# INTERNALIZATION AND THE PERPETUATION OF THE STIGMA OF MENTAL ILLNESS:

# UTILIZING DIAGNOSIS THROUGH EDUCATION

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### **Abstract**

# INTERNALIZATION AND THE PERPETUATION OF THE STIGMA OF MENTAL ILLNESS:

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Under the Supervision of Dr. Richard A. Rogers, Ph.D.

This paper provided a review of literature regarding the concerns of clients diagnosed with a chronic mental illness and the expectations they and their families may experience as stigma. The three levels of stigma reviewed and described by the author were communal, institutional, and self-stigma. Since ultimately, the impact of stigma brought about and interpreted by the various levels of stigma listed above were confronted by the individual upon whom such stigma was perceived, the author concentrated the focus of this paper on the perceptions of self-concerning stigma. Following the collection of information and academic quotes, there is a section of recommendations and conclusions.

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## **CHAPTER I**

## INTRODUCTION

The various diagnoses of illness, especially mental illness, introduced their own language. "I am bi-polar" and "I have cerebral palsy" became the way a patient began to describe not only a circumstance of wellness but also a state of being and sense of belonging. The language of these conditions vaguely described an existing condition with little attention to the degree, severity, or even prognosis. As diagnoses multiplied treatment ensued. At the time of this study, a line of medical, psychological, and spiritual professionals offered expertise to the best of their ability. First, an explanation of what it was that a diagnosis would cause one to be called for the rest of his or her days. Second, they proposed treatment options intended to help instill coping mechanisms aimed at dealing with the chronic and incurable nature of various ailments. Third, professionals took their best guess as to a prognosis (how the future should proceed after treatment.)

A current view of treatment was that a patient who learned to advocate for his own treatment was the ideal help in successfully achieving his own treatment goals. Reaching this level of "self-help" might have been difficult. Many individuals lacked the cognitive ability to be an advocate and still more had not the self-efficacy to do the work of wellness. The high functioning client had the ability in most cases to learn about the intricacies of his diagnosis. The professional had the ethical responsibility to offer a prognosis directed toward hope. The Rogerian ideal of unconditional positive regard could only be exercised if the negative implications of a diagnosis were addressed and intentionally balanced by an accounting of gifts that also defined one's circumstance.

Illness was accompanied by its own lexicon. In the section, Definition of Terms, a list of words that appeared redundantly throughout the literature, was defined using just a simple dictionary. The reason these words were listed was that many words have various meanings.

Often people assume they know what a word means and that the person with whom they are communicating agrees with that definition.

Wanting to answer the questions of how the introduction of the lexicon of diagnostic language was internalized by the patient and how that lexicon could become empowering rather than disabling had led to research the dichotomy of labeling theory.

Labeling was a way of categorizing people and their conditions, attitudes, and reactions to said conditions that would help professionals and the diagnosed determine viable treatment options in the hope of creating that ideal advocate for one's own best life. Diagnostic labels were necessary for accessing appropriate services and often the money to pay for those services. Unfortunately, labels had both denotative and connotative meanings that greatly influenced the type and quality of treatment offered and a potential client's ability to receive that help. In the case of psychiatric labels, there was often little positive interpretation of these labels by anyone.

As of 1997: no study has tested the relative positive and negative effects of labeling. The Author compares the importance of perceived stigma versus the receipt of services for the quality of life of persons with chronic mental illness. Results show that both stigma and services received are significantly associated with quality of life, but in opposite ways. (Rosenfield, 2008)

The individual, the greater community, and the institutions of our society often impeded the success of many persons with chronic mental illness.

At the time of this study, there were two competing applications of labeling theory. The first defended the use of labels as necessary and beneficial for the individual; the second believed that the emotional and cognitive price of labeling on client attitudes and opportunities outweighed its benefits. Even though organizations such as the National Alliance for the Mentally Ill (NAMI) had made wondrous strides in creating a more accepting and supportive atmosphere for people diagnosed with mental illness and their families, so much more was left to do. A clear example of this fact was that in the research of key words that applied to this paper, the words that were most effective for finding information were not "denotation" or "connotation" but "stigma" and "mental illness." The negative implications of such word choices once again received more attention than the positive, even among the supposedly educated community.

"People suffering from mental illness and other mental health problems, are among the most stigmatized, discriminated against, marginalized, disadvantaged and vulnerable members of society" (Overton & Medina, 2008, p. 143). One of the reasons for the perpetuation of these biases was the concept that the behaviors associated with a diagnosis of mental illness were always negative and extreme. Mental illness existed on a continuum. "There are many degrees of mental illness. This fact does little to dissuade the belief that these conditions are incurable, a moral shortcoming and somehow contagious" (Overton & Medina, 2008, p.143). These incorrect assumptions somehow seemed enough to justify the negative perceptions of a diagnosis that led to exclusion of an individual with a mental illness from the greater society.

Van Vliet identified three major types of discrimination inflicted upon the mentally ill:

1) Social stigmatization (that which is perpetuated by the lesser community)

- 2) Institutional discrimination (that which denies the equal access to jobs or any other normative activity expected to preclude perception of societal success)
- 3) Self-stigmatization (2008).

Van Vliet identified the third as the most important and directly addressable. As the term "self-stigmatization" implied, the person at the forefront of the battle for positive forms of inclusion, regardless of diagnosis, was the "self."

## **Statement of the Problem**

Sufferers of mental illness and other mental conditions were faced with both internal and external stigmatization that significantly affected and reflected upon the accomplishment of life's ordinary goals and the milestones of self-efficacy. Questions addressed in this study were the following:

- To what extent did treatment and the internalization of perceived stigma, resulting from a diagnosis of mental illness or disability, influence a client's self-esteem and choices?
- How could the stigmatization caused by a psychiatric diagnosis be negated using education?

