation.” (1963b, p. 65)

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[12] I asked the questions about disclosure during the interview chronologically before asking any questions about stigma so that I would not influence the responses.

Jen described a general feeling of embarrassment in front of her co-workers when she had to leave a work-related event early due to the effects of a migraine, yet she was more concerned about hiding her migraine and leading people to believe that she was sick with something else.

Karen and Donna both described concerns that disclosure about migraine could make them be viewed as unreliable and less effective, and they were worried about how a disclosure like that would impact their future at their jobs. Karen, an assistant college professor, was concerned about getting tenure and promotion, and Donna, who worked for a publishing company and oversaw a national staff, was concerned about being removed from the 'fast track.' For these individuals, their perception was that revealing their medical condition would have left them vulnerable to obstacles for job advancement. In some cases, discrimination was mentioned as an additional factor, aside from concerns about reputation. As Goffman stated, "We tend to impute a wide range of imperfections on the basis of the original one…" (1963b, p 5).

There were at least a couple of individuals who referred to their sex when discussing their non-disclosure about migraine. Vita, the 71-year-old female adjunct teacher talked about: "… how women used to be seen as hysterical…" and Ted, a 61-year old male, a former Executive Vice President, described how "…a migraine just wasn't an acceptable thing for a man to have…"

It is worth noting that both of the individuals quoted above are over 60 years of age, and were referring not only to their sex, but to an earlier time period as well. Similarly, Martha, who is 75 years old, discussed the difference in the way migraine etiology was understood in the past: "… today people have much more knowledge about it, but at that time [it was] people who were nervous…would get migraines, or it wasn't considered a real disease..."

Susanna's response to the question about why she chose not to disclose demonstrates that one person can take many factors into account before arriving at a decision *not to* disclose. Susanna talked about the nature of her profession, the appearance of weakness, the lack of understanding, and the perception of non-acceptance.

Finally, in addition to what the study participants actually *said* about the factors involved in their decision not to disclose, I reviewed the demographics of those who did not disclose. I found the following three interesting patterns: With only one exception, all of the people who *did not disclose* were aged 50 or older. In addition, a high percentage of males, relative to total number of males in the study, did not disclose. Finally, those who did not disclose tended to have a higher level of education. As a reminder, these findings apply only to this study and cannot be generalized.

Findings: Non Disclosure – Coping Mechanisms, Hiding Behaviors, Passing Strategies

Once I knew the factors that led an individual to not disclose his/her migraines in the workplace, a second related question is what happened with those who did not disclose?

I was interested in hearing about the coping mechanisms, hiding behaviors, and passing strategies that the people who did not disclose used, in order to assist them in their goal of keeping their migraines hidden. I found that there were a variety of strategies used. Some individuals who chose not to disclose took specific steps to 'pass' (Goffman, 1963b) in the workplace as a person without migraines. Goffman describes a strategy that he refers to as "passing" (1963b) that individuals may use to avoid a potential stigma; passing is concealing a discrediting social status or a stigmatizing attribute. As explained by Goffman, " Because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent." (Goffman, 1963b, p. 74)

Below, I summarize some of the strategies and behaviors used by the participants in this study to avoid disclosing their migraines.

Hillary, Susanna, and others described how they just kept working through the migraines, despite the pain and/or migraine-related effects. Many learned how to pace themselves or modify the way they worked when they had a migraine, without anyone noticing. For some people, like Engrid, an attorney and administrative law judge, and Donna, the publishing executive described earlier, who was concerned about being removed from the 'fast track', the flexibility provided by the characteristics of the type of jobs that they held in their careers was a big help in allowing them to keep their migraines hidden. Engrid stated that she "covered it well" because for most of her life, even though she always held jobs that involved a lot of public interaction, people who dealt with her in the workplace had no idea that she got migraines unless she told them.

While some individuals took passive steps such as working through migraines, modifying work, or using flexibility to cover, there were also those who took more active steps and told false stories when they had migraines. This range is illustrated by Goffman's statement regarding managing information: "….the extent of passing can vary, from momentary and unintended at one extreme to the classic kind of deliberate total passing." (1963b, p. 80).

Ted fell into the active, deliberate, total category. Ted was once told ‘Nobody who gets migraines is going to work for me!’, and as discussed previously, he also told me that he thought it was perceived that a migraine wasn’t an acceptable thing for a man to have. Before retiring from owning his own pet supply business, he was an executive vice president of marketing and sales. Ted described the elaborate steps that he took to cover his migraines. When he needed to call in sick with a migraine, he pretended to have something else: like the flu or a hangover. He perceived that it was more acceptable to tell his workplace that he couldn’t come to work because he had a hangover from drinking the night before, than to say that he had a migraine! Ted provided me with intricate details of his strategies for how he would handle a migraine while on a business trip. These strategies were acceptable in his mind, whereas disclosing that he had a migraine would not have been acceptable.

Many participants in this study who did not disclose worked constantly to hide their migraines. For some individuals, these strategies required creativity and proved to be very time-consuming.

However, despite the perceived advantages, ‘passing’ is not without its price: “The phenomenon of passing has always raised issues regarding the psychic state of the passer. First, it is assumed that he must necessarily pay a great psychological price, a very high level of anxiety, in living a life that can be collapsed at any moment.” (Goffman, 1963b, p. 87). In effect, individuals who do not disclose and who ‘pass’ are pretending to have a somewhat different identity.

Findings: Perceptions of Stigma

In Chapter 6, I reported and discussed the study data about stigma in the workplace. I asked whether individuals were concerned about stigma at the workplace or if stigma was a factor in their decision making about disclosure. I wanted to find out about the relevance of stigma and the impact of stigma on migraines in the workplace. I found that there was an almost equal division among the responses.

Table 9, Concerned about Stigma, in Chapter 6, presents the findings of the question about Stigma. Of the **40** participants in this study, I found the following: **21** responded that they *were* concerned about stigma, and **19** responded that they *were not*.

I reviewed the demographics of those who answered affirmatively about stigma and compared them against the demographics of those who answered negatively about stigma, to check for any differences between the two groups. I could not find any difference in terms of age, race, or educational status, between the two groups. The only difference that I found was in terms of sex: There were twice as many males in the "yes-stigma" group as there were in the "no-stigma" group. However, due to the low number of males in the overall sample, this result should be interpreted with caution. Again, these findings apply only to this study and cannot be generalized.

Stigma is a complex concept. The circumstances surrounding stigma can depend partly on the nature of the stigmatizing condition, the specific situation, factors relating to the individual, and whether the condition is visible or invisible.

In addition, according to Conrad (1986), the stigma associated with an illness may be dependent on whether the individual can be blamed or held responsible for its occurrence, whether the illness has potentially serious consequences for others, and/or whether it results in a decreased level of competence. All of these have important implications for the workplace.

“The lesson from a constructionist standpoint is that there is nothing inherent about a condition that makes it stigmatizing; rather it is the social response to the condition and some of its manifestations, or the type of individuals who suffer from it, that make a condition stigmatized.” (Conrad & Barker, 2010, p. S69)

As was the case with disclosure, responses about stigma demonstrated both ends of the spectrum. One on end of the range, there were those individuals who perceived no stigma with migraines at all and who gave no thought to stigma, and at the other end there were those who thought about stigma quite a lot.

Not surprisingly, there were many individuals who were concerned about stigma due other people’s lack of understanding about the condition because it was viewed as ‘just a headache’. As Hillary indicated, this lack of understanding was not present during contact with other people who also had migraines, or who knew someone with migraines, because those people presumably understood. Goffman described these people as ‘sympathetic others’ (1963b, p. 19-20).

As I indicated in the section on factors involved in non-disclosure, many individuals do not disclose because of fear of subsequent negative attitudes and behaviors towards them. For some, the reason for the stigma was the fact that migraines can’t be proven (credibility) or they believed that there is a perception that there is something ‘wrong’ with people who have migraines.

Engrid, the 64-year old attorney and law judge, gave her opinion as to where the stigma originates:

> "… I don't think it's the fact that you have a migraine that's the stigma. I think the stigma is that you are in some way incapacitated by something that everybody thinks is nothing and doesn't take seriously…and somebody looks and says but it's just a headache, it's nothing ….that's where the problem is. I think it's the disconnect…."

A common theme was concern of not being seen as reliable. Adrienne, the assistant to the president of an international sport association, was one of these individuals. In fact, she was pregnant at the time I interviewed her, and she talked about a constant struggle between needing to take care of herself when she got a migraine, but also still wanting be seen as reliable and competent. This concern was also shared by Donna (the publishing executive on the 'fast track') and Karen (the assistant professor up for tenure), who I discussed earlier regarding their reasons for non-disclosure. Lainy, a chief financial officer, said that she didn't want people looking at her "differently."

Ted, the 61-year-old former executive whom I discussed earlier regarding his active passing strategies, reported that he was concerned about stigma. He discussed it in the context of his sex and the time period:

> "… until I was working for myself, it was pretty much something you…weren't open about. And in some cases, had to really hide it…I didn't *have* migraines, because men didn't get migraines. Back in the late 1960's almost to 1980, that's why this study is interesting, you couldn't tell anybody you had migraines."

Like Ted, some of the male participants talked about migraines and stigma in terms of masculinity. This can be viewed as a gender issue because some men were reluctant to say that they got migraines because of concerns of stigma, since they believed that migraines were viewed as a 'woman's disorder' or a sign of weakness. It is worth noting that when Ted changed careers from being an executive in the corporate world, to owning his own pet supply business, he felt comfortable enough to disclose his migraines. Vita told me that "…one of my sons gets migraines, I think, but he won't admit that's what they are. He's a macho man."

From some of the older study participants, like Ted above, I heard about the difference in the way migraines were viewed in earlier time periods.[13] Aside from the quote from Ted (above), I provided other some examples in the section on Factors for Non Disclosure. Looking at this from a socio-historical perspective, it seems that the time period is also an important factor/variable that influenced the decision to disclose, perceptions of stigma and identity, as well as even the diagnosis of migraine.

Findings: Perceived Self-Identity

Although identity is not a central concept of this study, I did explore the transcripts in order to examine what themes and issues emerged regarding identity. Unlike with disclosure, stigma, and accommodations, I did not ask any questions specifically on the topic of identity, although the concept was explored through conversations on the many other topics that we discussed. Identity is an extremely complex topic and is closely intertwined with other concepts such as, but not limited to, culture, location, gender, social and political factors, historical time period, stigma, and guilt.

An individual's sense of self is connected to how others react to him/her. The self-perceptions of an individual can be influenced by the attitudes and expectations of others. Since this dissertation focused on migraines *in the workplace*, the individual's social identity and perceived self-identity were of special importance. Because I was

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[13] Similarities can also be drawn with the way some other invisible disabilities were viewed in earlier time periods. One example would be learning disabilities, when affected individuals were often stigmatized and accused of being lazy or dumb, and no accommodations were made in school or work.

primarily concerned with stigma and disclosure, the management of spoiled identity was also of importance.

It is often the case that the individuals participate in the creation of ‘spoiled identity’ through disclosure of the particular characteristic at issue, in this case, migraines. People with migraines, especially when they experience migraines in the workplace, are often stigmatized. I wanted to ascertain how the lived experiences of the individuals in this study (both the ones who disclosed and the ones who did not disclose) influenced their self-perception of workplace identity. By using content analysis, I was able to examine the relationship between migraines and self-perception of workplace identity and thereby the management of spoiled, hidden identity in the workplace.

In Chapter 6, I reported and discussed the data about perceived self-identity in the workplace, in terms of what themes and issues emerged. A condition like migraines can be very challenging to an individual’s identity, including workplace identity, due to the nature of migraines: unpredictable, episodic, chronic, and disabling. Many individuals in this study described struggling with reconciling their identity.

