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Jana Taylor 4/17/2012

Marred by Association: Coping with the Stigma of a Loved One's Mental Illness

by

Jana Taylor

Dr. Tracy L. Scott Adviser

Department of Sociology

Dr. Tracy L. Scott

Adviser

Dr. Cathryn Johnson

Committee Member

Dr. Melvin Konner

Committee Member

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Jana Taylor

Dr. Tracy L. Scott

Adviser

An abstract of a thesis submitted to the Faculty of Emory College of Arts and Sciences of Emory University in partial fulfillment of the requirements of the degree of Bachelor of Arts with Honors

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#### Abstract

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The works of individuals such as Erving Goffman and Peggy Thoits have unveiled the harsh reality of stigma and it's ability to affect not only the mentally ill, but those closest to the mentally ill as well. In an attempt to contribute to a topic lacking a solid collection of research, I explore the ways in which close family members manage and negotiate the stigma associated a loved one's mental illness. I conducted 10 in-depth interviews with students who have either a parent or a sibling with a mental illness. During these interviews, I addressed the challenges and experiences associated with having a mentally ill loved one, coping mechanisms utilized by individuals, and main motivations for employing a given coping mechanism. This paper presents major trends that serve to extend theories on coping mechanisms to a new population by focusing solely on family members. To conclude, I will discuss how this paper can direct future research.

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## **Introduction**

Mental illness came to be and has remained heavily stereotyped and stigmatized within society. Society subscribes to the belief that the mentally ill are a violent and dangerous population whose disease, despite the acknowledgment of some form of a brain dysfunction, is still strongly correlated with stress. Society opts to keep a fair amount of social distance from the mentally ill for many support the notion that the mentally ill's proper place is somewhere within a psychiatric ward. The mentally ill's perpetual misrepresentation in the media merely serves to reinforce these uninformed, stereotyped perceptions. The mentally ill is a population whose undesirable symptoms and tendency to be misunderstood has left them to cope with a stigma.

During the late 20<sup>th</sup> century Goffman argued that a blemish on one's individual character such as a mental illness leaves one looking for a manner in which to manage and negotiate the stigma linked to his illness. An individual may find himself striving to pass for "a normal" by concealing all symptoms of his mental illness and only disclosing such potentially discrediting information to a select few. Peggy Thoits further expanded upon Goffman's initial thoughts on coping mechanisms by examining the use of deflecting and challenging in her study sample. Some of those diagnosed with a mental illness may opt to cope with the stigma by simply saying, "That's not me," for whatever reason the individual deems appropriate. Others may opt to cope by challenging the stigma and stereotypes because they're simply incorrect. Despite the manner in which a mentally ill individual opts to manage and negotiate his stigma, he is still, in one way or another, coping.

Through the works of Goffman one can also see that stigma doesn't solely effect the individual himself, but those extremely close to the individual. Those close to a mentally ill individual must manage something Goffman labeled as courtesy stigma. This is the point at

which research fails to properly address a very important question. The works of Goffman and Thoits have shown that individuals employ coping mechanisms to manage and negotiate the stigma linked to their mental illness, so wouldn't it only be logical that close family members would manage courtesy stigma? After all, close family members do posses a form of stigma. This question is the main aim of the research at hand. This research strives to uncover the coping mechanisms close family members such as a child or a sibling utilize to manage and negotiate courtesy stigma.

#### **THEORETICAL BACKGROUND**

## **General Symbolic Interactionist Frame**

The main theoretical frame behind past bodies of research and the frame setting the tone for this paper is symbolic interactionism. "From the perspective of symbolic interactionism, *society* is a web of communication or interaction, the reciprocal influence of persons taking each other into account as they act...Society, as a web of interaction, creates persons; but the actions of persons create, through interaction, society" (Stryker 2003, 3-4). It's important to emphasize the three basic premises of the symbolic interactionist frame. The first of these premises states that individuals act towards objects based upon their assigned meanings. "Such things include everything that the human being may note in his world – physical objects such as trees or chairs; other human beings…institutions, as a school or a government; guiding ideals, such as their commands or request; and such situations as an individual encounters in his daily life" (Blumer 1969, 2). Human beings can only act towards something through the use of the meanings that have been assigned to the given object. The second premise shifts gears a bit and centers around the process through which meanings come to be created. Social interaction serves as the vehicle for the formation of meanings. In other words, social interactions develop things and their meanings. Thirdly, "the use of meanings occurs through a process of interpretation in which actors communicate with themselves, selecting, checking, regrouping, transforming, and using meanings to form and guide their actions and interactions in situations in which they find themselves" (Stryker 2003, 5). In other words, an individual's interpretation during a social interaction can modify and internally manipulate the given meanings assigned to objects.

The general idea of the symbolic interactionist frame is that symbols derive their meanings from interactions and symbols have the ability to be manipulated based upon these interactions and one's interpretation of these interactions. "The meaning of everything and anything has been formed, learned and transmitted through a process of indication – a process that is necessarily a social process (Blumer 1969, 12). It's imperative to remember that these meanings, despite their elements of realness, are merely social constructions (developed within social interaction and society).

Some argue Blumer's original three premises fail to properly articulate certain aspects within them. His premises lack the needed elaboration in order to fully express their inherent conceptualizations. Snow (2001) addressed this issue by creating what he deemed to be more inclusive to all ranges of work. Snow's work includes four principles. In order to fully understand objects surrounding one's self, one must not only consider the qualities intrinsic to objects, but one must also be mindful of interactional contexts ("web of relationships") in which these objects exist. This is an important consideration for meanings and implications come as a result of the interactional contexts in which objects are embedded and from which objects

emerge (Stryker 2003). Snow refers to this notion of interactional contexts as the principle of interactive determination.

The principle of symbolization states that features of people's environments gradually acquire meanings and become objects that evoke feelings and actions from within individuals (Stryker 2003). Snow's principle of symbolization is similar to that of the heart of Blumer's conceptualization, but it places a lesser emphasis on the generation and imputation of meanings. Snow's principle of emergence addresses the rise of new symbolizations. New symbolizations emerge when previously operative meanings prove to be insufficient in dealing with the given issue at hand (Stryker 2003). The creation of symbolizations is an ongoing process; one that serves to meet the needs of situations as they arise. The principle of human agency categorizes individuals as beings who construct their own lines of actions. Individuals have the capacity to engage in interactions in accordance with their own will and not based upon a pre-set line of action. It's important to bear in mind that Snow's principles are not to be taken at odds with Blumer's original premises, but rather "Snow sees his elaboration of the principles of symbolic interactionism as at least implicitly in Blumer's premises" (Stryker 2003, 6).

#### The Formation of the Self and Others within Social Situations

According to the symbolic interactionist frame, *others* within a situation can be defined by linking them to a recognized social category of actors. A social category of actors represents a certain type of person one can be within a society. For example, one's profession may place them within one social category or perhaps one's race may place them within another social category. Each social category has behavioral expectations. These behavioral expectations are referred to as the *role*. We define others by placing them within a social category, which in turn sets the tone for their expected behavior. Depending upon the situation, however, it may be more difficult to accurately place an individual within one social category. This individual may seem to fit the criterion for multiple social categories. This can result in conflicting behavior expectations because multiple sets of behavioral expectations are in play (Stryker 2003).

Another key player within a social interaction is the *self*. The self is a social structure that arises in social experience (Mead 1956, 204) and not something an individual devises on his own. "The meaning of self, like the meaning of any significant symbol, develops in and through interaction, and self, like any significant symbol, implies a plan of action (Stryker 2003, 7). Much of one's behavior is based upon habit and ritual, and the self only activates when behavior becomes problematic. What is meant by problematic is a situation in which one cannot act solely based upon habit, but rather must engage in this reflexive thinking and respond accordingly to one's role.

The process of *role-taking* refers to an individual's anticipation of other's responses. Much of role-taking touches on what Mead refers to as the generalized other or the process where by one is putting himself in the position of others and seeing the world as they do. "The attitude of the generalized other is the attitude of the whole community…he must then, by generalizing these individual attitudes of that organized society or social group itself as a whole, act toward different social projects at any given time it is carrying out, or toward the carious larger phases of the general social process which constitutes the group's life and of which these projects are specific manifestations" (Mead 1956, 218-219). It can be compared with a stage of self-reflection. Role-taking allows an individual to predict and track the foreseeable ramifications of one's own actions. An individual then has the ability to reformulate those actions into something else (Stryker 2003). This alteration or production of roles based upon the perceived responses of others is referred to as role-making (Stryker 2003). Through the process of roletaking, an individual is able to internalized the view of the generalized other and in turn modify their role (role-making) based upon this role-taking.

#### Labeling the Mentally Ill

Bruce Link's modified labeling approach lays a good foundation for understanding how the process of managing and negotiating of stigma begins. Link's modified labeling approach breaks down into five, distinct steps each marking a different phase in the labeling process. As demonstrated in the symbolic interactionism frame and excerpts from Mead's theory on the self, the acquirement of the generalized other (role-taking) allows an individual to take on the attitude of the community as a whole towards topics such as mental illness. According to Link's approach, this is where step one begins. Step one represents societal conceptions as a whole in regard to things such as what it means to be a mental patient (whatever that may actually mean). This step relies heavily on the fact that individuals internalize societal conceptions.

Step two tackles the distinction of being labeled or not labeled. To be labeled, as stated by Link, merely means the given societal conception becomes relevant to the self (e.g. entering treatment for a mental illness creates a link to the mentally ill label). "A seemingly innocuous array of beliefs becomes applicable to oneself; it now matters whether one believes that people will devalue and discriminate against a person who is in treatment for mental illness (Link 1989, 403). Scheff (1984), in his original labeling theory, expressed the idea that once an individual had been deemed mentally ill, the stereotypes associated with his illness become activated in others. As one may presume, to remain not labeled simply means societal conceptions are irrelevant to the self.

Once one has become labeled (step three), one fosters some form a (coping) response, whether it be secrecy, withdrawal, or education for "stigma and stereotypes become personally relevant and threatening" (Thoits 2011, 7). If one remains unlabeled, no response is elicited. Step four states that "if people believe that others will discriminate against them or devalue them because of a status they possess, powerful and unfortunate consequences can ensure. They may feel shame or believe that they are set off from others and thus are very different" (Link 1989, 403). Step three and four seem similar, however, step three addresses an actual response from the individual where as step four deals with negative consequences such as lowered self-esteem. The fifth and final stage brings forth the very important issue of increased vulnerability to future disorder (stigma and labeling induces a state of vulnerability). The overarching theme of Link's modified labeling theory is the process where by an aspect of Mead's generalized other becomes relevant and pertinent to one's self and, in turn, creates a sense of differentness and leads to not only a response, but also negative consequences on one's self-esteem and increased vulnerability.