## **Delimitations of the Research**

Research was conducted through the Gateway Technical College (Racine, WI), Karmann Libraries (University of Wisconsin-Platteville) and Hedberg Library (Carthage College, Kenosha WI) during the spring semester of 2010. Primary searches used Multi-Search, EBSCO Host, and sagepub.com.

Keywords for the search included the following: stigma, diagnosis, stereotypes, mental illness, labeling, education, counseling, health, rumination, identification, identity, mindfulness-based cognitive therapy, perception, bullying, and logotherapy.

## **Method of Approach**

A review of literature related to research, studies, editorials, and anecdotal evidence related to the stigmatization of people with mental illness and other mental conditions. Also considered were the language of diagnoses and potential solutions to the negative internalizations of said diagnosis as attributed to communities and institutions and their relationship to identity and self.

### **Definition of Terms**

## Advocate

1. a person who pleads for another's cause; a lawyer 2. a person who speaks or writes in support of something; be in favor of (p. 20).\*

# Bullying

1. *n*. persistent threatening and aggressive behavior directed toward other people especially those perceived as smaller and weaker. \*\*

### Chronic

1. lasting a long time or reoccurring often: as said of a disease, and distinguished from acute 2. having had an ailment for a long time [a chronic patient] 3. continuing indefinitely; perpetual; constant [a chronic worry] 4. by habit, custom, etc.; habitual, inveterate [a chronic complainer] (p. 254).\*

### Confront

1. to face, stand or meet face to face 2. to face or oppose bodily, defiantly, or antagonistically 3. to bring face to face with [to *confront* one with the facts] 4. to set side by side to compare (p. 298).\*

### Connotation

1. the act or process of connoting 2. something connoting; idea or notion suggested by or associated with a word, phrase, etc. in addition to its explicit meaning, or denotation ["politician" has different *connotations* from "statesman"] 3. *Logic* the sum of all the attributes thought of as essential to the meaning of a term (p. 301).\*

# Contagious

1. spread by direct or indirect contact; communicable; said of disease 2. carrying or liable to transmit, the causal agent of a contagious disease 3. for the care of contagious patients 4. spreading or tending to spread from person to person [contagious laughter] (p. 306).\*

## Cure

1. *n*. a healing or being healed; restoration of health or a sound condition 2. a medicine or treatment restoring health; remedy 3. a system, method, or course of treating a disease, ailment 4. spiritual charge of persons in particular district; care of souls 5. the work or position of a curate *vt*. 1. to restore to health or a sound condition; to make well 2. to get rid of or counteract (an ailment, evil, bad habit) 3. to get rid of a harmful or undesirable condition (p. 347).\*

### Denotation

1. the act of denoting 2. the direct implicit meaning or reference of a word or term 3. an indication or sign 4. [rare] a distinguishing name; designation 5. *Logic* all the individuals or objects to which a given term applies (p. 377).\*

## Diagnosis

1. The act or process of deciding the nature of a diseased condition by examination of symptoms 2. A careful examination and analysis of the facts in an attempt to understand or explain something 3. A decision or opinion based on examination 4. A short scientific description for taxonomic classification (p. 388).\*

## Disease

1. any departure from health; illness in general 2. a particular destructive process in an organ or organism, with a specific cause and characteristic symptoms; specif., an illness, ailment 3. any harmful or destructive condition, as of society...infect or derange... ailment refers to a chronic annoying disorder of whatever degree of seriousness (p. 403).\*

## Disorder

1. *n*. a lack of order; confusion; jumble 2. a breach of public peace; riot 3. disregard of system; irregularity 4. upset of normal function; ailment *vt*. 1. throw into disorder; derange 2. upset the normal functions or health of Syn. See *confusion* (p. 405).\*

## Education

1. the process of training and developing knowledge, mind, character, etc. esp. by formal schooling; teaching; training 2. knowledge, ability, etc. thus developed 3. a) formal schooling at an institution of learning b) a stage of this [a high school *education*] 4. Systematic study of the methods and theories of teaching and learning. (p. 444).\*

# Efficacy

1. power to produce effects or intended results; effectiveness (p. 445).\*

## External

on or having to do with the outside; outer; exterior 2. on, or for use on the outside of the body [a medicine for external use only] 3. a) outwardly visible b) existing apart from the mind; material 4. originating outside; acting or coming from without [an external force] 5. a) for outward appearance or show; superficial [external politeness]
 b) not basic or essential [external factors] n. 1. an outside or outward surface or part 2.
 Outward appearance or behavior; superficialities (p. 496).\*

### Externalization

1. to make external (p. 496).\*

### Gift

1. something given to show friendship, affection, support etc. present 2. the act, power, or right of giving 3. a natural ability; talent [a gift for languages] (p. 589).\*

# Identity

1. sameness in all that constitutes the objective reality of a thing, oneness 2. the distinguishing character or personality of an individual.\*\*

III

1. characterized by, causing, or tending to cause harm or evil; specif. a) morally wrong or bad; evil b) causing pain, hardship; adversity c) not kind or friendly; harsh, cruel d) promising trouble; unfavorable; unfortunate; unpropitious [an ill omen] 2. not healthy, normal or well; having a disease; sick; indisposed 3. not according to rule, custom, desirability, etc.; faulty; imperfect (p. 699).\*

### Illness

1. the condition of being ill (p. 699).\*

### Incurable

1. not curable; that cannot be remedied or corrected n. a person having an incurable disease (p. 713).\*

## Internalization

1. to make internal; to make (others esp. the prevailing attitudes, ideas, norms, etc.) a part of one's own pattern of thinking (p. 736).\*

## Label

1. formerly, a) a narrow band of cloth b) a narrow strip of ribbon attached to a document to hold the seal 2. A card, a strip of paper marked and attached to an object to indicate its nature, contents, ownership, destination 3. a descriptive word or phrase applied to a person, group, theory, etc. as a convenient generalized classification 4. An identifying brand of a company...*labeling* 1. to attach a label; to mark with a label 2. to classify as; call; describe 3. to differentiate (p. 785).\*

