

OBSESSIVE COMPULSIVE DISORDER  
AND SUPPORT GROUPS

by

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ABSTRACT

OBSESSIVE COMPULSIVE DISORDER  
AND SUPPORT GROUPS

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The purpose of this qualitative study used several methodologies in order to discover why individuals with OCD choose to participate or not participate in a face-to-face and/or online support group. The primary researcher conducted a focus group, in-depth individual interviews, and open-ended online questionnaires. Three types of participants were recruited for this research: individuals with OCD who were currently in a face-to-face support group, individuals with OCD who were not currently in a support group, and individuals who were part of an online OCD support group. The two theoretical perspectives informed the research: the Health Belief Model (HBM) and the Theory of Reasoned Action (TRA)/Theory of Planned Behavior (TPB).

Discussions with participants' revealed people with OCD participated in support groups in order to communicate with others who could understand what they were going through, learn information that could help them with their condition, and receive and provide support and encouragement. Reasons people with OCD did not participate in support groups included: a lack of awareness of support groups, social anxiety and fear about participating, and previous unsatisfactory experiences with past participation. The study also found that people with OCD feel stigmatized and tend to hide their condition from others. The study also contains additional information about participants experience with OCD and their outlook on support groups.

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## CHAPTER 1

### INTRODUCTION

#### 1.1 Obsessive Compulsive Disorder

Every person experiences stress and has to learn how to juggle responsibilities. While some people are strong willed and can easily tackle the challenges that come their way, for others, it is not so easy. Imagine living in a world of fear and no matter what you do to try to make the anxiety and worry go away, nothing works. Obsessive compulsive disorder (OCD) is a brain disorder where the emotional part of the brain mislabels actions and objects that many would not perceive as dangerous but to that individual those actions or objects are unsettling. A particular thought or urge becomes stuck in the patient's minds, and he or she is unable to let it go. OCD has been also described as a case of the "mental hiccups" where the brain is locked in on a particular thought, feeling, or belief (OC Foundation, 2008).

Today OCD is recognized as a common psychiatric disorder. It wasn't until the 1990's that doctors and physicians developed an understanding of the disorder, allowing patients to begin receiving proper treatment. One in 50 people currently have OCD and twice that many have it at some point in their lives. In addition, one third to one half of adults reported their symptoms began during their childhood (OC Foundation, 2008).

This study will address the reasons OCD sufferers participate or do not participate in face-to-face or an online support groups. Two theoretical frameworks, the Health Belief Model and Theory of Reasoned Action/Theory of Planned Behavior, will explore an individual's attitude, motivation, influences, and behavior toward support group participation. By looking at patients' views on face-to-face and online support groups, this study will examine why patients with OCD participate or do not participate in support groups.

### 1.1.1 Facts

OCD is an anxiety disorder that affects more than 4 million Americans (American Psychiatric Association [APA], 2006) in which time-consuming obsessions and compulsions interfere with ability to carry out normal tasks and greatly affects an individual's social life. Rodriguez and Georges (2001) defined OCD as, "An anxiety disorder that is characterized by intrusive and uncontrollable thoughts and/or by the need to perform specific acts repeatedly. A disturbed individual may have either obsessions (thought related), compulsions (action related), or both," (p. 465). People who suffer from this disorder are trapped by repetitive thoughts and behaviors they know are senseless and disturbing, but cannot refrain from doing them. OCD is the fourth most common psychiatric disorder in the United States following depression, substance abuse, and phobias (Rasmussen & Eisen, 1992) and it is more common than schizophrenia, bipolar disorder, or panic disorder (National Institute of Mental Health, [NIMH], 2007). OCD affects 1-3% of adults and 1-2% of children and adolescents (Heyman, Mataix-Cols, & Fineberg, 2006).

This disorder is a condition affecting men and women of all ages and is not bound geographically or ethnically. One-third of OCD cases begin during childhood years and carry on into adolescence where it is often onset by puberty (Mental Health America, 2006; OC Foundation, 2008) and the median age of onset is 19 years (Kessler, Berglund, Demler, Jin, & Walters, 2005). However, others do not show signs until their later adult years. Even though OCD has been seen as a condition similar to phobias, people with phobias can avoid the stimulus that causes the person to feel fear. On the other hand, people with OCD cannot avoid the feeling of fear because intrusive disturbing thoughts do not escape easily (Mavissakalian, Turner, & Michelson, 1985).

### 1.1.2 Problem

For many years, researchers believe OCD was a rare disease affecting only a small portion of the population. The World Health Organization rated OCD as a leading cause of disability (Doron, Kyrios, & Moulding, 2007). Not only is this condition seen as a disability but it

has also been noted as the longest and most costly of all anxiety disorders (Turner, Beidel, Spalding, & Brown, 1995), and some cases going undetected as long as 17 years (Hollander & Wong, 1998). The average amount of time it takes an individual to recognize their condition from the time of onset is 7.5 years (Goli, Krishnan, & Ellinwood, 1991). Many sufferers keep their condition hidden (NIMH, 2007) making it difficult for physicians, teachers, and the general public to recognize their problem. OCD has also been known to have high comorbidity rates (McLean, Whittal, Thordarson, & Taylor, 2001), making it more difficult to diagnose when there can be another condition such as depression or anxiety disorders at hand. Heyman et al. (2006) noted, "The shame and secrecy associated with it [OCD], as well as lack of recognition of its characteristic symptoms, can lead to delay in diagnosis and treatment," (p. 424). Because patients try to keep their condition a secret, many fail to seek proper treatment (NIMH, 2007) and in some extreme cases sufferers have become resistant to treatment (Mishra, Sahoo, & Mishra, 2007). It was not until the 1980's that doctors began to recognize OCD as a more prevalent issue. Although education and awareness has increased in the last 20 years, many people are not receiving proper treatment for their condition (Torres et al., 2007).

