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A Family 'Affear': Three Generations of Agoraphobics

by

Sherri Elizabeth Green, B.A.

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Arts
Department of Sociology
College of Arts and Sciences
University of South Florida

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Dedication

I dedicate this thesis to my loving husband, Thomas Green, who continually supports my academic endeavors, insists I'm not too old, and always cheers me on; to my brilliant son, Shawn Bach, for holding my hand while I walked those first steps into academia, for staying by my side because I felt I couldn't do it alone, and for still providing me with courage and inspiration to achieve my goals; to my radiant daughter, Susan Bach, for completing our family and giving everyone a reason to smile; to my beautiful granddaughters, Bethany, Aubrey, and Daphney Bach, for whom I hope to set an example; and, to my late mother, Mary Wippel, for teaching me exactly what type of person not to be.

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ABSTRACT

My thesis explores the disabling condition agoraphobia with panic disorder across the life spans of three individuals who are related: 63 year old Grandmother, her daughter - 43 year old Mother, and her grandson - 23 year old Son. As their life stories are told, glimpses of experienced stigma, emotional management, creation of identities, and coping mechanisms are revealed. These are analyzed using the sociological theories of Goffman, Ellis, Cahill, and Davidson. The notion of nature versus nurture is most apparent in Son's story which details the effects of growing up with Grandmother's severe agoraphobic episodes. While each individual does have similarities in their experience of this disorder, nevertheless they each cope and manage in very different ways.

I begin by offering a quick look at my own experience with the disorder. I then provide a definition of agoraphobia with panic disorder, its etiology and risk factors. I discuss the prevalence of the disorder and how it affects the individuals' quality of life. I present Grandmother, Mother and Son's life stories followed by an analysis of their experienced stigma, emotion management, and coping mechanisms. Of particular interest, is Son's life story followed by his personal depiction of the evolution of his anxiety, his theory concerning causes, and his methods of control.

My methodology was selected, first, because Priestly (2003) suggests taking the life span approach is of vital importance when studying a disability. Second, while many assertions have been made about what influences the onset of this disorder; little is known about what the individuals actually experience and how it affects their emotions and social interactions. The use of qualitative methodology allows for a more in-depth understanding of these individuals' thoughts, perceptions, and emotional reactions to their illness and interactions that cannot be known through quantitative methods. In addition, this may provide us with the tools to create successful interventions that will lessen the discomfort of the individuals and will also allow us to find ways to reduce the harm inflicted by society while adding knowledge about the social and emotional experience of this disabling illness.

Chapter One: Introduction

It is a beautiful sunny day; blue skies and big, fluffy white clouds. I feel excitement coursing through my veins about beginning the interviews. My participants are enthusiastic to tell their stories and I can't wait to hear them. I have been working with an agoraphobic help group for years and have always desired to complete research on a more one to one level. All the group participants describe very different triggers for their panic attacks, different responses to these attacks, and different coping strategies. I am hoping personal interviews will provide information for the causes of these differences and provide insight into their true social experience.

Traffic is light so driving is pleasant and there's a great song on the radio. I tap the steering wheel in time with the music and sing along as I drive, uncontrollably smiling to myself. I am also thrilled to have a male participant because agoraphobia currently afflicts primarily females. While the number of participants is far too small for gender comparisons, I am hoping to gain some insight into how this particular man narrates his lived experience of agoraphobia. Quite suddenly and for no apparent reason, my chest starts tightening, my heart beat increases, and my hands on the wheel begin to sweat. I stop singing and frown; I know what's coming. I feel like its becoming hard to get a breath. My stomach becomes queasy; my mouth goes dry and swallowing becomes difficult. I slow the car, however the closer I get to the participant's house; the more and more difficult it becomes to take a breath. I pull my car into their driveway and

shift into park. I relax my hands on the wheel and close my eyes. I breathe deeply through my nose, hold it, and slowly count 1...2...3...4... ..5...6 I slowly blow the air out through my mouth and begin again. In through the nose, hold, count...out the mouth, again. Finally the relaxation breathing takes effect. My racing heart beat slows, my chest loosens, and I can take a breath.

I truly hoped I would not have a panic attack today of all days; but it is something I have little control over, yet I have learned how to make them go away fairly quickly. I refer to myself as a “recovering agoraphobic”, it makes other agoraphobics laugh; it makes me laugh, too. College has been my biggest challenge in life; I am unable to utilize avoidance. When I first began, I couldn’t attend classes without my support person. By the time I started on my Bachelor’s, I was finally able to attend classes on my own. The classes were huge and I could simply blend into the woodwork. This worked very well until I reached grad school. The small classes did not allow me to hide anymore. The first semester I frequently cried in class. It is one of my outlets for when the anxiety gets too high; the crying releases the anxiety. I often wondered if my peers and professors thought I was nuts.

I tell myself I can do this; I have done everything they’ve thrown at me in school. I grab my notebook and recorder, get out of the car on legs still shaky, walk to the door, and ring the bell. I can do this, I know I can.

Chapter Two: Agoraphobia with Panic Disorder

Defining Agoraphobia

Agoraphobia is perhaps best conceptualized as a behavioral result of reoccurring panic attacks. The main features of Agoraphobia with Panic Disorder are anxiety and fear (DSM-IV-TR 2000). Anxiety occurs in a variety of places or situations in which individuals feel they cannot escape without incurring embarrassment, difficulties, or confrontations; in essence, they feel trapped. Common triggering situations may include being in crowds, traveling over bridges, and standing in lines. Public transportation and being away from home alone also creates distress among these individuals. This high level anxiety then triggers a panic attack (AllPsych (a) 2004).

The onset of a panic attack occurs suddenly and without apparent reason, and then dissipates as suddenly as it occurs. These attacks cause the individual to experience devastating fear and anxiety as well as extreme physical and mental distress. Physical symptoms may include nausea, chest pain, racing heartbeat, lightheadedness, hot or cold flashes, difficulty swallowing, shortness of breath, shaking, sweating, and feelings of choking. Mental symptoms revolve around uncontrollable thoughts of going crazy, pervasive feelings of impending doom, being detached from oneself, not being real, or losing control (AllPsych (b) 2004; Mayo Clinic 2007). Furthermore, individuals with agoraphobia have a nearly constant fear of dying. The duration and frequency of panic attacks vary

as widely between individuals as they do among the attacks themselves. An attack may last anywhere from seconds to hours and individuals may experience several attacks a day or only one or two per year and everything in between. However, it only takes one panic attack to create a sense of fear in the individual strong enough so that the situation in which the attack occurred is avoided if possible (DSM-IV-TR 2000). Furthermore, many individuals develop anticipatory anxiety, a “prolonged state of anxious anticipation of having another panic attack” (AllPsych (b) 2004). In extreme cases, anticipatory anxiety may plague an individual during all their waking hours. Finally, panic attacks, avoidance, and anticipatory anxiety combined may result in severe Agoraphobia in which individuals become housebound and rarely, if ever, leave their homes (AllPsych (a) 2004). Treatment of severe cases is challenging primarily due to the unknown causes of Agoraphobia with Panic Disorder.

Prevalence of Agoraphobia

The number of individuals diagnosed with mental illness has been rapidly increasing in the United States for the last fifty years. In fact, the number of disabled mentally ill today is six times higher than in the 1950's. Furthermore, the United States Department of Health and Human Services reports a drastic increase, from 1987 through 2003, of over 149,000 new cases per year (Whitaker 2005). Anxiety disorders, which include agoraphobia, social and specific phobias, panic disorder, generalized anxiety disorder, and obsessive compulsive disorder, are among the most commonly diagnosed mental illnesses in the United States (Weissman & Levine 2007).

Currently, Agoraphobia with Panic Disorder “has emerged as a significant social problem” (Reuter 2006:1). It has been found to occur twice as often among females as males; generally occurring amongst white, middle class housewives. The gender difference may be a consequence of current social and cultural aspects that support the more prominent expression of avoidance coping strategies. In the United States, approximately five per cent of the population suffers from Agoraphobia with Panic Disorder. This number may soon be on the rise as more and more individuals are reporting the experience of panic attacks due to the higher stress levels of daily life. This, in turn, may lead to a negative impact on quality of life (Mayo Clinic 2007).

Etiology and Risk Factors

Recent psychological and sociological research gives a better understanding of Agoraphobia with Panic Disorder, yet an exact cause for any individual is still unidentified. Psychological research has suggested that probable causes are a multifaceted combination of genetics, traits, and life experiences. Stressful situations, extreme trauma, and prolonged anxiety have been identified as precursory factors. The key risk factors reported are the female gender, a tendency toward nervousness, and alcohol or substance abuse (Mayo Clinic 2007).

Sociological research has explored the social factors that influence the onset of mental illness and how that mental illness then affects social factors which in turn affect social structure. This aim is based on sociology’s initial

investigation into mental illness conducted by Emile Durkheim. Durkheim's (1964 [1895]) theories concerned the rules and standards defined by social groups and societies about what is and is not pathological. This varying definition, by group or society, of the "pathological" has the benefit of reinforcing the norms and values of a particular social group or society. Therefore, what constitutes mental illness is socially and culturally relative. An essential element influenced by Durkheimian ideas is "the focus on behavior" (Busfield 2000).

Several sociological studies have reported that stress factors are a major influence in developing this disorder (Pearlin 1989, 1999a, 1999b; Aneshensel 1999; Thoits 1999; Wheaton 1999; Dohrenwend 2000; Schwartz 2002). Other studies suggest that historical, gender related, and/or boundary issues are of significance (Davidson 2000b, 2001; Bankey 2001; Reuter 2002, 2006, 2007). Evidence in support of the social environment significantly influencing the onset of mental disorders has been reported (Link & Phelan 1995; Fremont & Bird 1999). Finally, Joyce Davidson (2000a) suggests that the fear involved in anxiety attacks is essentially a fear of society itself.

Effects on Quality of Life

A full blown attack of agoraphobia can render the individual housebound or even bound to a particular room. For the many individuals afflicted with agoraphobia with panic disorder who are not housebound, a reality must be created in which they function within society while outside of society's norms. For example, these individuals rarely leave their homes without a "support person"

and minimal interactions, common in everyday life, present a challenge for them. It is an invisible disability that others do not recognize until the individual has an anxiety attack in “public” giving the impression of difference which invites stigmatization.

Agoraphobia with Panic Disorder increasingly limits activities of daily living as panic attacks create learned avoidance of places and situations. Those individuals who become housebound must rely on others for all their needs. The home is the only place these individuals feel truly safe. This disorder leads to 1) depression, many times over having no control of the situation they find themselves in; 2) further anxiety as they worry when the next attack will come, what will it do to them, and if they're having a heart attack; 3) feelings of isolation, guilt, and hopelessness due to their dependence on others and not being able to take care of themselves. Numerous individuals turn to self medication through alcohol and substances to relieve themselves of these unwanted feelings. These methods only make things worse (Mayo Clinic 2007).

Chapter Three: Methods

In this study I set out to discover what individuals with agoraphobia with panic disorder actually experience and how it affects their emotions and social interactions. I asked, “How has this disorder affected the ways in which you see yourself and how others treat you?” I wanted to find out if they experienced stigma and what coping mechanisms they have developed to deal with any perceived stigma. I also wanted to discover how they cope with their disorder as well as how they cope with emotional responses concerning themselves or others. In order to accomplish this goal, I decided to utilize case study methodology in which I studied one case, a family with three individuals with agoraphobia with panic disorder. I am interested in this type of approach to research because it centers on understanding behaviors, emotions, processes, and difficulties through narratives and interpretation. It looks at circumstances and how they affect everyone involved (Stake 1995).

In order to fully investigate and understand the “entire spectrum” of mental illness, Lawton (2003:35) reports that in the study of mental health, “sociologists are going to have to be more open-minded to the use of alternative and sometimes unconventional ways of collecting data”. With that said, methodologically, I decided to develop a combination of in-depth interviewing, the go-along interview, observation, and personal experience. Prior to this process, however, I was invited to meet with the participants at their home to fully explain

the issues I wanted to discuss and how the interviews would work. The participants were encouraged to express any potential concerns. They were not coerced into participating in any way. They were, in fact, excited.