# Language

1. a) an expression or communication of thoughts and feelings by means of vocal sounds, and combinations of such sounds, to which meaning is attributed; human speech b) the ability to express or communicate by this means: human speech c) the vocal sounds so used or the written symbols for them 2. any means of expressing or communicating, as gestures, signs, animal sounds, etc., used for the transmission of information 3. all the vocal sounds, words and ways of combining them common to a particular nation, tribe, or other speech community 4. the particular form or manner of

selecting and combining words characteristic of a person or group, or profession...to have the same attitudes or beliefs as another (p. 792).\*

## Logotherapy

1. *n*. an approach to psychotherapy that focuses on the "human predicament," helping the client to overcome crises in meaning. The therapeutic process typically consists of three types of values: (a) creative (e.g., work, achievement) (b) experiential (e.g., art, science, philosophy, understanding, loving) (c) attitudinal (e.g., facing pain and suffering). Each client is encouraged to arrive at his or her own solution, which should incorporate social responsibility and constructive relationships. Also called meaning-centered therapy. See also Existential Psychotherapy developed by Austrian Psychiatrist Viktor E. Frankl. \*\*

#### Mental

1. of or for the mind or intellect 2. done by, or carried on in, the mind 3. Having a mental disorder; mentally ill 4. For the mentally ill 5. Having to do with mind reading, telepathy, etc. (p. 887).\*

## Mind

1. memory, recollection or remembrance 2. what one thinks; opinion 3. a) that which thinks perceives, feels, wills, etc., the seat or subject of consciousness; intellect or intelligence b) thinking or perceiving part of consciousness; intellect or intelligence c) attention, notice d) all of an individual's conscious experiences e) the conscious and unconscious together as a unit; psyche 4. the intellect in its normal state; reason; sanity 5. a person having intelligence or regarded as an intellect 6. a way, state, or direction of thinking and feeling (p. 904).\*

### Mindfulness

1. *n*. full awareness of one's internal states and surroundings, the opposite of ABSENT-MINDEDNESS. The concept has been applied to various therapeutic interventions-for example, mindfulness based cognitive behavioral therapy, mindfulness-based stress reduction, mindfulness for addictions, and MINDFULNESS MEDITATION-to help people to avoid destructive or automatic habits and responses by learning to observe their thoughts, emotions and other present moment experiences without judging or reacting to them.\*\*

## Negative

1. containing, expressing, or implying a denial or refusal; that says no 2. The opposite to something regarded as positive a) lacking positive character or quality; lacking evidence, affirmation, having the effect of diminishing, depriving, or denying b) *Biol*. directed away from a source of a stimulus c) *Logic* denying the subject or predicate of a proposition d) *Math* designating a quantity less than zero, or one to be subtracted, minus (p. 951).\*

# Perception

1. *n*. the process or result of becoming aware of objects, relationships, and events by means of the senses which includes such activities as recognizing, observing, and discriminating. These activities enable organisms to organize and interpret the stimuli into meaningful knowledge.\*\*

## Positive

1. formally or arbitrarily set; conventional; artificial 2. definitely set; explicitly laid down; admitting of no question or modification; express; precise; specific, assured 3. a)

having the mind set or settled; confident b) over confident, dogmatic 4. showing resolution or agreement; affirmative, certain 5. tending in the direction regarded as that of increase, progress 6. making a definite contribution, constructive 7. unrelated to anything independent of circumstances; absolute 8. that has, or is considered as having, real existence in itself, not just in the absence of other attributes 9. based or asserted as based, on reality or facts 10. concerns only with real things and experience; empirical; practical 15. *Math* a value greater than zero (p. 1112).\*

#### Rumination

1. to go over in the mind repeatedly and often casually or slowly 2. to chew repeatedly for an extended period.\*\*

## Self

1. the identity, character, or essential qualities of any person or thing 2. one's own person as distinct from all others 3. one's own welfare, interest, or advantage; selfishness [obsessed with self] (p. 1291).\*

### Self-esteem

- belief in oneself; self respect 2. undo pride in oneself conceit, pride (p. 1292).\*
   Semantics
  - 1. the branch of language concerned with the nature, structure, and the development of and changes of the meanings of speech forms or the or the contextual meaning... 2. b) the branch of semiotic dealing with the relationships of signs and symbols and the concepts, feelings, or with the referential meaning 3. the relationship between signs and symbols and the concepts, feelings associated with them in the minds of their interpreters; notional meaning 4. loosely, deliberate distortion or twisting of meaning (p. 1293).\*

## Shame

1. a painful feeling of having lost the respect of others because of improper behavior, incompetence, etc., of oneself or another 2. a tendency to have feelings of this kind, or a capacity for such feeling 3. dishonor or disgrace 4. a person or thing that brings dishonor or disgrace 5. something regrettable, unfortunate, or outrageous

## Stereotype

1. a one-piece printing plate cast in type metal from a mold taken of a printing surface, as a page of set type 2. an unvarying form or pattern...a fixed or conventional notion or conception, as a person, group, idea, held by a number of people, and allowing for no individuality, critical judgment, etc. (p. 1396).\*

# Stigma

1. formerly, a distinguishing mark burned or cut into the flesh, as of a slave or criminal
2. something that distracts from the character or reputation of a person, group; mark of
disgrace or reproach 3. a mark, sign indicating that something is not considered normal
or standard 4. a small mark or scar opening on the surface of a plant or animal as a pore,
eyespot 5. a spot on the skin one that bleeds (p. 1399).\*

(Definitions taken from Webster's New World Dictionary, 1978.)

- \* (Definitions taken from APA Dictionary of Psychology, 2007.)
- \*\* (Definitions taken from *Merriam Webster Online Dictionary*.)