I identified seven themes relating to identity. Many of these themes overlap with one another so they are not seven separate, distinct themes. Several of them have already been discussed in relation to other topics. I describe them more fully in Chapter 6, but I summarized them below:

Migraines as Contested Illness or not Legitimate: Many participants spoke of their fear of a perception of migraines not being viewed in the workplace as a legitimate condition. I already discussed this in several sections earlier. Conrad and Barker describe a category of illnesses called “contested illnesses” in which “Physicians, the public, and sometimes even sufferers themselves question the authenticity of the symptoms and the mental stability of the sufferer." (2010, p. S70). Therefore, labeling is sought by some individuals as a way to legitimize their condition (Brown, 1995) while others avoided the potential for labeling because of its perceived connection to stigma and identity. Some individuals perceived that their migraines were viewed as medically suspect; they often felt as though they were expected to just 'overcome' their migraines and go to work, since migraines were not perceived as a 'legitimate condition'.

Making Sense of Illness, Illness Identity: This was categorized by individuals who tried to form a kinship with colleagues at work who either 'understood about migraines' (either from knowing someone with migraines or who actually got migraines themselves). Some individuals discussed the importance of finding an ally *in the workplace* who understood. (Refer to earlier comments about 'sympathetic others.') Conrad and Barker discuss how individuals with medical conditions can form an illness identity:

> "Chronic illness can prompt an evaluation of one's former life and identity, and in some cases, the creation of a new illness identity (e.g., cancer survivor)…medical sociologists have documented how laypeople sometimes create and join illness-based social movements…based on illness identities" (2010, p. S72)

Many participants in this study belonged to migraine support groups, since that was my initial recruitment source. This would seem to support the assertion above.

Effect of Episodic Illness on Self (Sometimes Sick, Sometimes Well): People with migraines move back and forth, repeatedly, between times when they are healthy and times when they are having periods of disabling illness. This seemed to have an effect on their perceived self-identity, including their identity at the workplace. This can be very disconcerting because sometimes they are healthy and able to work as usual, sometimes they are sick and cannot work effectively, and sometimes they cannot work at all. To complicate matters even more, many individuals spoke about the unpredictable nature of migraines, the back-and-forth between ‘migraine’ and ‘non-migraine’ time periods that can change from hour to hour, and how that affects their ability to function in the workplace. For example, Lainy recalled her frustration when, at a fairly new job, a severe migraine occurred without warning at a work-related special event.

Strong Emotions Felt (i.e., Guilt, Depression, Decreased Worth). Individuals in this study reported or expressed a wide range of emotions, including guilt, depression, anger, embarrassment, fear, shame, failure. A couple of individuals expressed feelings of failure, such as “I feel like a failure,” or self-loathing, “I hate myself every time I have to miss work.” It seems as though for some, the migraines had the impact of decreasing their sense of worth at the workplace. However, this varied from person to person, and may also be influenced by other factors beyond the scope of this study. Many individuals gave examples of staying at work while sick, rather than giving the ‘wrong’ impression by leaving early because of an illness that is not well understood by others. Feelings of guilt and depression were the most common in this study, when talking about how the migraines affected their work life.

Concern regarding other’s perceptions of being seen as unreliable: or weak, inferior, incompetent, etc. There were many participants who expressed concerns regarding *other’s* perceptions in terms of competence: being viewed as unreliable, weak, inferior, incompetent, and/or less effective. I already discussed this in the section on Non

Disclosure Factors and the section on Stigma. This may have its roots in what O'Brien stated as: "The capitalist workplace culture is ultimately a 'macho' culture in that it denies any weakness or dependence. Everyone is supposed to be independent, effective, and productive." (O'Brien, 2005, p. 31) Individuals talked about their professional identity and reputation and images of being strong. They didn't want their public identity to be one of someone who has migraines or is sick/disabled, and this deviation from the norm affected their self- image.

Stigma's affect on Self Identity, Spoiled Identity, Social Identity: Another factor that contributes to the self-identity of an individual with migraines is whether he/she believes that there is a stigma attached to it, and if so, how he/she handles that stigma. I already covered issues related to Disclosure and Stigma earlier in this section. Some individuals who disclosed their migraines had feelings of self-acceptance. However, many of those who disclosed but felt a stigma with migraines and those who chose not to disclose, engaged in stigma management. Goffman (1963b) observed that keeping the stigma hidden from the public, which is one strategy for managing discrediting knowledge about the self, may partially explain the coping strategies that individuals use in response to stigma.

Concerns that they are accused of faking or lying or malingering, because they do not look sick (invisible or hidden condition): People with migraines do not always exhibit physical signs when they have a migraine. Therefore, since the condition may not be visible, it may arouse suspicion from others at the workplace during a migraine episode. For example, Russell, the crane operator and construction company owner, told me that his co-workers have accused him of being on drugs or drunk, when he had a migraine, because of the look in his eyes and his inability to think clearly. Many individuals told me about colleagues thinking that their migraines were an excuse to get out of work, ‘people think you’re making it up’ or that they were exaggerating.

Hypotheses

Prior to beginning this research, I had three tentative hypotheses that I sought to explore/validate.

H-1 regarding those who choose not to disclose: One tentative hypothesis was that some of the employees who chose *not* to disclose (kept the migraines hidden) chose to ‘pass.’ They felt as though they were seen as hard workers, they had a legitimate medical condition known only to themselves; whereas others who chose *not* to disclose thought they were seen in a negative light as “slackers” for needing to take off from work when not feeling well. I believed that those who chose not to disclose in the workplace, made their decision based on a consideration of risks vs. benefits. This turned out to be true for this study, for some, but not all, of the participants.

Risks of disclosure include: potential rejection, fear of discrimination, loss of social support, stigma, loss of employment, fear of subsequent negative attitudes and behaviors.

Benefits of disclosure include: Access to practical support (changes in work arrangements such as reduced hours, decreased pace, reduced work load, adjustments to physical environment), social support (increasing the understanding of supervisors and colleagues about the effects of the illness), legitimacy, and ensuring that illness does not affect performance (providing explanation for frequent workplace absences.)

H-2 regarding reactions to disclosure for those who did disclose: A second tentative hypothesis, prior to beginning the research, was regarding those employees who *did* disclose their migraine conditions. I believed that some of them encountered negative reactions, such as being seen as weak (stigmatizing), being seen as self-indulgent (when requesting accommodations), being viewed as not having a legitimate condition (feeling the need to justify or validate their condition); whereas some of them encountered positive reactions and felt legitimized. This also turned out to be true for this study.

H-3 regarding how disclosure decisions are made: My third tentative hypothesis was that the disclosure decisions were made based on a complex weighing of the risks versus the benefits. My theory was that the employee's decision about whether or not to disclose the existence of a migraine headache condition in the workplace would be based upon a number of factors, and that the decision would be made only after careful consideration of these factors. These include desire for access to support, need for accommodation in the workplace, frequency and severity of the migraines, fear of potential rejection or discrimination, and gender bias. This turned out to be true for this study, for most, but not all, individuals. Most of the participants in this study did choose to disclose their migraines.

Other Findings

I briefly describe four additional findings *related directly or indirectly to migraines in the workplace* that emerged as a result of the data analysis from the interviews.

There are Individuals with Migraines at High Levels of Employment: This study demonstrated that people with migraines can be found in high-level occupations. For example, the participants in this study included 2 self-employed business owners, 3 executives at the vice president level (VP, Senior VP, Executive VP), a chief financial officer, 1 attorney/judge, 3 psychologists, and 3 college teachers. (See Table 2, Occupational Titles of Participants, in Chapter 5). When migraines occurred, these individuals, like many others in the study, sometimes called in sick, left early, or went to a dark office; they may have difficulty with performance due to concentration issues or medication. Many stayed extra hours to make up for missing work. However, these individuals emphasized the importance of the fact that they are still capable professionals who don’t want to be seen as unreliable. So this rebuffs any myth that someone with migraines cannot hold a high-level job.

Unmet Workplace Expectations and Uncertainty: Another concept that appeared broadly in the interviews was expectations at the workplace; both those of the employee and the ones perceived by the employee. Many of the responses demonstrated significant misunderstandings in the workplace on the part of employers and colleagues regarding the definition, ramifications, and serious nature of migraines. There was some variation in how this impacted on the individuals emotionally. Many individuals with migraines had various perceived expectations *from their employers*. Some individuals experienced depression, guilt and/or anger associated with these expectations, especially when they were not met. This served as a disappointment and a source of frustration for many participants.

While many of the participants found the workplace to be a positive, supportive place, this was not obviously not the case for all individuals in this study. Many individuals expressed anger during the interview at the way they had been treated.

As I indicate in the interview excerpts in Chapters 5 and 6, there was an overwhelming sense of a lack of awareness in the workplace regarding migraines. Several individuals talked about uncertainty at the workplace and fear of losing their jobs. Some participants felt enormous relief when their requested accommodations were made, both because it allowed them to perform their duties (keep their jobs) and it validated their condition (preserved their reputations).

Demographic Differences: The only notable demographic differences I found in the study were related to sex and age, as discussed earlier, for stigma and factors for non-disclosure. I found the following three patterns for non-disclosure: With only one exception, all of the people who *did not disclose* were aged 50 or older. In addition, a high percentage of males, relative to total number of males in the study, did not disclose. Finally, those who did not disclose tended to have a higher level of education.

In terms of stigma, I could not find any difference in terms of age, race, or educational status, between the two groups (stigma: yes/no). The only difference that I found was in terms of sex: There were twice as many males in the "yes-stigma" group as there were in the "no-stigma" group. Ted, the 61-year-old former executive, described how: "…I didn't *have* migraines, because men didn't get migraines," and "…a migraine just wasn't an acceptable thing for a man to have…" However, due to the low number of males in the overall study, this result should be interpreted with caution.

As a reminder, these demographic findings apply only to this study and cannot be generalized.

Misdiagnosis and Multiple or Extreme Treatments: There are many treatments for migraine, including over-the-counter treatments, prescriptions, abortive and prophylactic, holistic and alternative medicine. I asked participants about their past and present treatments, not to analyze data and form conclusions, but to provide me with enough background information and context for each individual's situation and responses to the other questions. Although it is beyond the scope of this study to provide a full report of those responses (which could be another dissertation!), I found that a large number of the participants in this study either spent years being misdiagnosed or had tried numerous or extreme treatments.

I heard several stories of long periods of time until the diagnosis of migraine was finally given. Fenno spent over 20 years from his first migraine until diagnosis. Madelin remembers having what she believes were migraines as a child, but despite medical testing and visiting doctors for most of her life, she did not receive an official diagnosis of migraine from a neurologist until she was in her mid-60's -- about 60 years from time of first migraine until diagnosis! A handful of individuals thought, or were told, that they had sinus infections.

Ted, the 61-year old male, a former Executive Vice President, who I described when discussing non-disclosure, explained his years of misdiagnosis in terms of his sex as well as the time period: He said that "in my generation…" he went to very good doctors for years and they said it was sinus but never "… diagnosed migraines. And yet these same doctors were seeing women with the exact same symptoms…" and diagnosing them with migraine. This is an interesting commentary on both time period *and* gender.

Sacks discusses how some people with migraines may be so desperate for relief that they are willing to undergo surgical procedures performed for the treatment of migraine: "… desperate sufferers from migraine have presented a perennial target for well-meaning surgical procedures, which at best may be worthless or procure transient remission, and at worst may be grossly fraudulent or mutilating." (1999, p. 251-252)

Several of the individuals in this study had tried or were undergoing extreme measures/treatments to try to treat the migraines. Russel, Karen, and Leo reported getting nerve blocks injections in the neck/head. Karen, who had tried over 50 different medications, brought a list of all her past and present medications with her to the interview to illustrate what she had tried. Several individuals brought pages from their medical records, or copies of important letters. Karen also reported having had impacted wisdom teeth removed at great expense because a dentist told her that they could be causing the headaches. Julia had a tooth extracted, and had tried acupuncture, chiropractic, rolfing, hypnosis, holistic treatments, biofeedback, and laser treatments. Two individuals were hospitalized for taking too much pain medication. Many participants were using Botox, even though it was not FDA-approved for migraine purposes at the time that I conducted the interviews (2008). Leo, who was experiencing chronic daily migraines and was on extended leave from a senior vice president position, had surgery in which tissue was removed from his sinuses, because his physician was convinced that this was the cause of the migraines. Leo told me: "…I joke about the fact that it didn't cure my migraines, but I can breathe better." Leo also had plans for an upcoming three-day hospital stay for intravenous DHE (dihydroergotamine) treatments. Vita, a college adjunct teacher of English with almost 30 years of experience, was told by not one, but two, neurologists that she had a brain tumor. (Two other neurologists told her that she did not.) And this very dramatic story: Brown was told that her migraines were hormonal, and as a result, she had a partial hysterectomy.