Because OCD creates a feeling of isolation and shame among sufferers, researchers have discovered when compared to the general populations, people with OCD tended to have more of a negative repercussion on their quality of life when it came to social functioning, emotional problems, and mental health (Rodriguez-Salgado et al., 2006). The researchers also discovered quality of life was more negative for people who suffer from intrusive and uncontrollable obsessions than compulsions.

### 1.2 Social Support

Social support has been defined as any action or behavior that functions to address multiple interpersonal needs that include relational (emotional support), conformational (reassurance of worth), and instrumental (tangible or informational) care (Cutrona & Russell, 1990). DiMatteo and Hays (1981) explained support is not a single concept, it can function in

two ways: tangible support (physical resources that benefit the individual) or psychological support (values, attitudes, beliefs, and perceptions). Support has been known to help influence and motivate a behavior change in a positive way (Clark, Whelan, Barbour, MacIntyre, 2005). Society has found ways for people to receive the support they need by establishing face-to-face and online support groups for many different health conditions and contexts. A limited amount research on OCD and support groups (Black & Blum, 1992) and few OCD support groups exists. It is important to look at how individuals with OCD perceive support and what methods of support do they use and see helpful in order to determine their attitudes toward support groups.

### 1.3 Theoretical Perspectives and Frameworks

This study used two health related theories as a framework to help understand support group participation in OCD patients: the Health Belief Model developed by Janz and Becker (1984) and the Theory of Reasoned Action/Theory of Planned Behavior developed by Ajzen and Fishbein (1980). Both models look at the individual's perceptions, beliefs, and attitudes toward a given health behavior. In this study, they are used as a framework to determine what factors are significant in discovering an individual's reasons for seeking support for their OCD.

#### *1.3.1 Health Belief Model*

The Health Belief Model (HBM) is one of the most widely used frameworks in health behavior (Janz, Champion, & Strecher, 2002). The model is a value-expectancy theory that is used to explain and predict health behaviors by studying the attitudes and beliefs of individuals (Janz & Becker, 1984; Rosenstock, 1974) and has been used to explain change and maintenance of health-related behaviors (Janz, Champion, & Strecher, 2002). The basic components of the HBM are derived from two variables: (1) the value the individual places toward a particular goal and (2) the belief of the likelihood that a given action will achieve the goal (Becker, Haefner, Stajislav, Kirscht, Maiman, & Rosenstock, 1977). If an individual believes that a negative health condition can be avoided and has a positive expectation that

taking action will avoid the condition, the action is likely to occur. Researchers have also used it to look at an individual's desire to avoid or prevent illness (Janz & Becker, 1984). The model states that preventative health behaviors are influenced by six factors that determine an individual's perception toward health behavior: perceived susceptibility, perceived severity, perceived benefits, and perceived barriers, cues to action, and self-efficacy. HBM theorizes individuals will not seek preventative health treatment or help unless they have high levels of health knowledge and motivation. It is a model that has been broken down into components and compared to other frameworks.

### *1.3.2 Theory of Reasoned Action/Theory of Planned Behavior*

The Theory of Reasoned Action (TRA) (Fishbein & Ajzen, 1975) and the Theory of Planned Behavior (TPB) (Ajzen & Fishbein, 1980) is a model of behavior change that explores the connection between behavior and beliefs, attitudes, and intentions. The TRA suggests that people's behavior is determined by their intention to perform the behavior. It also states that people's intentions are determined by two components: the attitude toward the behavior and their subjective norm, which are views important others have toward the behavior. The theory originally looked into voluntary behavior, suggesting an individual's behavior is derived from the intention to perform that behavior.

Over the years, Ajzen and Fishbein (1980) discovered people's behavior was not always voluntary and some people felt they had little control over their behaviors and attitudes. This resulted in the development of a new element in the theory, perceived behavioral control, which has to do with people's beliefs that they can control a particular behavior. This concept was added to account for contexts in which people's behavior is influenced by factors that are out of their control (Ajzen & Driver, 1991). The TPB proposes that an individual's behavioral intention, which is influenced by the attitude toward the behavior, the subjective norm, and the perceived behavioral control, will determine the behavior.

#### 1.4 Purpose of Study

The purpose of this study is for the researcher to learn what methods, if any, individuals with OCD use when determining whether to participate or not participate in a support group. Previous research has indicated that people with OCD viewed participation in the group in a positive way such as enjoying the friendships they made in the group, gaining insight and help with their condition, and not feeling so alone (Black & Blum, 1992). Therefore, this study was conducted in order to obtain participants reasons for why they participate or do not participate in a support group for their OCD, along with their views about support in general. Focus groups, individual in-depth interviews, and online questionnaires were used to gather information from OCD patients. The HBM and TRA/TPB are used to discover what attitudes and perceptions are significant when determining individual's reasons for participating or not participating in a support group for OCD.