### **CHAPTER II**

### **REVIEW OF LITERATURE**

## **The Stigma of Mental Illness**

At the time of this study, within almost every culture and subculture on earth there were agreed upon sets of behaviors and beliefs that influenced those behaviors that constituted what was appropriate and what was not considered appropriate. Culture spun a person's perception of self in relation to others also sharing common measurable\_likenesses of culture. Standards of behavior and the failure to emulate the behaviors and beliefs of a recognized culture began the processes of ostracism.

During the 19<sup>th</sup> century when people arrived at Ellis Island, officials were given a few seconds to decide if immigrants exhibited signs of insanity. If the immigrants were thought to be "insane" they were subjected to tests based on an illustrated guide to "signs" of insanity. These signs included behaviors such as acting like an Irish person, when in fact the individual was French. Individuals who were determined to be insane were sent back to their country of origin (Sayce, 1998). (Overton & Medina, 2008, p. 145)

The limitations resulting from being perceived as different often resulted in internalized stigma on the part of the affected individual.

Throughout the world stigma was a mark of shame and disgrace. The word comes from the Greek word "stigmata," which means to prick with a sharp stick and refers to a physical mark given to slaves and criminals. This was a wound of separation placed on a person that was meant to be seen by others. These perceptions of difference often implied that the wearer of such a mark was a moral or social detriment to the community in which the person lived. In the early 2000s, the community no longer inflicted such obvious and visible markings directly onto a person's skin. Instead, the "mark of Cain," was inflicted with words onto the mental and emotional identity of the person diagnosed with mental illness.

This paper assumed that the behaviors that identified a person as someone with a diagnosable mental illness, whether it was schizophrenia, a mood disorder, or a personality disorder, was practicing behaviors that limited his participation in the greater community and ultimately interfered with other valued relationships. It often took some level of objective observation and critique of those behaviors to alert the sufferer to the dysfunctional quality of interactions with others. Welcoming such critique was also a concern not usually addressed until after the person had become a patient.

## **Communal Stigmatization**

# Who is "community?

For the purpose of this paper, the author narrowed the word "community" to mean those people whose opinions, both negatively and positively, directly affected the indentified patient and his/her recognized position in the world. This "community" was made up of the persons that the patient would directly meet and with whom the patient interacted, specifically: family, doctors, therapists, store clerks, neighbors, and people at the bus stop. When referring to strongly held beliefs and biases of a majority of a particular group, the author used the term "greater community."

## **Creating and Recording**

In many cases by the time a person sought potential intervention, the person might have been questioning his sanity and the reactions of others to certain behaviors. The greater community had created various ways of recording such manifestations for permanence and recall, repeating these determinations to the greatest number of people. These records became the stigmata inflicted upon one another. Mistakenly, it was assumed that there was agreement in and with the understanding of the language contained within any professionally examined and determined diagnosis. There were not many professionals who would advise a potential "mental" patient to question a diagnosis. This was unlike seeking second opinions for physical illnesses. By the time most people with a mental illness sought treatment, they were affecting every person with whom they interacted.

Even the language suggested in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* had been studied and determined to be biased. "Some negative language is apparent in the DSM-IV…but the personality problems of patients with personality disorders are frequently described in even more negative ways in clinical reports and psychological test interpretation" (Hunter, 1998, p. 664).

When the language of the *DSM-IV* was applied to the conditions displayed by the patient, much of the information used in determining the diagnosis was anecdotal in nature and subjectively provided by the patient. Although some medical testing (such as brain imaging and hormonal balancing) was available to verify the existence of a physically based medical condition that might point a practitioner toward the reasons behind the existence of a mental illness, this testing might have been cost prohibitive and, therefore, was not often used.

Surprisingly, the people who interpreted the diagnosis of mental illness most negatively were the professionals from whom healing treatment was supposed to be available.

Unfortunately, medical professionals contributed to the development and internalization of stigma by their attitudes toward various diagnoses. Diagnoses could evolve from a tool for treatment to an internalized label, stigmatization, and a sense of shame. Therapeutic practitioners were primary contributors to this form of rejection through their attitudes, word choice, and inflexible view of the chronic nature of mental illness. Whether or not a particular mental illness was life long, some therapeutic practioners tended to regard all mental illnesses as if it could not change for the better and become a sign of growth and wellness.

The mental health care professionals were responsible for determining, recording, and explaining the repeated details implied by the language of a diagnosis.

The other source or negative language regarding clinical personality features may be the annoying quality of these disorders upon those who diagnose them. Although counter-transference in modern conceptualizations is ubiquitous, it probably needs to be managed to enhance a clinician's efficacy. Because clinicians and people generally have wide ranging emotional reactions to others, the use of an emotional reaction as a major basis upon which to arrive at a diagnosis presents problems. (Hunter, 1998, p. 675)

The greater community, like witnesses of a car accident, had to be willing to acknowledge that the understanding of words, like events of the accident were defined in relation to each person's point of view as well as that person's agenda. "It would be silly to blame all this scapegoating on doctors, for beliefs about sickness are not simply matters of pathogens but functions of social tensions too" (Porter, 1998; p. 1049).

In many cases of people afflicted with behaviors that warranted diagnosis, the family became the major opportunity for inclusion in social interaction. Mental illness was not contagious though many caregivers and family members were profoundly affected by the skewed behaviors and decisions of loved ones.

There are compelling reasons to believe that family caregivers may have an impact on their relatives' recovery from depression. Family members' hostile or critical behaviors, as well as their well-intended actions that backfire, are associated with greater depressive symptomatology in healthy and ill older adults (e.g., George, Blazer, Hughes, & Fowler, 1989; Martire, Schulz, Wrosch, & Newsom, 2003; Thompson & Sobolew-Shubin, 1993). ...[C]aregivers who feel more burdened by patients' depressive symptoms may be less able to be supportive with regard to the setbacks that patients encounter (e.g., medication side effects) and the difficulty of adhering to prescribed treatment (Hinrichsen & Hernandez, 1993; Perlick et al., 2004). This lack of support may subsequently compromise patients' ability to experience improvements in mood and to adhere to a medication regimen. (Martire, Schultz, Reynolds, Morse, Butters, & Hindrichsen, 2008, p. 447)

This tilting of reaction also created various levels of potentially mal-adaptive behaviors and coping mechanisms within a family. As the family is the primary source of information about how each of us is valued within a community, its participation in the genesis and perpetuation of stigmatization could not be excluded from this paper.