## **Goffman on Stigma**

Erving Goffman, in his *Stigma: Notes on the Management of Spoiled Identity*, has created something that has honed in on this ever so familiar concept of stigma and laid the groundwork for years of research. According to Goffman, "the term stigma, then, will be used to refer to an attitude that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed...a special kind of relationship between attitude and stereotype" (Goffman 1963, 3-4). The attitude Goffman refers to is one that reduces the stigmatized individual from a whole person to a tainted, discounted one who is no longer quite human. According to Goffman, three varying forms of stigma exist, but the form most relevant to the frame of this research is referred to as "blemishes of individual character." Individuals who have been diagnosed with a mental illness are be stigmatized based upon the perceived blemishes of their individual character. Crocker et al. put forward the idea that stigmatization occurs when an

individual acquires some attribute, such as a blemish of individual character, "that conveys a social identity that is devalued in a particular social context" (Crocker et al. 1998, 505). Society gradually constructs "a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences" (Goffman 1963, 5). It's important to remember that stigma is based upon relationship and social context, not within the person himself.

Each social identity has a concrete set of norms and behaviors (as discussed previously) attached that society finds permissible for a certain role or profile to sustain. These set of norms are, for the most part, widely held and diffused through out society (Crocker et al. 1998). "These stereotypes are learned early in life and are reinforced over time in ordinary interaction and by caricatures in the media" (Thoits 2001, 7). An individual may see himself acting in accordance with the stereotyped expectations for a mentally ill patient, which leads him to label himself as mentally ill (conception becomes relevant to his sense of self). He will conclude that due to his mental illness and label, he must accept the mental patient role as a social identity (Thoits 2011). The norms then come together to construct the individual's social identity (Goffman 1963, 65) and, in turn, set the permissible behaviors for this mentally ill role, directly leading to a sort of self-fulfilling process. The person continues to act in accordance with his mentally ill identity because that what's his social identity tells him to do, leaving him continually labeled as mentally ill, which then leads to the reinforcement of acceptable behavior and set norms for his unchanged social identity as mentally ill.

A stigmatized individual imagines how society perceives his stigma based upon the norms that form the set social identity (previously discussed topic of role-taking). "This appraisal results from an interaction between perceived cues (affective or semantic) in the immediate situation that make stigma relevant to that situation, the collective representations that the individual brings to that situation, and individual characteristics" (Major and Brown 2005, 402). This self-appraisal process of one's stigma can result in very specific responses. The responses can be involuntary or voluntary in nature. Involuntary responses include emotional and physiological responses such as anxiety (Spencer et al. 1999) or self-stigmatization and shame (Corrigan and Watson 2002); where as voluntary responses include responses such as coping efforts (Compas et al. 1999). For example, a sense of shame can result in concealment efforts (a manner in which one copes with his stigma). This concealment effort becomes an integral part of the personal identity, which is clearly a direct reflection of certain aspects of the social identity. "The stigma and the effort to conceal it or remember it become "fixed" as part of the personal identity" (Goffman 1963, 65).

In his research Goffman identifies a group that he labels the "wise", "namely persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded a measure of acceptance, of courtesy membership of the clan...the individual who is related through the social structure to a stigmatized individual...are all obligated to share some of the discredit of the stigmatize person to whom they are related" (Goffman 1963, 28-30). In a way, those close to the stigmatized individual carry a burden that is not really theirs. Goffman states that this "courtesy stigma" spreads out in waves, meaning those closest to the stigmatized individual receive courtesy stigma in its most intense form. This creates a fundamental reason as to why close relations with a stigmatized individual have a tendency to be avoided or ended. "More recent research has shown that stigma by association may cause fear, low self-esteem, shame, distrust, anger, inability to cope, hopelessness, helplessness and increased burden for family members"

(Werner and Heinik, 2008). Courtesy stigma may result in suffering for the courtesy group without the ability to defend themselves against treatment though methods such as self-elevation.

On the other hand, however, "persons with a courtesy stigma provide a model of "normalization," showing how far normal could go in treating the stigmatized person as if he didn't have a stigma" and these individuals are "always ready to carry a burden that is not "really" theirs" (Goffman 1963, 30-31). These intimates serve as a protective cycle. The assigned stigma and associated ramifications don't solely become real for the stigmatized individual himself, but also for those closest (intimates). Just as the stigmatized must manage their stigma, those bearing the burden of courtesy stigma must manage it in some manner as well. The question at hand now is how the courtesy group manages and negotiates the very real stigma passed via mere association.

## **EMIPIRAL BACKGROUND & CONCEPTUAL REFINEMENT**

#### Societal Perceptions of the Mentally Ill

Up to this point, the development of self, the application of labels, and stigma have been discussed, but how exactly does this generalized other perceive the mentally ill? What stereotypes and generalizations have come to be applied to the mentally ill population? "Early studies (1950s) found that, not only was the public's orientation to mental illness largely uninformed by the current psychiatric thinking of the day, but public conceptions were suffused with negative stereotypes, fear, and rejection" (Phelan et al. 2000, 189). The root of this tendency to liken mental illness with character differences was rooted in the narrow definition of mental illness, which was comprised of extreme terms. These extreme terms were one's that the public not only feared and avoided, but also devalued (Star 1952). Research completed by Nunnally (1961) commonly noted the application of negative adjectives such as "dangerous," "dirty,"

"cold," "worthless," "bad," weak," and "ignorant" to those who have been labeled insane. Despite the incorporation of education programs through out the United States since the 1950s, there has been little to no reduction in the public stereotyping of the mentally ill and their perceived dangerousness. Cumming and Cumming (1957) also ascertained from their research that people rather keep a fair amount of social distance from those who have been diagnosed with a mental illness. "The mentally ill are believed to be unpredictable, irrational, dangerous, bizarre, incompetent, and unkempt" (Thoits 2011, 8).

The 1970s, 1980s, and 1990s constituted a time period where the public persisted with their want for social distance, however, the desire for social distance now extended to those with problems such as substance abuse (Rabkin 1972; Phelan et al. 2000). "Over half of "consumers" (i.e., people with a mental health problem) in a national survey said that they have "often" or "very often" overhead friends, coworkers, or even mental health providers make pejorative comments about mental illness and those who suffer from it" (Martin et al. 2000, 210). The 70s and 80s, however, also marked a period of mental health advocacy groups joining forces with the medical sector in efforts to "medicalize" mental illness. Advocacy groups took these efforts a step further and attempted to reveal to the public that mental illnesses plague a greater proportion of the population than they may think. This was achieved by exposing the less severe, more prevalent mental illnesses such as anxiety and mood disturbances (Phelan et al. 2000; Rabkin 1972). In a way this served as an attempt to "normalize" mental illness.

Moving into the twenty-first century we still see large numbers of individuals unwilling to interact with people who suffer from mental illnesses such as depression or schizophrenia, despite an increased understanding of the link to a brain dysfunction (Phelan et al. 2000). Recent studies show that the majority of people in the United States and most Western nations, including well-trained professionals from mental health disciplines, still subscribe to stigmatizing attitudes about the mentally ill (Corrigan and Lundin, 2001). It's not solely individuals who perpetuate this idea that the mentally ill are dangerous and violent, but also institutions such as the media (news programs and films) (Corrigan and Lundin, 2001). "The media never portray persons with mental illness leading a normal life...it would be good to show normal mentally ill people, not only murdered or homicides" (Angermeyer 2003, 597).

Individuals still wish to stay as far away from mental illness as possible (Link et al. 1999). "One possible reason for this is that the symptoms themselves represent undesirable personal attributes that people want to avoid" (Link et al. 1999). Society feels that the mentally ill are all the same and the mentally ill population belongs in the loony bin (Angermeyer 2003). It's also important to note, however, that regardless of the acknowledgement of a brain dysfunction, large numbers (as high as 90% of respondents in Link et al. 1999) still believed mental illness has a strong correlation to stress. These results reflect the less than impressive effects of education and advocacy efforts that started back nearly 50 years ago through to the late twentieth century. This fact not only illustrates a lack of information and true knowledge, but also an incomprehensibility of the illnesses on society's part (Angermeyer 2003).

Another sign that education efforts failed is the increased perception of the mentally ill as dangerous individuals (Pescosolido 2000; Phelan et al. 2000; Link et al. 1999). The incorporation of dangerousness into individuals' description of the mentally ill has nearly doubled since the 1950s (Phelan et al. 2000; Link et al. 1999). Phelan et al. (2000) brings forth an interesting observation in that those who have mentioned dangerousness also, in some cases, referred to psychosis as well. In other words, the idea of psychosis still remains foreign and stigmatized (Phelan et al. 2000) where as the non-psychotic disorders have gradually become part of the "us"

category. These observations cannot conclusively show that the social climate has improved for those who suffer from non-psychotic disorders, however, it does show "the stereotype of the violent psychotic person has become stronger in our society than it was in the time when researchers first pointed out and lamented the existence of such negative stereotypes." (Phelan et al. 2000, 202).

The inclusion of dangerousness into the label of mental illness can also be considered as a driving force behind the continued desire for social distance. "Distressingly high levels of social rejection continue to mark the stigma that surrounds mental illness" (Phelan et al. 2000, 202). "If the symptoms of mental illnesses continue to be linked to fears of violence, people with mental illnesses will be negatively affected through rejection, through a reluctance to seek professional help for fear of stigmatization, and through fear-based by processes such as the "not in my backyard response" (Link et al. 1999, 1332-1333).

#### **Strategies for Coping with Stigma**

We understand through the works of Link and Goffman how mentally ill individuals begin to self-devaluate or self-stigmatize due to their negative social identity. According to Thoits, "there are definite hints in the empirical literature that some individuals reject others' damaging remarks and behaviors or refuse to see themselves in the ways that the public or acquaintances do" (Thoits 2001, 11). Not only does research show that some 21% of individuals have actively taken corrective action in a stigmatizing experience (Wahl, 1999), but, on the other hand, about half of hospitalized patients (with severe disorders) didn't initially identify themselves as mentally ill (Warner et al. 1989). Research also shows certain amounts of social distancing and resistance occurs to internalize self-stigma (Link et al. 2002; Ritsher and Phelan 2004). Past research serves as the needed evidence to show that certain mechanisms are used to cope with the stigma attached to mental illness.