#### 1.5 Methodology

This qualitative study collected three types of data: focus groups, in-depth individual interviews, and open-ended online questionnaires. In all three populations, the participants had to be of 18 years of age or older and be diagnosed OCD. The focus groups consisted of individuals who were a part of a face-to-face support group for their OCD. The in-depth individual interviews were completed with individuals who were not currently a part of a support group. For individuals who were not in the Dallas-Fort Worth area, they were asked to complete an online questionnaire. Open-ended online questionnaires were also completed by people who were members of the OCD Tribe, an online support group for OCD. In the current study, theoretical (using multiple perspectives) and methodological (using multiple methods) triangulation was used.

This method of triangulation is important because it helps ensure the validity of the study (Mackey & Gass, 2005), allows the data to be explained in more detail, and the researcher is able to compare data in multiple ways. Recruitment methods for this study consisted of a



snowball sampling method, where individuals with OCD referred others who had OCD and a non-probability sampling method, where fliers and advertisements were used to recruit people with OCD who were members of a face-to-face support group, an online support group, or people who were not in any form of support group.

### 1.6 Further Chapters

Chapter two explains the purpose of the study and current research in further detail. Through the review of literature, the chapter provides historical perspectives and information about OCD, mental illness, stigma, and support groups, both face-to-face and online. Chapter two also describes the theoretical perspectives of the Health Belief Model and Theory of Reasoned Action/Theory of Planned Behavior and their relevance to OCD patients' participation in support groups. Chapter three outlines the qualitative methods of data and analysis and discusses the participants recruited for the study. While chapter four discusses the results and findings, chapter five analyzes the data, discusses limitations to the study, and provides areas where future research can be helpful for understanding the needs for people with OCD.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 Social Support Groups

People can provide support to one another in many ways. Social support has been defined as any action or behavior that functions to address multiple interpersonal needs that include relational (emotional support), conformational (reassurance of worth), and instrumental (tangible or informational) care (Cutrona & Russell, 1990). DiMatteo and Hays (1981) described the two major forms of support as tangible and psychological. Naturally people think of support as having an emotional component, listening or providing an empathetic attitude. While both instrumental and emotional support is important to the individual, it is the perceptions of the individual that determine if they feel supported.

Support groups are outlets many people with OCD have turned to in order to receive emotional support while learning how to deal with their condition (OC Foundation, 2008) yet little previous research exists on OCD participation in support groups. Only one previous study has looked at support groups for people with OCD (Black & Blum, 1992) but mainly emphasized patient education and emotional support. The study established a support group for people with OCD and reported the methods to starting the group and the benefits the group had to offer for its participants. It never addressed online support groups or people who did not participate.

Previous research has examined the effects of support group participation on patients with depression (Houston, Cooper, & Ford, 2002) and suicidal patients (Barak & Dolev, 2006; Gilat & Shahar, 2007), finding positive outcomes from group participation. This chapter will provide an extensive literature review over facts about obsessive compulsive disorder, the stigma associated with mental illness, social support, support groups (both face-to-face and

online), and the frameworks of the Health Belief Model and the Theory of Reasoned Action/Theory of Planned Behavior.

## 2.2 Obsessions and Compulsions

Hyman and Pedrick (1999) described the five basic ways that OCD sufferers are typically classified based on their obsessions and compulsions: checkers, patients who repeatedly checking objects such as doors, locks, or the off settings on household appliances; washers and cleaners, who obsess about the possibility of contamination by germs, dirt, or viruses; orderers, who feel that items must be arranged in a exact, "perfect" way; hoarders, who collect insignificant items and having extreme difficulty to throw them away; people with scrupulosity, who obsess about religious or moral issues in which repetitive prayer and asking for reassurance is typical; and pure obsessionals, who experience unwanted, intrusive, horrific thoughts and images of causing danger or harm to others and who engage in repetitive counting, praying, or word repetition. While these are the basics of OCD, Hyman (1999) suggested it is common for people with OCD to suffer from a variety of these symptoms and no typical pattern exists to determine to when a sufferer will get rid of one symptom and take on a new one.

Obsessions are repetitive thoughts, images, or impulses that are unwanted and causes distress (Mavissakalian et al., 1985). For an individual with OCD, it is nearly impossible to escape the repetitive thoughts. Researchers have discovered four factors associated with obsessive characteristics: the loss of controlling negative thoughts, in which patients think about hurting a loved one; loss of controlling motor skills, in which patients shout obscene words or performing inappropriate actions; a high level of fear of contamination; and the performance of checking behavior (Rodriguez & Georges, 2001; Delorme et al., 2006). Over the years, more classifications of obsessions have been developed such as fear of harming others or themselves, fear of behaving unacceptably, and fear of making a mistake (Heyman et al., 2006). Ironically, individuals with OCD are able to recognize the senselessness of these thoughts yet they are not able to explain these thoughts by logic or reason (APA, 2006).