Practical concerns fell often on the shoulders of a primary caregiver (spouse, sibling, or child). The age of the identified patient made little difference. Adults and children alike accumulated coping skills to deal with the life-interrupting behaviors of the affected person.

These coping skills were often inadequate and required continued education. Practical concerns had been identified as major contributors to caregiver stress. The urgent concerns might have included but were not limited to providing the transportation necessary to access appropriate practitioners; overseeing medications; keeping track of the general economy of a household; maintaining a clean and functional home environment; and developing problem-solving skills for members of the affected family. The added burden that fell upon family members could be exhausting. The ability of the caregivers to avoid the frustrations of providing this care colored the attitudes of said caregivers.

Programs that treated the family as a unit recognized that successful intervention needed to include coping skills for everyone who was a participating member of the household. Cooperation in such cases was rarely all-inclusive. Much of the help available became accessible only after an agency, such as Child Protective Services, was alerted to potential abuse within a household. According to the research, even though participants in such family-agency interactions identified the case worker as a resource, they often hesitated to accurately state their needs and the needs of their family because they feared that children might be removed from the house. Children, especially those in single parent households, feared being separated from parents and siblings.

Over the last decade, an increased awareness of the needs of families affected by parental mental illness has resulted in the development of various interventions and programs (Cowling, 2004). Such strategies are most often directed to meeting the unmet needs of the child (e.g., averting risk, developing resilience) or the parent with the mental illness (e.g., their mental health concerns, parenting responsibilities) rather than incorporate the needs of the family as a whole. In addition, to the best of our knowledge, no standards or

guidelines for the types of programs best suited to such families has been presented.

(Rupert & Maybery, 2007, p. 362)

The educational solution offered to the client must be developed while keeping the family of the client in mind. One might have expected to locate stigma within the community of family as the impression that the identified patient left with people outside the family. Examples of the evidence of such an impression would be, "your mom's crazy" or "you're just too weird" being some of the gentler things people feel free to say out loud directly to the patient and their loved ones. However, the stigma inflicted upon the patient had more to do with a contagious attitude of negativity within the family and a resistance to change, characterized by a lack of cooperation with healing and the rejections of suitable interventions. Balance required that all participants contributed their best to solutions, yet determining what was best was subjective.

# **Maintaining Illness**

Persons rarely were so isolated as to not have familial relationships. Keeping in mind that there was a genetic component to some mental disorders and that there were educational limitations within a family's base of knowledge, maladaptive behaviors were often passed from person to person and sold to the learner as normalcy within the family group. These maladaptive behaviors were default behaviors that did not require much effort to find and use. *Acting out* by any member of a family group to maintain a sense of control was common. Bad behaviors used to establish a sense of control, such as yelling or hitting, were in their own way efficient. Such behaviors redirected the immediate responses of the punished person, though they did little good to encourage healthy, long lasting change. Inflicting punishment was rarely recognized as a bad thing in itself. Culturally, persons were taught that if punished, the person had done something wrong. Being "normal" in this case did not recognize what was best. Confronting "normalcy"

required positive interpretation of situations, doable solutions that fit the circumstance of the family, a willingness to move toward change by experimentation and testing, and ultimately choosing to use the new tools one could acquire through intervention and education. The following ideas were according to Fisher & Harrison (2005):

Jackson (1957) used the term homeostasis to describe the natural tendency of families to behave in such a manner as to maintain a sense of balance, structure, and stability in the face of change. Significant to the concept of homeostasis is the notion that, as one family member experiences change in his or her life, the entire family will be affected and in some way adjust. Family members can adjust overtly and covertly in an effort to maintain this balance and will exert much effort during times when this balance is threatened...families can avoid losing their structure and become chaotic systems.

(p.192)

For a long time it had been customary to deny or downplay the unacceptable behaviors of the family as a whole. It was not uncommon for a person suffering the effects of a mental, emotional, mood, or pain disorder to self-medicate. Self-medication frequently followed the rules of what was acceptable in a family. Use of drugs considered to be "not so bad" might have included alcohol and marijuana.

These choices compounded the ailments of mental illness with the addition of addictive behaviors, requiring dual diagnoses. Such choices were counterproductive when directing the patient toward the possibility of wellness. In some cases this form of self-treatment was encouraged by the family as it kept the identified patient quiet.

Persons within the family unit might have avoided disclosing information that alerted others to incidences of violence and street drug use, as well as abuse of prescriptions for fear that

the police or other authorities would treat such occurrences as punishable rather than treatable. This was an example of the investment a family would make to avoid global changes. The added concerns of improperly treating a psychiatric ailment allowed family members to treat the identified patient as if the patient were the problem. The family functioned and pulled together in order to deal with the problematic behaviors. Corrigan (2004) pointed out that "[1]ess than half of survey participants reported participation in appropriate psychotherapies, less than a quarter were involved in family therapy, and only about 10% received intensive case management" (p. 615). The identified patient in turn fulfilled the role implied by diagnosis in order to maintain what was familiar. "Reilly maintains that the disturbed Euro-American family system needs a symptom bearer, and this would be the member who is susceptible to drug abuse" (Fisher & Harrison, 2005, p. 201).

The absence of challenge to these projections further cemented the stigma fostered by these negative attitudes and the multitude of names a family could apply to the identified patient. The issues associated with a psychiatric condition could be aggravated by these circumstances.