The additional findings discussed briefly regarding the four topics above (high-level employment, workplace expectations, demographic patterns, and misdiagnosis/extreme treatments), although not part of the intended original research, seemed relevant to include in this section as information for supplemental findings.

In conclusion, the findings of this qualitative research study examine the self-reported experiences and perceptions of individuals with migraines as they relate to the workplace. I do this through the analysis of interview data from a somewhat diverse sample of 40 people of various ages, educational backgrounds, and occupations, from across the United States. I explore their perceptions of workplace attitudes and factors surrounding employee disclosure of migraines at the workplace and other related topics.

In this section of the Chapter, I discussed the dominant themes, the findings and conclusions from the data regarding the research questions and related topics. However, there are two additional topics from the data worth mentioning that are *not directly relevant* to this study. These topics arose two ways: 1) during the course of the interviews, many people talked about other things as a natural part of the conversation, and 2) the last question that I asked of each person was, ‘Is there anything else that you would like to share with me that you think is important that we haven't yet discussed?' Or, 'Is there anything else that I haven't asked you about that you think is important for me to know?'

One of things that people discussed that I found the most interesting was their emotional coping mechanisms and overall philosophies, not specifically for the workplace, but for life with migraines in general; I gathered some of the illustrative comments around that theme. Secondly, many individuals talked about migraine's effects on their relationship with spouse/partner, family, or social life. So I also gathered some of the comments around that theme. Since these are not part of the research, I did not analyze them nor provide commentary; I simply provide a few interview excerpts grouped around each of these two topics, and included them below. These comments are just a few of the many that were voiced during the interviews.

<u>Quotes about Philosophies, Pragmatism:</u>

> "I surround myself with compassionate people…Anybody who is not going to understand my headaches, they can't be part of my life…If you don't understand it, you can't be a part of it." [Morgan, event planner, female, 48]

> "…you live in the world and you figure out a way to stay in the world as much as possible and to keep yourself as comfortable as possible. And to make whatever accommodations you have to make…I think that if you don't look at it pragmatically, you'll have a lot of trouble with it, because then you feel victimized: which is not to say, that I have not on occasion, felt severely victimized. But I don't think that's a good psychological place to put yourself in…It's sort of this ongoing bargain you make with yourself about whether you are going to let this stop you. At what point you are going to let it stop you. At what point are you going to give in… am I sick enough not to go to work today… This is so typical of chronic conditions…It's a question of what, when, and what are you are going to permit to stop you… it's an ongoing bargain…I think to an extent it [having migraines] makes you… more resilient." [Engrid, attorney and administrative law judge, female, 64]

"… I guess the way that I look at it is everybody has something wrong with them. I used to say that having this was so horrible, and why did it have to be me?, but somebody always has it worse. And I feel like if this is what I have to deal with, then this is what I have to deal with…" [Jen, senior development officer, female, 30]

"… If they said, 'You would never have another headache in your life.', I would do whatever they tell me to do.…You wonder how you accomplish all that in your life, because I spend so much of it in pain. But you learn to work through it." [Julia, retired elementary school teacher, female, 67]

Quotes about family, spouse, and social life :

"…I think the one thing that really popped into my head is the support that I get from my husband. You know, he never says, 'Oh you got another migraine.'... He never says that. He's very sympathetic. He's very supportive. And that makes an enormous difference in my life. It's so much easier to cope with…. Having that support, and I know not everybody has it… I've talked to people…who've said, 'Oh, my husband doesn't get this at all. He just gets kind of ticked off when I can't go and do something with him.' I can't imagine living like that. …I'm just very lucky…It's a huge part of what helps me cope with all of this…I get into a mode of depression and frustration and anger, and he can really help diffuse that…having someone to lean on when you're in that much pain." [Kellie, self-employed owner of design and remodel firm, female, age 54]

"…with my wife…she's like, you gotta tell me when you have a migraine so I know …and so… absolutely it's an issue between me and her. She used to feel that I would just get a migraine when it was convenient, trying to get out of something, and I can certainly understand how people would think that, because there are no set rules…there is no rhyme or reason to it. So I understand how somebody who doesn't have it and didn't grow up with somebody who had it, could [think] that maybe they're trying to take advantage … like with my wife, oh he doesn't want to go see my parents, he's making it up…so I kind of understand that, and so that's one of the big difficulties of having a migraine. It's having the people close to you believe you when you're having one… [there were] a number of times …I had a migraine and … I've been married over 20 years…sometimes my wife thinks I'm using it as an excuse…" [Bill, computer systems, male, 50]

"Actually, it probably had more of an impact on the social [things]…because of work. Because there were a lot of times, when…I managed to, let's say, make it through the day, but then I couldn't do the social stuff, like with my family, in the evening. Or on a weekend…if I

> had a bad migraine during the week I might just be recovering all day Saturday. Or I had to skip social things…to cover for the stuff at work that I hadn't done that week." [Ted, retired owner of pet supply business, male, 61]

There were a few other topics not directly related to the workplace that were mentioned by many participants including: problems with insurance companies (disagreements over medications, limiting medications, reimbursement issues), migraines being hereditary (relatives with migraine, fears of passing migraines on to children), the psychological toll of migraines, the frustration of treatments that didn't work, trying to finding the right doctor (not all doctors are knowledgeable), and financial cost of migraines.

3.Recent Developments

Although a full description of recent related developments is beyond the scope of this study, I provide a brief discussion of recent developments in the *medical and legal fields* as they relate to this study, in this section of the Chapter.

Recent Medical Developments:

As I indicated in the previous section, I gathered information from participants about their past and present treatments for migraine, and I found that many of the individuals in this study had tried numerous and/or extreme treatments. Some of the participants in this study still had not found an effective migraine treatment, despite trying many different options.

Although I am unable within the scope of this research study to provide a full report and discussion of the responses in terms of the various treatments used by the participants, I did review this information.

Many of the people in this study, especially the people in the older age ranges, described how different migraine treatment was ‘in the old days’/ ‘back then’. I heard about negative experiences with doctors in the 1950’s and 1960’s, who ‘knew nothing’ about migraines. Maria, age 60, told me that in the 1970’s doctors “didn’t know what migraine was.” Londoner, age 63, discussed how when she was in her 20’s and living in England, at the time the only medication available for migraine was *aspirin*. Kellie described how for a long time, the only medication that was available was *ergotamine*, and the doctors would ‘throw up their hands’ and say ‘I just can’t do anything for you.’ But this was before a class of drugs called triptans became available (in the early 1990’s.) Stafford and Shoquist stated: “The introduction of triptan migraine drugs, specifically, improved the migraine-treatment picture dramatically…The drug options for treating migraines are head and shoulders above the ones that were available a few decades ago.” (2003, p. 18). Just as triptans were a new development back in that era, research on new migraine treatments continues to develop in the present for future generations.

At the time that the interviews for this study took place (in the year 2008), Botox had not yet been approved for migraine, yet several of the participants in this study had either tried it, or were actually using it with success, off-label[14], when other treatments had not worked, or in conjunction with other treatments.

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[14] In this context, by ‘off-label’ I refer to when a physician prescribes or uses a medication for a specific purpose that it has not specifically been approved for by the Food and Drug Administration.

Since then, Botox, which is probably best known to the general public as an anti-wrinkle injection used for cosmetic purposes, was approved by the Food and Drug Administration in 2010 for the prevention of chronic migraine in adults. Chronic is defined as patients with a history of migraine and suffering from headaches on 15 or more days per month, with headaches lasting 4 hours a day or longer. ("'Devine' Intervention: For Migraines, Botox Gives Blessed Relief", Vitality, North Shore LIJ, Spring 2011, p. 10). Botox blocks neurotransmitters in the brain and is administered in an outpatient setting. According to the National Headache Foundation,

> "The recent approval of Botox injections for migraine prevention has been big news. Botox (Onabotulinumtoxin) was approved by the FDA in October of 2010 specifically for chronic migraine, meaning an average of 14 or more migraine days per month. It is not approved for episodic migraine or other types of headache such as tension-type headache or cluster headache. Botox has been used off-label (without FDA approval) for migraine for some time…" ("Advances in Headache Treatment, NHF Headlines, Winter 2011, Number 177, p.3.)

One of the individuals in this study was about to begin a 3-day hospital stay for intravenous DHE treatment. According to the National Headache Foundation, at some point in the future, it may no longer be necessary to be hospitalized to receive DHE via intravenous.

> "Levadex, which delivers dihydroergotamine (DHE) through what's called the TEMPO inhaler, looks extraordinarily promising. DHE is a great drug that has been used to treat acute migraine for over 50 years,

> but always has been in search of a good delivery system. Currently, it works best when administered intravenously in the clinical setting…” (“Advances in Headache Treatment, NHF Headlines, Winter 2011, Number 177, p.3.)

According to the National Headache Foundation, “…there are over 30 pharmaceutical and biotech companies currently researching or developing new drugs, medical devices, delivery systems and procedures.” (“Advances in Headache Treatment, NHF Headlines, Winter 2011, Number 177, p. 1.) and “…there are trials being done on sumatriptan in patch form and a new nasal spray…novel inhaled ways of getting migraine drugs into the system…” (p. 4.)

The above are examples of the gains and ongoing progress being made in migraine treatment. As migraine treatments continue to evolve and improve, and further breakthroughs are made, the effects of migraines should be less pronounced for individuals in all areas of life, including at the workplace.

Recent Legal Developments

As I explain in Chapters 2 and 3, the Americans with Disabilities Act (ADA), passed in 1990, is a law that protects the rights of individuals with disabilities who were discriminated against due to disability. However, legal decisions by the Courts significantly limited the ADA’s impact on employment discrimination (see Chapter 3, Definitions of Disability).

Beginning in 1999, several decisions/rulings made by the U.S. Supreme Court severely narrowed the definition of disability, and as a result, also narrowed the eligibility requirements for ADA protection. In 1999, the Supreme Court decided that individuals with impairments who functioned well due to the use of mitigating measures, such as medication, hearing aids, and prosthetics, were not covered by the ADA, even if those individuals were discriminated against because of that disability/impairment[15]. The Court stated that when determining whether an individual was 'substantially limited' in one or more life activities, employers could take into account 'mitigating measures' that an individual used to deal with the effects of an impairment. The fact that the Courts took these mitigating measures into account when deciding whether a person had a disability under the ADA limited its scope/coverage.

In another Court decision, in 2002, the Court interpreted the definition of disability very narrowly[16] by imposing a more restrictive standard on individuals to demonstrate that they were substantially limited in performing major life activities. They decided that a major life activity only covered activities that are of central importance. This restrictiveness created a very high standard for individuals to qualify as disabled and limited the type of individuals who could be covered by the ADA.

An article by Paralyzed Veterans of America provides the following observation: "… in the years following the legislation's passage, courts made a number of decisions that frustrated Congress's intent and severely limited the definition of disability, leaving many people with disabilities excluded from the ability to work and contribute…" ("Improving Employment Access", Paraplegia News, June 2011, p. 25)

The narrow interpretations of the definition of disability kept many claims cases from being heard on the merits of the cases themselves; instead, the cases became caught

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[15] See Chapter 3, the three court cases from 1999 - Sutton v. United Air Lines, Inc., Murphy v. United Parcel Service, Inc., and Albertson's, Inc. v. Kirkingburg,

[16] See Chapter 3, the court case from 2002 - Toyota Motor Manufacturing.,Kentucky. Inc. v. Williams

up on whether or not the person bringing the claim was actually disabled. This limited the usefulness of the ADA and resulted in a denial of protection for many people with disabilities.