A compulsion is an intentional behavioral repetitive act that is performed in response to an obsession. Usually the compulsion is derived from internally constructed rules or a in a superstitious fashion (Jenike, Baer, & Minichiello, 1990). For example, an individual who has a counting problem may have to turn the lights on and off seven times every night before going to bed. Even though OCD sufferers know that what they are doing is illogical, they cannot help themselves from completing the compulsion. These behaviors can be physical and/or mental and are intended to neutralize or relieve the discomfort of the obsession. Physical compulsions consist of cleaning themselves and their environment; hand washing; checking, making sure the door is locked, retracing driving routes to make sure they did not hit someone; ordering and arranging, lining up shoes in closet a certain way; hoarding, having severe problems with getting rid of items such as newspapers, mail, clothes, ect.; asking others for reassurance, asking repetitive questions about something that is bothering them. Mental compulsions are acts such as counting, repeating words silently, ruminating, (Heyman, Mataix-Cols, & Fineberg, 2006). For individuals who have religious compulsions of scrupulosity, their compulsions may consist of repetitive praying or saying religious phrases repeatedly. These compulsions are usually seen by the individual as a form of relief that temporarily reduces the associated anxiety. Just like with obsessions, OCD sufferers realize that these actions are irrational, but no matter how hard they try, they cannot keep themselves from doing them.

Obsessions are repetitive thoughts, images, or impulses that are unwanted and causes distress (Mavissakalian et al., 1985). For an individual with OCD, it is nearly impossible to escape the repetitive thoughts. Because obsessions and compulsions are closely related, many people who are diagnosed with OCD deal with both. People are diagnosed as having OCD when they begin to have obsessions or compulsions that become time consuming, cause serious distress, and/or interfere with their everyday functioning and social life (Black & Blum, 1992). Even though OCD sufferers will realize their actions and thoughts are irrational, they cannot stop themselves from carrying out these “rituals” to help relieve the anxiety. An example of a ritual would be an individual repetitively washing his hands because he/she feels dirty. The

rituals are seen as a severe problem when people spend up an hour or more a day on the rituals, interfering with their daily routine. Even though the ritualistic behaviors may ease the anxious feeling, people with OCD do not get pleasure out of the compulsions (NIMH, 2007).

### *2.2.1 Treatment*

Many researchers and physicians are puzzled because a root cause for OCD has not been identified. Because the cause is undetermined and every individual case is unique, researchers are steadily searching and testing possible theories that could help people discover what triggers the onset of OCD. Research has indicated OCD is a result of a chemical imbalance in the brain that even though the root cause cannot be directly determined, scientists have discovered genetics to be a factor (NIMH, 2007). Medication often helps the patient maintain balanced brain chemistry, but variations of the disorder make it hard to determine the root cause.

Although doctors have not discovered a known cure for OCD, patients can be treated in many ways for the disorder. Usually doctors and psychiatrists begin treatment by prescribing medication. An estimated 40% to 60% of patients treated with a selective serotonin reuptake inhibitor (SSRIs) will respond to the medication (Feusner, 2005). Therapy is also recommended with a licensed social worker, psychologist, or psychiatrist. The therapy usually consists of cognitive behavioral therapy (CBT), a treatment that focuses on patterns of negative thinking and the beliefs that supports those thoughts. This form of therapy identifies and monitors thoughts, assumptions, beliefs and behaviors that are related to debilitating negative emotions. By identifying the thoughts that are dysfunctional, inaccurate, or simply unhelpful, the individual learns to replace or transcend the negative thoughts with more realistic and useful ones. Exposure, response, and prevention therapy (ERP), on the other hand, attempts to break the line between the obsessive thoughts and the compulsive rituals. In such cases, individuals expose themselves to their obsessions, which stimulate a high level of anxiety (e.g., touching something contaminated), and then deny themselves the ritual (e.g., washing their hands). This results in the patient trying to refrain from performing their compulsions or mental rituals when

they feel anxiety. Through this type of therapy, patients learn over time how to manage situations that increase their anxiety. Although some studies have shown ERP treatment to be successful (Mavissakalian et al., 1985), other researchers have also determined this form of therapy may not be effective (Mishra et al., 2007). One reason for this is because patients usually refuse to practice ERP because of the high level of anxiety that is involved (APA, 2006) and previous research found that more OCD patients drop out of therapy that involves ERP treatment (McLean et al., 2001).

### 2.2.2 OCD Research

OCD is a condition that has received more attention over the last 15 years (OC Foundation, 2008). Previous research has examined the symptoms of OCD (Doran et al., 2006; Nadine, Brown, & Wheatly, 2008), OCD in different cultures (Chavira, Garrido, Bagnarello, Azzam, Reus, & Mathews, 2008), genetic factors (Hemmings, 2008; Schooler, Revell, Timpano, Wheaton, & Murphy, 2008; *Genetic and environmental influences on obsessive compulsive symptoms in adults*, 2008), age of onset (de Mathis et al., 2008), comorbidity (Becker-Nissen & Hove Thompsen, 2008; Chavira et al., 2008; Schooler et al., 2008), and most common treatments (Fairfax, 2008; Fineberg, Hughes, Gale, & Roberts, 2005; Himle, Fischer, Van Etten, Janeck, & Hanna, 2003; Himle, Van Etten, Janeck, & Fischer, 2006; Lambert, 2008; McLean, Whittal, Thordarson, & Taylor, 2001; O'Connor et al., 2005; Torres et al., 2007). One study looked at the different types of OCD, their symptoms, and the levels of severity among the participants (Riskind & Rector, 2007). Even though research varies in OCD and is continuing to grow, little research has been done on OCD and support groups (Black & Blum, 1992).