A few of these mechanisms include techniques such as challenging and deflecting (Thoits 2011). Thoits notes, however, forms of resistance such as challenging and deflecting can only be employed if the individual understands and accepts a few main principles. Individuals must acknowledge their mental health status (being mentally ill), whether they accept this as a personal identity or not. Individuals must also understand that if their mental health status were to be disclosed to the public, it could easily shape their public identity. Finally, individuals must understand that there are cultural meanings attached with their illness. "Meanings include the label's pejorative character, stereotyped behavioral expectations, and the possibility that discrimination will be directed at its carrier" (Thoits 2011, 12).

"Stigma deflection strategies are usually cognitive in nature" and individuals "view these stereotypes as inapplicable to themselves – as "not me" (Thoits 2011, 13). This type of deflecting can occur in three different forms. The general stereotypes associated with mental illness tend to represent the most severe of cases (typically schizophrenia) and often times these stereotypes don't actually match the symptoms of most mental illnesses, including those of schizophrenia. This mismatch of symptoms makes it easy for an individual to deflect and say, "That's not me. I'm different" simply because the symptoms don't correspond (Gove, 2004). The second deflection strategy employed by stigmatized individuals is to place their mental illness low on their salience hierarchy. In other words, individuals view their mental illness as only a small part of their identity, due to its discrediting character (Stryker 1980). Their mental illness becomes a part of their identity that doesn't depict the majority of their identity (no intrinsic or extrinsic rewards and great costs), which makes their mental illness not representative of themselves. "One's mental illness is "not me" because it is "a small, unimportant part of me" (Thoits 2011, The final deflecting strategy "is to define the nature of one's problem in terms that are less discrediting and stereotyped than mental illness: "I'm not mentally ill; I've simply had a nervous breakdown/am suffering nervous exhaustion/ am anxious/am depressed" (Thoits 2011, 13). Individuals view their problem as a mental health problem, but more of a temporary, less severe form of a mental illness (Estroff et al. 1991). This makes them unlike the other mentally ill individuals, which makes stereotypes and stigma inapplicable. Deflection strategies leave a mentally ill individual reasonably immune to stereotype threat and supply the individual with the needed "out" to keep himself unscathed by stigma (Thoits 2011).

Individuals who employ challenging strategies attempt to change or alter people's views and behaviors. "Challengers share deflectors' beliefs that mental illness stereotypes are ''not me,'' but they add a further qualification by arguing that those stereotypes are ''not me because they're wrong" (Thoits 2011, 14). Individuals may take it a step further and explain how these stereotypes aren't representative of not only themselves, but also most patients with mental illness. Similarly to deflection strategies, varying challenging strategies exist. The first challenging strategy, the most indirect, is to behave in ways that contradict stereotypes. By acting in a contradictory manner, individuals are invalidating the beliefs held by others about mental illness (Thoits 2011; Crocker et al. 1998).

A less passive way of challenging the stigma associated with mental illness is to educate others about mental illness and psychiatric care. Thoits emphasizes that "educating others may be successful with intimates but backfire with non-intimates, and it may produce an overall "no effect" on self-regard or other quality of life outcomes" (Thoits 2011, 15). Educating the community as a whole is important, but it can be seen as almost more imperative to educate

school children (prevents the perpetuation of stereotyping and stigma), mental health professionals, and opinion leaders (they have the ability to influence large numbers of people within the community) (Thoits 2011). There is also the strategy of confronting or actively contesting others' unjustified beliefs and acts. Confronting can be enacted in the form of disagreeing with biased statements, opposing inappropriate jokes, or challenging the legitimacy of an individual's beliefs. An individual risks antagonizing those around him and creating social tension (Kaiser 2006), however, such confrontation can increase one's self-esteem.

When reviewing challenging strategies, an emphasis must also be placed on the efforts of the collective group and not solely that of the individual. Collective group challenging can occur in the form of advocacy and activism by consumer groups whose main goal is to alter societal beliefs and lessen, if not eliminate, the discriminatory practices of the system (Thoits 2011). Corrigan and Lundin (2001) bring forward three methods for collective action: contact, education, and protest. Contact is a strategy where by individuals educate one another through the use of personal stories and real information while still providing opportunities for questions and answers from the group. Contact serves as a successful strategy for it has the potential to subvert the stereotypes associated with mental illness (Couture and Penn 2003). Education, as one may suspect, simply stands for presentations and other methods of communication that get information about mental illness to an uninformed audience (Thoits 2011). Group protests call attention to public statements, depictions in the media, and discriminatory practices within social and industry policies. Collective efforts to challenge stigma not only boost self-esteem, but also function as an outlet to create change.

In his work on managing the spoiled identity, Goffman expands upon the notion of concealment, also referred to as passing, as another method to managing one's stigma. Passing

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serves as a method that allows one to reap the enormous rewards associated with being considered "normal" for one is actually attempting to pass as "normal." However, a sort of double life forms (Goffman 1963, 77). There's the front that the stigmatized individual creates in order to pass for normal and then the real individual. Stigmatized individuals lead double lives in that some individuals think they know about a given individual (the appearance presented via means of passing) and others who really do know the "real" individual.

Leading such a double life, however, directly increases the risk for an accidental slip, which is partially why passing correlates to a high level of anxiety. Those not bearing the burden of such a heavy stigma perform unthinking routines that for a non-normal become cumbersome, management problems (Goffman 1963, 88). These daily routines become strenuous because they are no longer solely about performing the routine itself, but now it becomes about actively carrying out these routines while simultaneously passing and managing how one is passing. For example, Goffman refers to the development of relationships. For a normal the massive time commitment essential to forming a new relationship is not burdensome; where as for the non-normal, passing individual this significant amount of shared time heightens the probability that discrediting information will be released.

Goffman has identified this "passing" trend within the stigmatized populations; however, the manners in which individuals actively attempt to pass as "normal" are pertinent as well. One notable passing method (also referred to as techniques of information control) includes eradicating any signs that may be attributed to a given stigma (stigma symbol) and/or creating a façade that displays the symbols of another, less worthy of attention stigma. "Stigmas signal significant social boundaries, and passing allows individuals to transgress the lines that permeate most sites of interaction" (Renfrow 2004, 488). This technique provides individuals with the ability to escape the set expectations thrust upon them by others based upon their group membership and its related stigma (Renfrow 2004). By no longer exhibiting the signs associated with a given stigma, individuals can pass as normal and are no longer forced to act in accordance with the social identity associated with their stigma.

A second, more employed strategy has to do with the division of one's world. By division of one's world, Goffman is referring to the separation of the world into a large group to whom the individual tells nothing and a smaller group to whom the individual is not only open with, but also relies upon (Goffman 1963, 95). According to Corrigan and Lundin:

"Some people may choose to deal with stigma by selectively disclosing their history with mental illness. They may decide to avoid public disapproval by not sharing their difficulties with everyone. Instead they seek out a small number of persons who are likely to empathize with their challenges and support efforts in pursuit of their goals."

Of course with all of these concealment techniques certain management must be utilized. A prime example is disclosure. A stigmatized individual may opt to wait to tell his close ties about his newly acquired stigma for fear of immediate rejection, but then perhaps with time eventually shares his discrediting secret.

Techniques of information control don't serve as the only noteworthy form of concealment. The use of covering tactics also function as concealment tools. A stigmatized individual may opt to cover a portion of his stigma, which reflects a concern over the standards fortuitously linked with his stigma. What Goffman means by this is to say that an individual who happens to be blind while simultaneously suffering from facial disfiguration may opt to wear dark glasses, which reveals his blindness, but hides his facial disfiguration (Goffman 1963, 103). A stigmatized individual may also intentionally strive to restrict the display of certain symbols, perhaps failings, typically associated with the given stigma, even if those around constitute that small world of informed persons. A near blind individual may opt out of reading for it will bring his stigma to the surface, despite the awareness of the close friends surrounding him (Goffman 1963). "Those with a stigma may have to learn about the structure of interaction in order to learn about the lines along which they must reconstitute their conduct if they are to minimize the obtrusiveness of their stigma" (Goffman 1963, 105). The important thing to remember still remains that the normal and the stigmatized are merely perspectives generated in social situations making them both merely a social construction with real, harmful consequences and management tools.

As Goffman mentioned in his "Stigma: Notes on the management of spoiled identity," there is a type of wise person (abreast of the private life of a stigmatized individual) whose relationship with this stigmatized individual leads him to be treated in the same manner as the stigmatized individual (Angermeyer et al. 2003). According to past research, which still remains quiet limited, 56% of respondents in a survey distributed to National Alliance on Mental Illness (NAMI) members stated stigma much or very much affected families of a mentally ill person (Wahl and Harmann 1989). Affects included disrupted family relationships with both the mentally ill individual and other family members and damaged self-esteem. In a survey of caregivers' (working with schizophrenia, bipolar disorder, and schizoaffective disorder) perceptions of devaluation of patients and their families (Struening et al. 2001), 45% either agreed or strongly agreed that "most people look down on families that have a member who is mentally ill living with them." Phelan et al. (1998) discovered that half of parents and spouses who had responded to open-ended questions reported concealing recent hospitalization of their loved one. Research has also shown that courtesy stigma can illicit feelings of fear, shame, anger, inability to cope, low self-esteem, and increased burden for family members (Werner and Heinik,

2008). The existence of courtesy stigma is evident from both the work of Goffman and the existing empirical research; however, a body of extensive research on the topic is still missing. This serves as the starting point for the study at hand.

#### **RESEARCH QUESTIONS**

This study will explore the issue of courtesy stigma. Particularly, how do close family members manage and negotiate the stigma associated with a loved one's mental illness? Do close family members employ the same coping mechanisms as their mentally ill loved one? Which coping mechanisms are more common? Are altogether new coping mechanisms utilized? Do particular contexts call for particular coping strategies?

#### **METHOD**

My study is exploratory and seeks to extend on a theoretical framework (theoretical extension; see Snow, Morrill, Anderson 2003) to a new case (courtesy stigma). My research question strives to unveil the coping mechanisms used by family members to manage and negotiate the stigma associated with the mental illness of a loved one. Thus, qualitative research is the method best suited to my purposes. I opted to use qualitative methods in the form of indepth interviews for it serves as the most fitting manner to collect the necessary information. Indepth interviews provide a lot of rich, raw data on individuals' thoughts and feelings attached to this very real aspect of their lives. It allows for elaboration on concepts such as family coping mechanisms by incorporating individuals' experiences. An in-depth interview fosters an open dialogue, which will allow me to take a more significant look into the thoughts and feelings of the people within my study and, in turn, create a deeper understanding of their experiences.