The ADA Amendments Act (also known as ‘ADAAA’) was a response to the Supreme Court’s interpretation of certain terms in the 1990 ADA law. When Congress enacted the ADA Amendments Act, this expanded the range of individuals covered by the ADA. As a result of the ADAAA, the focus was brought back to whether discrimination had occurred and what accommodations employers need to provide, instead of whether the individual had a disability.

The goal of the ADA Amendments Act was to restore workplace rights and protections of the ADA that had been narrowly interpreted in court cases since the ADA became law. The ADA Amendments Act overturned several US Supreme court decisions that narrowed the disabilities that qualify for ADA protection.

By overturning these four Supreme Court cases, courts could no longer consider (take into account) the effects of mitigating measures when defining disability[17]; and the more restrictive substantial limitation of major life activity standard would no longer apply. The result would be an increase in number of individuals covered by the ADA. The definition of disability would be interpreted more broadly.

The ADA Amendments Act was signed into law on September 25, 2008; and it went into effect on January 1, 2009. The final regulations to implement the ADAAA were published on March 25, 2011. “EEOC’s regulations to implement the equal employment provisions of the ADA Amendments Act are effective as of March 25,

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[17] The ADA Amendments Act makes an exception, to allow employers to consider the use of corrective lenses, such as normal eyeglasses or contact lenses, in determining whether an individual has a vision-related disability.

2011." (Equal Employment Opportunity Commission, 'Notice Concerning the Americans With Disabilities Act (ADA) Amendments Act of 2008' http://www1.eeoc/gov//laws/statutes/adaaa_notice.cfm , Accessed 8/13/2011) "The regulations list a set of principles that guide the determination of whether a person has a disability." [under the ADA Amendments Act.] ("Amendment Act Defines Disability", ABLE NEWS, May 2011, p 2.)

> "These regs are designed to simplify the determination of who has a 'disability' and make it easier for people to establish they are protected by the Americans with Disabilities Act (ADA)…ADAAA states the definition of disability should be interpreted in favor of *broad* coverage of individuals. The effect of these changes is to make it easier for individuals seeking protection under ADA to establish they have a disability within ADA's meaning…the regs set forth a list of principles to guide the determination of whether a person has a disability. For example, the principles provide that an impairment need not prevent or severely or significantly restrict performance of a major life activity to be considered a disability…Following ADAAA's dictates, the regulations focus attention on how the person was treated rather than on what an employer believes about the nature of the person's impairment." ("Final ADAAA Regs Published", Paraplegia News, June 2011, p. 19)

The U.S. Equal Employment Opportunity Commission (EEOC) is the agency responsible for enforcing Title I of the ADA, which prohibits employment discrimination against people with disabilities on the basis of their disability.

The EEOC has several reference materials and official documents available on their website: http://www.eeoc.gov/laws/statutes/adaaa_info.cfm to assist individuals and employers in understanding the changes as a result of the Americans with Disabilities Amendments Act and the regulations, including a Notice, an Information Sheet, and Question and Answer documents. The question and answer document answers questions about the final regulations to assist in understanding the regulations and the ADAAA.

The following is taken directly from the Information Sheet on the Equal Employment Opportunity Commission's website, and it explains about the differences in the definition of disability under the Americans with Disabilities Act Amendments Act:

> "On September 25, 2008, the President signed the Americans with Disabilities Act Amendments Act of 2008 ("ADA Amendments Act" or "Act".) The Act emphasizes that the definition of disability should be construed in favor of broad coverage of individuals to the maximum extent permitted by the terms of the ADA and generally shall not require extensive analysis. The Act makes important changes to the definition of the term "disability" by rejecting the holdings in several Supreme Court decisions and portions of EEOC's ADA regulations. The effect of these changes is to make it easier for an individual seeking protection under the ADA to establish that he or she has a disability within the meaning of the ADA." (Equal Opportunity Employment Commission, 'ADA

Amendments Act of 2008'

http://www.eeoc.gov/laws/statues/adaaa_info.cfm Accessed on

8/13/2011)

To clarify even further, the EEOC sets out more specific guidelines on a Notice concerning the Act:

> "The Act retains the ADA's basic definition of "disability"…However, it changes the way that these statutory terms should be interpreted in several ways. Most significantly, the Act:
>
> - Directs EEOC to revise that portion of its regulations defining the term "substantially limits";
> - Expands the definition of "major life activities" by including two non-exhaustive lists:
>   - The first list includes many activities that the EEOC has recognized (e.g., walking) as well as activities that EEOC has not specifically recognized (e.g., reading, bending, and communicating);
>   - The second list includes major bodily functions (e.g., "functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions");

> - States that mitigating measures other than "ordinary eyeglasses or contact lenses" shall not be considered in assessing whether an individual has a disability;
> - Clarifies that an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active; …"
>
> (Equal Employment Opportunity Commission, 'Notice Concerning The Americans with Disabilities Act (ADA) Amendments Act of 2008' http://www1.eeoc/gov//laws/statutes/adaaa_notice.cfm , Accessed 8/13/2011)

For individuals with episodic impairments (examples given are insulin-controlled diabetes or cancer in remission), what this means is that they will be covered even if they are not currently experiencing any effects of their impairments.

Below are some excerpts from the question and answer document (Q&A) that even more fully delineate some of the points described above:

> "The ADA Amendments Act of 2008 (ADAAA) was enacted on September 25, 2008, and became effective on January 1, 2009. This law made a number of significant changes to the definition of "disability." It also directed the U.S. Equal Employment Opportunity Commission (EEOC) to amend its ADA regulations to reflect the changes made by the ADAAA. The final regulations were published in the Federal Register on March 25, 2011." (Equal Employment Opportunity Commission,

‘Questions and Answers on the Final Rule Implementing the ADA Amendments Act of 2008’ http://www1eeoc.gov//laws/regulations/ada_qa_final_rule.cfm , Accessed 8/13/2011)

From Q&A to clarify about definition of disability, major life activities -

> “Congress found that persons with many types of impairments – including epilepsy, diabetes, multiple sclerosis, major depression, and bipolar disorder – had been unable to bring ADA claims because they were found not to meet the ADA’s definition of “disability.”
>
> “The final regulations provide a non-exhaustive list of examples of major life activities:…seeing, hearing, eating, sleeping, walking, standing, sitting, reaching,…learning, reading, concentrating, thinking, communication, interacting with others…”

From Q&A to clarify about episodic impairments -

> “The ADAAA and the final regulations specifically state that an impairment that is episodic or in remission meets the definition of disability if it would substantially limit a major life activity when active. This means that chronic impairments with symptoms or effects that are episodic rather than present all the time can be a disability even if the symptoms or effects would only substantially limit a major life activity when the impairment is active. The Appendix provides examples of

> impairments that may be episodic, including epilepsy, hypertension, asthma, diabetes, major depressive disorder, bipolar disorder, and schizophrenia. An impairment such as cancer that is in remission but that may possibly return in a substantially limiting form will also be a disability under the ADAAA…"

From Q&A to clarify about mitigating measures -

> "The ADAAA and the final regulations provide a non-exhaustive list of examples of mitigating measures. They include medication, medical equipment and devices, prosthetic limbs, low vision devices (e.g., devices that magnify a visual image), hearing aids, mobility devices, oxygen therapy equipment, use of assistive technology, reasonable accommodations, and learned behavioral or adaptive neurological modifications. In addition, the final regulations add psychotherapy, behavioral therapy, and physical therapy to the ADAAA's list of examples."
>
> "The ADAAA and the final regulations direct that the positive (or ameliorative) effects from an individual's use of one or more mitigating measures be ignored in determining if an impairment substantially limits a major life activity. In other words, if a mitigating measure eliminates or reduces the symptoms or impact of an impairment, that fact cannot be used in determining if a person meets the definition of disability. Instead, the determination of disability must focus on whether the individual would

> be substantially limited in performing a major life activity without the mitigating measure.”
>
> “The ADAAA allows consideration of the negative effects of a mitigating measure in determining if a disability exists. For example, the side effects that an individual experiences from use of medication for hypertension may be considered in determining whether the individual is substantially limited in a major life activity.”

From Q&A to clarify the purpose of the changes -

> “The changes to the regulations reflect changes made by the ADAAA itself, which are intended to make the primary focus of an ADA inquiry whether discrimination occurred, not whether an individual meets the definition of “disability.””
>
> (Equal Employment Opportunity Commission, ‘Questions and Answers on the Final Rule Implementing the ADA Amendments Act of 2008’ http://www1eeoc.gov//laws/regulations/ada_qa_final_rule.cfm , Accessed 8/13/2011)

The following comments provide a short summary of the ‘before and after’ effect of the ADAAA:

> “Employment law changed dramatically with the passage of the ADA Amendments Act of 2008 (ADAAA), which went into effect on January 1, 2009. The law corrects a series of decisions by the Court that

> narrowed ADA's scope of protection and excluded individuals the act was originally designed to protect, including people with epilepsy, diabetes, and muscular dystrophy…Prior to ADAAA, the Court had focused on determining whether a disability qualified for coverage under ADA rather than whether unlawful discrimination had occurred – and many whom Congress had intended to be covered were excluded. Under ADAAA, 'courts [are required] to focus primarily on whether discrimination has occurred or accommodations properly refused.'" ("Celebrating ADA: Has it been 20 Years?" Paraplegia News, July 2010, p. 18)

> "…President Bush signed into law ADAAA to restore Congress's original intent regarding the scope of who would be determined to be a person with a disability…With the release of EEOC's regulations, employers across the country will have a clear set of guidelines and rules of the road to ensure equality for Americans with disabilities. This will help ensure civil rights protection for people with 'invisible disabilities'. Moreover, EEOC's regulations restore the original intent of Congress to cover many disabilities that had been excluded by the courts…"." ("Improving Employment Access", Paraplegia News, June 2011, p. 26)

As a result of the ADAAA, the focus is now on whether or not discrimination occurred (not on whether the individual has a disability). In my opinion, because of the major changes resulting from the ADAAA in terms of how the definition of disability is interpreted, this has the potential for a positive impact for individuals with migraines (as well as employees with any hidden/invisible disability or episodic condition) in the workplace. This is because 1) the definition of disability is being interpreted more broadly, 2) mitigating measures can no longer be considered, and 3) episodic conditions or impairments are being considered as if active. All three of these changes are favorable to people with these types of disabilities, and it is likely that individuals who were not covered by ADA protections under the 1999 and 2002 Court standards would be entitled to protection under current standards.

4. Limitations

I acknowledge that there are several limitations with this research study in terms of the data findings and conclusions drawn.

As I discussed previously, I interviewed a non-representative sample of individuals with migraines. Because I did not randomly select these individuals, and my sample was not statistically representative, my findings may not generalize to the broader population. Therefore, the findings cannot and should not be generalized to all individuals with migraines in a workplace setting. This was *not* my intent when undertaking this research; I was not trying to infer that the participants in this study were representative of the population of all employees who have migraines. I was instead interested in exploring different occupations and revealing patterns that may reflect, contradict, or prove the hypotheses presented in the research methodology. Since this was an initial study on investigating migraines in the workplace from the employee viewpoint, my focus was on a qualitative exploration of that topic. Because this dissertation is a pilot study, a piece of exploratory research (since there seems to be nothing published about it to date), the issue of representativeness should not be seen as a deficiency. While this limits the ability to generalize the experiences of those interviewed as typical, this type of non-representative sampling is appropriate for exploratory research. Findings and conclusions from this research study can be used to generate questions that would be useful in larger, random sample style research. A study whose goal is to generalize its findings would need a quantitative study design/methods and a representative sample.