### 2.3 Stigma

Stigma is a concept dating back to ancient Greece, when people who were considered criminals, traitors, or slaves, were physically branded, visually sending a message to others that they belonged to a deviant or undesirable group (Goffman, 1963). Although today people are not physically branded, certain conditions still carry a social stigma and stigmatized individual experience negative psychological repercussions such as lack of social interaction, low self-

esteem, and depression from being stigmatized. Stigma has a psychological effect in which individuals feel the sense of shame based on a specific subgroup or culture they belong to (Hindshaw, 2005). According to Goffman (1963), stigma is a “discrepancy between virtual and actual social identity” (p. 3). When individuals are stigmatized, they are seen as “not quite human,” (Goffman, 1963, p. 5). The stigmatizing characteristic may be visible such as race, gender, or physical handicap. According to Goffman (1963), not all forms of stigma are directly observable. Goffman divided stigma into three categories: physical deformities, character blemishes, and tribal stigma. Tribal stigma includes race, religion, and nationality while character blemishes include mental illness and homosexuality.

### *2.3.1 Stigma and Mental Illness*

Mental illness is seen by some researchers as the most stigmatized condition an individual can have (Hindshaw, 2005). Research has also shown that the medical community even recognizes the stigma with mental illness (Murdock, 2006). When comparing the importance of mental health care Murdock (2006) stated:

There is a continuum between mental health and mental illness, [Surgeon General David] Satcher said. As long as people subscribe to the notion that mental illness is someone else's problem, he said, it will not be resolved. We can't ostracize people because they are mentally ill. (p.1)

While research also shown mental health treatment has become more accepted in society and perceived stigma has declined (Mojtabai, 2007), some still believe the stigma remains one of the largest challenges the entire mental health field faces (Hindshaw, 2005).

### *2.3.2 Effects of Stigma*

Jones et al. (1984) described three distinct effects of stigma: (1) stigma sets a person apart from others, (2) stigma links the stigmatized person to undesirable characteristics, and (3) stigma leads to societal rejection and isolation of the stigmatized individual. One of the most devastating effects of stigma is feeling ashamed and embarrassed (Link & Phelan, 2006; Hindshaw, 2005). When individuals see their identity as abnormal, they become internally

stigmatized and have a difficult time with social interaction and continuing a normal way of life. Victims of stigma have to live with the repercussions of prejudice, stereotypes, and ridicule, leading them to become silent from the shame (Hinshaw, 2005). Stigma has a negative impact on the sufferer's life, which affects the individual's attitude and behavior. Secrecy or withdrawal from others is common because the individual tries to avoid the feeling of rejection. Link and Phelan (2006) noted, "The result may be strained and uncomfortable social interactions, more constricted social networks, a compromised quality of life, low self-esteem, depressive symptoms, unemployment, and loss of income," (p.528). Link, Struening, Neese-Todd, Asmussen, and Phelan (2001) found when an individual's self-esteem is lowered, feelings of unworthiness and self-doubt increase. Goffman (1959) discussed that when individuals experience stigma, they hide away who they are and present themselves to others as how they believe they ought to be seen. Negative experiences during interpersonal exchanges, which resulted in embarrassment, shame, or even doubt within the individual, prompt them to adjust their behavior (Link et al., 2001; Goffman, 1963). No matter what the circumstance, the goal of the stigmatized individual is to do whatever is necessary to avoid the feeling of isolation and rejection.

Many studies have focused on the consequences of stigma and mental illness (Baldwin & Marcus, 2006; Corrigan, 2006; Hindshaw, 2005; Link et al., 2001; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Mann & Himelein, 2004; Murdock, 2006; Rusch, Lieb, Bohus, Anglin, Link, & Phelan, 2006; Sirey, Bruce, Alexopoulos, Perlick, Friedman, & Meyers, 2001). Previous studies found stigma associated with mental illness has serious impacts on the individual sufferers and affects their perceptions of themselves and their condition. Sirey et al. (2001) found an individual's perception of stigma led to non-adherence to treatment and medication regimes.

#### 2.4 Media's Portrayals of Mental Illness and OCD

In order to understand why people with mental illness struggle with stigma, it is important to study the external influences that can affect this community. The media has helped shape



public opinion about the mentally ill community (Steadman, 1981). Unfortunately, the media's portrayal of the mentally ill is not always accurate (Wahl, 1992). Television, movies, and print media are all forms of communication portraying people with mental illness as violent, deranged and unpredictable (Hindshaw, 2005; Phelan, Link, Stueve, & Pescolido, 2000; Pirkis, Warwick, Francis, & Mcallum, 2006; Wahl, 1995; Wahl, 2003). Since the 1950s, people's perception of the mentally ill as violent has substantially increased (Phelan et al., 2000). Since OCD is considered a mental illness, the stereotypes and themes associated with the mentally ill reflect upon them as well. In 2002, USA network premiered, *Monk*, a comedy series about a detective who suffers from OCD. Although this is not the first show to portray a character with a mental illness, it is the first show to educate and enlighten the public about OCD through television. While some may believe that the media's perception of *Monk* is not accurate portrayal of OCD, others praise and believe it great that television is showing OCD in a positive light (Johnson, 2008).