Next, in seeking formal informed consent to participate, I was aware that individuals with mental illness require special attention to ensure they are not put in anxiety producing, stressful or unpleasant situations which could be a cause of psychological harm. While the three family members were exceptionally attracted to participating, extremely interested in telling their stories, and professed they would be comfortable being interviewed in their homes and in my “going along” on routine outings, I made it clear that they were free to terminate an interview or withdraw from the study at any time without providing a reason to do so. As an agoraphobic with panic disorder, myself, I was aware that having conversations about anxiety/panic attacks may be anxiety inducing. I further offered to stop an interview, take a break, or reschedule the remainder of the interview if their anxiety increased.

After that, I wanted to ensure the complete confidentiality of the individuals and their stories. The tape recordings were erased after transcription and the tapes were destroyed. Only pseudonyms were used to identify all transcripts, and I kept my name code list in a separate locked file. Despite my precautions, however, as in any case study, the nature of the stories told may give clues to the participants’ identities. They were fully informed of this possibility as a risk of participation. My objective, and primary responsibility, during this research was to prioritize the needs and well being of my participants. I obtained informed, written

consent prior to participation. Then, at the start of each interview or observation, I explained the study once more and answered any questions. I again made it clear that they were free to terminate an interview or withdraw from the study at any time without providing a reason to do so. Once all my explanatory and ethical goals had been met, I began my research.

First, the informal in-depth interviews were conducted in the manner of guided conversations. They were tape recorded and transcribed with the use of pseudonyms. This allowed the participants to tell their stories in their own words, using their own language, and personal, subjective perceptions. The interviews provide biographical information, perceptions of stigma, development of coping mechanisms, and experienced emotions. Furthermore, they afford a glimpse into the participants' social interactions and their perceptions of these interactions with others. Finally, they recreate the participants' lived experience with this disorder. In conducting these interviews, I gave full leeway to the participants to go off on tangents. This may have increased the amount of time needed to complete the interviews, but it afforded a much more relaxed and productive atmosphere for the participants with minimal anxiety. Grandmother was quite the story teller, but, at times, hers was a lengthy rhetorical narrative that provided nominally. She had to be frequently guided back to responding to the questions asked. Mother was the least forthcoming in the beginning, but then gradually opened up as the project progressed. Son was the most open - discussing without hesitation his experiences with his disorder.

Second, the use of the go along interview, which combines interview and observation, permitted me to observe the participants “while accessing their experiences and interpretations at the same time” (Kusenbach 2003:463). These interviews required hand written notes in addition to being tape recorded and transcribed; notes and tapes were destroyed after transcription. These interviews provided a distinct picture of everyday life and a view unique to individuals with this disorder as leaving their home is one of their most difficult accomplishments. I made use of the “natural” go along by following the participants on outings in familiar environments. These situations were not contrived; they were regular outings which occur normally in their lives. Grandmother’s choice for the go along was to spend the day at a series of garage sales. I joined Mother for her weekly grocery shopping. I went to Walmart, the video store, and Sonics with Son.

Third, I conducted observations of the three participants as they interacted with one another in their home. This entailed detailed field notes and tape recordings to be transcribed with notes and tapes destroyed post transcription. I felt that in interviews, participants do not engage in their normal activities and that during observation it is difficult to determine their interpretations of their experiences. Therefore, I conducted both which provided a more rounded picture at the home front. The go along interviews provided a better picture of their lives in public and observational data of their behaviors and interactions with others. The findings presented in the following Chapters make use of all of three of these sources of data.

Finally, I am an individual with agoraphobia with panic disorder. I have experienced panic attacks and anxiety for 35 years. I have had severe agoraphobic episodes in which I was house bound from days to months. Acquiring a post graduate degree has been terrifying at times, especially the requirement to speak in front of others. However, I have worked very hard to recreate my own identity. I will not allow this disorder to rule my life. I have a shared experience with my participants, which has given me insight into their experiences as well as understanding, but my experience with the disorder differs as greatly as it does between my participants.

Chapter Four: The Participants – Grandmother, Mother, and Son

To begin my story of discovery, I would like to introduce the participants. As is customary in any good story, the reader needs to get to know the main characters. In this story there are only four main characters: the three participants and myself. In qualitative research it is important to remember that as the researcher, every analysis and interpretation I make will be subjective. No matter what methods I utilize to remain objective, my thoughts, feelings, experiences, and perhaps more importantly, my opinions, will trickle into everything I see and hear. Therefore, I, too, am a main character. The three participants are members of the same family; three generations twenty years apart. There are two females, Grandmother and Mother, and one male, Son. The supporting characters include Mother's husband, Son's wife and daughter, and a variety of individuals we meet on our go along interviews.

In describing my main characters, I use a live span approach. Priestly (2003) suggests that this approach is an excellent way in which to bring to light the dynamics of disability over the years as it highlights issues of stigma, coping strategies, and emotional management. Priestly (2003:4) suggests that viewing disability across the life span helps to examine "the ways in which disabled lives are understood, organized and governed within societies", and avoids "an oversimplification of disabled people's collective experiences and the marginalization of issues" (2003:33).

Furthermore, the study of mental illness based on the lifespan approach to disability allows for a better analysis of the social constraints faced by individuals with this disorder (Mulvany 2000; Lester & Tritter 2005). The detailed analyses obtained of individual experiences are of vital importance to the sociology of mental health. The occurrence of exclusion from main stream social activities experienced by these individuals can create social disadvantages and a feeling of being oppressed. This approach allows for “examination and identification of the social barriers that deny or restrict access for people with a serious psychiatric disability” (Mulvany 2000:585). Of particular interest in this study is the fact that the lifespan narratives of the participants are interwoven. Thus, we hear three voices telling a shared family narrative – a story which has different “truths” for the three characters.

The First Generation: Grandmother

Grandmother is a 63 year old Caucasian who looks and dresses much younger than her chronological age. Grandmother pretty much rules the roost on all matters in her household and she insisted on being interviewed first. She did not, however, want to start with the in depth interview as I had planned. She wanted to begin with the go along interview. Grandmother loves to go to garage sales and, for the most part, no one wants to take her. Mother and Son claim she is too embarrassing in public. So, naturally, Grandmother wanted me to take her to garage sales.... for four hours on a Saturday morning. She had the addresses all written down and mapped out when I picked her up; she was very excited. It was a unique experience for me. I am, what I would call, too polite, to say and do

the things she did. She was, as always, over the top. She spoke loudly, cracked jokes, and stated opinions, usually negative, about the people and their wares. She told me, “You never pay the price they ask...you have to jew ‘em down. They expect you to dicker with them.” At first the responses of others at the garage sales were fairly positive. They laughed at her jokes although they did appear somewhat uncomfortable at her forward manner. As the morning wore on, though, Grandmother stopped trying to please others and began making negative comments about the others and their wares such as: “Have you ever thought about dieting?” or “What a bunch of junk. Do you actually expect people to pay for this shit?” The response of others at this point ranged from vaguely disguised anger, as they whispered to each other about her, to visible outrage over her words. At one sale, she was asked sternly, yet politely, to leave. She laughed all the way to the car.

About half way through the morning, I started waiting in the car. I was frazzled. My own identity was being threatened. Was I in jeopardy of having a panic attack myself? Despite this discomfort, the go along interview provided fascinating insight to Grandmother’s response to others and reactions of others to her. It also provided a more relaxed environment for conversations about her disability and her feelings about her interactions with others.

In our conversations during the “go along” interview as well as in the in depth interview conducted at home, Grandmother tells us she has “suffered from this illness for fifty years now”. She explains that it started when her family moved to Tennessee when she was thirteen. She experienced extreme culture shock

and was made fun of in school because she was so smart and “talked proper”. In addition, she believes that the intense fear she felt when riding in the car while her father drove drunk and her mother prayed they’d survive intensified the effects of the move and increased her risks for the disorder. Grandmother discloses that her natural mother died during childbirth when Grandmother was only two years old. She tells us that her step mother was the only mother she knew and, as such, does not refer to her as a step mother.

A divorce when Grandmother was twenty two, leaving her to raise her daughter alone, led to her first full agoraphobic episode. She was unable to go to work or stores, relying on her parents to bring necessities. She deteriorated to the point that she could not leave the house at all. Her father “forced” her to go to the hospital and check herself into the “psych ward”. Grandmother reveals:

My father was never understanding of what I was going through and had little patience for it. He always told me, “It’s all in your head,” and I would tell him, “You’re right, that’s exactly where it is”. My daughter wasn’t allowed on the psych ward, so my father would bring her where I could see her from my window and have her wave. It broke my heart. I was there for two long weeks.

Grandmother informs us that this was in the early sixties and the medicines the doctors prescribed were mostly to keep her from feeling the effects of the panic attacks. They started her on muscle relaxants to keep her chest, neck, and back from “feeling tight” and tranquilizers to keep her “calmed down”. This permitted Grandmother to resume a more normal lifestyle through getting a new job, at her father’s business, driving again, and caring for her daughter.

Despite his lack of understanding, Grandmother's father filled the support person role enabling her to leave the home to work. She was fired for missing work several times, and subsequently rehired, until she felt stable enough to get a job away from her father. However, her new boss quickly became a father figure and filled the support person role.

[Name] was like a father to me. I could go to him with any problems I was having. He helped me with money, bought things for my daughter, and understood when I was having trouble with my illness. He even helped me get my first house on my own and a new car.

Upon moving to a new area, Grandmother found a new doctor. He prescribed newer medications, although of the same type, which Grandmother insists is what kept her going. In addition, the new doctor was an osteopathic doctor and provided neck and back manipulations similar to a chiropractor. Grandmother did not go a week without seeing him for over twenty five years; in rough times, she saw him two to three times a week.

Also during this time, Grandmother married, and later divorced, an alcoholic man twenty five years her senior. She explains that she "had" to marry him due to a neighbor reporting her for having a man she wasn't married to spend the night. She feared they would take away her daughter and thought if she had a husband the authorities would leave her alone. Moreover, it began a twenty year "feud" with this neighbor and her family. Grandmother entered what she termed her "Hawaiian Phase" which included redecorating the house and learning Hawaiian dances. She found a steel guitar player and performed at bars.

Once divorced, she began dating a man she worked with. He was four years younger. She married him a month before her twenty eighth birthday. Little did she know that another full agoraphobic episode was in her near future. Her mother, to whom Grandmother was very close and upon whom she relied, died suddenly. Following the funeral, Grandmother took to her bed and did not leave for many months. Once again she was told it was all in her head. This time it was her new husband that did not understand what she was going through. Her daughter was nine years old, by now, and Grandmother decided to have Mother help her hide her illness. She had her daughter do all the cooking and cleaning before her husband got home so he wouldn't know she wasn't doing it. She told Mother it would be their little secret. It didn't help their relationship much and Grandmother states that husband #3 began an affair with the wife of a friend of theirs. She explains further that she found out when he became ill with fever and talked about it during his delirium. However, this was the pivotal moment that brought her out of her severe agoraphobic episode:

Anger has always provided a sudden way out for my illness and especially for panic attacks. The anxiety quickly dissipates if I get really pissed and when I heard him talking about that bitch, I got extremely pissed.

Once out of her bed and functioning again, Grandmother divorced her husband and went back to work. Again, she found a job that provided a father figure in her new boss and soon came to rely on him heavily. She went to him for advice and money problems, and, he too, was understanding of her illness and

made allowances for her. As with her other jobs, this made Grandmother unpopular with fellow employees. She started working a second job, as well. She said she needed extra money to support her daughter. Her night job was bartending and before long she was dating again. She fell in love with a drummer from the band that performed at the bar and in next to no time married husband number four. She continued working two jobs until her father passed away when she was thirty three.

The loss of her father did not bring on a severe agoraphobic episode. Grandmother tells us that she never got over being angry at her father for divorcing her mother eight years earlier. Her father had some money and owned property. It was divided between Grandmother and her two brothers. Grandmother used the money to remodel her home, build an addition, and put in a swimming pool. Her daughter's teenage years were one of the most normal periods in Grandmother's life. Grandmother began attending her daughter's school functions such as band concerts, football games, and parades. She got along well with her daughter's friends and threw frequent parties for "the kids". At a home coming game, she dressed in a skunk costume and marched around the football field with the marching band.

At thirty five, Grandmother divorced husband number four. She quit her day job but continued bartending. She was having a lot of trouble with panic attacks. She decided her medication wasn't enough and began to self medicate with alcohol and marijuana. She dated several men, once having three dates in

one night. She made numerous trips to the emergency room because her chest hurt so much she thought she was having a heart attack.