This study has the following limitations, and the findings that I reported in the earlier section should be interpreted with these limitations in mind:

First: This study is limited by the relatively small size of the sample (number of study participants = 40). Even if the sample had been representative, the relatively small sample size also would most likely limit the ability to generalize the experiences of the individuals interviewed. While the sample size used in this study is more than adequate for the rich description necessary to explore the participants' migraine experiences, it would be too small to perform meaningful comparative analyses for statistical purposes. However, as stated previously, this was not the purpose of my analysis. By studying even a relatively small number of sufficiently diverse cases in depth, which is often the case with qualitative research, I was able to perform the type of qualitative analysis that was necessary to demonstrate a range of ideas and experiences. When considering sample size for qualitative studies, the sample should be large enough to ensure that the researcher hears a variety of perceptions from the population. The sample size in this study is a reasonable number for a qualitative study whose purpose is to explore a range of individual attitudes and perceptions. In qualitative studies, such as this project, researchers are looking for meaningful patterns and themes within the data, based on an exploration of the experiences, views, and perspectives of the participants. Even though the sample sizes may be smaller, qualitative research allows a broad range of cases and perspectives to be presented in greater detail than a quantitative study.

Second: The participants in this study were chosen based on self-selection, so selection bias needs to be taken into consideration. Because of this, there may be differences between the study's participants and non-participants. Since the individuals who participated in this study were self-selected, they may have been more inclined to participate because they were motivated by the possibility of contributing to the research or by the donation I would make to the National Headache Foundation. All study participants seemed highly motivated. It is possible/probable that frustrated or dissatisfied individuals and /or individuals who had more negative experiences joined this study, because they wanted to tell someone their story; while people who had more positive workplace experiences or had no job-related stories to tell didn't feel the need to join a study such as this one. So although many of the interviews reflected negative experiences, it can't be concluded that people with migraines are mostly unhappy with their workplace experiences. I recruited participants mostly, but not solely, via emails and announcements through the National Headache Foundation (see Chapter 4, Methodology). As a result of the recruitment methods that I chose to use, approximately 75% of the study participants reported hearing about the study through the National Headache Foundation. Those individuals may have had information that was unavailable to individuals who were not familiar with this association. I didn't have any information about individuals with migraines who *did not participate* in the study. Although my participants were a diverse group of individuals in many respects, since they were self-selected makes it possible/probable that other perspectives were missed.

Also because the participants were self-selected, I had no real control over the class background and workplace of the individuals who chose to participate in the study. This is significant. One cannot assume that the experience of migraines in the workplace, or the factors surrounding their disclosure, is not affected by social and cultural factors. For example, a white male lawyer in his 50's at a prestigious law firm, versus a young black female worker at a fast food restaurant; one would think that these could be very different kinds of affairs for these two individuals.

Third: This study was based on retrospective, self-reported data and measures. Using self-reported data may not always be accurate because participants may remember things differently from what actually happened. The use of self-reported data may result in some amount of incorrect counting because of under-reporting or over-reporting for a variety of reasons. Therefore, using self-reported data of participants may not be as accurate as using actual measurement data. Individuals may not remember things accurately, may not report items correctly, might misunderstand questions, might underestimate or overestimate, might perceive things differently. Some examples of items which could potentially be susceptible to some of these possibilities in this study include: reactions to disclosure; effects of migraines on absenteeism. Also, with self-reported information, there is always the additional risk of social desirability bias (giving socially desirable answers to the interviewer.) I did not evaluate the accuracy of participants' reporting; I assumed that their statements were accurate.

Taylor and Bogdan describe the possible errors of self-reporting as an "obvious limitation" of the open-ended, qualitative interviewing type of research method in general: "…data are generated from interviews and consist of verbal accounts…. primarily based on what people said to us and not what we observed them do." (1998, p. 245). Because of the method that I chose to conduct this research, I was not able to report actual behaviors in the workplace, only my participants' perceptions of them. For example, what I was able to report is subjectively perceived workplace identity- -not identity as perceived by others in the workplace (reputational identity) or as observed by me had I been in that workplace. My data consists of perceptions, not actual behaviors. However, given the subject matter of this research study, observing actual behavior would have been impossible to capture by a researcher as it occurred.

As the basis for this study, I interviewed individuals to explore their retrospective reflections on their experiences. I relied on retrospective accounts from the participants, which has many of the same drawbacks as self-reporting. All past behaviors and past discussions had to be remembered from individual's memories. However, this could have resulted in different estimates of events, illnesses, and interactions than direct observation or actual measurement would. This is a significant, known limitation of the retrospective design in general. However, retrospective reporting is a useful way for individuals to reflect on their past experiences. Because of errors in recall in self-reporting (mentioned previously) and in retrospective reporting, in general, it would be more accurate to observe behaviors in the field instead of using retrospective reporting (asking retrospective questions). However, given the subject matter of this particular study, this would have been an impractical if not impossible solution.

But even with direct observation, there are limitations. ‘Researcher’s writings are always interpretations of what they *think* their research subjects are doing. But their insights are always limited, because they cannot know for certain what is really going on.” (Esterberg, 2002, p.16).

In addition, I did not seek any objective, independent information to verify any of the retrospective memories (e.g., attendance records) or interview any other individuals for their perspectives or verification (e.g., co-workers). I relied on what the individuals participating in the study told me.

Fourth: I measured only a handful of demographic and other background variables: age, sex, highest level of education, state of residence, racial/ethnic background, occupational title (see Tables 2, 3, 4 in Chapter 4). Individuals with migraines are not a homogeneous group. I did not measure other possible items such as social class, marital status, income level, or socio-economic status; partly because in this study, I was not concerned with undertaking a subgroup analysis of all of those variables. I did consider the inclusion of additional measures; however, because of the nature of this study, including additional variables would not have been feasible. Therefore, I was not able to evaluate any relationships between those (unmeasured) variables and the main topics that I studied. It is possible that by including one or more of these additional variables, for example, income level, I may have discovered some patterns. It is also possible that one or more of the variables that I did not include may account for some of the differences that I recorded.

Fifth: Another limitation is lack of diversity in the sample: (in terms of sex, racial minorities, and to some extent, education). Although the individuals in this study represented a variety of ages (ranging from 20's through 70's) and a variety of different states and educational backgrounds, there was a lack of diversity in a few areas: most notably, sex and race/ethnicity. Only 6 participants were male and only 4 participants were non-White. In addition, although different educational backgrounds and 13 different states were represented, the sample was heavily slanted towards college-educated individuals and the Northeast. So, the study participants were mostly female, white, and college-educated. Although I already stated that I was not trying to generalize, this sample is most likely not representative of the broader population of individuals with migraines because of this; for example, findings do not reflect individuals from all racial groups since there were so few racial minorities in this study.

However, as mentioned in Chapter 4, Methodology, I wasn't trying to get a representative sample of all racial groups. It was more important for me to get a sample of different occupations and workplaces regardless of race. This was an exploratory study. One suggestion for future study could be to get a larger representation from different races. (See Nicholson, Rooney, Vo, O'Laughlin, & Gordin, 2006, for a comparison of Caucasians and African-Americans with migraines.)

Although the number of men in the study was much smaller than the number of women, I previously provided statistics to indicate that the (reported) prevalence of migraine is much higher for women. Additionally, even though only 6 men were included, I believe that their perspectives as men with migraines was represented in this study.

Since the overall sample size was relatively small to begin with, and there was not enough diversity (variation) within some of the demographic measures, there would have been too few entries per cell to use statistical- type computer programs[18] to perform statistical analyses. For example, small cell sizes prevented me from conducting any analyses by subgroup such as male vs. female, white vs. other racial backgrounds, college educated vs. those without a college education, which might have revealed some interesting findings. Although I did make comparisons in my study, they applied to my study only.

In addition, although a variety of occupations were represented in this study, it would have been beneficial to include a higher number of blue collar workers, manual workers, and members of the lower-wage workforce. These groups were under-represented in this study and therefore their perspectives were not well represented. My study's lack of adequate inclusion of this segment of the workforce, and by extension, lack of representation of their perspectives, is an important limitation.

Only a limited number of people who could be considered blue-collar workers were part of my study. In contrast to the example of men that I provided earlier, I do not believe that the perspectives of blue collar workers with migraines was adequately represented in this study by these individuals. It would have been interesting to compare the experiences of white collar workers with blue collar workers. I did not set out to interview mostly white collar employees, but that is how the sample developed.

Also, I did not conduct any individual occupational title comparisons (e.g., teachers vs. psychologists) since I would have needed a larger number within each title.

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[18] However, as mentioned throughout many times, this is a qualitative study, rather than quantitative.

Non represented states (heavy Northeast representation): Although I only analyzed the primary residence at time of interview, there were individuals who had lived in multiple states over the course of their lives. Allison, the 35-year-old senior clinical trials associate, currently lives in New Jersey, but has lived in 6 other U.S. states, as well as outside of the country. When I asked her, she replied that she did not notice a difference in her migraines among states. Martha, the 75-year old elementary school teacher, currently lives in Washington, but has also lived in 6 other U.S. states.

Sixth: This limitation pertains to the migraine diagnosis. Although I only accepted into the study individuals who confirmed that they had been diagnosed with migraine *by a physician*, I again relied on what the individual told me, since I used self-reports. I did not confirm/verify the migraine diagnoses with medical documentation or diagnostic tests given by independent medical personnel. Therefore, this limitation concerns the accuracy of diagnosis; I assumed that participants would have no reason to give me false information since they were not benefitting personally from the study. I also did not ask participants about any other illnesses or medical conditions that they had. So unless they mentioned a co-existing medical condition to me on their own (and many did), this information was not included in my research. Therefore, I was unable to tease out and eliminate the possible effects of co-morbid conditions, since this was beyond the scope of this research. I also did not attempt to measure the severity of participants' migraines, although tools exist for this purpose, or do any type of analysis based on that, since this was also beyond the scope of this study.

Seventh: Limitations of the qualitative coding analysis method: The process of coding and analyzing qualitative data itself has limitations. In Chapter 4, Methodology, I describe the coding system I used to capture and record the presence of relevant themes. One of the difficulties in analyzing qualitative data is that there is no single method or rule for how to analyze it. The sensitivities and activities of the researcher therefore often govern what particular sense is made of what is said or seen.

One problem with this approach is "the potential endlessness of options for coding and comparisons. Open coding could be applied to all passages of a text, and the categories which are found… are very numerous could all be further elaborated. Passages and cases could be endlessly compared with each other ….often a great many codes and potential comparisons result." (Flick, 2002, p. 185). Therefore, it is up to the researcher to subjectively decide which categories to choose and which ones to leave out, and which are related to the research question.

Despite the limitations listed above, this study provides a detailed picture of the issues that the study participants faced in the workplace and examines their perspectives on a number of related topics.

5. Implications; Directions for Future Research

Implications

Some of the findings of this research study have policy and/or practical implications, such as increasing public knowledge or bringing greater awareness to the policy-making process.

Strengths and Contributions: While there is much attention in the literature to work-related causes of chronic illness and the impact of chronic illness on work productivity, less attention has been paid to the management of chronic, episodic illness in the workplace *from the employees' perspective.* The sociological study of migraines in the workplace has implications for many fields. For the field of disability, it provides insight into the perspectives of persons with a hidden disability/condition such as migraine. This work fits into the study of medical sociology and health and illness in several ways. It focuses on the perceptions of people with a chronic illness, on their everyday workplace situations. Concentrating on everyday situations helps ground our conclusions empirically and allows us to find ways to improve the lives of people with migraines.

This work also serves to create more understanding about the lives of individuals with migraines and raises awareness of migraine as a legitimate neurological disorder. There are also implications for workplace/occupational sociology, in the areas of workplace accommodations and workplace identity. This exploratory analysis contributes to the literature in both medical sociology and disability studies, by including the first-person accounts and narratives of people with migraines. Therefore, this research is relevant to many different disciplines, including medical sociology, sociology of health and illness, disability studies, work and occupational sociology.

This study's strengths include its design, the research questions, the high motivation of the participants, the scope of the topics covered, and the range of different occupational titles included. Despite the study limitations (listed in previous section), this study provides important new information to the field of migraines. Participants provided rich data for this exploratory study.