For those who criticize the show, it is being blamed for inaccurately describing OCD. Dr. Su Won Kim, associate professor of psychiatry at the University of Minnesota, has treated thousands of patients with OCD and does not feel that the series really shows the true life of the OCD patient (Hewitt, 2004). One of the problems is Monk has a long list of fears, from germs and needles to public speaking and airplanes. Monk's fears are forms of "phobic disorders," which is not true OCD (Hewitt, 2004). In other words, what Monk is seen to suffer from is forms of "agoraphobia," which is an abnormal fear of being in public, and open spaces. Kim said "I've seen over 2,000 patients with OCD, and none of them have complained of having trouble going on an airplane," (Hewitt, 2004). Unlike agoraphobic who can avoid being in public place and thus avoid their fears, people with OCD are not able to avoid their obsessions and compulsions.

For others, *Monk* is seen as a show that offers a positive outlook for people with OCD (Johnson, 2008). The show has received awards because it offers a voice and challenges the stigma that people with OCD face. The show portrays Adrian Monk as a detective who can carry on a career and can accomplish his goals, therefore giving him a positive identity and

showing that people with OCD can be successful. Because Monk is such an orderly character, he pays attention to fine details that others do not notice, making him a really good at his job. This relationship between his career and condition has put a positive spin on OCD and has gained popularity among organizations such as the OC Foundation and the Anxiety Disorders Association. Johnson (2008) said the show encourages viewers who identify with Monk to engage in self-diagnosis, which can help them reach out to take care of their particular needs.

Even though some say Monk has represented a new era for OCD in the media, little research has been conducted on the image of OCD in the media. People with OCD have claimed public images of OCD may be less harsh than those of mental illness (Fendell & Limberato, 2007). Man and Himelein (2004) discovered the public images of mental illness are often over exaggerated and inaccurate. This can be a threat to patients leading them to believe stigmatization is more widespread than it actually is.

### 2.5 Language and Labeling in Stigma

Not only has the media played a role in enforcing stereotypical images of OCD, everyday language and stereotypes also affect the OCD community. Language is a powerful means of communication. People not only use language as a way to send and receive messages, but as a way to create labels and give meaning to concepts and things. These meanings are learned at a young age where children begin to repeat these stereotypes heard and form stigmatizing attitudes toward others. Children are taught to use words such as retard, psycho, and crazy towards disliked peer (Wahl, 2002). Society also promotes phrases such as, "What an insane statement!" or "Are you crazy?" creating an image of mental illness as abnormal from others (Hindshaw, 2005). Rather than teaching children the proper names and meaning of mental illnesses, society perpetuates degrading language, hurting the image of the mentally ill.

Along with using language to create a negative image, labeling is another practice used that reinforces stereotypes. When someone is labeled as "bipolar," "obsessive-compulsive," "schizophrenic," or other mental condition, that individual's entire view on themselves and their life from then on is seen through that label. However, Gove (2004) also discussed labeling and

mental health treatment as leading to positive well-being effects for patients. Labeling can offer reassurance that what the individual is going through has a medical cause and can help patients head in the right direction in terms of receiving proper treatment. The problem is when external cues, such as the media and interaction with other people in society, portray inaccurate and negative images and stereotypes through images and language.

### 2.6 Government Sources of Stigma

The government also plays a role in promoting stigma towards individuals with mental illness. The medical field and the government are the organizations responsible for distributing proper treatment and ensuring that the sufferers get the help needed. Sadly, the people and families who try to seek help face many challenges within the current system (Stengler-Wenzke, Troshbach, Dietrich, & Angermeyer, 2004). In his study, Lambert (2006) said the government is providing inadequate funding for mental health. Currently more than 12,000 people with a mental illness in Chicago are inappropriately placed in nursing homes, and people who are discharged from state hospitals end up homeless because they do not have the cooperation from community services to help them obtain and maintain a job (Lambert, 2006). According to Murdock (2006), mental problems affect more than a quarter of all Americans each year in which they are stigmatized by not receiving the proper funding or attention they deserve. Unlike physical illness, for which patients have many opportunities to seek adequate funding and care, mental illness does not have the same advantages. Wahl (1999) said people with mental illnesses have problems finding independent housing, do not have enough money for food and rent, and have a hard time maintaining a driver's license or custody of a child.

Another issue mental illness patients struggle with is obtaining and keeping a steady career. Because of the symptoms and functional limitations associated with an individual's condition, many believe that these individual's are "less capable members of the workforce," (Baldwin & Marcus, 2006, p. 388). In a study performed with men who suffered from substance abuse and mental illness, Link et al. (1997) discovered the majority of men believed if people knew they had been hospitalized for their condition, they would be treated differently. Sixty-nine

percent of participants felt as if people looked down on them because of their condition, while 50% believed employers would refuse to hire them, 56% believed women would not marry them, and over 70% had experienced rejection associated with their condition. Occupation retention is a concern for people with mental illness. Many believe they will lose their job if their boss or co-workers discover their problem. Baldwin and Marcus (2006) studied mental illness and stigma and job discrimination and discovered that people with mental illness had been refused employment opportunities and/or promotions, had difficulty in changing jobs, and had been laid off or forced to resign because of their condition (Baldwin & Marcus, 2006). They also found people with mental illness who reported experiencing stigma on the job had received significantly lower wages than people who did not have a mental illness, and they were able to tell when they were being discriminated against.