The emergency room doctor gave me a shot to calm me down. He said there was nothing wrong with my heart and that it was just panic. I was annoyed by the way he said 'just panic', if he had to experience what I had to go through, he wouldn't say just panic. I told him the shot wasn't doing any good and he said I gave you enough to knock out a horse and I said, well you better give me some more.

Between the anxiety and the alcohol, Grandmother soon developed an ulcer. She tells us that the ER doctor told her, "Finally, you actually have something physical wrong with you". They told her to stop drinking so Grandmother switched to cream drinks like Pink Squirrels. She felt the cream would "coat her stomach" much in the same way milk does and it would be okay. It wasn't, and the ulcer got worse. Grandmother quit drinking, "except for some wine now and then"; however, she increased her marijuana usage.

The panic attacks were so frequent that, once again, Grandmother was unable to go to work. She turned her home into a retirement home specializing in mental patients. It was similar to what is now called an Assisted Living Facility. At that time, individuals referred to as mental patients included those with Alzheimer's and dementia. She kept her new master bedroom and bath and changed the dining room into a bedroom for her daughter. She had six residents to start with and hired an African American maid to help with the cleaning and laundry. The business provided Grandmother with extra cash and the maid invited her to her home to play a card game called Tonk. Tonk was a gambling

card game, similar to Gin Rummy that was played predominantly in African American communities. Grandmother went every week, made friends, and found a new drug dealer to supply her with marijuana.

These new friends invited her to a gospel concert and she loved the band so much she threw a pool party for them. She began dating the drummer who was fifteen years her junior. Some of her daughter's friends smoked pot also, so she invited them over to try the new, "more potent" pot. She fell in love with the young drummer and they were married when she was thirty six. She rented a house across the side street which was on the main road and rented out her bedroom to two more residents. She added another bedroom which could be rented at a higher price because it was a private room. Unfortunately, this was the late seventies and people were not very accepting of interracial marriages. The newlyweds received a bomb threat in their mailbox. Grandmother moved to the house behind her home because it was more secluded, but it did not deter the harassment. Someone burned a wooden cross in their front yard.

All of this frightened husband number five quite a bit so Grandmother moved them back home to the master bedroom. Her husband toured with the gospel band and this was a source of great anxiety for Grandmother. She was always positive he was cheating on her with a "groupie". She did everything she could to stay closely linked to the band. She bought [Name] new drums, she designed and made stage clothes for the band members, but she could not go with them. Due to her agoraphobia, Grandmother did not travel anywhere. Even when her daughter was a child, when they went "on vacation", she simply drove

to a part of the city her daughter didn't recognize and stayed at a motel with a pool. As her panic attacks and anxiety worsened, she fought more and more with her new husband as she continued to accuse him of wrong doing. Between the fear and stress of racial threats and Grandmother's accusations, [Name] left on a tour and never came back.

Shortly after, Grandmother's daughter won a full scholarship to a college in Illinois. Grandmother panicked:

I told [Name] (Mother) she couldn't go. It was too far away. I needed her to help me run the business and I needed her to take care of me. I couldn't have her so far away. Why don't you go to a college here? I said. It wasn't fair to me, I said, and she stayed. In Florida, anyways, but she still went to college, in Miami. She didn't stay to help me...she...uh...she abandoned me in my time of need. [Grandmother is crying] I lost my business and my house because of her.

Grandmother couldn't run the business due to her agoraphobia and panic attacks. She couldn't get a job. She sold the house and, with no where else to go, she forced herself to travel and join her daughter at school. The college provided her with a room to stay in for a couple months and in that time Grandmother convinced her daughter to go home with her. They rented a house and got jobs together working at the same restaurant. Grandmother cooked and Mother waitressed.

They saved their money and rented a better house, but, yet again, Grandmother suffered a severe agoraphobic episode and was unable to work. After Mother became pregnant, Grandmother insisted the only way for them to

survive was to open another retirement home. When they found a suitable house, Grandmother approached their landlord for a loan for the down payment. One month after Son turned a year old, they opened their new retirement home. The home became profitable. Mother, however, continued to hold outside employment due to Grandmother's uncontrollable spending. The spending eventually led to Daughter obtaining a second part time job. Grandmother grew tired of Mother's constant complaining about her spending and decided to go back to work.

We only had one car, I couldn't drive anymore, and I couldn't work unless I had a way to escape so I made [Name] (Mother) drive me to work and wait in the parking lot. [Laughter] She had [Name] (Son) with her and he about drove her nuts. [Laughter] At first, it was only part time in the mornings, but it built up to full time. [Name] really bitched then. I know it might have been hard on them, but I had to get my own money and I needed their support.

Mother had to give up her second job once Grandmother began working full time. When the company changed locations, Grandmother stopped working and up till now, has not worked again. Mother encouraged her to apply for Social Security Disability and it was granted. This allowed Grandmother to begin seeing a psychiatrist and obtain the latest medications for anxiety. Grandmother entered what she refers to as her "Biker Phase". She befriended the head of a biker gang that lived across the street, attended their parties, and dressed in biker fashion, i.e. tight jeans, leather jackets, etc.

After nine years, they sold their property to a developer and bought back the house Grandmother sold when Mother went to college. Grandmother was happy to pay cash for the house because “no one could take it from me ever again”. There was even money left over which allowed Mother to work only part time to pay for food and utilities. Grandmother entered her “Vietnam Veteran Phase” which entailed attending meetings for supporters, wearing POW tee shirts, and letting homeless veterans stay at their home. She began going out to karaoke bars and found one that was a “private club” with a \$2 membership fee. Grandmother spent the surplus money quickly and Mother had to work full time.

[Name] (Mother) didn't like my new friends from the club and she especially didn't like me taking [Name] (Son) along. But, these people loved me and weren't always bitchin' at me and in a bad mood. [Name] (Mother) never wanted to do anything fun anymore and rarely supported me with my illness.

Grandmother gave Mother's bedroom to the KJ (karaoke jockey, i.e. a disc jockey for karaoke) she met at the karaoke club so Mother bunked with Son. Then Grandmother moved another man in and he bunked with Son, so Mother made a small room at one end of the family room behind an entertainment center. Grandmother moved a woman (with whom she shared her bedroom) into the house. She moved another couple in as well. When Mother complained, Grandmother kicked her out and was furious Mother did not continue paying the bills. Son stayed with Grandmother:

She [Mother] moved in with some bum she had been dating and she knew my disability would not be enough to live on.

She refused to pay the utilities and didn't trust me to give me money. She would go to the store and buy food for us and the dogs and that's it. She said she had her own bills to pay and why should she pay the bills for me when I kicked her out. So, I sold all her stuff she couldn't take with her.

Grandmother's new friends eventually found places to live. Son moved in with Mother, and, at 58, Grandmother had a radical hysterectomy. By then, Mother had rented her own home with Son and Grandmother appealed to her to let her move in since she would not be able to care for herself after surgery; Mother finally agreed. Grandmother lost her house to foreclosure because she had mortgaged it to loan her brother money to start a business. After two years, they were once again able to buy a home of their own; the home they all share today.

The Second Generation: Mother

Mother is a 43 year old Caucasian woman who looks close to her age and appears tired. She is currently married and works outside the home. With Mother, I conducted the in depth interview first and then joined her for her weekly shopping trip. One of the most interesting aspects of the go along process was watching the participants transform into their chosen "public" identities. Mother's transformation was the most dramatic. Riding in the car to the store, she was smiling and laughing. She was pleasant and engaging during our conversation. Upon entering the grocery store, however, her entire demeanor changed. She appeared to be a totally different person. Her pattern of speech, walk, and facial expressions changed. She began her breathing exercises almost immediately and once she began shopping, she stopped talking to me. She displayed anger if

others got in her way or if an item was not stocked and she swore under her breath most of the time. The response of others to Mother at the grocery store was clearly avoidance. She did look kind of scary. From the look on their faces, even clerks thought twice about offering her help. Again, as a person with agoraphobia, I found my own identity somewhat threatened by Mother's actions and the reactions to her from others.

In describing the lifespan of her experience with agoraphobia she begins by saying:

I remember my first panic attack vividly. I was sixteen and late for class. Just as my hand was about to touch the door knob, my chest tightened up hard and fast. I couldn't breathe. I knew exactly what it was cause Mom had been telling me about them all my life...a panic attack. Knowing doesn't help, though. Nothing and I mean nothing, could have made me open that door at that moment. I was paralyzed with fear. Finally, I was able to turn and flee to the restroom where I remained until the bell rang ending class and then I went home.

Mother tells us she has no idea what brought on the disorder other than perhaps being "genetically predisposed and life-long exposure". After more than twenty five years with the disorder, Mother explains that while she cannot control it, she does not allow it to control her, "most of the time, anyways". Since her first panic attack, she has researched the disorder, kept up with current and in-trial medications and treatments, and developed ways to deal with anxiety that allow her to continue to function in a more normal manner. Mother states she does not take any medication for the disorder, however, due to anxiety regarding taking pills. She feels this stems from seeing her mother take "several pills, several

times a day”, while she was growing up. Mother further states that this may also be an issue of control. Many agoraphobics are what would be referred to as “control freaks”. It is a coping mechanism that allows them to control their environment to avoid anxiety and panic attacks.

After that first panic attack, Mother tells us her life was not affected very much. She continued to participate in many extracurricular functions such as the debate team, band, and track. She states the only obvious effect she noticed was an “obsession with punctuality”. Mother performed in solo competitions, the Senior Talent show, and filmed commercials for a mass media project. She agreed to join her boyfriend at a Christian college in Miami after turning down a full scholarship as her mother [Grandmother] requested.

Granted, I was afraid after that first panic attack. I didn't want to become like my mother...dependent on pills and not able to travel anywhere. I was really terrified of an agoraphobic episode like my mom has...I was 16 and had my whole life ahead of me and things I wanted to do.

The first agoraphobic episode Mother remembers her mother having was when Mother was nine years old and in the fourth grade. Her grandmother had died and her mother simply stayed in bed. Mother tells us that her mother set up a checking account for her so she could do the shopping. Everyday after school, she would clean the house and cook dinner for the family. Grandmother had told her they had to keep it a secret from Mother's stepdad. So on Saturday mornings while stepdad was at work, Mother did the grocery shopping and the laundry.

I remember the first time I went to the grocery store. I rode my bike right into the store...I didn't know you weren't allowed to. The manager pulled me aside and explained... he showed me where to put my bike. I thought the old ladies were mean to me, always bumping me and fussing at me about what I thought I was doing. But the meat man was the nicest...he taught me how to choose nice pieces of meat.

Since the age of five, Mother had been doing the dishes and learning the basics of cooking. The rest she learned from cookbooks. Mother had to bake a lot; her stepdad ate a whole pie or cake every night for dessert, and grew to enjoy it. Later, in high school, she would win first place in a cake baking contest.

Mother made straight A's in school and had minimal friends. Her best friend lived next door. At the age of twelve, Mother got her first job as a busgirl in a restaurant. She worked in the evenings and rode her bike. Mother tells us Grandmother was divorced by then and working two jobs, so she wanted to help out. In the summer, Mother started waitressing and bought her first car for a hundred dollars from her boss. She states, at this time, her mother didn't drive much and Mother drove the car on back roads to run errands. At thirteen, Mother bought her first motorcycle. Mother rode the motorcycle to school because she didn't like riding the school bus and also so she could occasionally skip school.

Mother was a typically active teenager: attending parties, swimming, bike riding, and roller skating. Although she had played the keyboards since she was five, she joined the school band to learn to play the drums. Once Grandmother opened the retirement home, Mother had additional home duties. Mother assisted the residents with dressing and cooking breakfast every morning before

school. After school, she cleaned, helped cook dinner, and assisted the residents with showers. Mother got pleasure from working with the elderly residents and tried to make their lives happy. She decorated for all the holidays, created a weekly fast food night, and held a theme party once a month.

I think their favorite party was the luau. We had a hula contest and I got a grass skirt for the contestants to take turns wearing. Everyone wore leis and I cooked Hawaiian food and played Hawaiian music. It was a blast. They were like my extended family...I truly loved them.