#### **Concepts and Measures**

Before proceeding any further, working definitions for various aspects of the research question must be established. Mental illness, to different people, means different things. The National Alliance on Mental Illness has a list of 16 illnesses that qualify as mental illness. Some of these mental illnesses include bipolar disorder, borderline personality disorder, dissociative disorders, dual diagnosis and integrated treatment of mental illness and substance abuse disorder, major depression, obsessive-compulsive disorder, schizoaffective disorder, and schizophrenia. The term family member refers to the sibling or child of a mentally ill individual. I have chosen such strict boundaries because, as stated by Goffman, those closest to the individual will bear the brunt of the courtesy stigma. These family members, due to the intensity of the courtesy stigma, are more likely than any other family member to utilize coping mechanisms or directly feel and experience Goffman's courtesy stigma. The final concept, coping mechanisms, simply means the manner in which an individual manages and negotiates the stigma associated with their loved one's mental illness. The broader term includes mechanisms such as Thoits' deflection and challenging and Goffman's varying forms of passing, which are all expanded upon above (Thoits, Goffman).

The two main concepts that will be measured are the perceived stigma associated with a loved one's mental illness and the coping mechanisms used. I will get at the topic of stigma by asking participants a simple question: how do you think society perceives the mentally ill? When addressing the topic of coping mechanisms, I cannot be as direct. I will start with broad questions such as please describe your experiences with your loved one's mental illness or how do you think having a mentally ill parent/sibling has effected your childhood/life? Hopefully such questions will allow the subject to start speaking and gradually open up. I can then move onto

questions such as what challenges do you think having a mentally ill sibling/parent created for you while you were growing up? This will give me an opportunity to ask the participant how they have managed these challenges. Based upon certain aspects of their responses, I can request more details or ask the participant to expand on particular things. The combination of this set of questions should lead the participant to reveal the coping mechanisms they employ. If needed, there's always the option of directly asking the participant the coping mechanisms they feel they use when handling the stigma associated with a loved one's mental illness.

#### Sample

The main goal in the sample selection process was to acquire a group of individuals who could speak to having a loved one who is mentally ill. Due to the accessibility of the Emory undergraduate population and the specific requirements to participate in the study, I have selected to obtain my sample of respondents based on convenience. The use of a convenience sample wasn't informal interviews with friends or family, but rather I accepted all Emory undergraduates who were willing to participate while still fitting the criteria. The specific criterion for participation along with the private nature of the study severely limits those who qualify to respond. Being an Emory student myself may have served as a motivator for individuals to help a fellow student participate in the study. Snowball sampling also became a key part of gathering the sample. The criteria for the study are extremely specific and it's not improbable to believe that some respondents may be connected to another individual or two who fits within the criteria of the study. I needed a total of 20 Emory undergraduate students (no set gender proportions), above the age of 18, who are United States citizens, and who have either a sibling or a parent who has been formally diagnosed with a mental illness.

## **Data Collection**

The recruitment process was completed via Emory's email system called LearnLink. This provided an easy outlet to reach a vast array of individuals with great ease. Emails were sent to various conferences over the LearnLink system (class conferences, writing center, Greek organizations, and religious organizations that I had access to). Announcements were also made within classrooms. Students who wished to participate had already been provided with my email and phone number. They were able contact me via whichever means best suited them. There was no compensation provided for participation in the study. Individuals participated based upon interest alone. The biggest issue associated with the recruitment process was individuals' unwillingness to participate, even if they qualified. Mental illness within families tends to be a more private matter that not all individuals are comfortable speaking to a stranger about. This created somewhat of a deterrent for certain individuals.

When creating the interview guide, I started with a list of general topics that I hoped to get at during the interview. This list of general topics correlated with what information needed to be obtained in order to address the research question at hand. From this list of topics, a semistructured interview guide was created in order to lead to direction of the interview. This semistructure interview guide provided a few broad questions that would allow the respondent to start talking about their experiences in a manner in which they see fit. These questions were meant to get the respondent talking freely. A list of more specific questions had been created as a method to get at the necessary information if respondents hadn't touched on the main topics.

The interview isn't attempting to gather information about the mental illness of the loved one, but rather the feelings and experiences of the individual so no questions were asked directly about the loved one's mental illness. At times, however, respondents did discuss their loved ones' mental illness or certain aspect of the illness. The interview guide starts by asking the respondent to generally speak about what it's like to have a parent or a sibling with a mental illness. The respondents were asked to be as detailed as possible with their responses. The respondents were also asked to explore the challenges they had faced in having a mentally ill sibling or parent and how they managed those challenges in the past and currently. The interview also touches on how the respondents think having mental illness within their family had perhaps made their childhood different than those around them. I, as the interviewer, used my discretion and asked the respondents to expand upon certain things mentioned in a response and asked questions that were not directly written on the semi-structured interview guide, but that pertained to something a respondent may have said in a prior response. At this point, depending upon the series of responses I had received, I may have opted to directly ask the how respondents manage and negotiate the stigma associated with a loved one's mental illness. I also asked the respondents to briefly describe how they feel society views the mentally ill.

The interviews took place at a site of the respondent's choosing somewhere on Emory University's main campus or on the Clairmont campus. All interviews ended up taking place at either the Dobbs University Center on Emory's main campus or the SAAC on Emory's Clairmont campus. I narrowed it to Emory University's main or Clairmont campuses for ease and accessibility. As Emory students, they spend much of their time on campus and have access to buildings and quiet study rooms almost whenever needed. I left it up to discretion of the respondent to choose the final location because I wanted to ensure I was getting the most accurate data possible without causing any form of emotional distress to the respondent. It's not that my questions generally push respondents to a point of emotional distress, but I wanted the respondent to feel as comfortable as possible within the setting. Much of the information I collected isn't necessarily public knowledge nor does the respondent want it to become public knowledge. The respondent had to feel as comfortable as possible with the setting for if he wasn't fully comfortable he may have held back on information that he choose to disclose.

Interviews were expected to last approximately 30 minutes to one hour. In reality, the average interview ended up lasting 45 minutes. Interviews were not recorded to ensure the confidentiality of the participant. The lack of a recorded interview prevented any identifiable or personal information from being discovered. No written consent was obtained either for written consent provides further information for the identification of participants. Respondents were given the consent form and once it had been completed, they gave a verbal agreement to participate in the study. The information gathered during the interviews was stored as mental notes until immediately after the interview when I recorded not only general impressions, but also all information obtained from the respondent's responses. In order to ensure key aspects of responses were not lost during the remainder of the interview, I created jotted notes (key works, little phrases, or quotes) especially anything pertaining to coping mechanisms. These jotted notes allowed me to recall responses with greater ease and accuracy.

#### Analysis

I analyzed the collected data by coding the information and compiling it into a MAXQDA file, which served as a way to explore certain elements of interviews in relation to one another. Through the use of the interview guide plus a small portion of the initial data (e.g., 3-4 interviews), I developed an initial set of descriptive codes. Although past works from researchers such as Peggy Thoits don't directly address the current research question, work has been done on mechanisms employed by individuals coping with their own stigma. These works also served as reference points when creating the initial coding list. This stage in the coding

process is referred to as the open coding phase.

As I gathered an increasing amount of information, the coding process progressed and led to the development of sub-codes and the refinement of initial descriptive codes. The finalization of the core codes included eight categories including background, mental illness of family member (if mentioned), societal views of mental illness, effects on childhood, challenged attached to have a mentally ill loved one, coping mechanisms, motivators for selected coping mechanisms, and narratives. Each overarching code has multiple sub-codes to get at the specifics associated with each code. The coding list and typed interview reports were imported into MAXQDA. MAXQDA served as a workspace to organize data, mark comparisons and draw connections.

#### **RESULTS**

#### **Societal Beliefs**

The trends noted within the results regarding respondents' views on society's perception of the mentally ill align with much of the past research conducted. Society supports the preconceived notion of the mentally ill just being crazy:

"Society believes a mentally ill individual is someone who walks down the street in a bath robe and slippers saying things to himself. Society simply cannot comprehend how any form of mental illness doesn't directly lead to an individual doing "crazy" things."

The three most widely acknowledged perceptions respondents noted, besides the mentally ill merely being crazy, were the mentally ill's propensity to be viewed with a sense of fear and violence, their increased likelihood to be linked with homelessness or poor economic standing, and an element of being misunderstood or unknown. Amy expanded upon this and explained how society tends to just assume the mentally ill are lazy, unemployed individuals who in some ways create their own poor economic condition:

"Society believes the mentally ill are a group of individuals who typically have a poor economic standing, if they aren't homeless. Society believes in many ways that the mentally ill create their own poor economic situations through their own agency."

Along with laziness, respondents also discussed society's perception of the mentally ill lacking the capacity to hold down a job as another key factor driving the supposed poor economic standing. Some respondents took this a step further and widened it to not only include poor economic standing, but also poor social standing. Having a diagnosed mental illness automatically diminishes your social status, despite the possibility of possessing some high status attributes such as a high status profession.

Cathy discussed the portrayal of the mentally ill in the media. Part of what has perpetuated the belief that the mentally ill are dangerous, suicidal, psycho killers is as a result of shows such as Law and Order and others popular television shows: Cathy stated how prior to her loved one's diagnosis, she fell victim to the stereotyped versions of mental illness in the media:

"I only knew schizophrenia from watching TV shows like Law and Order SVU, and when you hear about that kind of stuff, it's super extreme. The people usually end up doing something like killing themselves or sexually assaulting people."

Even in the news, mental illness somehow manages to be linked solely to the violent crimes occurring in society. Other respondents included the belief that society sees mental illness merely as a reflection of an innate weakness, something inherent, which creates differentness. As if these individuals are to blame for if they had been stronger they could overcome their mental illness. Mental illness isn't considered a perpetuating disease, but rather an ailment whose cure lies in one's self-determination and inner strength to overcome obstacles. Respondents such as Dana and Beth also expressed how much of society incorrectly associates mental illness with a sub-par upbringing or a bad family dynamic.

Some respondents such as Amy and Cathy emphasized the main problem with society's

perceptions of the mentally ill is the fact that much of these perceptions are extremely uninformed and lack a solid foundation of valid information. Society has continually made, conscious and unconscious, judgments about the mentally ill that simply cannot be substantiated with real information. Amy also noted a certain intimidation factor, which keeps society at a far enough distance to make it nearly impossible to garner what could be deemed an informed opinion:

"There is also an intimidation factor and I think it's associated with dangerousness and discomfort. I think its extremely unknown and the people who don't know about it are the people who are most turned away or intimidated by it and they don't even try to and talk about it or understand it."