### 2.7 Medical Professionals and Stigma

Research has shown professionals tend to promote a lower set of expectations and demeaning attitude towards people with mental illnesses (Wahl & Harman, 1989). Even though many of the individuals in mental health care are genuinely committed, these trained professionals convey an attitude that sets an image of superiority toward the patients (Hindshaw & Cicchetti, 2000). Goffman (1959) mentioned how first impressions between the employees and the patients are crucial in order to begin on the right foot. He noted, "Similarly, attendants in mental institutions may feel that if the new patient is sharply put in his place the first day on the ward and made to see who is boss, much future difficulty will be prevented," ( p. 12).

### 2.8 OCD and Stigma

Limited research has been conducted over obsessive compulsive disorder and stigma (Fennell & Liberago, 2007; Knapp, Henderson, & Patel, 2002; Simonds & Elliott, 2001). Stigma is a feeling many people with OCD face throughout their lives (Fennell & Liberago, 2007). Although stigma can affect individuals with OCD through societal experiences and interactions with others, many suffer from self-stigma, a process where individuals recognize their symptoms and diagnosis themselves as being different from others before an official diagnosis

is made (Fennell & Liberato, 2007). Although people with OCD are not “crazy” they often think they are and avoid getting help (El-Sayegh, Bea, & Agelopoulos). The problem with self-stigma is assumptions and predictions are made of how others will treat them without even experiencing the stigma. In their study Fennell and Liberato (2007) found many an OCD sufferer who disclosed their symptoms and condition to family, coworkers, or friends experienced both positive and negative effects. The researchers found examples of negative effects of disclosure as marital problems and problems with boss and co-workers, while positive effects of disclosure were family being more understanding, resulting in reduced feeling of stigma.

Research has also discovered individuals with OCD have higher unemployment rates, low academic achievements, lower average income, and have a higher dependence on social security, compared to those with no psychiatric morbidity (Knapp, Henderson, & Patel, 2002). People with OCD expressed they feel that society sees them as a “joke,” and their condition is viewed as a “tolerable mental illness,” (Fennell & Liberato, 2007, p. 317). However the study discovered many people with OCD felt their condition was not portrayed as harsh as mental illness but felt OCD was a disorder and not an illness. Fennell and Liberato added, “They may be less stigmatized but people may not realize the severity of the disorder,” (p. 317).

Research has shown that families of OCD sufferers have also experienced discrimination and stigma in their everyday lives (Stengler-Wenzke, Troshbach, Dietrich, & Angermeyer, 2004). The study determined relative members of OCD sufferers experienced stigma in the following ways: feeling embarrassed by the sufferer’s symptoms, feeling misunderstood by others in their immediate social environment, and feeling misunderstood by medical professionals due to the lack of empathy expressed. Researchers discovered relatives tended to help the sufferer hide their illness because they knew OCD was an unknown disease and they wanted to do everything possible to avoid the embarrassment and stigmatized attitudes from others (Stengler-Wenzke et al., 2004).

### *2.8.1 OCD and Medical Misdiagnosis*

One of the major problems people with OCD face is receiving adequate treatment. A lack of trained professionals who specialize in OCD results in frequent misdiagnoses (Grabill et al., 2008; Simonds & Elliot, 2001; Stengler-Wenzke et al., 2004). Without a proper diagnosis, OCD patients do not receive the proper medication or therapy for their condition. Grabill et al. (2008) stated, "Contributions to this problem include inadequate and ineffective screening, difficulty in differentiating OCD from other anxiety, mood, and neurological disorders, and individuals' hesitance to report symptoms because of their embarrassing or abhorrent nature," (p. 4). OCD patient's relatives reported the illness was not defined and treated properly until after several misdiagnoses were made by the professionals (Stengler-Wenzke et al., 2004).

### 2.9 Social Support

One of the ways advocacies and organizations are reacting to the needs of OCD patients is by offering support groups, a place where struggling individuals can seek information and help. On the TV game show *Who Wants to Be a Millionaire* the contestants have an option known as "phone a friend" where they are able to call one person they feel can help them out the best if they are stuck on a particular trivia question. In life, people do the same thing when they need help. Social support can be viewed as "phoning a friend" because the individual chooses who they want for help and how they plan to do about doing it.

Pilisuk and Parks (1980) described support as, "A range of interpersonal exchanges that provide an individual with information, emotional reassurance, physical or material assistance, and a sense of the self as an object of concern," (p. 158). DiMatteo and Hays (1981) explained support can be provided in two main ways: tangible support, providing physical resources that benefit the individual such as buying groceries or transporting a patient, to the doctor and/or psychological support, helping someone deal with illness in terms of their values, attitudes, beliefs, and perceptions. Support has been known to help influence and motivate a behavior change in a positive way (Clark et al., 2005).

However, Grande, Myers, and Sutton (2006) discovered the majority of cancer patients were not aware of their doctor's opinions of support group participation. However, they did find that when doctors' views were known, they were significantly related to support group participation. This shows that communication between doctors and patients is vital and can have a considerable impact on a health behavior. Dobkin, Civita, Paraherakis, and Gill (2002) believed physicians should work with patients early on to help determine support sources for them to be able to help with their recovery.

Patients can receive support face-to-face, over the phone, and on the Internet. The individual has the ability to choose who to turn to or which type of support they desire. In terms of mental health, face-to-face as well as online support groups have evolved as places where individuals seek help.