Mother admits it was a little rough living in a dining room changed into a bedroom as a teenager. She didn't want her friends to see her room; she felt she would be embarrassed. After the remodelling, Mother had had two rooms: her bedroom and her "play" room where she entertained her friends. With the addition of the pool, however, Mother was able to hold lots of pool parties. On her sixteenth birthday, Mother got a set of drums and a new motorcycle. She graduated high school with honors, at seventeen.

Graduating high school was the most traumatic experience of my life. I loved going to school...all my friends were there...all my activities and interests were there. I felt lost and alone. Yes, I was going to college with my boyfriend, but it wasn't where I wanted to go and I felt guilty about my mom. I didn't know what I was going to do.

Mother had to work full time to pay her college bills and was always behind. This and the strict rules and regulations of the Christian school created a

great deal of stress and the beginnings of depression. Additionally, Mother was required to volunteer for a suicide hotline, which added to her depression, and to teach a Sunday school class. Both reduced the number of hours she could work and make money. Shortly after the second semester of Mother's first year began, Grandmother showed up without warning. The college gave her a room to stay in, but Mother had to buy the food. Grandmother wanted Mother to come home with her and get a place to live together.

I was actually relieved. I couldn't take the stress anymore and I wanted to be home more than anything. Mom had lost the house, but I would still have the familiarity of home. My boyfriend was pissed and I didn't care...I was kind of sick of him...he made me feel pressured all the time. This is when we should get married and this is how many kids we'll have and when we'll have them and on and on. Also I was sick of that school's strictness...and I was having panic attacks every week. I agreed after a couple months and we went home. [Sigh]

Mother and Grandmother rented a small, two bedroom house and Mother went out to find a job. Mother soon discovered she had a hard time going in to apply for jobs and if she did make it in, froze up during interviews and was unable to respond to questions. By this time, Grandmother was working as a cook in a restaurant and got Mother a job as a waitress. Mother admits it was easier to go to work with Grandmother as her "support person". Mother, who had first tried alcohol when she was 12, began drinking heavily.

What can I say...it calms you. You don't have panic when you're buzzed. I didn't want to think about the implications. I didn't want to be afraid of what was coming or worry when I'd have another panic attack. I started goin' out three four times a week. Cripes, Mom [Grandmother] had stopped being

*able to work again and I had to work two jobs to pay the bills,
I deserved to be able to relax once in a while.*

It was at her second job, running a snack counter in a bowling alley, that Mother met her first husband. Mother discloses she thought of him as her “Prince Charming” and describes him as “handsome and foreign, intelligent, and rich”. Mother fell head over heels in love. They had a whirlwind romance which included trips out of town to disco clubs and attractions like Disney World. [Name] proposed to Mother at midnight on New Year’s Eve. He told her he was leaving for college in Virginia in January and wanted them to be engaged so Mother wouldn’t “slip away”. In February, Mother found out she was pregnant. She immediately quit smoking and drinking. [Name] (Fiancé) was not supportive.

Mother continued working two jobs as long as she could and was promoted to warehouse manager at an art supply company, her day job. The promotion included a raise allowing Mother to quit her second job. She was embarrassed about being single and pregnant and stopped going out socially. In her eighth month, Mother could not perform her duties at work and took a leave of absence. Her boss’s partner provided her with assembly work she could do at home. Four days before her 20th birthday, Mother gave birth to an 8 pound, 11 ounce baby boy, Son. Grandmother wanted Mother to use her last name for Son so she could tell everyone he was hers since Fiancé wasn’t around to sign the papers, but Mother refused and gave him her last name.

*It didn’t stop my mother from telling her in-laws from husband #5
that the baby was hers, though. She said that with his dark hair*

he looked more like her anyways. Whenever we were at a store and someone asked who the mother was, she always said it was her. I really got tired of it, but that's my mom...anything to get attention. It was easier to just ignore it cause there was no stopping her.

Mother returned to work when Son was two weeks old taking him with her. After three months she started going out socially again, drinking, and smoking. Mother struggled to make ends meet working only one job.

Finally, with a loan from their landlord, Grandmother and Mother purchased a big two story house to convert into a retirement home. Mother cleaned the house, painted it inside and out, and purchased furniture. Grandmother developed relationships with social workers for referrals. Within one month they had their first resident and had no vacancies by the end of the second month. Mother served breakfast, made the beds, and cleaned the bathrooms before she went to work. She came home on her lunch break to serve lunch and served dinner after work. She did the laundry and shopping on Saturdays. Despite making good money from the business, it wasn't long before Mother had to get a second job to make ends meet because of Grandmother's uncontrollable spending.

Mother changed jobs frequently, never staying longer than a year or two if that long. She was able to work a variety of jobs and called herself a "Jane of all trades". Mother describes applying for jobs "torturous" but it was not enough incentive to keep her at jobs longer. Mother tells us that it was surprising how easily she was hired after all the trouble she went through just to go in and fill out

an application. She is unable to say exactly what it is that allows her to stay at a job or what it is that makes her leave. She calls it a “comfort level” and states that if that comfort level is violated, she will walk off a job without hesitation. She says it more often has something to do with co-workers. Mother tells the story of one job she was hired for and never even showed up. “By the end of the interview, my comfort level was gone and I never went back...I couldn’t”

Then Grandmother suggested she take the Postal exam. Mother scored very high and was hired almost immediately. The Post Office paid well and offered excellent benefits. The only downside was the hours. Mother went to work at 6 PM and got off at 4 AM, there was always 2 hours mandatory overtime. She continued her schedule of work with the business. When Son was about two years old, his father came back. Fiancé and Grandmother insisted Mother get married. Mother wasn’t sure she wanted to anymore, but she gave in. The relationship was rocky from the start. Her new husband felt he didn’t need to work because Mother’s job paid well, the business made good money, and his father sent them \$2000 a month.

Mother did not handle this very well. She felt she was the sole supporter of the entire family. Husband put the \$2000 in a savings account every month and refused to touch it. Mother began having panic attacks regularly and going shopping was difficult. With the exception of work, whenever Mother was in public, she began wearing dark sunglasses at all times.

I can’t explain it...it was something about the eyes. I felt if people could not see my eyes, I would be all right. I just

couldn't go around a lot of people unless my eyes were hidden. I wore those big plastic ones like the old people wear over their glasses that wrap around the sides and top...I was totally protected.

The marriage deteriorated quickly and Husband decided to go to a college in Texas. Mother discovered, once again, that she was pregnant. Upon his arrival, Husband obtained a lawyer and sued Mother for divorce, child custody, alimony, and child support. Mother took their custom made wedding rings, sold them, and hired her own lawyer. By the time the sheriff tried to serve her divorce papers, she was divorced. Mother was feeling truly awful and went to see her doctor. He told her she was suffering from acute anxiety and sleep deprivation. Mother had a miscarriage and a break down. She awoke one morning covered in hives the size of oranges and her eyes were swollen shut. The doctor gave her Benadryl shots to no avail. He could find no cause for the hives and told her it must be her nerves.

After four years with the Post Office, a record for Mother, she took a leave of absence and eventually resigned when she realized she no longer had the strength to force herself to go to work. At 26, it was Mother's first severe agoraphobic episode.

I always had to force myself to do things like go to work. I refused to let the panic attacks keep me from doing what I needed to do to take care of my family. But when the anxiety manifested in physical form, I was already weak from lack of sleep and stress, and I didn't have the strength to force myself anymore. I told my mom [Grandmother] she would have to stop spending so we could live off the business.

Mother also forced herself to do things for Son. He was becoming especially outgoing and was a “people magnet”. Mother explains she didn’t want him to be influenced by, and therefore learn, her disorder. Mother states she took him anywhere he wanted to go and, although she wore her dark glasses, forced herself to endure crowds of people and not to run away when he attracted people. Mother tells a story of when she took Son to see the Clydesdale horses near their home. The Rowdies [professional soccer team] were practicing outside the arena. Suddenly, the captain of the team runs over and asks if he can hold her son. Then he calls the whole team over. Mother states her panic level was at a “10” (on a 1 to 10 scale) by then, but she held her ground. She didn’t want Son to miss this opportunity to meet professional sports players. Son had his picture taken with the captain and then they went home.

Mother states they did pretty well for a while and she slowly recovered from her agoraphobic episode. Sadly, the grocery store remained her arch nemesis as the place that caused the most anxiety and panic attacks for her. She felt she had to be the one that went because Grandmother would spend too much and not get what they needed. Mother admits she once spent four hours wandering the store without getting what she went there for.

I went up and down the aisles, but I couldn't think. I kept re-reading my list, but I couldn't find anything I was looking for. I began to worry what the people thought about me...I had been there such a long time and there were only a couple things in my basket. I was confused and felt dazed. I finally gave up and went home to have my mother repeat

her usual phrase when I failed at something, "Can't never did do nothing". I thought it sure must be easy for the one who never has to do anything.

Grandmother got tired of not spending and got a part time job. Mother had to drive her to work, with Son, and then wait in the parking lot until she got off work. Mother states it was really annoying being so "supportive", but she tried to have fun with Son. There was a field and railroad tracks nearby so they would play in the field and pick flowers. They collected the sparkly rocks by the tracks and had picnic snack times. During this period of her life, though, Mother gained quite a bit of weight and grew more and more uncomfortable around others. She developed what she refers to as her "bitch persona"; she felt it was a useful tool to keep others away.

Grandmother stopped working when the company changed locations and Mother suggested she apply for disability. Their business property was sold to a land developer. They bought back the house that Mother had grown up in and after a couple months, she was able to start a part time job. Between Grandmother's disability check and money left over from the sale of the property, Mother only needed to work for food and utility money. However, the left over money disappeared quickly and Mother was forced to return to full time work.

I got a letter from the bank saying one of my checks had bounced. I said that's not possible and went to the bank. The money was gone...all gone...and she (Grandmother) had nothing to show for it. It was sixteen thousand dollars. I was just sick...I couldn't believe it. The bank account and the house were in both our names. Mom said we had to do that to protect ourselves from our exes, but I just didn't know

anymore. I couldn't trust her anymore. She had always told me I couldn't survive without her, but I was really wondering if I could continue to survive with her.

While Mother worked, Grandmother began frequenting a karaoke bar and took Son with her. This was a cause for many arguments. First, due to Son's age, second, the money spent, and third, the people Grandmother brought home with her. Grandmother moved people in while Mother was at work until Mother ended up sleeping on a pallet she'd made on the floor behind an entertainment center. Mother had had it. She angrily informs that all her clothes were in a laundry basket and she used a cardboard box for a night stand on which to place her alarm clock. After many heated arguments, Mother states that Grandmother "kicked me out and then expected me to keep paying the bills for her so she could go out and blow her disability check".

It was the biggest mistake of her (Grandmother) life...letting me find out that I could make it on my own. Sure, I stayed with some friends until I saved enough money to get a place of my own, but I did it...on my own. It hurt so much that [Name] (Son) stayed with my mom, but it didn't take long before they were arguing all the time and he came to stay with me. We rented a little house close to his school and were doing fine...we were so happy. I got a new job. I had fewer panic attacks and was more relaxed...for the first time in years really.

Mother tells us that even though Grandmother asked to move in with them many times, she always declined. She felt they were very happy and doing well on their own. Son had lots of school friends that hung out at their house and they gave parties. Mother was experiencing a freedom she had not truly experienced

before and didn't want it to end. Nevertheless, when Grandmother was scheduled for a surgery that would require someone to take care of her post op, Mother gave in. She states she would have felt guilty if she did not take care of her mom, "family takes care of family...period". Since their little house was only a two bedroom, Mother once again gave up her room. She decided they needed a bigger house and got a second job to save up a down payment.

Mother found a HUD home that only required a \$2000 down payment with three bedrooms and won the bid. When they first moved in, they did not have a refrigerator or stove. They kept their food in an ice chest until Mother could buy a used fridge. Mother continued working a second job until she had completed furnishing the house, fixing it up, and had a "small nest egg". Then she informed Grandmother and Son that she would no longer work two jobs, she was tired and getting too old to support everyone. She worked a record six years at one job, met her current husband there, and continues to share the HUD home with her family.

The Third Generation: Son – The Evolution of Anxiety

Son is only 23 years old. His life narrative is just beginning and the lifespan experience with agoraphobia that he describes is unfolding as he tells his story. At the present time he is married and has a child. They all live in the family home with Grandmother and Mother. As in the case of Mother, we began with Son's in depth interview. I then accompanied him on a go along to Walmart, the video store and Sonics. He combines his errands into one trip so as not to

leave the house more often than is necessary. Son appeared to be both recognized and well liked in these places.