Professional help for the family as a whole needed to be comprehensive. Interventions needed to include education in proactive problem solving, stress management, respite care, and information regarding the details of diagnosis and prognosis.

Self-help was the most accessible venue of treatment for those loved ones caring for the patient experiencing a mental illness. For the purposes of this paper, self-help included but was not limited to voluntary attendance in support groups, popular press books explaining varying topics regarding pseudo-psychology; i.e., *You can Heal Your Life*, Louise Hay and *The Power of Intention*, Dr. Wayne W. Dyer, etc. Many self-help groups were not attended and guided by professional support, leaving much of the information about a diagnosis open to the best guess

and most biased fears of the one seeking help. This was not necessarily unethical as the professional was placed in the position of relying on the patient to choose to inform others of the diagnosis and its potential degree. A professional was usually only allowed to speak of any part of treatment if the patient was a threat to self or others under subjective interpretations of the written code of ethics as follows:

- Counselors recognize that trust is a cornerstone of the counseling relationship.
- Counselors aspire to earn the trust of clients by creating an ongoing partnership, establishing and upholding appropriate boundaries, and maintaining confidentiality.
- Counselors communicate the parameters of confidentiality in a culturally competent manner ...
- Counselors do not share confidential information without client consent or without sound legal or ethical justification. [B.1.c. Respect for Confidentiality]
   (American Counseling Association, 2005; p. 7)

The families of people with mental illness had often dealt with its intrusion into the family for long enough to realize something needed to be done, but "by whom" became the question.

Early in the diagnosis there might have been a sense of hopelessness and inescapability for sufferers and their families. Families and the potential patient rarely sought help until after the identified patient had lost all sense of reason and responsibility for his or her actions and decisions. It was often the acting out of the disorder that most effectively sent one to seek treatment. Unfortunately, it was the acting out of behaviors related to the existence of a condition that cemented in the mind a perceived stigma. Corrigan (2004) wrote:

Despite the plethora of evidence-based interventions, services researchers are familiar with two disconcerting trends vis-à-vis effective treatment: (a) Many people with mental illness never pursue treatment, and (b) others begin treatment but fail to fully adhere to services as prescribed. (p. 614)

The climate surrounding treatment might or might not have been welcoming. Quality of care was truly determined by the quality of hope instilled in the patient during the explanations of a recognized ailment and the treatment of said ailments for the issues and concerns brought on by the diagnosis. Also, according to Corrigan (2004), persons did not always follow doctors' orders:

These problems are further exacerbated by the number of people who obtain mental health services but fail to fully adhere to component prescriptions. A recent review of 34 studies of compliance with psychiatric medication found, on average, that more than 40% of persons receiving antipsychotic medication failed to fully comply with prescribed regimens (Cramer & Rosenbeck, 1998). (p. 615)

Failure to instill hope throughout treatment neglected to acknowledge that a person had the ability and practice to internalize the language of diagnosis. Language itself, no matter what the use, was formed in infancy. Developing meaning was a natural process of cultural education. It should not be surprising that persons newly diagnosed with psychiatric concerns had to learn what was comparable to learning a new or otherwise foreign language. Meissner (2008) offered information about how language was interpreted by very young children:

Ogden (1990) noted that "The achievement of symbol formation proper allows one to experience oneself as a person thinking one's thoughts and feeling one's feelings. In this way, thoughts and feelings are experienced to a large degree as personal creations that

can be understood (interpreted). Thus, for better or worse, one develops a feeling of responsibility for one's psychological actions, (thoughts, feelings, behavior). (p. 71) Stern (1985) also noted that it makes parts of experience more shareable and allows for mutual creation of meanings that would not have been possible before. It also allows the child to begin construction of a self-narrative (p. 29).

Much of the internalization of the language of diagnosis could be initially negative, counterproductive and stigmatizing. Misunderstanding of this new language may become more negative without intervention/education to promote self-efficacy and healthy self-concept. At the beginning of a diagnosis there might have been a "honeymoon" period in which the patient now had some reassurance that there really was "something wrong." A diagnosis moved into a more concrete existence. No longer in the imagination, there was a reason for the way one acted, spoke, and felt. Often as soon as the information was realized and shared outside of the practitioner's office, internal and external stigmatization began in the client and in the community with whom the client had chosen to share.

## **Institutional Stigmatization**

Institutional stigmatization was the consideration of the systems that were prevalent within our culture that dominated social interactions. Stigmatization was comprised of the limiting factors inflicted upon the individual that acted as barriers to the full participation in and enjoyment of those things that would make social and societal success possible.

Stereotype, prejudice, and discrimination can rob people labeled mentally ill of important life opportunities that are essential for achieving life goals. People with mental illness are frequently unable to obtain good jobs or find suitable housing because of the

prejudice of key members in their communities: employers and landlords. (Corrigan, 2004, p. 616)

The assumption that avoiding appropriate necessary treatment in an effort to not be labeled mentally ill was effective was only in part true. Persons suffering psychiatric concerns may have a variety of negative interactions with the systems that were intended to keep the greater community safe and informed. Background checks and credit reports could have quickly identified a person's source of income. This information would have easily identified a person receiving disability payments. A person thus identified would have been hard pressed not to answer questions about the ailment. Even though it might have been identified as illegal to ask such questions, it would have been hard to prove that not answering those questions would have been a reason for disqualification when applying for housing or employment.

Another source of public information was the media. News media were a primary source of the information that shaped the attitudes of the public. Stories linking crime and mental illness were considered more newsworthy than positive stories concerning the mentally ill.

In a simple content analysis of five American newspapers taken over six weeks between Jan. 10 and Feb. 20, 1998, I found 394 stories that invoked mental health or illness, of which almost two-thirds were either crime reports or commentary that linked mental illness and crime. (Smellie, 1999, p. 25)

Ultimately, only 10% of reporters placed on the "crime beat" had any background in psychology or its related fields.