One of the reasons that I wanted to include people from different types of occupations was to hear different perspectives; for example, from Ted and Leo, I heard a corporate executive perspective. One suggestion that was made to me during the research proposal stage was to limit my study to one occupation. I replied that this was not what I wanted, because this would eliminate the richness of discovering how migraines impact people in different occupations.

The interviews provided a detailed picture of the problems/issues that the study participants faced in the workplace. This research and analysis adds to the literature on migraines by having the advantage of offering the perspective of the individual with migraines at the workplace. This study provides unique descriptive information not currently available.

To my knowledge, this is the first study that has examined the topics surrounding disclosure, stigma, and accommodations, in a sample of individuals with migraines in the workplace, and therefore it has the potential to address the research gaps on this issue.

I was unable to compare the findings of this study with previous studies, since none were available. Therefore, these findings provide important new information, especially for policy making regarding migraine in the workplace from a broader societal perspective.

Understanding/Education/Awareness: In this study, a very high number of individuals expressed frustration at the lack of understanding they encountered in the workplace regarding the nature of migraines.

Many of the individuals (who encountered a lack of understanding in the workplace) believed that part of the problem was that people in general don't understand, because they think a migraine is like a regular headache. As I discussed, the theme that I heard most often, regardless of occupation, and regardless of the specific topic being discussed, was the lack of understanding in the workplace regarding what migraines really are and how migraines are different from a 'regular headache'. A related theme was that of people at work (both colleagues and supervisors) not taking migraines seriously.

People don't seem to believe that migraines are as disabling as they are, and they don't realize the nature of the disorder.

One of my goals with this research is to raise awareness about migraines, especially in the workplace, but not just at the workplace. There seems to be a big concern from a lot of people who have difficulty in the workplace in trying to get employers to understand. The findings of this study could enlighten members of the public who are not familiar with migraines.

One of the reasons that I chose this research is that there was very little information available, and the public should be made aware that this is a serious condition for people with migraines. For example, this is not just something you get from eating certain foods that you can avoid; there are triggers at the workplace, some of which can be changed or avoided (with proper accommodations) but some of which cannot. It’s not just a headache that you take aspirin for; and the person is not a hypochondriac; it’s a serious neurological disorder that does affect people’s lives. With this study, I tried to raise awareness by speaking to different people and analyzing their stories.

The fact that so many individuals reported problems at the workplace and lack of understanding about migraines is <u>troubling</u>. In view of this finding, improved information about the nature of migraines needs to be made available and publicized, perhaps in the form of public outreach/awareness.

The findings of this study prove that educational interventions are needed, both at the workplace level and public level, that could have the potential to reach large numbers of individuals (including employers and employees) in order improve treatment of people with migraine. This type of education could bring long-term benefits.

My study demonstrates the need for additional education and outreach in general, but especially in the workplace. Therefore, the study has important implications for public awareness campaigns as well as training interventions with Human Resources Departments.

I am not suggesting that there be workplace training specifically on migraines, per se (this would be unreasonable and impractical). However, if this study is any indication, many frontline supervisors/managers are unaware that certain medical conditions can be invisible/hidden and/or episodic, yet still be serious, real, disabling conditions, and this information could be added to a training curriculum where applicable.

Concerns/Stigma: The findings that a) roughly 50% of the participants were concerned about stigma, and that b) the majority of participants who did not disclose did so for reasons related to stigma about to migraine, were discouraging/disturbing. This also demonstrates the need for additional education (see above.)

Productivity: As I describe in Chapter 5, work productivity of many of the study participants was affected either due to working with a migraine or by losing work time (calling in sick, arriving late, leaving early) due to a migraine. When you multiply reduced productivity by the number of people with migraines, the cost to the economy is high. According to the National Headache Foundation (2010), "…migraine and other headache disorders cost the US more than $31 billion and 9% of all lost labor annually…20% of all Americans will experience some form of migraine this year…" (National Headache Foundation, NHF Headlines, May/June 2010, p.11.)

Legitimacy: One significant related problem is that many people within the workplace, both employers and colleagues, question the legitimacy of migraines. I heard story after story from participants about employers and/or colleagues thinking that the individual was making it up, exaggerating, being overly dramatic, neurotic, etc, and about the bad experiences that they've had in the workplaces. The only people in the workplace who seemed to understand were those individuals who knew someone with migraines or those who got migraines themselves. The public's doubting of the legitimacy about migraines can be very frustrating, especially in a workplace situation.

One way that individuals with migraines attempt to gain legitimacy is in the form of a medical diagnosis.

Migraines are a serious disorder, especially in the workplace, where individuals have limited control over the circumstances. One of the reasons I wanted to do this research, is to raise awareness about what can trigger a migraine in the workplace, what it feels like, the effects on the workplace, and that it's not something the employee is doing on purpose.

The basic facts are that: Migraine is neurological in nature. Migraines are not like regular headaches. People with migraines usually have more symptoms than the head pain, and symptoms can be debilitating. Migraines can't be cured.

So many circumstances surrounding the migraines are beyond the individual's control. However, a lot of the individuals in this study tended to internalize this even though they knew the migraines were not their fault, and were not a weakness, and were not something that people bring on themselves. This research could educate individuals of those facts so that at least in one area of their lives, the workplace, individuals would not be faced with negative attitudes and constantly feeling as though they had to justify the condition, and they could obtain reasonable accommodations if needed.

<u>Accommodations:</u> The findings of this research also demonstrated the range and benefits of effective accommodations for people with migraines. Those findings were <u>encouraging,</u> in that there were so many different types of accommodations, many of which were effective, and also in that the majority of participants reported little or no difficulty in accessing them or having them implemented. The employers

were supportive, willing to work with the employees and their needs, and the requests were granted. In this study, the majority of participants reported positive responses in terms of requests for accommodations.

The most frequently-mentioned accommodation for individuals in this study was a flexible schedule (time flexibility in conjunction with a migraine), with 19 people – almost 50% - naming that type of accommodation. (This was defined as the ability to come into work late, leave work early, and/or not come to work at all, *when a migraine occurs*.) This is an interesting implication of this study as well, in that often when employers think of accommodations, they automatically think that the solutions will cost money. In the case of this study, the overwhelming choice for people with migraines was a type of accommodation that does not cost any money to the employer.

The conclusions from this study about accommodations can be added to the existing literature to increase the knowledge base on efficacy of making and implementing workplace accommodations.

<u>Discrimination and the Law</u>: Employers should be reminded of the fact that discrimination against people with disabilities (including invisible/hidden/episodic disabilities) is illegal, while also being made aware of the implications of the new broader 2011 regulations from the ADAAA. This will have a positive impact on people with migraines.

<u>Triggers:</u> As part of the research study, I asked each person if there were any particular triggers for migraine that were related to his/her workplace (past or present).

The most common work-related trigger reported in this study was stress/workplace pressure, with 50% of the people reporting that as a trigger. This is an interesting implication of this study as well; that it would be helpful to try to reduce stress at the workplace. Although many people commonly think of workplace stress as something that can't be changed, the following quote is from Adrienne, who travels extensively for business. She compared life in the United States with life in the Caribbean, where she has also lived and worked:

> "…And here in the States, especially coming with my culture, I was born and raised here, my family is from the Caribbean, and having the opportunity of traveling as extensively as I do, different countries, where I am exposed to different cultures… it really is stressful to live in the U.S. You see people with such high medications … and I think it's because…they don't do anything here to enforce people to just take a break. That organization I used to work for, would force you every hour to take at least a 15-minute break… The Caribbean is different. The Caribbean, 12 in the afternoon, people take a break, they go home, and they eat with their family. You can't do that here. You go to some of the Latin cultures, they do take a siesta. And they relax, and they go back to work with a big smile on their face. Don't have that here…You're so overwhelmed with the stress of work, and I don't think work in the U.S. is a healthy environment, and I don't think that anything is being done to try to create that atmosphere …And it's just sad that the way that the U.S. is structured, to me, it's sad, in that aspect…Everyone's so high strung….if you just watch people walking down the street, they don't walk around with a smile here. Go to the Caribbean, everybody's like, Hi! How are ya! You don't see that here….You walk with frowns, you're gonna end up with a headache. They get into a car, they're cursing. … Of course you're gonna have a headache if you're always like this, and tense and stressed…. But life here, it's so different…Everything is high stress… Because when I travel to these places [outside of U.S.] I'm relaxed. And it's [the migraines] not as frequent as what I get here." [Adrienne, assistant to president, female, 39]

Invisible Conditions: Migraines don't have an easily identifiable physical symptom. The findings of this study are not necessarily limited to migraines but may extend to having implications for people with other invisible or episodic disabilities or hidden conditions, as well. Many individuals explained how their migraines do not make them look sick in ways their employer expects a sick person to look, and therefore, how it is difficult to prove. The following three quotes discuss the skepticism surrounding invisible disabilities and are taken from an article about this topic:

> "Humphrey (2000, p. 65-67) indicates that there is a cultural skepticism and marginalization surrounding individuals with less tangible, fluctuating disabilities." (Lightman, Vick, Herd, & Mitchell, 2009)
>
> "Jung (2002) emphasizes that a visibly damaged or disordered body is perceived as incontrovertible proof of disability compared to the body of a chronically ill person who experiences disability in alternate, less noticeable ways." (Lightman, Vick, Herd, & Mitchell, 2009)
>
> "…the dominant discourse argues that one must be either entirely able or disabled with no in-between (Stone, 1995, p. 418)." (Lightman, Vick, Herd, & Mitchell, 2009)

Therefore, aside from interesting the segment of the population who has migraines, what I studied in this research is applicable to different kinds of chronic illness, since aspects of this study could be applicable to other types of invisible or episodic conditions.

Even physicians can be skeptical. Although this exchange took place years ago in an earlier time period, Ted, the 61-year-old former Executive VP, told me about what a doctor once told him:

> "…I remember mentioning it [that he had migraines] once to a company doctor in a physical…they sent you to … a Park Avenue specialist in New

> York City if…you are at an Executive level…and I mentioned that I had
> migraines…and he said, ‘No you don’t have those. Men don’t get them.’
> So I didn’t debate it at that point.”

Not all doctors understand about migraine. One doctor told Kellie, “You know, having sex is a really good way to abort a migraine.”

In summary, one implication is that this study will raise public knowledge and awareness (especially in the workplace) that migraines are a serious, real neurological condition; for all of the reasons indicated in the above sections. It will also add to the literature on migraines, invisible disabilities, accommodations, and other related topics. People who get migraines will hopefully find validation upon reading this study and perhaps reduce the level of stigma associated with this condition.

Directions for Future Research

This study provides some possible important areas for future research. Since this is an under-researched topic, there are several different directions that future research could take. In the limitations section of this chapter, I identified several limitations to the study, as well as potential solutions for future studies where possible.

Generalization (Larger studies with wider geographic representation): Whether or not the findings of this study generalize to the larger population of individuals with migraines in a workplace setting is unknown, and this could be the focus of a future research study.

As I discussed previously, I interviewed a non-representative sample of individuals with migraines. Because I did not randomly select the individuals, and my sample was not statistically representative, my findings might not generalize to the broader population.

Even if the sample had been representative, the relatively small sample size (n=40) also might limit the ability to generalize the experiences of the individuals interviewed. Findings from this research study can be used to generate questions that would be useful in larger, random sample style research.

Larger studies, including those with higher numbers of participants, plus recruiting individuals from more states other than the Northeast, would allow for this generalization if random sampling and other steps were taken to increase validity. As I pointed out, my study data was based on interviews with a relatively small number of people, mostly from the Northeast states.

In addition, larger studies with more variation would allow conducting analyses by subgroup such as male vs. female, white vs. other racial backgrounds, college educated vs. those without a college education, which might reveal some interesting findings or patterns.