The results show that society is largely uninformed when it comes to mental illness and they're inability to let go of the stereotypes they continually cling onto makes it difficult to see positive progress in the societal perceptions of mental illness.

#### **Mental Illness Cases**

The information disclosed by respondents about their loved ones revealed a wide variety of personal experiences despite the similarity in diagnoses. Diagnoses included manic depression, schizophrenia, and bipolar. Some respondents also noted some form of drug or alcohol dependence. Amy, for example, spoke about her loved one's struggle with manic depression. Amy's loved one was an intelligent student who excelled not only in school, but also actively participated in the debate team and swam his way to many college scholarship offers. Amy's loved one, like most high school students, experimented with alcohol; however, it was never anything her parents felt was significant enough to threaten his well-being. Four weeks into college, her loved one returned home requesting a chance to enter a rehabilitation program. Amy's loved one's rehab aimed at treating an addiction to crystal meth, cocaine, weed, alcohol, and painkillers. Once in rehab, Amy's loved one met another individual who ignited a heroin use.

After a long road of recovery (one and a half years), Amy's loved one finished treatment and remains under the care of a psychologist, a psychiatrist, and weekly AA meetings. Amy expressed how not all days are necessarily the best, but her loved one has come along way.

Betty respondent elaborated on her loved one's battle with paranoid schizophrenia. Similarly to the previous respondent, Betty's loved one received a diagnosis while in a rehab program for ecstasy, marijuana, and possibly small amounts of cocaine. The drug use exacerbated the psychosis, but some doctors believe the drugs had some part in triggering a preexisting biological disposition. Doctors also believe the possibility exists that Betty's loved one also suffers from bipolar disorder. Betty's loved one has found the correct combinations of medication and, except a few instances where her loved one has stopped her medication, is extremely high functioning, lives alone, and works a job. Betty joked that her loved one is the sanest out of her whole family.

Cathy elaborated on her loved one's struggle with bipolar disorder. The diagnosis came at a time when Cathy's loved one was experiencing a few other medical problems including recently receiving a multiple sclerosis (MS) diagnosis. Cathy suspected her loved one battled depression through high school, which came along with drinking. She stated that this drinking was done more in secret and not the typical social drinking. This drinking in secret gradually developed into alcoholism, which seemed to follow Cathy's loved one until the use of antiaddiction medication. The anti-addiction medication helped lead to a full recovery. During a significant life change in relation to work, Cathy's loved one began to deal with an increased amount of stress, which in turn triggered manic episodes. The original diagnosis of bipolar I was later switched to a diagnosis of bipolar II. Along with the bipolar disorder, Cathy's loved one has also suffered from suicidal tendencies. The illness has not only taken a toll on Cathy's loved one's marriage, but also daily life. Cathy's loved one is actively working to maintain a correct medication regiment and receives the necessary treatment to manage the illness.

#### **Challenging as Education**

Some respondents found employing Peggy Thoits' challenging to be an efficient tool to manage and negotiate the stigma associated with a loved one's mental illness. The most common form of challenging was educating others. Kim expressed how it's important to speak to those who don't understand what it's like to live with someone who has been diagnosed with a mental illness. Kim felt she had to ability to bring a certain perspective to those around her because others had not in fact had similar experiences growing up and could only speak to the stereotyped views of mental illness. Kim stated:

"You feel like you need to speak for people who don't really know what it's like to live with someone who's mentally ill."

Respondents felt they possessed not only the necessary knowledge, but also the will to educate those who have been and remain uninformed.

Sally felt the most effective way for her to educate those around her was to become more open to dialogue. By fostering open dialogue, she was able to share her experiences and give an accurate depiction of what her loved one's mental illness truly entails. This dialogue could shed some light on the discrepancies between stereotyped views and the truth. Betty did a final project on paranoid schizophrenia in an AP Psychology class to show that an individual could still be exceptional and talented in spite of a mental illness:

"In my AP psychology course, we started learning about paranoid schizophrenia, and I did a whole presentation on it. I was able to show footage of my loved one performing; she majored in operatic voice in college. I was able to show footage of her performing during the presentation, and talk about how someone with mental illness, though diagnosed, can still rise above this diagnosis and be exceptional, flamboyant, and really dynamic."

Kim also felt the a good way to educate others is to focus much of her academic work on mental illness. This serves two purposes in that Kim not only furthers her own education, but she now has the ability to not only speak to her personal experiences, but also more of the literary and scientific work behind mental illness.

The main motivation behind employing education as a management tool was directly linked to the respondents' beliefs about society. Respondents stated that much of society is uninformed about mental illness. Some respondents such as Sally, Kim, and Dana felt that education was a tool that could be used to combat this ignorance and give others the opportunity to get a better grasp on mental illness. Other respondents felt that education was essential to the process of stigma reduction:

"I'm definitely more open about talking about it because only if people are okay with talking about mental illness will the stigma associated with mental illness lessen. I know creating dialogue is what's going to make the stigma change and go away."

If society could understand more than just the stereotyped version of mental illness, the stigma surrounding it would gradually dissipate. Betty also took the stance that education served as a technique to defend not only her loved one, but also the mentally ill population as a whole.

Not only do the results show challenging in the form of education, but there is also a second aspect of education that can be noted. Although this aspect doesn't fall directly within the realm of what Thoits' expands upon as challenging in the form of education, it can surely be considered as a form of coping through the use of education. A couple respondents such as Betty and Kim found themselves self-educating in order to more fully understand the illnesses of their loved ones. These respondents are shifting the focus from educating others as a form of coping to educating themselves. Prior to their loved ones' diagnoses respondents admitted being somewhat uninformed. Not only was an intrinsic desire to comprehend facets of each illness present, but

respondents felt this acquired knowledge also made it easier to cope and deal with some of the more negative aspects of the disease. For example, Kim explained how if she couldn't fully grasp what bipolar disorder was, how could she offer the support not only her loved one needed, but also herself.

#### **Challenging as Confrontation**

Two of the respondents, Dana and Betty, who employed challenging in the form of education also confronted negative comments or jokes made in their presence. These were the only two respondents who utilized confrontation. Betty and Dana speak out against the not so discrete discrimination that all too often occurs in conversation and all to often remains unchallenged. Dana mentioned that she felt particularly sensitive around comments passed throughout her life and has no problem saying, "Hey, that's inappropriate," or "Don't make comments like that." Betty stated that she is fully willing to speak up and say, "My loved one has schizophrenia. Stop talking about it like that and stop making fun of people." Both respondents are incorrect and simply inappropriate.

#### Deflection

Coping in the form of deflection, which can also be referred to as the "not me" mechanism, was far less utilized. Not one respondent in the sample fully employed any of the three deflecting mechanisms. What is meant by fully employed is in relation to the form of deflection where individuals use a mismatching of symptoms as a means to reject the diagnosis. Cathy and Betty passed comments about the symptoms of their loved one's not fully matching or doubting a few symptoms, however, neither used this as a reason to reject their loved ones' diagnoses. Betty expressed the possibility that her loved one's diagnosis may have been a little extreme for the main reason that she had always been unclear if her loved one's drug used triggered these episodes or if her loved one sought refuge in drugs to cope with these episodes:

"I don't know, I feel like her diagnosis was a little extreme, almost. Because, again, the confusion about whether or not she was having episodes because of drug use, or she was trying to use drugs to like quell the episodes; it's really unclear to me, and I don't know if she even knows which came first."

In this way Betty was unsure if the symptoms fully matched because she was unsure of the real catalyst. It's imperative to emphasize, however, that Betty never stated her loved one's diagnosis was unsubstantiated or her loved one didn't in fact have a mental illness.

Cathy respondent indicated that her loved one didn't match the key signs listed for a bipolar diagnosis except for her loved one's mood swings:

"Depression is for sure, but then, you know, the seven indicators of bipolar or whatever they are, my loved one doesn't really fit any of them to a T except he does have emotions that swing a lot."

Once again, this was not used to negate her loved one's diagnosis. The information communicated technically fits within deflecting in that both Betty and Cathy stated their loved one's symptoms don't necessarily match and creates somewhat of a hint of doubt, but this information was not used to give credence to the claim that either loved one wasn't mentally ill. Although this fact may seem to make these bits of data irrelevant, both respondents took the time, unsolicited by any question, to incorporate these details into their answers, which directly shows a certain level of importance in their eyes. Neither Betty nor Cathy showed any significant similarities that could present a connection relating to the disclosure of such information.

### Internalizing

Several respondents internalized a lot of what surrounded their loved ones' mental illnesses. Respondents stated that if they simply bottled everything up, in a way, they could avoid it. Although internalization was never heavily emphasized in any of the past research that lays the groundwork for this study, the results revealed this as a significant coping mechanism. For some of these respondents, their loved ones' mental illnesses have created such a sore spot that it has grown to be something that's easier not to think about or deal with at certain times. Cathy stated, "I just try and not talk about it and avoid it a little bit because it is such a touchy subject." Others such as Kim found that a lack of someone to speak to about the difficulties of having a mentally ill loved left them with no choice but to internalize everything for their own well-being.

"My loved one's mental illness was never a real topic of discussion in my home. Of course we were all aware what was going on, but no one wanted to really talk about it. My family had also, on many occasions, told me this was not to be mentioned outside of our home. I had no one to vent to within my home and I wasn't able to go to my friends or anyone not in my family. I just started to internalize everything because that was the only way to deal with everything going on around me."

Internalization became an easier way of dealing with everything going on around these respondents.

Amy explained how she tries to the best of her ability to not really talk about it. Amy speaks with her mother pretty much daily and they have their own way of asking if either of them has spoken with the loved one, but other than that she tries to avoid any conversation on the topic. Cathy spoke about the wide range of emotions linked with her loved one's mental illness. She dealt with anger and then guilt for feeling angry. She also indicated that thinking about her loved one's mental illness also elicits feelings of great sadness because of the stigma linked to it and the struggle her loved one faces daily:

"At first, I was really angry, and then I started to feel guilty, and now it's just like sad. I deal with it the best I can, but it's super hard."

These range of emotions weigh very heavy on her and sometimes it's easier to just internalize everything and push it aside.

In all cases where internalization was cited, at least one other management tool was also

used to cope. No one respondent solely relied on internalization as a manner in which to deal with a loved one's mental illness and the stigma attached to the illness. Each respondent who employed internalization communicated how difficult it is to deal with the heaviness of a loved one's mental illness and what comes along with the diagnosis. Some respondents mentioned how it creates a bit of a sore spot. Internalization was almost used as a way to escape from dealing and coping in other ways. Managing through challenging or passing takes effort, if not great effort, and some respondents conveyed that sometimes it's easier to avoid reality. Of course, as stated previously, other respondents had to bottle it all up because there wasn't anyone or anything to confide in.