Untreated or poorly treated individuals with psychiatric concerns often attracted the attention of neighbors and in turn police by their socially inept behaviors. Smellie (1999) noted the existence of the following:

...huge traffic between prisons and mental hospitals, and the growth in use of mental hospitals as *de facto* prisons for repeat, violent sex offenders. This so-called "transinstitutionalization" is one of the most vexed issues in criminal justice and mental health policy, particularly as mentally ill people in prison rarely get adequate treatment, let alone get better. (p. 25)

The greater community used prejudice to efficiently, if not correctly, dismiss those it might have considered to be too different from itself.

People with mental illness are often judged by their behaviors, but this does not reflect their whole being. With spoiled collective identity, the stigmatized person is reduced in the minds of others from a whole and normal person to a tainted, discounted one...stigma arises when an actual social identity falls short of a societally defined ideal identity (Overton & Medina, 2008, p. 144.)

The greater community was rarely exposed to an opportunity to positively interact with those diagnosed with mental disorders. This seemed strange as it was estimated that numbers as high as one in five would experience at least a minor and treatable diagnosis for a period of six months or more. Since these numbers varied from article to article the author hesitated to apply a quote supporting this assumption. An acceptable level of fear based on little truth or information appeared to be tolerated by the greater community as a whole.

Citing a 1999 Surgeon General's report, Grayson (2004) wrote the following: "In the 1950s, the public did not distinguish mental illness from ordinary unhappiness and worry and tended to see only extreme forms of behavior--namely psychosis--as mental illness." And the majority feared the mentally ill, highlighting unpredictable and violent behavior... people today are more fearful of the mentally ill, particularly those

with psychoses, than they were in the 1950s--even though the experts can prove a very low risk of violence or harm. (p. 6)

At the time of this study, there were more labels for psychological concerns than ever before. The acronyms and abbreviations were confusing and complicated. Only those with the luxury of understanding, proper treatment, and a life that they wished to preserve could celebrate the existence of a diagnosis as a part of themselves. This level of confidence reflected the investment that a patient was willing to afford toward wellness. Only people don't develop an identity, both personal and social, in a vacuum. Acknowledging that people belong because they were, and letting that be the determinant of whether or not institutional stigma applied to their choices assumed a developmental level that took time and positive experience to attain. This was what the work of wellness was meant to accomplish. With success a person with a diagnosis remained a person first and foremost.

Hypomania and depression can spread across members of a group like wildfire. That is, in part, what moods are for--to affect others in a group. So we have to acknowledge that mental illness can have a powerful effect on those close to it (Jamison, 2006, p. 534).

So the questions became clear and simple, "who were they?" and "who were the larger community?" The sense of separation created by the stigma of mental illness was nothing more than a state inflicted from the imagination that told each person who each believed he or she was and where each best belonged. The accuracy of such a determination demanded flexibility and adjustment to change. It seemed a simple allowance to afford self and others.

## **Self-Stigmatization**

Self-stigmatization occured when a person had an inadequate set of tools for communicating personal medical information. It was easy to forget that a psychiatric or

psychological diagnosis was a part of one's medical information. Unlike cancer, which at one time was referred to as "the big C," psychiatric diagnosis had not moved into the realm of expectation that implied a miracle cure. The brokenness of illness was hard to shake as the expectation of understanding was denied. Self-stigma was built over time as a diagnosis was shared. Researchers had equated a greater sense of stigma to lower self-esteem, lesser degree of education, and economic limitations of a client. All of these conditions and concerns contributed to a lower degree of self-efficacy. The romantic notions of clarity and understanding that accompanied the initial diagnosis failed to hold up as time and rejection persisted.

Part of this misunderstanding was that diagnosis rarely had clear and decisive singular treatments. Medication once established, often was not permanently or perfectly established. A person's level of confidence in his or her judgment could have been doubted by the person him or herself. Overton & Medina (2008) wrote,

After hearing negative feedback and experiencing an onslaught of negative actions, they begin to see themselves in a negative light. People who have been diagnosed with a mental illness often find that their self-image and confidence are sacrificed by living under the pressure and negative expectations. (p. 147)

It was not a great surprise that negative connotations and false assumptions connected with the existence of a mental illness were often overwhelming. This type of an interpretation could have been as debilitating as the condition itself. Also located in Medina & Overton, 2008, p.147, "In 1999, the Surgeon General's report pointed to stigma as a key variable in understanding the course of illness and outcomes for people who have been given a psychiatric diagnoses" (Corrigan, Green, Lundin, Kubiak, & Penn, 2001, p. 147).

Both the client and the practitioner needed to be aware of self-handicapping. Larson and Buss (2008) wrote, "Self-handicapping is a process in which a person deliberately does things that increase the probability that he or she will fail" (p. 479). These deliberate sabotages might have been disguised as "bad habits" and, thereby, not recognized as within the control of the person who failed and was handicapped.

## **Improving Self-Efficacy**

People have been taught many beliefs about what they were responsible for and capable or not capable of doing. These beliefs about the self and how one related to others dictated how one saw oneself in relation to the world. The ability to make proactive decisions, good choices, and to assist in the creation of a "good" life was called self-efficacy. The theories regarding self-efficacy were argued for by psychologist Albert Bandura. Bandura believed that "people have intentions and forethought, they are reflective and can anticipate future events, they monitor their behavior and evaluate their own progress, plus they learn by observing others" (Larson & Buss, 2008, p. 412).

High self-efficacy beliefs could lead a person through persistent successful effort and higher goal setting; whereas, lower degrees of self-efficacy might result in difficulty setting appropriate goals and in seeing those goals through to completion. This process was a cognitive activity and was, therefore, a teachable concept. By designing goals whose individual tasks could have been accomplished in manageable steps, even the most complicated goals could be accomplished.