<u>More Diverse Studies</u>: Most of the participants in my study were white, female, college-educated, and worked in white collar occupations. As a result, the data included few perspectives from male, non-college educated, blue collar backgrounds, and few perspectives from a minority racial background. Some of these are significant limitations that could be addressed through future research.

More diverse studies would also allow comparisons by race, sex, education, or occupational group, which might show interesting findings from a sociological standpoint. White participants and participants from racial/ethnic minorities may have similar experiences and perceptions in certain areas; however, there may be significant differences in other areas. Findings do not reflect individuals from all racial groups since there were so few racial minorities in this study. One suggestion for future study could be to get a larger representation from different races.

I recruited participants mostly, but not solely, via emails and announcements through the National Headache Foundation (see Chapter 4, Methodology). As a result of the recruitment methods that I chose to use, approximately 75% of the study participants reported hearing about the study through the National Headache Foundation. Those individuals may have had information that was unavailable to individuals who were not familiar with this association.

Future studies are needed to investigate some of the conclusions that I made based on the findings. It is possible that some of these conclusions were reached because of the high number of whites, college-educated individuals, females, individuals familiar with NHF, and/or white collar employees in the study. Further research is needed to demonstrate whether the findings replicate, especially when the individuals have different backgrounds from those in this study.

<u>Examine Variables not included:</u> Future studies could examine one or more variables that I did not include as part of my research (some of the ones I mentioned were income level, social class, socioeconomic status, but there may be others), which may

reveal additional findings and patterns. The addition of unmeasured variables might influence the findings.

Include More Males: As I stated, only 6 men were included in this study. However, I believe that their perspectives as men with migraines were represented in this study. As a result of the size of this study and the number of men, this study was not large enough nor did it contain enough male participants to draw any conclusions about the role of sex. Men and women may have similar experiences and perceptions in some areas, however there may be significant differences in other areas. The perspectives of the male participants who I did interview demonstrated that this is an important issue that deserves further study. Although topics specific to men were present in the narratives that I collected, this was not a major point of investigation in my research. Future research concentrating on males could explore this more thoroughly.[19] Therefore, additional research is recommended to elaborate on the role of sex.

Recruit from Non-White Collar Occupations: Similarly, although a variety of occupations were represented in this study, the majority of individuals were from white collar occupations. However, a study that includes perspectives of blue collar employees, manual workers, and/or members of the lower-wage workforce, all of which play a significant role in the American workforce, is an idea that deserves further research. These groups were under-represented in this study, and therefore their perspectives and experiences with migraines in the workplace were not well represented. As I mentioned

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[19] I see parallels with, for example, men with breast cancer. Since breast cancer, like migraines, is a condition that primarily affects women, research and focus usually targets women. But men also can and do develop these conditions, albeit in much smaller numbers.

with racial/ethnic minorities above, if more people from these types of occupations had been included, I might have heard additional perspectives. Refer to my earlier example about the middle-aged white male lawyer and the young black female fast food worker.

The inclusion of blue collar employees may also allow for a comparison between blue collar and white collar employees. It is quite possible that by using recruitment sources geared toward reaching blue collar employees, a researcher would simultaneously be able to reach a large number of male participants, addressing one of the other ideas above.

Study Other Regions /International**:** Yet another possible direction for research is that this study could be replicated not only throughout the United States (as already mentioned), but also outside of the United States, which could significantly impact the findings and provide some fascinating insights. Studies that are replicated in regions other than the one I used may hear about things that are very different from what I discovered. There are so many things that could be explored: cultural differences, people living in poverty who are unable to afford doctors or medications.

People with migraines who have financial difficulties face problems in not being able to afford their medications. Some migraine medications are very expensive. When a lot of workdays are lost, people run the risk of losing their jobs, and their socioeconomic level may decrease. There were several people in this study who were not able to afford their medications, but they were not the majority.

Some of what I discuss here may pertain to high-poverty, high-immigrant, and/or high-minority areas of the United States as well. One colleague (not from this study) told me that in Mexico, only rich people are said to have migraines because only they can afford to get diagnosed. The poor people there may get migraines too, but they don't get diagnosed because they can't afford to pay the doctor, nor can they afford to take off from work even if they got a migraine. They work 12 hour days, they wouldn't get paid if they took off from work, and they fear losing their jobs.

In many other countries, workers are not protected by programs and rights such as workers' compensation, the ADA, employer-paid health insurance, or Medicaid.

One of the points demonstrated by the Mexico example above is the difference between migraine prevalence itself and migraine *diagnosis*. The lower rates of migraine (or migraine diagnosis) that may be found in poor, ethnically diverse, minority regions, both within and outside of the U.S., may be due to a number of factors. As sociologists, we know that these may include limited access to health care, lower use of medical services, language barriers, cultural issues, discrimination, lack of information, and inadequate healthcare.

In summary: Future research should examine the extent to which all of these play a role, since any of these factors (the low number of males, blue collar, high school educated, non-Northeast, non-NHF, etc.), may lead to different numbers in the rates of disclosures, stigma, and in the experiences of the types of reactions, factors leading to disclosure, if the study were to be repeated under different conditions.

One intriguing direction for future research is to build on this study by making one or more of the many modifications listed above. More research is needed to determine whether the findings in this study would be repeated.

Sociologists would be able to further my study of migraines in the workplace by implementing any of the important research modification areas listed above and using a social constructionist approach.

6.Closing/Final Thoughts

My selection of migraine as the disability/condition for this research study was a strategic choice aimed at providing an answer to how disclosure of a hidden disability is handled in the workplace.

This dissertation studied various aspects of migraines as they related to the workplace. This study explored how individuals with migraine headaches handled different workplace experiences. I examined how people with migraines assigned meanings to their interactions in the workplace. I focused only on individuals with migraine headaches. The reasons why I chose migraine have been previously stated. As I described earlier, the social construction of a migraine in a given context is contingent on the lives of the individuals or groups that are doing the constructing.

In a future study, medical sociology researchers would be able to choose to research a different type of hidden/invisible or episodic condition in the workplace. The issues of disclosure, stigma, embodiment and identity, disability, health/illness, discrimination, accommodations, etc., may remain the same; however, the individuals' perceptions, insights, and experiences, and the specifics surrounding the condition chosen, would be different.

I attempted to explore understanding of the experience of migraines in the workplace within the wider scope of the lived experience of an invisible, episodic disability. This study offers a useful report through which the personal accounts and lived experiences of people with migraines at the workplace can be examined.

The general public does not seem to be aware of the huge burden that migraine places on individuals. Below is Engrid's opinion, when talking in general about people with migraines:

> "I think that this is a group of people who at best have been ignored and at worst told that it was 'all in their heads.' And the headaches have had a substantial negative impact on their lives at best, and at worst, have devastated their lives." [Engrid, attorney and administrative law judge, female, 64]

The National Headache foundation states that: "Migraine is a disease that causes disability, harms families, and ruins lives – it is never "just a headache."…we believe that more people will come to recognize the terrible impact of these invisible diseases." ("Changes and Growth", NHF Headlines, National Headache Foundation, Spring 2011, pg. 2.)

Donna expressed frustration because of the huge impact of migraines on people who get them, combined with her belief that not enough attention is paid to this condition:

> "And the thing that makes me angry is that I think because it's something that people don't understand, and it's something people don't see, and it primarily affects women, and it's not addressed. You know, they don't put the research money into it, people are discriminated against badly, it's just kind of shoved off to the side, and people lose their whole lives, they lose millions and millions of work hours a year…." [Donna, marketing director, female, 52]

As the summaries and excerpts from Chapters 5, 6, and 7, indicate, my study demonstrated that migraines impacted not only people's careers, but also their daily lives, finances, relationships, life outlooks, and interfered with goals and plans that individuals had made.

Participants' migraines affected many aspects of their work lives: employment status and/or ability to work, which in turn affected family and social relationships. For many of these individuals, work life was a struggle between maintaining a sense of integrity (taking control, managing to overcome pain vs. not demanding too much of their bodies), the worker identity they wanted to project (that of the excellent worker / model employee), while not placing additional demands on their bodies. Many of the participants reflected on the impact that migraines have had on their overall identity as a worker in general, not specific to any one particular workplace or occupational title.

Donna talked about the impact of migraines on her work life in general:

> "I think the hardest, the thing that's taken me such a long time to realize, because it's so un-discussed…I thought for the longest time...I was so successful when I was younger, when I was… at the beginning of my career. And then got so derailed, I thought it was all me…That I had done something wrong. And to really understand, and some days it's still hard, that it really is about the headaches and the condition…it wasn't that I did a bad job… you're trying so hard to keep up for so long, with all these things stacked against you, I was always trying to catch up." [Donna, marketing director, female, 52]

As I have shown in Chapter 7, there have been a lot of changes over the past few decades. Physicians are more knowledgeable about migraines. Information about migraines is more readily available to the public, especially since the Internet has made access to information much easier. There are different types of medical treatments available now for migraine and other new treatments are being researched, as described in section 3 of this chapter. The laws protecting the rights of people with disabilities have been expanded, for example, the passage of the ADA Amendments Act in 2008, and the accompanying regulations in 2011. All of these developments suggest gains for people with migraines.

However, to some extent, the following statement remains true (and could be applied to the workplace as well):

> “…disability is still mistakenly viewed as something someone else has. Persons with disabilities are viewed as the other…” (O’Brien, 2005, p 136)

The disclosure of migraines in the workplace and its effects on employee attendance, performance, productivity, identity, and morale (well-being) is an important topic in occupational/workplace health. The findings of my study can provide direction for future research, occupational health initiatives, and policymakers. This study represents an advance in the understanding of migraines associated with the workplace.

Aside from its contribution for people within this field, my study also offers valuable information to employers, family members, policy makers, and practitioners, who seek insights relating to work and organizations.

I hope that this research study eliminates some of the myths and stereotypes associated with individuals with migraines. By extension, I also hope that it reduces some of the disparities in treatment at the workplace, by increasing the awareness of migraine as serious, episodic, chronic, neurological condition. As I stated in the implications section of this Chapter, I believe that increasing awareness is key.

"After all, any policy response to a problem is determined by how the problem is defined or framed in the first place." (Conrad & Barker, 2010, p. S74.)

I close this dissertation with a quote from Lee, who talked about the importance of bringing awareness and education to the workplace:

> "It's important to bring that awareness to the workplace so that it is recognized as an ailment it is perceived as. Thankfully, we are making strides medication-wise, and there's other therapies for that [migraines] besides medication. And I think bringing that awareness out is important. I think the more people read about it, the more educated they will become about it, and be able to help the people that they work with and understand it better." [Lee, foundation director, female, 52]

APPENDIX

Appendix A

INVITATION LETTER

Lisa Pollich, a doctoral student in Sociology at the City University of New York invites individuals who have had migraine headaches to participate in a study on the experiences of people with migraines in the workplace. If you are an individual who has experienced migraine headaches that impact on your work, or a workplace that impacts on your migraines, you might be interested in participating in this study.

I invite you to participate in this exploratory research study to share your story and insights. Currently, I am planning to conduct telephone interviews between February and May 2008. Day, evening, or weekend interviews are available. You will be interviewed by the project's principal investigator to discuss your experiences and choices regarding migraines and the workplace.

The researcher will ask questions about your migraines and treatment, your employment situation, the effects of your condition on your employment (past or present), whether or not you have disclosed your condition to your employer, the factors that contributed to your decision whether or not to disclose, any special accommodations that you requested, the reactions to that request, and perceptions of workplace identity.

Your participation is voluntary and would involve a time commitment of 30 to 45 minutes for the telephone interview. If you choose to participate and then decide to stop, you may do so with no penalty. For each completed interview, the researcher will donate $10 to the National Headache Foundation. Your identity will be kept confidential.

To participate, or if you have any questions, please contact Lisa Pollich, at workmigraine@aol.com, providing your name and a contact telephone number. I look forward to hearing from you.