Son reports his first panic attack occurred between the ages of 14 and 15, yet he recalls experiencing anxiety and depression as young as 6 or 7 years old. Son tells his story openly; much more deeply and vividly than either Mother or Grandmother. With Mother and Grandmother it feels almost as if we only scratched the surface of what they actually go through in their daily lives. Perhaps it is because they have had many more years practice hiding their disorder, particularly the panic attacks, from public view; in essence, finding it difficult to fully trust and truly open up. Perhaps it is because Son knows himself better and is more familiar, factually, with the disorder. This shows in his words about anxiety:

No one should assume that they know what it is like to go through something until they have gone through it. Sometimes you share with people the reasons that you are anxious and all they want to tell you is how ridiculous your beliefs are and wonder why you would have anxiety over something like that. Well, a lot of things seem ridiculous to me, but perhaps they are very real to other people. Taking for granted someone's suffering because you can't rationalize it in your belief system is insensitive and asinine.

I feel Son tells his story better than I could ever hope to and I will, for the most part, share his words rather than my own. A story from his childhood exemplifies the toll the disorder extracts on everyone involved and the contribution of Grandmother to his disorder:

When I was a child my Grandmother did not work. She said that because of her Agoraphobia she couldn't work; which left my mother as the one working to pay the bills. The problem with that was my Grandmother loved nothing more than to spend money. She had credit cards to all of the major stores and spent a fortune on the Home Shopping Network. My Great Uncle used to say that my grandmother could shovel money out the back door with a teaspoon faster than my mother could shovel it in the front door with a snow shovel. This left my mother usually working two or three jobs, so the vast majority of the time that she was at home she was sleeping, and she wasn't getting much time for that. That meant that I spent most of my time with my Grandmother. She was depressed most of the time and she was always worried that she was going to die. I can remember being in grade school and I would get home and I would go and lay down with my grandmother and hold her while she cried. I even got a stuffed pig from Santa when I was five that had the word smile embossed on his shirt. I told her that it was a magic pig and that it could make her sadness go away. She played along with this for a while. Whenever she would start to weep I would get the pig and she would stop crying. But, the pig's magic power wore out soon and she would say that her sadness was too much for him to take away. I remember a lot of the time when I was at school I would have anxiety because I would be worried about her. Wondering if she had such a hard time getting through the afternoon without me there to console her, how hard were her days, and how was she getting through them. My grandmother drove my mother crazy with her constant fear that she was dying. On little or no sleep I can remember my mother driving her to the doctor or the hospital. When we got to the doctor my mother would sleep in the car and I would go inside with my grandmother. I remember that when the doctor gave her new medicine she had to take it in the waiting room and wait for an hour to make sure that she wasn't going to have an allergic reaction to it.

Son attended Kindergarten through second grade at a private school and it was just before third grade that the business was sold and the family moved. They moved back into the home in which Grandmother raised Mother. Mother was excited for Son to attend the schools she had attended. In addition, Mother

did not feel she could continue to afford private school. However, the plan was short lived:

About three months into the school year my grandmother said that public school was ruining my character and demanded that I leave public school and attend home school with her as my teacher. She might have said that it was my attitude, but I knew that it had a lot more to do with the fact that she didn't want to be without me during the day. Because when it came down to it we really didn't do much school work, I spent most of my time trying to cheer her up and being her companion.

Grandmother continued to have an enormous influence on Son's daily life and development. It affected his personal relationships, such as with friends and other family members; it even affected his relationship with Mother. When asked about friends outside of school, Son responded:

If I had a birthday party there would be a lot of kids there. But I never really had many kids over like to play at my house or to spend the night. And I don't think I ever spent the night at anyone else's house until I was in high school. My grandmother was very particular about things like that. You couldn't ever make her feel slighted or like she wasn't your favorite person in the world or there would be hell to pay. I can remember being a very young child and going off and doing things with my mother. I was usually very excited about this because I didn't get to see my mom that much because she worked all the time. And we would have fun and then I would come home and try and go hang out with my Grandmother and she would give me the cold shoulder. She would say why didn't I go hang out with my mother and I would tell her my mom had gone to work or bed, which ever was applicable and she would say that I didn't want anything to do with her when I was with my mom and that I left her alone to have a miserable and lonely afternoon, so she didn't want anything to do with me. This would cause me anxiety because she had already strongly forged my bonds of co-dependency and I did not want to be alone. However, her anger never lasted more than an hour before she would come and get me and we would hang out again. I would be happy because I had someone to be with and didn't realize that we were just keeping the whole sick cycle alive.

During these grade school years, nevertheless, Son did participate in class plays, productions, and choir. His family was supportive as Mother attended all performances and Grandmother attended most. He explains that Grandmother did not make him feel guilty about these activities because “she loved to brag and boast”, so anything he did that she could run around and say that he got all of his talent from her, she loved. As stated earlier, Son was aware of Grandmother’s disorder including the agoraphobia, anxiety attacks, and depression by the time he was five: “It was one of her favorite things to talk about.” But with Mother, he was not aware of her disorder until he was a late teen. Son explains that Mother was very good at hiding her anxiety from him, the way he hides his from his daughter.

Son reveals it was as he entered his teenage years that anxiety began to become a problem for him culminating in his first panic attack between 14 and 15, which he describes in detail:

I was riding in the backseat of a friend of mine’s car. It was a small car, a two door. Anyway there were two people in the front seat and two of us in the back, it was night time. My friend that was driving, it was his car, he had just got these new speakers installed and he turned on this song called Journey Into Bass and turned the bass and volume all the way up. I could feel the boom of the base in my head, but more importantly in my chest. The boom in my chest was so extreme that it made me feel as if I couldn’t breathe. I began to sweat immediately and profusely, I could feel my heart beating in my chest so hard, I knew in that moment that I was not going to be able to get any air and that I was going to die in the backseat of that car. These were some of my really macho friends and I knew that I couldn’t show anything being wrong. I just bit my tongue and forced myself to move my head in rhythm to the music. I wanted to cry, but I knew that I couldn’t. I got home and thought about what had happened. I was

able to interpret the fact that I was alive as proof that I was wrong when I assumed that I wasn't breathing. I realized that I had had a panic attack and I was automatically fearful of the potential of having another one. In fact the fear of having another attack stayed intense for about a week. After that it was not so much of an intense fear, but it was a fear nonetheless.

Son further discloses that after the first panic attack, the attacks continued coming every few weeks. He sometimes had them in public which caused him to try and find a private space. He states he couldn't always find one, but no one ever knew he was having an attack. Son felt that hiding the attacks did not worsen their symptoms other than causing more anxiety about having an attack he could not hide. As a teenager, Son felt hiding the attacks was very important because:

It was embarrassing, and it was a sign of weakness, at least that is how I thought about it then. I was an intimidating guy. I beat people up that bothered my friends, I played all the contact sports, I talked a lot of trash. I couldn't begin to imagine what my social life would have been reduced to if even one person in my social group would have seen me crying or afraid. Showing these emotions simply wasn't an option.

However, the anxiety did affect Son's performance at school, especially in regards to tests. He explains that he was always on edge about having an attack and tests gave him further anxiety, so sometimes when the anxiety would begin to "well up" during a test, Son would simply "Christmas tree" the answers, and usually "bomb the test", just so he could escape before an attack occurred.

In his high school years, Son feels, for the most part, that his anxiety did not affect his social relationships, although he did avoid participating in activities

he felt would cause him anxiety. He was a football player, a wrestler, and a member of the JROTC's drill team and honor guard. Son states he knew that he was challenged by his anxiety and, to a point, he thinks that helped him raise his opinion of himself by the fact that he was able to keep anyone from knowing the inner turmoil that he was experiencing a lot of the time. He worked in the summer time at Mother's place of employment due to his need for a "support person" (Mother).

Shortly after graduating high school, Son began experiencing more anxiety. He was able to work at Taco Bell with "substitute support persons" for awhile because he had good friends there. However, as he took jobs where he knew no one, he usually wouldn't make it a day. Son explains that he would have an anxiety attack and then find a way to sneak out and never return. Finally, he started working in bars with his best friend and was able to thrive in that environment. He seems to only be able to work when he can establish the work place as a comfortable place to be. If he is not comfortable then his anxiety spikes and he is immediately filled with an overwhelming desire to get to his home – the home in which his mother and grandmother still live.

Son explains that, to a point, agoraphobia affects every relationship in his life; with his wife, friends, and family. If his anxiety is high he tends to be grumpy and will be quicker to snap at everyone. If his anxiety causes him to forebode or become depressed than he withdraws from everyone and lies in his bed. Many times his wife and his mother can't understand why he is depressed. When he is anxious he is not good at explaining much, so there is confusion and a lack of

communication. Also, when his anxiety is high and he begins to obsess about matters regarding his own mortality, he seems to lose his ability to empathize or understand that much about anyone else's problems. He feels that makes him a bad listener, a bad friend, and someone easy to get angry with. In addition, Son feels agoraphobia affects his physical health and well being stating that while he is good at worrying himself sick, he is not good at figuring out what he is actually worried or anxious about. He feels this is best explained through a story:

Well about two summers ago I started having really bad anxiety. It was the day after my daughter's birthday and I had decided to go over to my friend's house to hang out after she was in bed. Well I had been there for a few hours when my stomach started to feel funny. I tried my hardest to ignore it but I could feel my anxiety slowly creeping up on me. I left and went home and went to bed. About an hour later I woke and knew immediately that I had to throw up and I did. Throughout the rest of the night I was up and down throwing up. I had a fever and chills and was miserable. This went on till about noon the next day. My daughter and my mother also became sick. Once I was out of bed and on my feet I started looking for the diagnosis. I called my friend who I had visited the night before and asked if he had become sick, he had not. Now I knew that the source of the vomiting was something in the house because the only people afflicted by it were me and two other individuals that lived in my home. That is when I set my eyes on old Stormy the cat. This cat had once been a pet of the family, but by his own choice he moved himself outside and became an outside cat. Now, the reason that he was in the house on this day is that he had become very sick and had come in the house to get better. The other factor at play here is about a week before this I had adopted a new dog for my daughter, a puppy. And the puppy was obsessed with the sick old cat and kept licking the damn thing. I probably only stood there looking at the cat for about thirty seconds and my brain had worked in overdrive to figure the whole thing out. The cat was rabid, the dog had been licking the cat and then licking us and had passed the rabies virus on to us and that was the reason we were vomiting. And since vomiting is one of the first symptoms of rabies, and once you show symptoms of rabies you are too late for treatment, I also knew in that moment that not only I but the two people that I love the most in this world were going to die. My anxiety took me over at this point I demanded that the cat be taken immediately to be tested. I was greeted with opposition from my

mother and grandmother; but they quickly succumbed to the presentation of the macabre possibilities that I was presenting in the most unrelenting way possible. The cat was taken to Animal control and killed, it's the only way you can test for rabies, and his test was negative. Now, one would think that that would have been the end of the anxiety pertaining to rabies, but it wasn't, not by a long shot. I began to obsess about the vaccinations of the pets we had, the possibility of a bat coming in a hole in the roof or a crack in the window, me and my family being around other people's pets, stray pets, wild animals, and any other way you could possibly contract rabies. I would call people and I would ask them about their pets to make sure they were still alive. I would do this weekly until I had proof that if the animal had been rabid when me or my family had been exposed to it, it would have died, and then I could relax about that. I remember some friends of mine invited me out to a beach café for a poetry reading and they had a girl they wanted me to meet for a possible romance kind of thing. And I gotta tell you this night was doomed from the beginning. For starters my friends arrived and I met them there before the girl that they wanted me to meet got the[re and one of my friends was sick. This put my anxiety up right off the bat because she seemed to have a wicked cold and I had no interest in catching it. Then to make things worse we go inside to get our coffee and there is this huge dog walking around, he belonged to the owners. The damn thing has on no collar, no tag, just a bandanna. And in the face of not knowing you always assume the worst so I have to assume that this animal has not been vaccinated. So now I am trying to avoid this fucking thing like a madman and he just thinks I am the greatest thing since sliced bread, he wants to follow me everywhere I go and rub all over my legs. So I finally get outside and between the sick friend and the dog with no collar I am really becoming visibly afflicted by my anxiety. And then the girl shows up. Now, I may have extreme anxiety issues, but I am still a man. In my head I do my damndest to control my anxiety from showing so that I can turn on the charm. And I have to say that I was doing a really good job until this damn squeaky noise started. And I make the mistake of asking the group what the hell the noise is after about the third or fourth time. And the other guy in the group says it sounds like a bat. Now I managed to hold it together for about fifteen seconds after that and I sprang up and blurted out that I had to leave. People were asking me why and where I was going as I did my damndest not to run from the sidewalk table to my car. I got in my car and drove as fast for home as I could. Now this was a long time after all of the initial rabies anxiety had happened in my life, but faced with the threat of it I ran from a comfortable social situation, embarrassed myself, and sped away for home like a scared child. So yes you can say that I worry to the point that I experience negative effects. Sometimes I obsess and ruminate on a disease to the point that I becomes so anxious and

fearful that I can't get out of bed for days. Other times I worry until I nauseate myself. And the vast majority of the time I worry until I tighten up my neck and chest muscles so bad that I get these muscle knots in my chest and ribcage and can't move or they give me a wicked headache that also confines me to the bed.