#### Passing through the Division of One's World

The most widely cited coping mechanism, employed by all respondents to one degree or another, is passing. Once again, passing is the hiding of a deeply discrediting secret and passing for "normal." The dividing of one's world was the method employed by all respondents. Some respondents utilized other forms of passing in rare instances, but all respondents relied on the division of their worlds (in some instances heavily relied on the division of their worlds). Some respondents found it significantly easier to discuss their loved one's mental illness exclusively with other members of their immediate family where as other respondents found it helpful to discuss the matter with extremely close friends or significant others. A few respondents noted that they were open with family, some friends, and even in certain work or life situations where the topic happened to arise. No matter how an individual attempted to manage the division of his or her world, all respondents established some division.

Amy expressed that she prefers to keep the information about her loved one's mental illness very close to home except for the few, close individuals such as her best friend and her boyfriend that she confides in. The majority of the individuals she comes into contact with are left uninformed about her loved one's mental illness. Of her family members, Amy stated that she really only discusses the matter with her mother. It's not that she is unable to speak to her other loved ones, but rather she just finds herself habitually speaking with her mother. Jill indicated that she selectively spoke to certain members of her family about her loved one's mental illness and confided in three close friends.

"I ask friends to pray about it because then I can explain the whole situation and then they care and ask for specifics, and then they can give me kind of some sound advice. I feel like I don't have the whole responsibility of praying."

Jill's close friends are individuals who are a sort of third party as she stated and are removed enough from the situation. These individuals are removed enough from the situation in that they didn't know her loved one and never came into contact with the individual.

Frank found himself never discussing his loved one's mental illness with anyone outside of his family except for one isolated instance. Frank divulged information about his loved one's mental illness with one extremely close friend, which served to console this individual when her loved one was suffering from psychotic episodes.

"I opted to let my friend in on all of the things going on in my home as a way for her to feel a sense of comfort. It's difficult to discuss issues such as mental illness with others who you don't feel have the ability to relate in any way. Me opening up showed her I can listen, be compassionate, and understand what she is going through."

Even with this information being known by this close friend, Frank rarely found his loved one's mental illness to ever come up as a topic of discussion, even in the presence of his friend. Patty took a similar approach to how she divided her world in that she disclosed information about her loved one to certain family members and close friends. However, the close friends she divulged these details to weren't necessarily far enough removed to not know her loved one or come into contact with the individual. The manner in which these individuals opted to disclose a loved

one's mental illness remained static in that the selected confidents stayed the same.

Granted these individuals are all utilizing passing in the form of a division of their worlds, this group clearly represents a diverse group of individuals in that they opt to divide their worlds in different manners. This management tool serves as an overarching tool in which individuals can modify to fit their own situation and comfort level. This group also differs in that the span of time since their loved ones' diagnoses also greatly differs. Cathy had just recently been informed of her loved one's mental illness (within the last year and a half) where as another respondent's loved one had been diagnosed nearly eight years ago. Passing by dividing one's world is a definite management tool for those with mentally ill loved ones, but how an individual opts to exercise this tool is up to his or her discretion.

Two main forces drove respondents to selectively disclose information about their loved ones' mental illnesses. Some of these respondents felt it merely wasn't their business to tell. Beth expressed how it would be a violation of her loved one's privacy and she had no right to freely discuss his illness:

"My best friend from home knows, and I found that out by accident because I found out that her sister had a similar issue that I didn't know about. But other than that, it's my sister's privacy, so I don't tell my friends."

Beth's loved one should be the one to decide who is and who isn't made privy to the situation. The second motivator, which was noted in all respondents, was the fear of a skewed perception of their loved ones. Respondents feared the stigma associated with mental illness would weigh heavy in the eyes of others and alter how their loved ones are not only viewed, but also treated. Other respondents also expressed an additional fear of others having not only skewed perception of their loved one, but also themselves and their family. Dana stated:

"I didn't want people to think that my loved one was this like serial killer, psycho person. I also didn't want them to think that it was in some way my family. Just because it's a person in your family that has a mental disease, which there are plenty of families out there with that, doesn't make your family any less loving, and doesn't make your family any less functioning."

Dana feared the possibility of individuals thinking not only of her loved one in a negative way, but she also feared, that in some way, her loved one's mental illness would be deemed a reflection of flaws within her family. Perhaps something in the home life caused her loved one's mental illness.

#### **Transformation in Passing**

The remainder of the respondents who noted employing passing in the form of a division of world underwent a sort of transformation that occurred over the years. As the time from the original diagnosis progressed, this group of respondents gradually grew open to disclosing more information about their loved ones' mental illnesses. Some respondents solely discussed the matter with immediate family members and, with time, began sharing with close friends and others around them. Betty stated:

"I would say probably like six to preteen, like fourteen - I wasn't really talking about my loved one's diagnosis because I didn't know how to talk about it. I didn't know if it was appropriate to talk about, I didn't have the language to talk about it, and I was scared. I was just purely afraid to let people know what was going on. Now, I'm more than happy to talk to people about my experiences and share what I know about schizophrenia, and share my loved one's story as best as I can."

Some respondents even expressed their willingness to engage in open dialogue or discuss their personal experiences with whoever wanted to know more. It's important to note that these changes didn't occur in a short time span such as a few months, but rather over the course of years.

Kim felt that her loved one's mental illness was never a topic of conversation. It was something that was pushed aside in the household and it was not to be discussed outside the house. Many years later, when Kim had almost completed high school, she let two close friends and a boyfriend in on what was going on at home. She gave these individuals "an edited version" of the truth. College was a true turning point for this respondent. Kim found her ability to open up with friends grew along with her desire to pursue topics relating to mental illness in her schoolwork. Regardless of her newfound openness, she wouldn't consider herself at a point of total openness. Kim still considers herself to be in a process of altering how she divides her world. At this point in time, she is unsure if the process will ever be complete.

Betty originally viewed her loved one's mental illness as almost a dirty little secret:

"When I was a kid, when I was growing up, this information about my loved one, my loved one's health, felt like a dirty secret. And, so I would only tell my best friends this dirty secret. But, now it's not even worth it. It doesn't affect me the way it used to."

This secret wasn't something she knew how to talk about and surely didn't want to discuss it on a large scale. As Betty grew up, her desire to learn and understand the illness more flourished. Along with this desire, came a willingness and a want to share her loved one's story and almost educate those around her. Now, Betty finds herself being open with those around her. This is not a conversation that comes up daily, but when it does arise she's happy to engage in discussion.

One distinct link between each of these respondents and their vast transformation was time. Each of these respondents had been informed of his or her loved one's mental illness many years ago. The most recent diagnosis was nearly nine years ago with the first diagnosis being sixteen years ago. This set of respondents had a significant amount of time to not only process the diagnosis, but also deal with the emotions and managing, which comes along with such a diagnosis. For example, Betty spoke to gradually overcoming her fear of her loved one with time and wanting to understand more about mental illness and share this knowledge with others. Kim felt that with time she had accepted her loved one's diagnosis and no longer saw this individual as bipolar loved one, but rather just her loved one. Most of these changes occurred late in high school and during the college years, which unveils the possibility that the college environment supports individuals from diverse background with lessened sense of judgment. Sally stated:

"I think people, especially at schools like Emory, where people are a lot more educated, it's a lot different because people understand it's not something you choose or you're not being dramatic. There are so many psych-sociology like neuroscience majors that people understand, which makes me more open to telling people."

Most respondents noted a feeling of being surrounded by a more open-minded environment when they entered college. Two respondents expanded further by explaining the vast psychology and social psychology courses that helped foster an environment of understanding for students. Betty felt a sense of, "Wow, they're other people who have similar situations to my family." It's unclear if these two situational elements (time and new environments) work together and to what degree or if they stand separate of one another, but these elements have influenced this set of individuals in one manner or another.

Similarly to the individuals who didn't note a change in the manner in which they divided their worlds (passing), the respondents who did see a change were originally hesitant to divulge such private information in fear of skewing others' perceptions on their loved ones and their families. Beth didn't want people thinking her loved one was crazy. Another respondent expressed the fear of others thinking her family was this messy, crazy family who couldn't hold it together. For some other respondents there was the added element of not understanding how to talk about a loved one's mental illness. They didn't share information about it with many around them because they simply didn't know how. Some respondents sensed an inability of others to understand even if they opted to discuss a loved ones' mental illness:

"I only spoke to a couple of friends about it, I remember, and they were just so, you know, blown away by it, or they didn't, they didn't even understand what I was trying to communicate. They didn't have any idea what schizophrenia was."

These respondents were dealing with the situation first hand and, at times, couldn't find the words to explain it, so how could others, who have no experience, grasp what was being disclosed to them? It almost seemed futile to share with certain individuals.

Respondents gradually became more open for a variety of reason. Some respondents noted a desire to educate those around them. Kim felt she possessed the knowledge and experience to shed some light on the topic and she could only do this by opening up to others about what her loved one's mental illness actually is. Beth felt that the traditional views of her hometown kept her from sharing information about her loved one's mental illness. When she entered college she saw a shift from these traditional views to a more accepting, unbiased population.

#### **Eradicating Symbols of Stigma**

In a few instances respondents indicated using passing in the form of eradicating symbols of stigma. Respondents selectively chose when to and when not to have friends over to their homes in order to prevent others from witnessing episodes related to a loved ones' mental illnesses. Beth stated:

"There were a lot of times that I wouldn't have my friends over at my house because I was afraid that my loved one would have a breakdown. Sometimes my friends, who love my loved one, would tease my loved one but they didn't realize that it made my loved one really upset."

By doing this, friends only saw their loved ones when they were fully functioning. Others would be unable to detect a mental illness. One respondent spoke about how she almost filtered situations so her friends never saw her loved one acting crazy or displaying symbols linked with mental illness. If her friends saw her loved one acting out, they'd be inclined to just label her loved one as crazy and stigmatize her loved one from that point forward. Frank discussed the active efforts he made to keep others from being around his loved one during troubled times. For Frank, it was an active process of keeping his loved one's mental illness closed off from the outside world. These respondents were helping maintain the concealed nature of all symbols of their loved ones stigma and mental illness by eliminating the possibility of having other's witness psychotic episodes. These individuals were making sure the eradication of symbols of stigma remained constant.