Appendix B

(Department Letterhead not needed because the form is Oral Consent only)

CONSENT FORM (FOR ORAL CONSENT)

The reading of this consent form is being tape-recorded. Is acceptable to record this part of the conversation? ____ Yes ____ No My name is LISA POLLICH, and I am a student in the Sociology Ph.D. Program at The Graduate Center of the City University of New York (CUNY), and Principal Investigator of this project, entitled "Social Construction of Migraine Headaches: The Disclosure Dilemma." This is a research study of people's experiences with migraine headaches as they relate to the workplace. The study seeks to explore people's perceptions of workplace attitudes and factors surrounding employee disclosure of migraines at the workplace. I would like your permission to interview you about your experiences, and I will ask you to answer some questions about your migraines, your employment situation, and your workplace experiences.

This interview will last somewhere between 30 and 45 minutes. I will donate $10 to the National Headache Foundation for each completed interview. With your permission, I would like to audio-tape this interview so that I may record the details accurately. The tapes will only be heard by me and my advisors. All information gathered will be kept strictly confidential, and will be stored in a locked file cabinet, to which only I, and my advisor, will have access. You may refuse to answer any questions or end the interview at any time. If you choose to participate and then decide to stop, you may do so with no penalty. You may listen to all or part of the tape if you wish. You may elect to have the tape erased should you wish to withdraw from the study. The data will be kept for a period of three years following completion of the study, at which time all identifying information will be shredded/erased.

The risks from participating in this study are no more than encountered in everyday life. The benefit of your participation is that your comments will add to the generalized body of knowledge about this topic, since there is limited sociological research in this area. There will be approximately 25 participants taking part in this study.

I may publish results of the study, but names of people, or any identifying characteristics, will not be used in any of the publications. When I conduct the interview, I will therefore ask that you provide me with a "code name" that you would like me to use in my written analysis, or I could assign a code name to you if you prefer. Although your real name will be written down on the consent form, this will be kept confidential and locked away. If you would like a copy of the results of the study, please provide me with your address, and I will send you a copy.

If you have any questions about this research, you may contact me at (646) 344-7250, or workmigraine@aol.com, or my advisor David Goode, at (718) 982-3757 or goode@mail.csi.cuny.edu. If you have questions about your rights as a participant in this study, you may contact Kay Powell, IRB Administrator, The Graduate Center/City University of New York, (212) 817-7525, kpowell@gc.cuny.edu.

If you wish to have a copy of this form, I will send one to you. [Yes No] If so, please provide me with your name and address now:

Do you agree to have this interview audio-taped? [Investigator to circle one]:
Yes No

____________________________ __________ ______________________________ ___
Participant's name (in place of signature) Date Investigator's signature Date

What is the code name that you would like me to use? Choose a first name only. _____________

Or would you like me to choose a name for you? ____________________

Prior to beginning the interview, I would like to remind you that you do not need to respond to all questions.

Thank you for your participation in the study. I will now begin the interview.

Appendix C

INVITATION LETTER

Lisa Pollich, a doctoral student in Sociology at the City University of New York invites individuals who have had migraine headaches to participate in a study on the experiences of people with migraines in the workplace. If you are an individual who has experienced migraine headaches that impact on your work, or a workplace that impacts on your migraines, you might be interested in participating in this study.

I invite you to participate in this exploratory research study to share your story and insights. Currently, I am planning to conduct **in-person** interviews between May and June 2008. Day, evening, or weekend interviews are available. You will be interviewed by the project's principal investigator to discuss your experiences and choices regarding migraines and the workplace.

The researcher will ask questions about your migraines and treatment, your employment situation, the effects of your condition on your employment (past or present), whether or not you have disclosed your condition to your employer, the factors that contributed to your decision whether or not to disclose, any special accommodations that you requested, the reactions to that request, and perceptions of workplace identity.

Your participation is voluntary and would involve a time commitment of 30 to 45 minutes for the **in-person** interview. If you choose to participate and then decide to stop, you may do so with no penalty. For each completed interview, the researcher will donate $10 to the National Headache Foundation. Your identity will be kept confidential.

To participate, or if you have any questions, please contact Lisa Pollich, at workmigraine@aol.com, providing your name and a contact telephone number. I look forward to hearing from you.

Appendix D

{printed on GSUC Sociology letterhead}

CONSENT FORM (FOR **IN-PERSON** CONSENT)

My name is LISA POLLICH, and I am a student in the Sociology Ph.D. Program at The Graduate Center of the City University of New York (CUNY), and Principal Investigator of this project, entitled "Social Construction of Migraine Headaches: The Disclosure Dilemma." This is a research study of people's experiences with migraine headaches as they relate to the workplace. The study seeks to explore people's perceptions of workplace attitudes and factors surrounding employee disclosure of migraines at the workplace. I would like your permission to interview you about your experiences, and I will ask you to answer some questions about your migraines, your employment situation, and your workplace experiences.

This interview will last somewhere between 30 and 45 minutes. I will donate $10 to the National Headache Foundation for each completed interview. With your permission, I would like to audio-tape this interview so that I may record the details accurately. The tapes will only be heard by me and my advisors. All information gathered will be kept strictly confidential, and will be stored in a locked file cabinet, to which only I, and my advisor, will have access. You may refuse to answer any questions or end the interview at any time. If you choose to participate and then decide to stop, you may do so with no penalty. You may listen to all or part of the tape if you wish. You may elect to have the tape erased should you wish to withdraw from the study. The data will be kept for a period of three years following completion of the study, at which time all identifying information will be shredded/erased.

The risks from participating in this study are no more than encountered in everyday life. The benefit of your participation is that your comments will add to the generalized body of knowledge about this topic, since there is limited sociological research in this area. There will be approximately 25 participants taking part in this study.

I may publish results of the study, but names of people, or any identifying characteristics, will not be used in any of the publications. When I conduct the interview, I will therefore ask that you provide me with a "code name" that you would like me to use in my written analysis, or I could assign a code name to you if you prefer. Although your real name will be written down on the consent form, this will be kept confidential and locked away. If you would like a copy of the results of the study, please provide me with your address, and I will send you a copy.

If you have any questions about this research, you may contact me at (646) 344-7250, or workmigraine@aol.com, or my advisor David Goode, at (718) 982-3757 or goode@mail.csi.cuny.edu. If you have questions about your rights as a participant in this study, you may contact Kay Powell, IRB Administrator, The Graduate Center/City University of New York, (212) 817-7525, kpowell@gc.cuny.edu.

If you wish to have a copy of this form, I will send one to you. [Yes No] If so, please provide me with your name and address now:

Do you agree to have this interview audio-taped? [circle one]:
Yes No

____________________________	__________	______________________________
Participant's name~~)~~	Date	**Participant's** signature

____________________________	__________
Investigator's signature	Date

What is the code name that you would like me to use? Choose a first name only. _____________

Or would you like me to choose a name for you? ____________________

Prior to beginning the interview, I would like to remind you that you do not need to respond to all questions.

Thank you for your participation in the study. I will now begin the interview.

Appendix E

INTERVIEW GUIDE (LIST OF TOPICS)

Note: Items in italics were added to the interview guide either after pre-testing or as interviews progressed.

CODE NAME: ____________________ INTERVIEW DATE: ___________________

The interview will consist of seven major sections: a discussion of the employee's illness itself; a discussion of the workplace itself; the effect of the illness at work; disclosure and reactions; work adjustments sought and received; some questions about perception; and demographics.

SECTION ONE.

In this first section, I would like to get some background information on your migraine condition itself.

- How frequently do your migraines occur?
- Are you currently under treatment for diagnosis of migraine?
    - If no, skip to next question.
    - If yes,
        - What type of doctor is treating you?
        - What type of treatment has been recommended to you?
        - What type of prescription medications, if any, do you take?
- Do you have any specific "triggers" for migraine? If so, what are they?
  [will provide definition of 'trigger' if asked]
- *[LP added]: When did you get your first migraine? (age)*
- *[LP added]: When were you initially diagnosed with migraine?*
- *[LP added]: Describe what it feels like when you get a migraine.*

SECTION TWO.

In this section, I would like to ask you some questions about your workplace situation.

1.Is the workplace situation that you want to describe, based on a current employment situation or a past employment situation?

2. At that employer, please tell me:

    3.What type of business is this?

    c. What type of work did you do there?

    d. How long did you work there?

        e. Were there any specific triggers for migraine at that workplace?
    4. Is there another workplace situation that you will be telling me about, or just this one?

(Note: Question 2 can be repeated if there is more than one workplace situation.)

SECTION THREE.

Now I am interested in hearing from you, in your own words, specifically about the effect of the workplace on your migraines and/or the effect of your migraines on your workplace. Please tell me about your experiences.

(fill in)

SECTION FOUR

The next set of questions deal with disclosure and reactions to disclosure.

1. Did you at some point disclose your migraine condition to someone at work?
    a. If no, skip to question 2.
    b. If yes: To whom did you disclose? (coworkers, supervisor, HR)
2. What were the factors that went into your decision to [disclose / not-disclose.]
3. [ask only if answered yes to question 1.] What was the response to your disclosure?
4. [Repeat question 3 if disclosed to multiple levels.]
5. *[LP added]: [ask if chose not to disclose] – Can you describe to me some of the mechanisms you used to assist you in keeping your migraines hidden?*

SECTION FIVE

This section deals with accommodations, also called work adjustments.

1. At any point, did you feel that you needed accommodations (or adjustments in your workplace) in order to perform your work, due to your migraine condition?
2. (If no, skip to Section 6.)
3. If yes, what type of accommodations?
4. Did you ask for those accommodations?
5. (If no, why not?)
6. If yes, how did you frame your request for accommodations?
7. How was your request for accommodations received? (What was the reaction? – positive, negative)
8. Were your requested accommodations granted? (What was the response?)

SECTION SIX

In this section, there are some specific questions related to your perceptions about the workplace situation.

1. Were you concerned about stigma related to your migraines in the workplace? – [after answered, ask followup question:] In your decision-making about disclosure, was 'Stigma' at the workplace, a factor? [If asked, I will provide definition of 'stigma']
2. If your migraines caused you to miss work, were you concerned about your sickness absenteeism? [If yes, please describe your concerns.]
3. If your migraines had an impact on your work performance *or productivity*, were you concerned about that? [If yes, please describe your concerns.]
4. Can you describe any other workplace challenges related to your migraines (such as physical, psychological, identity, or social issues that arose while at work)?
5. Were there any best and worst experiences with bosses/supervisors or colleagues when dealing with your migraines at work, that you would like to share with me?
6. *[LP added]: Did anything "good" ever come out of having migraines?*

SECTION SEVEN

In this final section, I have a few questions to help gather demographic information.

1. What is your gender? (Male, Female)
2. What is your age?
3. What is your racial background?
4. What is your ethnic background? *[3 and 4 were later combined]*
5. What is the highest level of education you have earned?
6. Are you currently working? *[LP added: If not currently working, ask for reason for not currently working, e.g., on disability, on leave of absence, unemployed]*
7. *[LP added]: If answer to # 6 is yes, what is your job title? If answer to # 6 is no, what was your title at your last job?*
8. *[LP added]: What is your state of residence? [If more than one, use primary.]*
9. *[LP added]: How did you hear about this study?*

That brings us to the end of my questions.
Is there anything else that you would like to share with me that we haven't yet discussed?

(fill in)

Thank you very much for your time and cooperation.

Definitions (if asked)

Migraine triggers: are things that can lead to a Migraine for you. They can be factors such as foods, habits, and environmental factors, stress, sleep habits, weather changes, lighting, hormone fluctuations, odors, noises, travel, medications, or any number of things.

Stigma: [definition by MSN Encarta online – accessed 11-15-07 – http://encarta.msn.com/dictionary_/stigma.html] – A sign of social unacceptability. The shame or disgrace attached to something regarded as socially unacceptable.

Demographics: [definition by Wikipedia online – accessed 11-15-07 – http://en.wikipedia.org/wiki/Demographics] – Demographics refer to selected population characteristics often used in research. Commonly-used demographics include race, age, income, educational attainment, and employment status. Distributions of values within a demographic variable are of interest in research.

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