Counselors and professionals working alongside a client in the process of goal-setting needed to be pragmatists. Regardless of whether a psychiatric diagnosis existed, the ability to learn also existed. Self-efficacy could have been improved through modeling. Choosing

mentors who had the ability to do the things the client in transition hoped to be able to do was another positive learning opportunity. Clients who chose to assume the role of a student no longer had to worry about stigma of diagnosis, as they are no longer measured themselves by the shortcomings of a particular set of negative beliefs but were affording themselves the opportunity of learning. Learning was proactive and productive.

## The Place of Education

Taking on the responsibility of counselor assumed that one would evaluate, educate, and exemplify a life style that was most supportive of the best interest of the client. Building upon the client's ability to learn presented teachable moments. A barrier to a client's ability to see the potential of the teachable moment was past rejection within the learning environment. Motivating a client to remain in the present moment, seeing only new opportunities was challenging. When internalizing the information that surrounded any chronic condition, one could have chosen between two opposing beliefs: hope or despair. One could have asked a very simple question to discover which was the basic operating belief, "do I live in a cooperating universe or not?" The answer was clearly the place to start in any counseling relationship.

By not demonizing the existence of a chronic mental condition, one could have advocated, maintained attention toward the latest information, and fulfilled the ethical obligation toward being an effective advocate. Sartorious (1998) wrote,

We should examine our own attitudes and try to increase our tolerance and capacity...we should be active and loud advocates...we should change the focus of our attention in clinical work, research and teaching from clinical symptoms and psychopathology to the quest for ways that could make the life of people...more tolerable...we should be ready,

willing, and demanding to learn from others about the ways they have used in dealing with stigma. (p. 1059)

These attitudes would need to continue to evolve as persons proceeded to become ever growing professionals and people who valued the mind, body and spirit connection.

#### **CHAPTER III**

## CONCLUSION AND RECOMMENDATION

It is contention of this researcher that directing a client to evaluate both positive gifts and urgent concerns that may be present because of the existence of a condition warranting diagnosis can be influenced by word choice regarding the descriptors and attitude of the practitioners.

Learning and consistently employing a positive lexicon creates the most advantageous environment for the acceptance of a diagnosis. Empowering the client fosters the growth of knowledge and inspires the self-efficacy necessary to become one's own best advocate this research will attempt to offer an educational solution accessible for the high-functioning client that is intended to negate the negative internalization of diagnostic language.

The educational solution offered to the client must be developed while keeping the family of the client in mind. This author expected to locate stigma within the community of family as the impression that the identified patient left with people outside the family. Examples of the evidence of such an impression would be, "your mom's crazy" or "you're just too weird" being some of the gentler things people feel free to say out loud directly to the patient and their loved ones. The assumption that persons outside the family would be the greatest source of embarrassment was incorrect. The stigma inflicted upon the patient had more to do with a contagious attitude of negativity within the family and a resistance to change, characterized by a lack of cooperation with healing and the rejections of suitable interventions. These factors caused wonder in the mind of the author. It was as if the family needed the identified patient to be the one who was sick or exclusively off balance. Balance required that all participants contributed their best to solutions, yet determining what was best was subjective.

The person most responsible and effective in the process of wellness is the person described by the diagnosis. An empowerment of the client is at the heart of a successful treatment regardless of which illness a client suffers. Even the small change in language referring to a client instead of a patient empowers a sense of healing.

Also, importantly acknowledged is a balanced attitude toward all of the attributes of a psychiatric condition. Dr. Kay Redfield Jamison has written books describing how with the existence of a bipolar disorder came with not only racing thoughts and an unpredictable temper, but also great imagination and intelligence. Historically, artistic genius has been associated equally with "madness." When a person is allowed to embrace the whole of his/her diagnosis an opportunity to explore a change of attitude and opportunity is present.

Authenticity and genuineness are goals set forth in the education of counselors.

Authenticity and genuineness are also appropriate goals for the client in achieving acceptance of self. When measuring "self" with regard to how others perceive one, the person expends large amounts of energy and confusion. No two people see or experience anything in exactly the same way. Giving a client permission to set an individual standard for life that does not hurt another can act as a basic empowerment.

Self-evaluation is the process of making a list of one's attributes without judgment. If a person examines the self without making some of those attributes either good and others bad, one can begin to create a measurement based solely on what works well to achieve goals or what behaviors and choices no longer serve in achieving the best life. Exchanging self-evaluation for self-criticism is a teachable skill.

Using affirmative language is a simple yet not always an easy way of confronting the negative words that repeat in a person's head, including those that echo a diagnosis. Separating

the past from the present negates the shoulds and oughts that limit the ability to adjust and change. When individuals receive and learn about the details of a diagnosis, these persons are put in a position of choosing how to interpret the things that are learned.

Positive affirmations can help to change the expectations related to a diagnosis. It seems true that when waking with the thought that it is going to be a productive day, that day goes well; the same is true of expectations of failure. This is best known as a self-fulfilling prophecy.

Counselors should avoid the concept of "specialness." Being "special" is deceptive; rather than naming what is good in a person it implies that some are more special or better than others. People are all sacred and individually designed. Any comparison between two people is inherently unequal because all people are different. Some may have learned more in one area than another, but this is true of everyone. A person's strength is just that, a strength, not to the exclusion of others.

If individuals look upon all of the circumstances of life as opportunities to learn and grow, they become contributors to the resolutions of temporary concerns rather than victims of circumstances persons cannot escape.

The practitioner should allow and answer questions no matter how unimportant they may seem at first. The ability to question allows the seeker to gather information without applying a specified order to that information until after the seeker places importance where he or she chooses. Also, the counselor should never underestimate a seeker's ability to locate and apply solutions in unexpected ways. Look upon what is learned with respect for the process of learning rather than a predetermined product.

Ultimately, educators and self-educators have a greater responsibility to teach someone how to choose rather than what to think.

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