#### **DISCUSSION**

#### **Relation to Thoits and Goffman**

Before delving into the connections that can be drawn between this research and the works of Thoits and Goffman it's important to reiterate one main factor. The works of Goffman and Thoits pertain to coping mechanisms used by the stigmatized individuals themselves. This study examines how close family members such as children or siblings cope with the stigma associated with that loved one's mental illness. The results merely serve as a theoretical extension to the works of Goffman and Thoits. The results may find that the coping mechanisms noted by Thoits and Goffman carry over to the sample addressed in this study. The findings may also differ from the works of Goffman and Thoits in that close family members may not opt to employ certain coping mechanisms utilized by stigmatized individuals. The possibility also exists that all together new forms of coping may be unveiled. In no way is this research meant to prove or disprove the works of Thoits and Goffman.

My work stands to show that the coping mechanisms employed by stigmatized individuals have the ability transcend boundaries and also serve as coping mechanisms for those managing courtesy stigma. Starting with the works of Thoits, the results provided by this study depict trends of respondents employing challenging in the form of education and confrontation. Family members have found educating those around them serves as a useful tool to cope. Education allows individuals to use their past experiences to expand upon others' knowledge about mental illness. If society, individually and as a whole, can obtain a better grasp on what it means to be mentally ill then perhaps the heavy stigma surrounding such illnesses will gradually diminish. In a way, education serves as an outlet for individuals to defend not only their mentally ill loved ones, but also the mentally ill population as a whole.

Of the four respondents who employed challenging in the form of education, all have been managing and negotiating the stigma for many years. In other words, none of these individuals have a newly diagnosed family member. Kim who felt that she had the ability to shed some light on what bipolar disease actually is and educate those around her has been managing the stigma for nearly 16 years. Other individuals who have mentioned challenging in the form of education were made aware of their loved ones' diagnoses anywhere from 9 to 15 years ago. In their responses individuals also conveyed that they had not always been so willing to step up and attempt to educate those around them through means of their own personal experiences. A gradual transformation occurred over time in which individuals arrived at a point where they could be open to new, more proactive ways of managing the stigma.

It is also important to note, however, in two cases, were individuals have also been managing the stigma associated with a loved one's mental illness for many years (both upwards of 8 years), they didn't discuss education as a method of managing and negotiating stigma. This could merely mean these individuals have not arrived at the same point as other respondents. Perhaps these respondents will never employ challenging in the form of education. It's difficult to say concretely whether time effects one's decision to employ challenging in the form of education as a management tool or if it's merely differences in individuals' personalities. However, these results could stand as the basis of a significant trend.

My results also reveal that Thoits discussion of challenging in the form of confrontation serves as another coping mechanism that close family members employ. Close family members speak out against the not so subtle discriminatory comments that seem to be thrown about during daily conversation. Research shows that close family members find these comments to be merely unjust and incorrect. Research also shows how close family members feel they stand in a position to step up and speak out against these comments because of their direct knowledge and the real life experiences.

The two respondents, Dana and Betty, who actively challenged acts of discrimination slowly began to utilize this challenging mechanism as the years drew on. This could be a reflection of one of two things. The first being, similarly to that of educating others, to make use of confrontation as a tool for stigma management may be part of a process where individuals step by step become comfortable challenging others. Another possibility is the real risk of creating social tension and antagonizing others through the use of challenging. Some respondents who don't use challenging in the form of confrontation may not want to deal with the possible outcomes of confrontation. These two respondents may have been hesitant for some time for similar reasons and as time passed, they may have grown less and less fearful of the possible social tension and antagonizing that may ensue.

The findings of this study not only align with Thoits' work on challenging as a coping mechanism, but also, to a certain degree, deflection strategies. Close family members, at times, hold the belief that a loved one's symptoms don't fully match the typical symptoms. However, the findings don't fully support the tendency for close family members to use this as a tool to reject their loved ones' diagnoses. In others words, results suggest that Cathy and Batty believed

their loved one doesn't fully fit the stated profile for his or her mental illness, but this doesn't serve as concrete grounds to repudiate the diagnosis. Now, having said that, it's important to emphasize the fact that this may merely be a result of the sample. These findings may be a reflection of a population who has a greater willingness to accept the diagnosis and hasn't gone through a process of denial. Another sample may show a greater numbers of individuals rejecting a loved one's mental illness due to some misalignment between symptoms and the typical patient profile.

Aligning with the works of Goffman, close family members utilize passing as a coping mechanism in order to manage the stigma associated with their loved ones' mental illnesses. The most widely employed coping mechanism within the findings is the division of one's world. Close family members sensor the information disclosed to those around them depending on a variety of different factors. The manner in which one goes about divulging information is very subjective in that a lot of personal factors go into the decision such as respecting a loved one's privacy, ability of others around to relate, the fear of a skewed perception of a loved one or the family as a whole, or merely one's ability to find the appropriate language to converse about such matters. In short, close family members of a mentally ill individual do in fact divide their world as a way in which to cope with the stigma, but there's not set method as to how this is done.

The findings not only revealed the application of Goffman's division of one's world to a new population, but the findings also showed a gradual transformation that occurred for some respondents. This transformation was marked by a shift from a tendency to remain more closed off and maintain a somewhat tight knit group of people an individual discusses his loved one's mental illness with to an exspansion of this group and a willingness to be more open, even with

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people not necessarily close to the individual. These respondents are individuals who had been made aware of their loved ones' diagnoses many years ago. A very real possibility exists that this trend was noted within this set of respondents for they have had the time to not only process and accept the diagnoses, but also somewhere within that process perhaps fear judgment less (entering more open, knowledgeable populations) or believe that discussing their experiences will garner some benefit for not only themselves, but also the mentally ill population as a whole (for example stigma reduction).

My findings also show Goffman's notion of eradicating symbols of stigma within the realm of coping mechanisms close family members utilize. It's more of a modification of Goffman's original theory in that close family members filter and manage situations so a loved one won't be placed in a position where they may exhibit signs of stigma. For example, preventing close friends from witnessing a loved one's psychotic episodes. Results show close family members eradicating symbols of stigma, however the manner in which they can best do this is to help control what those surrounding their loved ones happen to observe. Close family members help conceal symbols of stigma when loved ones themselves may be struggling to fully eradicate the symbols associated with their stigma.

We note the research diverging from the past works of Thoits and Goffman in five main ways. Findings do not show close family members using challenging in the form of behaving in contradictory ways to stereotypes. This form of challenging was expected to remain unused for respondents have not been diagnosed with a mental illness themselves therefore behaving in ways that contradict stereotypes wouldn't serve to accomplish much. Close family members wouldn't be expected to act in "stereotypically mentally ill ways" because they don't have a mental illness. The second form of challenging not noted in the findings was challenging as a collective group. None of the respondents participated in collective group challenging in that none of them were involved in either some form of an advocacy or activist group. This tendency could be as a result of a few possibilities. Firstly, perhaps respondents have no innate desire to participate in any form of collective challenging at this point. One respondent mentioned wanting to eventually work with mental health in one fashion or another, which could potentially lead to some form of collection challenging in the future, but not currently. It's important to bear in mind that all respondents are enrolled as Emory undergraduate students and they may have not found an outlet for them to serve as a member of an advocacy or activist group. Lastly, to partake in collective group challenging one must be fairly open with the nature of their loved one's mental illness and, at times, to a fairly large scale. Individuals might not be at a point where they have the ability to be open to that extent for a whole host of reasons.

Deflection in the form of justifying a loved one's mental health problems with a more temporary nervous breakdown wasn't cited in any of the findings. There is the possibility that this trend may be as a result of the more long-term diagnoses that were present in the sample. Most diagnoses had occurred at least four years ago. The period of time that has passed may have negated any thoughts that a loved one is merely suffering from a temporary nervous breakdown. However, there was one more recent diagnosis within the last year and this respondent also didn't reveal any inkling that her loved one was dealing with a temporary breakdown. Not only had all respondents accepted their loved one's diagnosis for what it was (a mental illness), no respondent even indicated the thought of it being something more temporary. It's important to emphasize that, yet again, this may be a mere reflection of the sample.

Not a single respondent found placing "having a loved one with a mental illness" low on

their identity salience hierarchy as a useful coping mechanism. In spite of the fact that having a loved one with a mental illness did have an effect on each respondent in some way, none of the respondents expressed the feeling that having a sibling with a mental illness became part of their identity. When respondents were asked to tell a little bit about themselves, each individual stated the number/gender of their siblings and about their parents, but no one followed up by telling me which loved one was mentally ill. It's evident that each respondent felt these individuals were part of their identity for they spoke about them when asked to talk about themselves, but the mental illness of their loved one wasn't in any way linked to their identity, at least initially.

Yet another trend not noted within my findings was close family members covering a portion of their loved one's stigma. It's most plausible to believe this coping mechanism didn't transfer over to this new population because the only individual who has the ability to truly cover a portion of a stigma is the loved one himself. For example, a loved one may opt to cover scars from self-inflected bodily injuries during a time of psychotic distress. A close family member, despite an existing yearning, cannot make the decision to cover a portion of a loved one's stigma. Having said that, close family members can suggest to a loved one that perhaps covering a portion of their stigma may be beneficial in the long run. However, results didn't reveal this trend either. This could merely be a reflection of the sample, the stigma symbols their loved ones possess, or maybe this merely isn't a coping mechanism employed by any group of close family members.

The findings reveal a new coping mechanism not mentioned in the works of Goffman and Thoits: close family members use of internalization as a coping mechanism. Results show close family members keeping much of what goes on around them bottled up for reasons such as a lack of an option to discuss emotions and experiences with those surrounding them as well as a desire to escape the heaviness of their loved ones' mental illnesses. We see this trend always cooccurring with some other form of a coping mechanism. In other words, close family members can't solely employ internalization as the manner in which they cope with the stigma associated with their loved ones' mental illnesses. Many individuals expressed how their loved ones' mental illnesses create sore or soft spots and often trigger a wide variety of emotional responses, which drive family members to avoid the situation in a way. Close family members most likely employ another form of coping when utilizing internalization because there is only so much that one can actually handle internalizing. It seems as if it would be very difficult, if not nearly impossible, to continually avoid a situation that is a very real part of these individuals' daily lives.

The combination of qualitative interviewing methods, convenience sampling, and a reduced sample size hinder the study's ability to generate generalizable findings (Babbie 2007). However, my findings bring new depth to the topic of how close family members cope with a loved one's mental illness. With a very small body of pre-existing research, my findings add to a foundation that will serve as a launching point for further research. Participants in this study are similar to other family members with a loved one with a mental illness making the coping mechanisms they chose to employ likely parallel with that of other close family members with a mentally ill loved one:

Insofar as the dynamics of the group we study and the constraints to which they are subjected decide their behavior, we can expect the same behavior from any other group with the same dynamics and the same constraints. (Weiss 1994, 27)

Although I cannot make any vast generalizations based on my methods, I can reliably suppose that similar coping mechanisms are employed by other individuals who also have a loved one with a mental illness. Despite the non-representative nature of my sample, my research has succeeded in uncovering some of the coping mechanisms employed by Emory students with a mentally ill loved one.