In addition to rabies, Son has periods of anxiety over many other medical causes including Hantavirus, Deep Vein Thrombosis, strokes, heart attacks, Bubonic Black Plague, Macular Degeneration, anthrax poisoning, food poisoning, Botulism, SARS, Bird Flu, Ragged Red Fiber, Cancers, Aneurisms, Tuberculosis, Methalyn Resistant Stapphalocacus Auroras, Encephalopathy, Billarubic Encephalopathy, Alzheimer's, and Mad Cow Disease. While the three generational home provides him with feelings of protection it is not his refuge from these fears. He spends countless hours on the computer researching these ailments.

Chapter Five: Analyzing the Lived Experience of a Family “Affear”

Analysis of the narratives constructed by Grandmother, Mother and Son reveal four important themes: Experienced Stigma; Creation of Identities; Emotion Management; and Coping and Control Strategies.

Experienced Stigma and Creation of Identities

Within the social and cultural context, according to Goffman (1963), society has developed ways to categorize and allocate characteristics thought to be “normal” to individuals in a particular group. Certain actions and appearances of group members are expected and then demands are created of these “social identities” which, in turn, become normative expectations. If an individual does not meet the characteristics of a particular group, he/she is deemed different. If this difference is perceived as a characteristic that falls short of societal expectations, the individual is, “reduced in our minds from a whole and usual person to a tainted, discounted one”. This is stigma. Goffman described stigma as “an attribute that is deeply discrediting within a particular social interaction” (1963:3). Particular actions and behaviours of agoraphobics, especially during panic attacks, might be considered stigmatized under the category of “blemishes of individual character”, one of the three categories, associated with weakness of character inferred from such conditions as mental disorders, alcoholism, addiction, and so on. Each participant reports the experience of stigma – though

they respond to stigmatizing situations in very different ways.

Grandmother

For the first half of Grandmother's life she did not disclose her condition to anyone, with the exception of family and medical professionals. She created identities that allowed her to fit into whatever group she chose to be with. She dressed the part, learned the language, and assimilated into the group. She kept her differences hidden. However, upon experiencing a panic attack in public or when with the group, her "cover was blown" forcing Grandmother to seek out a new group to join with a new identity to create. From Hawaiian performers to bikers, strippers to veteran supporters, Grandmother changed her identity frequently to maintain an alliance with a group. Unfortunately, Grandmother's focus on her "illness" was an identity in itself. She identified herself as an agoraphobic; a disabled person with a debilitating, incurable illness rather than an individual with agoraphobia.

You should see the way people look at me when I'm having a panic attack. They act like it's something they can catch. I know people think I'm crazy or having some kind of fit. Why can't they have some compassion? Sometimes I just wish I could crawl into a hole and die when I have an attack in public.

Goffman (1963) describes two types of stigma, the discredited and the discreditable. With discredited stigma the individual may assume his differences are known because they include physical handicaps, deformities, and other "visible" conditions. These individuals have to deal with their stigma in nearly all

interactions. On the other hand, discreditable stigma has more to do with conditions of an “invisible” nature such as epilepsy, criminal histories, homosexuality, and so on. The interaction management strategies of these individuals are more complex as they choose who, if anyone, to inform about their stigmatized condition. Agoraphobia with panic disorder would be considered a discreditable type of stigma because they may pass as ‘normal’ until an anxiety attack in public exposes them.

I've tried telling people about my illness hoping to provide more understanding, but it doesn't help. I think that unless someone has experienced what I'm going through, they just can't comprehend it. Neither my daughter nor my grandson have it as bad as I do so they're no help. People treat me like I'm not a normal person, but I am...I just have an illness.

The pressure of idealized, normative identity and conduct is most clearly seen in these marginalized individuals whose condition forces them into a discreditable group. When these individuals attempt to pass with the purpose of establishing themselves as “normal”, feelings of separation and uncertainty surface as a result of limited social interaction (Goffman 1963). Members of “discreditable” groups must create public identities based on the idealized, normative identity. They then must attempt to maintain behavior that is considered acceptable. Only in this way may these individuals assimilate into, and achieve full acceptance of, a large segment of the population.

Continuing in this strain, Davidson (2000a) based her theories on the work of Merleau-Ponty. She suggests that agoraphobics’ anxiety in public places can

be indirectly drawn from other individuals. She explains that an individual's experience of the public space is essential to their individuality and that their identity is a result of their distinctive location within society. The day-to-day experiences of creating a public identity and maintaining behaviors not entirely their own increases the potential of anxiety attacks. Furthermore, Davidson suggests that the agoraphobic condition creates an overly sensitive awareness of feelings, a point which should be included in further research.

As suggested by Davidson (2000a), Grandmother experienced more frequent anxiety and severe bouts of agoraphobia, despite increased medication, with the increase of public identities she created. She questioned her self-worth. Stress was increased and management became increasingly difficult when she happened upon a member of a group she had left, for instance, and her appearance identified her as member of another group. Grandmother would attempt to communicate using a former identity while maintaining the current identity which added confusion and induced anxiety. Furthermore, she allows her fearful thoughts to manifest which causes her to believe she is going to die. This is the reason for many trips to doctors and hospitals; sometimes as often as three times a week. In her later years, Grandmother has primarily stopped creating identities and focuses on eliciting sympathy for her "illness".

Mother

Mother feels that she has experienced stigma for most of her life, but not always due to her panic attacks. For as long as she can remember, people have

referred to her as “unique or different” when they were “being kind” and “weird or odd” when they weren’t. Mother admits that the “bitch persona” she created as an adult made things worse. She also admits she frequently displays behaviours that would not be considered socially acceptable. She states she has lived by the credo of “I march to the sound of a different drummer” ever since her teenage years and has a strong aversion to just being a “member of the herd”. When all of this is combined with her disorder, Mother states she experiences stigma everywhere she goes.

I'm always an outsider...I'm never a member of the group. People always look at me funny and I can tell when they're talking about me and laughing at me...which is most of the time. I have the worst time at red lights...of all places...panic rises up and I can barely breathe.

Mother does not attempt to meet the characteristics of any particular group, and therefore, she is deemed different by society. She most definitely falls short of societal expectations and is consequently viewed, according to Goffman (1963), as a tainted, discounted individual. The type of stigma Mother experiences is described as discreditable, however, Mother does not endeavor to create a public identity based on the idealized, normative identity. She does not try to maintain behavior that is considered acceptable. Her created “bitch persona” identity is to keep others away. As a result, Mother is unable to assimilate into, and achieve full acceptance of, a large segment of the population.

Mother's situation is better explained with the theories of Joyce Davidson (2000a). Davidson suggests that agoraphobics' anxiety in public places can be indirectly drawn from other individuals. Truly, Mother's anxiety is directly related to and increased by the presence of others. This is commonly referred to as social anxiety disorder. Davidson further explains that an individual's experience of the public space is essential to their individuality and that their identity is a result of their distinctive location within society. The day-to-day experiences of creating a public identity and maintaining behaviors not entirely their own increases the potential of anxiety attacks. Mother does not even attempt to maintain acceptable behaviors and feels she lacks a personal identity. Furthermore, she has learned what day to day experiences increase her anxiety and potential for panic attacks and clearly avoids these situations when at all possible.

Son

At first glance Son's response to perceived stigma is nearly invisible which is what he wishes his disorder to be: invisible. He seems to feel the need to hide his disability from others in order to fit in. By doing this he is therefore putting himself in Goffman's (1963) "discreditable" category and must spend a lot of time managing the decision about when, where and to whom he can safely disclose his identity as a person with agoraphobia. He seems to use his home as his "safe space" – a space created for him by his mother and grandmother who, because of their own experience are unlikely to stigmatize him and since they already know about his disorder, he doesn't have to face issues of disclosure.

Similar to Grandmother, Son creates a public identity based on the idealized, normative identity. He attempts to maintain behavior that is considered acceptable so that he may assimilate into, and achieve full acceptance of, his professors and peers at school. Unlike Mother, he is careful to live up to societal expectations. At times he is overly ingratiating as he agrees with others when he doesn't truly agree simply to avoid any conflicts. Yet he possesses strong personal views:

I don't like outside much, never have. There is something too overwhelming about it for me. I prefer to engage in fun activities at home or at a friend's house. I don't like bridges or feeling lost when driving, I hate germs and disease, I don't like rodents, or wild animals, or people that do not vaccinate their pets. I don't like smug and judgmental people, I hate atheists and liberals, and I really don't like riding with other people, I have to be the one driving. I hate feeling trapped, and small spaces, and I hate it when things are not put in alphabetical order.

Many of these "hates" could not be discussed in the public realm as they violate acceptable social norms of our time. Therefore, Son maintains a calm, quiet demeanor which allows him to "fade into the woodwork". If anxiety occurs in public, he seeks private space for an attack to run its course. Unfortunately, as discussed earlier (Davidson 2000a), this daily experience of creating a public identity and maintaining behaviors not truthfully their own increases the probability of anxiety attacks.

Emotion Management and Coping and Control Strategies

In a study of wheelchair users, Spencer Cahill (1994) demonstrated how individuals with disabilities manage the emotions of others in public life while at the same time managing their own. He explains this is done to “assure one another of their civility and goodwill so as not to evoke embarrassment, fear, or anger, in others” (1994:300). They accomplish this through several mechanisms such as humour, avoidance of embarrassment or anger, and inducing sympathy. The public acceptance sought after applies as well to an agoraphobic with panic disorder when an anxiety attack occurs in public. Ellis (1991: 25) suggests researchers should “examine emotional experience of this kind...by looking “into the details of the process by which people come to feel the way they do”. Naturally, people are very much dependent on one another and seek to create networks of relationships and culture. They accomplish this through the interpersonal management of emotions between themselves and others. In the case of agoraphobics, however, these social circles may become smaller and smaller due to the invasion of anxiety attacks and the subsequent portrayal of difference. Again, while all three participants must manage their own emotions and those of others, they use different strategies to do so.

Grandmother

Grandmother habitually sought out new groups because none of those people knew of her illness. New social groups became a way of self medicating because she was able to be someone different than who she was in those

groups. However, before long the membership in the group would become an anxiety inducer because she would experience fear of exposing herself, being thrown out of the group, and losing the comfort that she had found there.

Grandmother primarily utilizes the coping mechanisms of humour and inducing sympathy. She is the type of person that likes to be the center of attention at all times. To gain acceptance into groups, she created an identity to match the group and then utilized humour to help people to like her and make them feel happy. Unfortunately, her relationships with others are commonly short lived. Either she has a public panic attack or her true identity leaks through. Her true identity is control oriented with an extreme focus on Grandmother's needs and wants. She has had five failed marriages and multiple short lived friend relationships. Of the two long term friend relationships, these individuals allow Grandmother to take charge. Her only life long relationships are with family members, rocky as they may be.

In addition, Grandmother exhibits the defence mechanisms of reliance on pharmaceuticals, self medication, control, and avoidance. These are generally employed to secure less anxiety. As she drifted away from creating identities, Grandmother began to inform everyone she met of her "illness" in an attempt to induce sympathy. This illness definition provides no self blame and permits Grandmother to project a disabled status and garner the attention she craves.

Szasz (1974) suggests that people begin to define themselves by their mental illness. He explains through this example: When you have a cold, you say, "I have a cold", when you have the flu, you say, "I have the flu", and when

you have cancer, you say, "I have cancer". Conversely, when individuals with mental illness have schizophrenia, they say, "I'm schizophrenic", when they have Bipolar disorder, they say, "I'm Bipolar" and when they have Agoraphobia they say, "I'm an agoraphobic". The point is that when people have the flu, they don't say, "I'm the flu"; they are not defining themselves by an illness.

Much of what Szasz is very true of Grandmother. She tends to define herself by her mental ailments. It may be that she defines herself by her mental illness because she knows that mental illness limits you in some way. By invoking the mental problem she can lower the expectations and accountability placed her by others. In this manner, Grandmother is able to diffuse responsibility for her 'uncontrollable' actions and behaviors.

Mother

Mother feels angry most of the time, especially when she can feel her anxiety increasing. She uses relaxation breathing to calm her anxiety and, hopefully, to prevent a panic attack. She frequently feels "cheated" somehow based on the fact she is the only one (of the three) that literally forces herself to go to work. She practices avoidance behaviours stating she has learned which life situations cause the most anxiety or the highest tendency for a panic attack. Her greatest challenge remains the grocery store and explains that she must have a list, the list must be in the order she will find the items in the store, and any deviations cause her great anxiety.

*Frequently, my husband or son will accompany me to the store.
They think they're helping...they don't realize how much worse*

they make it sometimes. If they're talking a lot they distract me from my mission and I get confused. I must have everything in a system and organized to succeed. Then the bitch persona will come out and I'll blame them for rushing me and for not letting me get what I need. I'm a big blamer when I have anxiety.

Organization and systems are the coping mechanisms Mother feels allow her to continue to function normally. She has a system for washing dishes, hanging laundry, and running errands. She does it the same way, in the same order, every time. When running errands, she plans out her route in a circular pattern and does not deviate. She experiences anxiety if someone even stacks dishes in the dish drainer “incorrectly”. The first thing she does when she gets to work, since she has a shared work area, is organize the area. Each item has a specific location, everything neat and orderly. She gets very upset when co-workers make a mess of the office and must clean it up before she is able to work. Due to her compulsions, she rarely gets along with co-workers.

Unlike Grandmother, Mother does not make an effort to manage the emotions of others in public life while at the same time managing their own. Cahill (1994:300) explains this is done to “assure one another of their civility and goodwill so as not to evoke embarrassment, fear, or anger, in others”, but Mother does not seek public acceptance. Ellis (1991: 25) suggests people are very much dependent on one another and seek to create networks of relationships and culture. They accomplish this through the interpersonal management of emotions between themselves and others. If they do not do this their social circles may become smaller and smaller due to the invasion of anxiety attacks and the

subsequent portrayal of difference. Mother does not seek to create relationships with others. Her social circle simple consists of her family; she has no friends, she goes to work and comes home, and occasionally attends outside functions with the family, only.

Son

Because of his youth, Son's coping and control strategies are a "work in progress." He tells me he is getting better at "looking under the surface" within himself and tries to figure out the real causes of anxiety. He mentions the James-Lange Theory and elucidates:

You see a bear in the woods and you run, you realize you are afraid because you interpret your heart is beating quickly, your anxiety is up, and the fact that you are running. You look back and see the bear and decide that is what you are afraid of. I believe that people with anxiety problems that have their anxiety and physiological responses spike for no apparent reason look around for a bear to blame, but there is no bear to be found. So, we decide we are afraid of the first thing we locate visually that we can construe as threatening. Like a sick cat that could be rabid, or a piece of mail that could be full of anthrax, or a squeak that could be a bat.

Son further expounds the root causes of anxiety to be the things agoraphobics don't want to acknowledge. The example he gives for this root cause is anxiety in regards to problems with relationships, worries of failure, or major life changes. He states agoraphobics allow these anxieties to come without realizing why and then assign the anxiety to an unrelated stimulus.

The specific technique Son utilizes to control his anxiety is logic. He realizes this may sound strange to others, however, he has actually been able to control rising anxiety:

Say I am anxious and I feel like I have a certain disease like Hantavirus. I go the website for the CDC and I look at the symptoms and I find the way that they don't match my own. This lowers my anxiety, I also book mark the site in my favorites. That way in about four or five hours when I catch myself having anxiety about it again I go back and re-read what I had seen earlier and I feel my anxiety go down.

Son informs me that panic attacks are a part of his everyday life. This does not mean that he experiences one every day and states that is probably the most terrifying part about them. Panic attacks can occur, say, every day for ten days and then not occur for fourteen days and then suddenly start again; they stop and restart at any time with no warning. He explains that he would rather have an attack every day if he could only schedule it:

I mean, if I could have one panic attack every day for the rest of my life at noon I would take that over the fear and the uncertainty associated with not knowing when and if one was going to come, every day of my life.

Chapter Six: *Conclusion*

In this thesis I have discovered what individuals with agoraphobia with panic disorder actually experience and how it affects their emotions and social interactions. The effects of agoraphobia with panic disorder are threaded throughout this thesis. Through the participants' personal perceptions, thoughts, and feelings a canvas has been painted that details what the individuals really experience and how it affects their lives. Furthermore, this thesis brings to light the dynamics of disability over the years as it highlights issues of stigma, coping strategies, and emotional management. As Ellis (1991: 25) suggested, these participants' social circles have become smaller and smaller due to the invasion of anxiety attacks and the subsequent portrayal of difference.

I have agoraphobia with panic disorder and, as I surmised, experience the disorder very differently than the participants for this thesis, as they experience it differently from each other. As we have seen, although Grandmother has more bouts of severe agoraphobia, she will go to great lengths to be a member of a group. Unfortunately, this habitual desire to fit in has become another source of anxiety. She has created acceptable identities which sometimes included changing her pattern of speech and mode of dress, as well. Mother, on the other hand, has no desire to be a member of any group other than her family. It is only within the self imposed confines of her familial relationships that she truly attains feelings of safety. Perhaps it is partially due to an experience she once suffered

at a doctor's office. Her mother (Grandmother) had talked her into seeing a doctor and beginning medication to calm her anxiety. There was a visiting doctor from another state and he began to question Mother about her disorder. He stated he had never met an "agoraphobic" and then proceeded to "make fun of me" in Mother's perception. Mother has not seen a medical professional for her disorder since and does not take medication.

Son, who appears to be the most balanced from the outside, perhaps suffers with the disorder the most. He is in nearly constant panic over germs, diseases, and death. Although his coping strategies calm him, they are strategies that must be repeated over and over again throughout the day. Obviously, Son was genetically predisposed for the disorder, but it may have never developed if not for the learning experiences during his formative years and all the way through his childhood. Although Mother worked hard to hide her disorder from Son, Grandmother did not. She, in essence, taught him how to be an agoraphobic including all the possible co-morbid disorders such as depression, claustrophobia, and compulsive.

However, of the three, Son would be the "happy medium". He does not constantly try to initiate into groups, yet is comfortable being a member of a group if he chooses to be. He also does not continually avoid others or create identities to keep people away or ingratiate himself to them. He is not "over the top" like Grandmother or a "societal oddball" like Mother. Like Son, Mother is a combination of genetically predisposed and learned behaviors. She remembers her mother taking "handfuls of pills" everyday, all day since she was a small

child. Upon discovering it was others that created more panic inside her, she created an identity to simply keep others away from her, thus, in her mind, reducing the possibility of increased panic.

Amazingly, in a support group, where I met these participants, everyone is calm and happy; they appear completely normal, as in without panic. When together, they feel as if they are safe; although each experiences the disorder differently, they all experience it. In group, they do not have to worry if someone will make fun of them or look at them like they're crazy. They do not have to worry about not fitting into society. They have their own society, their own group. Even the psychologist that heads the group discussions is considered an outsider. Each has a strong conviction that "if you haven't experienced it, you can't understand it...period".

I refer to myself as a "recovering agoraphobic". I call myself that because I have not had a severe episode in years, I attend college, and I work. I go out socially and turn many of my academic assignments into self imposed therapy. Other agoraphobics find this reference hilarious because they don't believe you can ever truly recover from agoraphobia. You can take medications to reduce depression or calm the anxiety and ward off panic attacks. You can develop coping mechanisms and behaviors to get you through the day. You can learn how to manage your emotions and techniques to shorten a panic attack when it strikes. You can appear to be normal, but the underlying disorder remains waiting to strike when you least expect it. And you learn to fear that, above all else, you fear that the most.

In the end individuals who suffer from agoraphobia are no different than you and I. They are mothers, they are sons, they are daughters, they are fathers, and they are grandmothers. Some of them take medication, some don't. Some find a way to cope and live a productive life while others do not. In the end the panic that many individuals stigmatize agoraphobics for experiencing is the same panic that people without agoraphobia experience. The difference remains solely in the truth that when non-agoraphobics panic they have a societally acceptable panic inducing experience; where agoraphobics panic in response to stimuli that are not viewed by the vast majority as being legitimate sources of panic induction. However, no matter what makes you panic; imagine a world in which that involuntary response of panic could make you the recipient of mockery and stigma. That is how an agoraphobic feels, living in developed shame due to their automatic responses; that is perhaps one of the saddest things in the world.

In conclusion, I believe the methods I chose were able to capture the nuances of the participants' experiences with anxiety. I hope to have inspired the readers to recognize the contribution of Sociology to the study of mental disorders. The contribution of sociological explanation is to emphasize the fact that individuals are simultaneously sociological and psychological creatures. Each individual is affected by unique personal histories and experiences as well as the familial, social, structural and cultural contexts in which they live. These three participants have a built in support system with each other. Individuals without this type of support system may experience much more difficulty with

societal demands. We don't know what aspects of the experience of agoraphobia within this unique family might be shared by others.

Further, while the evidence from previous research clearly suggests that women are more likely than others to suffer from (or at least to report suffering from) agoraphobia with panic disorder than men, the reasons are not clear. I would recommend further research on males with this disorder. Since most of the research is conducted with young Caucasian females, more research is also needed regarding prevalence rates and social experiences in older individuals and individuals from other races and cultures. In short, further research with a wider variety of individuals is needed in order to explore the impact of gender, family structure, race, ethnicity, socio-economic status and other social and cultural variables on the lived experience of agoraphobia. Developing a greater knowledge base could lead to more appropriate public education and prevention strategies that could, in turn, lessen the suffering of those who live with agoraphobia with panic disorder.

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Appendices

Appendix A: Letter of Approval from the IRB

DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE

Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 □ Tampa, FL 33612-4799
(813) 974-5638 □ FAX (813) 974-5618

September 2, 2008

Sherri Elizabeth Green, BA
Department of Sociology
5251 78 Ave. No.
Pinellas Park, FL 33781
Attn: Sara Green, PhD

RE: **Expedited Approval** for Initial Review
IRB#: 107201 G
Title: *A Family 'Affear': Three Generations of Agoraphobics*
Study Approval Period: 08/29/2008 to 08/28/2009

Dear Ms. Green:

On August 29, 2008, Institutional Review Board (IRB) reviewed and **APPROVED** the above protocol **for the period indicated above**. It was the determination of the IRB that your study qualified for expedited review based on the federal expedited category number six (6) and seven (7).

Also approved were the informed consent forms.

Please note, if applicable, the **enclosed informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on page one of the form**. Valid consent must be documented on a copy of the most recently IRB-approved consent form. Make copies from the enclosed original.

Please reference the above IRB protocol number in all correspondence regarding this protocol with the IRB or the Division of Research Integrity and Compliance. In addition, we have enclosed an Institutional Review Board (IRB) Quick Reference Guide providing guidelines and resources to assist you in meeting your responsibilities in the conduction of human participant research. Please read this guide carefully. It is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,
Paul G. Stiles, J.D., Ph.D., Chairperson
USF Institutional Review Board

Enclosures: (If applicable) IRB-Approved, Stamped Informed Consent/Assent
Documents(s)
IRB Quick Reference Guide

Cc: Anna Davis/cd, USF IRB Professional Staff
SB-IRB-Approved-EXPEDITED-0601

Appendix B: Letter of Informed Consent

IRB Approval FWA 00001669	
IRB Number:	107201
From	8/29/08
Thru	8/23/09

Informed Consent to Participate in Research Information to Consider Before Taking Part in this Research Study

Researchers at the University of South Florida (USF) study many topics. To do this, we need the help of people who agree to take part in a research study. This form tells you about this research study.