I would also like to take the time to call attention to the great trouble I had recruiting a sample of twenty participants. As mentioned, part of my studies inability to create generalizable findings was the sample size, which later had to be reduced even further. After many arduous attempts to recruit individuals, I was forced to work with a sample of only ten interviews. I suspect much of the trouble I faced was due to individuals' unwillingness to discuss such a stigmatized, private matter with a complete stranger. I believe the stigma associated with their loved ones' mental illnesses kept many individuals, who did qualify, from participating in the study. This fact further displays the realness of the stigma and how it drives not only stigmatized individuals themselves, but also family members to hide this "blemish" from society.

Future research would not only serve the address the limitations of this study, but also address the significant gap in research on the topic as a whole. Large bodies of work exist that adddress how stigmatized individuals themselves cope and research also shows how this stigma can directly affect family members, but more research must take it a step further and actually examine how these family members manage a stigma so clearly affecting them. My work can stand as starting place for other works. For example, future research can re-examine the topic as a whole and incorporate larger and more varying samples and complete survey methods. These survey methods would allow for the research to reliably make generalizable claims. Future research could also further scrutinize noted coping mechanisms on their own and expose more specific patterns relating to who employs these coping mechanisms, how, why, and how the use of the coping mechanisms changes over time.

The final sample of this study was comprised of nine women and one man. This is yet another interesting place for further research. What makes women more willing to open up and discuss such matters? Perhaps it was merely a reflection of the population or maybe there is a greater trend behind this. I also believe examining how culture effects what coping mechanisms are employed would provide interesting insight into variations amongst even more varying populations. Research on this topic is far from being complete, if anything the research has just begun. Future research would not only foster a better understanding of the topic as a whole, but it might, one day, serve as a tool to educate society.

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## **Recruitment Email**

Dear student,

Hi, my name is Jana Taylor, and I am an undergraduate sociology major. I am currently working on a senior honors thesis about managing the stigma associated with a sibling or parents' mental illness. I am looking for volunteers who are willing to participate in one interview with me which will last no more than one hour. Interviews will take place at a location of your choosing on campus. All information will be kept confidential and your participation will in no way affect your class standing, course grade, graduation status, or standing with any faculty or staff at Emory.

You must be at least 18, a U.S. citizen, a student in the college and have a sibling or parent that has been diagnosed with a mental illness to participate in this study. I am unable to offer you compensation, but volunteer participants are crucial to my research project and I would greatly appreciate your help. If you are interested or have any questions, please contact me. Your participation is completely voluntary and you can choose not to participate at any time.

Best of luck with your own academic pursuits!

Thank you,

Jana Taylor Department of Sociology Emory University Tarbutton 225 Atlanta, GA 30322 Jhtayl2@emory.edu

## Emory University Undergraduate College Consent to be a Research Subject

<u>Title</u>: HONORS THESIS: The Management of Stigma Associated with Mental Illness from the Perspective of Family Members

Principal Investigator: Tracy Scott, Ph.D. Co-Investigator: Jana Taylor

#### Introduction

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. You can skip any questions that you do not wish to answer.

Before making your decision:

- Please carefully read this form or have it read to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. By signing this form you will not give up any legal rights.

#### Study Overview

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. The decision to join or not join the research study will not affect your class standing, course grade, graduation status, or standing with any faculty or staff at Emory.

You were chosen to participate in this study because you are a student in the undergraduate college at Emory University with either a sibling or parent who has been diagnosed with a mental illness, because you are at least 18 years old, and because you are a citizen of the United States. There will be 20 students total participating in this study. You participation in this study would last between 45 minutes and 1 hour. This study is being conducted as part of my Senior Honors Thesis under the direction of Dr. Cathryn Johnson.

The scientific purpose of this study is to explore the mechanisms used to navigate and negotiate the stigma associated with the mental illness of a sibling or a parent.

#### Procedures

You will be participating in an in-depth interview in which you will be asked about your experiences with the stigmatization of mental illness and how you navigate and negotiate this stigma. The interview will last between 45 minutes and 1 hour. With your permission, the interview will be taped using an audio recorder. Jana Taylor will be conducting the interview. The interview will take place at a location on campus that is easy for you.

#### **Risks and Discomforts**

A foreseeable risk of the study is breach of confidentiality.

#### Benefits

This study is not designed to benefit you directly. This study is designed to learn more about how individuals navigate and negotiate the stigma associated with the mental illness of a parent or sibling. The study results may be used to help other people in the future. There may be no direct benefit to you as a participant from this study.

#### Compensation

You will not be offered payment for being in this study.

#### Confidentiality

Certain offices and people other than the researchers may look at your study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board and the Emory Office of Research Compliance. Emory will keep any research records we produce private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

Study records can be opened by court order. They may also be produced in response to a subpoena or a request for production of documents.

There is a Certificate of Confidentiality for this Study:

What the Certificate of Confidentiality protects:

The National Institutes of Health has given this study a Certificate of Confidentiality. Emory would use it to block a legal request to give out study information. For example, if Emory received a subpoena for study records, we would say no. The Certificate gives Emory legal backup to say no. It covers information about you that could harm your image or finances. It also covers information about you that could harm jour insurance.

#### What the Certificate of Confidentiality does not protect:

The Certificate would not protect some information about you, including any information:

- you give out yourself
- someone other than you or Emory gives out
- that Emory must give to state public health offices about certain infectious diseases
- that Emory must give to law officials if child abuse has taken place
- that Emory must give to prevent immediate harm to you or others
- that Emory needs to give to the study funder

#### Voluntary Participation and Withdrawal from the Study

You have the right to leave a study at any time without penalty. This decision will not affect your class standing, course grade, graduation status, or standing with any faculty or staff at Emory.

The researchers and funder also have the right to stop your participation in this study without your consent if:

• They believe it is in your best interest;

## Contact Information

Contact Jana Taylor at 773-294-4123 or jhtayl2@emory.edu:

- if you have any questions about this study or your part in it, or
- if you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or irb@emory.edu:

- if you have questions about your rights as a research participant.
- if you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at <a href="http://www.surveymonkey.com/s/6ZDMW75">http://www.surveymonkey.com/s/6ZDMW75</a>.

# **Interview Guide**

- 1. Tell me a little bit about yourself.
  - a. Where you're from
  - b. Family
  - c. Education
  - d. Anything you deem to be relevant or important
- 2. How do you think society views mental illness?
  - a. Stigmatization
- 3. Tell me a little bit about what it is like to have a parent/sibling with a mental illness.
- 4. During your childhood, when was the first time you realized that your parent/sibling had a mental illness? What did you think?
- 5. How did you start to deal with this realization?
- 6. How do you feel it affected your life growing up? If not, why not? If so, how?
- 7. Do you feel that having a sibling/parent with a mental illness made your upbringing different than those around you? How?
- 8. What challenges do you think having a mentally ill sibling/parent created for you while you were growing up? Tell me about these challenges.
- 9. Are there challenges that you face now in your life? Tell me about these challenges.
- 10. How have you managed these challenges?
- 11. How have the ways in which you've managed your sibling/parent's mental illness and its stigma changed over the years? What do you think led to these changes?
  - a. Important people or factors that led to this change over time
  - b. Explain a little how you first managed it and explain in stages
  - c. Perhaps you never felt the need to manage the stigma attached
- 12. Compared to the viewpoint you explained earlier, do you think society's understanding and view of mental illness will change?
- 13. How do you think society will begin to understand mental illness in the future? What would spark this change?

# Codes

# • Background

- Home Town
- o Siblings
- SES
- o Age
- Parent's Marital Status
- Parent's Education
- Mental Illness of Family Member (if mentioned)
  - o Type
  - o Symptoms
    - Mental illness itself
    - Effects of mental illness such as substance abuse or suicide
  - o Onset
  - Medications
  - o Any other pertinent information mentioned
- Societal Views of Mental Illness
  - Positive
    - Non-stigmatized, non-discriminatory, non-prejudiced, well-respected
  - o Negative
    - Poor economic standing
    - Crazy
    - Stigmatized
    - Socially out casted
    - Feared
    - Associated things such as violence, homeless, and dangerousness
    - Uninformed perspective on the mentally ill
- Effects on Childhood/Life
  - Emotional responses
  - Household environment
  - o Changes in expected (normal) responsibilities
  - None due to later diagnosis
  - Increased burden
- Challenges attached to having a mentally ill loved one past or current
  - Added emotional stress
  - Increased sense of responsibility
  - Different responsibilities than what may be expected (e.g. sense of greater responsibility)
  - Increased burden

- Alterations to daily life (doing things one may otherwise not do if the family member didn't have a mental illness).
- Coping Mechanisms
  - Resistance
    - Denial about mental illness
      - It's not my family member, they don't fit that criteria
  - Mental illness kept within the family
    - Acknowledged within the family, but not shared as open information
    - Dealt with within the family
  - Openness about the mental illness
    - Attempts to enlighten/educate those around
    - Perhaps always open
    - Openness grown over time with life experiences
  - Shared with select individuals
    - Seeking refuge in others  $\rightarrow$  way to release some of the stresses
      - Provides a sense of reduced stress
    - Seeking advice of ways to manage the stigma or the mental illness itself
  - $\circ$  Internalization
    - Keeping everything to one's self
- Motivators for selected coping mechanisms
  - $\circ$  Self-protection
    - Embarrassment
    - Fear of being stigmatized in a similar manner (courtesy stigma)
  - Fear of a skewed perception of loved one
    - Don't want others to view their loved one differently
  - Protecting loved ones
- Narratives

# **Coping Mechanisms Table**

<u>Name</u>	Number of Years since Loved One's Diagnosis	Coping Mechanisms Employed
Amy	7	Division of World, Internalization
Patty	5	Division of World
Sally	9	Division of World, Internalization, Educates Others and Self
Beth	7	Eradicating Stigma Symbols, Division of World
Cathy	1	Division of World, Internalization
Jill	6	Division of World, Deflection of Stigma Symbols
Dana	15	Division of World, Education, Confrontation
Betty	15	Division of World, Educates Others and Self, Confrontation, Deflection of Stigma Symbols
Frank	12	Division of World, Internalization
Kim	16	Division of World, Internalization, Educates Others and Self