We are asking you to take part in a research study that is called:
A Family 'Affair': Three Generations of Agoraphobics

The person who is in charge of this research study is Sherri Green. This person is called the Principal Investigator. Her Faculty Advisor is Sara Green. No other research staff will be involved. The research will be done at a place of your choosing.

Purpose of the study

The purpose of this study is to examine the social experiences and perceptions of a family living with agoraphobia with panic disorder.

This study is being conducted for a master's thesis in the Department of Sociology.

Study Procedures

If you take part in this study, you will first be asked to participate in an interview in which the principal investigator will ask you a series of questions pertaining to your experience with agoraphobia with panic disorder. Second, you will be asked to participate in a go-along interview in which the principal investigator accompanies you when you leave your home to run errands or shop. Third, you will be asked to participate in an observation period in which the principal investigator observes your regular activities. The interviews and observation are designed to last from 1 to 2 hours. The interviews will be audio-taped using a tape recorder. The investigator will take hand written notes during observation.

Alternatives

You have the alternative to choose not to participate in this research study. Your participation is completely voluntary.

Benefits

We don't know if you will get any benefits by taking part in this study. Your participation may help others to better understand the experience of living with agoraphobia with panic disorder.

Risks or Discomfort

The only risks of participating in this study are the time it will take for you to complete the

interviews, the possibility that talking about your panic disorder may make you think about some things that are upsetting and the possibility that the details you give during your interview might make it possible for those who know you very well to identify you - even though your name will never be used. In order to reduce this risk, the PI may change some details in written documents (for example the town in which you live, the place you work, your exact age, etc.) If at any time during the interview, you decide that you would rather not participate, you can stop the interview and nothing that you have said will be used in this study.

Compensation

We will not pay you for the time you volunteer while being in this study

Confidentiality

We must keep your study records as confidential as possible. The audio tapes will be stored in a locked file drawer until we have finished transcribing them. The transcriptions will be kept for a minimum of three years. Once the transcription is complete, we will destroy the tapes. In the transcription, your name and any other identifying information will be changed, allowing the information you give to us to remain confidential. Your signed consent forms will be kept in a location different from your transcribed interviews so that they can't lead to identification. They will also be kept for a minimum of three years.

However, certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- 1 The Principal Investigator, and the faculty advisor.
- 2 Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.) These include:
 - the University of South Florida Institutional Review Board (IRB) and the staff that work for the IRB. Other individuals who work for USF that provide other kinds of oversight may also need to look at your records.
 - the Department of Health and Human Services (DHHS).

We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are.

Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study, to please the investigator. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study



New information about the study

During the course of this study, we may find more information that could be important to you. This includes information that, once learned, might cause you to change your mind about being in the study or allowing the Principal Investigator to use information about you. We will notify you as soon as possible if such information becomes available.

Questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, call at Sherri Green at 727-541-9757 or Sara Green at 727 974-2893.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the Division of Research Integrity and Compliance of the University of South Florida at (813) 974-9343.

If you experience an unanticipated problem related to the research call Sherri Green at 727-541-9757.

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent



Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect.

I hereby certify that when this person signs this form, to the best of my knowledge, he or she understands:

- 1 What the study is about.
- 2 What procedures will be used.
- 3 What the potential benefits might be.
- 4 What the known risks might be.

Signature of Person Obtaining Informed Consent

Date

Sherri E. Green, BA
Printed Name of Person Obtaining Informed Consent



Appendix C: Interview Guide

The interviews will be informal and semi-structured. The participants will be allowed to lead the way in telling the stories of their experiences. The following will be used as a guide rather than as a set of structured questions. The probes will only be used if the participants have trouble thinking of something to say about a particular part of their experience.

Tell me about yourself.

Probes:

Age

Work

Hobbies/recreational activities

Likes and dislikes

Tell me about your family members.

Probes:

Relationship

Age

Work

Hobbies/recreational activities

Likes and dislikes

Significant other

How long have you been together?

What is the earliest age that you can remember having anxiety?

At this stage of your life, what is the impact of your disability on your:

Work life

Relationship with significant other

Family life

Physical health

Emotional well being

Social life (relationships with friends, neighbors, relatives, etc.)

Recreational activities

Sense of what you are able to do

Sense of who you are

What specific things do you do to deal with your emotions at this time in your life?

What, if any, strategies do you use to deal with your anxiety?

Would you describe a typical day in your life now?

I'd like for you to think back over the course of your life so that I can get an idea of how things have been at various stages of your experience with agoraphobia with panic disorder. We'll start with you're your childhood, then your teenage years, your young adulthood, and then we'll move into your adulthood.

Childhood (pre-school through end of elementary school)

Tell me about your childhood.

What events/experiences stand out in your memory?

Tell me about your school experience.

Did you have friends outside of school?

What extra curricular activities were you involved in?

(2nd and 3rd generation participants)

Did your mother participate in, or attend, your extra curricular activities?

Were you aware of your mother's/grandmother's panic disorder?

Did your family have close friends, neighbors, or family members with whom you regularly did things at this time in your life?

Youth (middle and high school years)

Tell me about your teenage years.

What events/experiences stand out in your memory?

Tell me about your school experience.

Did you have friends outside of school?

What extra curricular activities were you involved in?

(2nd and 3rd generation participants)

Did your mother participate in, or attend, your extra curricular activities?

At what age did you first experience a panic attack?

If in public, how did other people react to your panic attack?

If these reactions were negative, how did you handle them?

What kind of medical, social, or other type professionals did you deal with at this time in your life?

What was it like for you?

Were there any special treatments/medications that you needed at this time?

Have your anxiety issues ever affected your performance in school?

In what ways?

At this stage in your life, what was the impact of your disability on your:

Family life

Physical health

Emotional well being

Social life (relationships with friends, neighbors, relatives, etc.)

Extra curricular activities

Work, if applicable

Sense of what you will be able to do

Sense of who you are

What specific things did you do to deal with your emotions at this time in your life?

What, if any, strategies did you use to deal with your anxiety?

Would you describe a typical day in your life during that time?

Young Adulthood (college age years)

Tell me about your young adult years.

Probes:

College

Work

Relationships

Hobbies/recreational activities

Likes and dislikes

Have your anxiety issues ever affected your performance in school?

In what ways?

At this stage of your life, what was the impact of your disability on your:

Work life

Relationships

Family life

Physical health

Emotional well being

Social life (relationships with friends, neighbors, relatives, etc.)

Recreational activities

Sense of what you are able to do

Sense of who you are

What specific things did you do to deal with your emotions at this time in your life?

What strategies, if any, did you use to deal with your anxiety?

Would you describe a typical day in your life at that time?

Adulthood and Ageing

Once you've reached adulthood, you've had anxiety for a number of years. I would now like to explore issues surrounding your experiences with anxiety.

Tell me how your anxiety has changed over the years.

What are the most effective strategies you have found to help you deal with your anxiety?

What specific things have you found help you the most in dealing with your emotions?

What periods in your life were the best and the worst, and why?

Situations

What type of situations trigger anxiety for you?

Do certain people trigger anxiety issues?

Who?

Why?

What difference is there between the ways you feel when you have anxiety around people and when you have anxiety when you are alone?

What difference is there between the way you feel when you have anxiety around individuals you know and when you have anxiety around individuals that you don't know?

What things have you ever done, or not done, in order to avoid anxiety?
What, if any, emotions you weren't really feeling, such as sadness, anger, lust, etc., have you put on in order to shift the focus off of your anxiety issues?
How have you ever overplayed your anxiety in order to gain attention from a certain individual or group?

In what way?

Places

What certain places or social settings do you avoid because you feel they will cause you to have anxiety?

What places do you feel less anxious in?

Disclosure

Describe an example of when you tell people about your anxiety issues.

What is it like to be around someone once they know about your anxiety issues?

Have you ever felt that people look at you or treat you in a different way when they know that you have anxiety issues?

Could you describe some experiences?

Tell me about an instance in which someone has spoken to you like a child, acted overly sympathetic or patronizing.

Do you find it easier to be around strangers or people that you know, regardless of whether or not they know about your anxiety?

Why?

Describe an example.

Others

If someone who knows about your anxiety issues makes statements suggesting that they don't believe in mental health issues, how does this make you feel?

How do you feel in the company of people that you know also have anxiety issues?

Do you feel that people place you in a group with other anxious people that they know, regardless of whether you are a part of that group or not?

How does this make you feel?

Tell me about an example.

Has anyone ever used your anxiety problems against you in an argument, such as bringing up situations or issues that they knew would trigger your anxiety?

Describe an instance.

Have people used their knowledge of your anxiety problems to try and gain leverage against you?

Describe an example.

Do you feel it because they knew you were afraid they may tell others?

What, if any, emotions you weren't really feeling, such as sadness, anger, lust, etc., have you put on in order to shift the focus off of your anxiety issues?

Have you ever overplayed your anxiety in order to gain attention from a certain individual or group?

In what way?

Family

Tell me about other members of your family that have problems with anxiety.

Who?

In what ways?

How are the ways that you experience anxiety similar/different to the ways in which your family members experience anxiety?

Has any of your family members ever used your anxiety problems against you in an argument, such as bringing up situations or issues that they knew would trigger your anxiety?

Describe an instance.

Have any of your family members used their knowledge of your anxiety problems to try and gain leverage against you?

Describe an example.

Was it because they knew you were afraid they may tell others?

What, if any, emotions you weren't really feeling, such as sadness, anger, lust, etc., have you put on in order to shift the focus off of your anxiety issues?

Have you ever overplayed your anxiety in order to gain attention from a certain individual in your family?

Describe an instance.

Relationships

Have you ever lost a friendship because of your anxiety?

Tell me about this loss.

How has your anxiety affected your romantic relationships, partnerships, or marriages?

Have you ever argued with a spouse or partner about issues that were directly related to your anxiety?

Tell me about one or two of the arguments.

Have these arguments ever brought about an end to one of these relationships?

Have you ever had relationships in which anxiety issues became the major topic of conversation?

How did that make you feel?

Have friends or partners ever used your anxiety problems against you in an argument, such as bringing up situations or issues that they knew would trigger your anxiety?

Describe an example or two.

Have friends or partners used their knowledge of your anxiety problems to try and gain leverage against you?

Was it because you were afraid they may tell others?

What, if any, emotions you weren't really feeling, such as sadness, anger, lust, etc., have you put on in order to shift the focus off of your anxiety issues?

Have you ever overplayed your anxiety in order to gain attention from friends or partners?

Describe one or two of these times.

Quality of Life

What kind of advice do your friends give you about your anxiety issues?

Have your anxiety issues kept you from doing things that you wanted to do?

What kind of things?

Why?

Have you ever felt that your anxiety has put you at a disadvantage?

In what ways?

In which situations?

What are some of the things that you dislike hearing the most in regards to your anxiety?

How has this disorder affected the ways in which you see yourself and how others treat you?

Professionals

How do you feel discussing your anxiety issues with medical professionals such as doctors or nurses?

What type of experiences have you had doing this?

What was their response?

Have you ever utilized a psychologist or psychiatrist for your anxiety issues?

How was that experience?

Did it help?

Do you use medications to control your anxiety?

Have you ever felt that people look at you or treat you in a different way when they know that you have anxiety issues?

Could you describe some experiences?

Has anyone ever spoken to you like a child, acted overly sympathetic or patronizing?

Employment

What type of work do you do?

Full time or part time?

Do you ever fear that people, such as bosses or co-workers, will find out about your anxiety issues?

Does that fear cause you to have more anxiety?

Have your anxiety issues ever affected your performance at work?

In what ways?

Society

How do you think society feels about people with anxiety issues?

How do you think mass media and entertainment portrays people with anxiety issues?

Are there any other comments you would like to make about your disability of living with agoraphobia with panic disorder?

What, if any, advice do you have to give to others with this disorder?

Are there any questions you would like to ask about me or my research?

Basic demographic information questions to be asked only if the information has not surfaced during the interview.

Age, Race/ethnicity, Education

Income - 1) <25,000, 2) 26,000-50,000, 3) 51,000-75,000, 4) >75,000.

Religious Preference

How often are religious services attended?