#### *2.9.1 Face-to-Face Support Groups*

Face-to-face support groups function to meet the needs participant's health concerns, security, and well-being and are organized in many different ways for different purposes (Pilsuk & Parks, 1980). Some groups are set up as mutual support groups, which are defined by Chinman, Kloos, O'Connell, and Davidson (2002) as a group of people who meet regularly to exchange information and give and receive psychological support. They are seen as helpful to the members because the environment is seen as a safe place for individuals to share their feelings with others who are going through similar experiences (Barak, Bon-Nissim, Suler, 2008). While some groups are led by medical professionals (doctors, nurses, psychologists, etc.), others are directed by lay people who have the disease themselves.

While a variety of support groups exist, most groups revolve around health concerns. Even though very few groups consider the group's purpose to be health maintenance, they tend to value disease prevention, combat loneliness and create a sense of belonging among the participants (Pilsuk & Parks, 1980). Some support groups focus on specific diseases such as AIDS, cancer, heart disease, or mental illness while others might be for similar symptoms but different diagnosis such as addictions (drug, alcohol, smoking, etc.). Support groups also exist

for people who lost a loved one (e.g. suicide or a traumatic event). Davidson, Pennebaker, and Dickerson (2000) studied all existent support groups in four major cities in the United States and discovered support was highest for diseases viewed as stigmatizing (e.g., AIDS, alcoholism, and anorexia) and lowest for less stigmatizing conditions (e.g., heart disease, migraines, ulcer, and chronic pain). Research has focused on support groups for a variety of health conditions such as AIDS (e.g., Simoni, Pantalone, Plummer, & Huang, 2007), cancer (e.g., Gidron, Chesler, & Chesney, 1991; Grande et al., 2006), diabetes (e.g., Christie, Romano, Thompson, Viner, & Hindmarsh, 2008), mental illness (e.g., Citron, Solomon, & Draine, 1999; Gidron, Chesler, & Chesney, 1991; Heller, Roccoforte, & Cook, 1997; Meisel, Solomon, & Draine, 1996), schizophrenia (e.g., Chein, Chan, Morrissey, & Thompson, 2004), and substance abuse (e.g., Dobkin et al., 2002). Support group research has also been conducted at the work place, discovering how coworkers deal with stress and burnout (Peterson, Bergstrom, Samulsson, Asberg, & Nygren, 2008) and how emergency medical workers cope with a mass shooting incident (Jenkins, 1996). While most support groups are intended to help individual sufferers, support groups are increasingly being designed for the family members and friends (Christie et al., 2008; Citron et al., 1999; Heller et al., 1997). Some groups are for family members alone while others encourage the family to join the sufferers.

Although support groups have been around for decades, not every individual with a health condition seeks them. In many cases, the individual may feel they do not need support and already receive it at home. However, others may either lack support at home or do not want to burden a close friend or family member. Welch (2000) found alcoholics reported they had no family or friends to help them stop drinking. In such cases, support groups are ideal because they allow for the individual to confide in people with whom weak ties, which are relationships that lack the intimacy and frequency as opposed to strong ties, which are relationships with family and close friends. Adelman, Parks, and Albrecht (1987) explained weak ties as, "Potential supporters who lie beyond the primary network of family and friends...weak ties may provide a vital lifeline to those who lack the requisite social and



cognitive skills for intimate relationships,” (p. 126). Weak ties consist of people who are socially distant from the individual’s primary social network such as associates from work, people at church, neighbors or “community agents” (e.g., teachers, doctors, hairdresser). Adelman et al. (1987) noted people who suffer from mental illness prefer and can benefit from the use of weak tie relationships when they do not want strong ties or are incapable of developing them.

#### 2.9.1.1 Benefits

One of the purposes of a support group is to provide a place where individuals can meet together for a common interest and seek help, advice, and converse about personal feelings and emotions. Support groups for health related conditions meet for disease prevention, combating loneliness, and create a sense of belonging to the individual (Pilsuk & Parks, 1980).

Many studies have found patients benefit from participating in a support group (Christie et al., 2008; Davidson et al., 2000; Dobkin et al., 2002; Grande et al., 2006; Harvard Medical School, 2006; Jenkins, 1996; Pilsuk & Parks, 1980; Peterson et al., 2008; Simoni et al., 2007; Spiegel, 1995). Support groups have been known to be a place where individuals can gain information (Harvard Medical School, 2006), reduce their level of anxiety and depression (Dobkin et al., 2002; Jenkins, 1996; Spiegel, 1995), and build their self-confidence and self-esteem (Christie et al., 2008; Peterson et al., 2008). Other studies have found that support groups offer emotional support and encouragement (Harvard Medical School & Spiegel, 1995), offer an opportunity to meet new people and make friends (Christie et al., 2008; Harvard Medical School, 2003; Peterson et al., 2008), and allow for individuals to express their emotions and feelings (Spiegel, 1995; Christie et al., 2008). Support groups have also been found to help with an individual’s overall health. Spiegel (1995) found patients that patients in a cancer support group experienced decreased anxiety, depression, physical pain, and even lived longer. In a study that focused on support groups and substance abuse, authors found individuals with higher levels of family support and support through social networks contained fewer signs of depression and alcohol consumption (Dobkin et al., 2002).

Grande, Myers and Sutton (2006) studied patients who had cancer and looked at support group participants and non-participants. Patients' reasons for joining the group included: a lack of support from others, positive beliefs they had toward joining the group, positive feedback from important others about group participation, positive beliefs the group was easy to join.

Grande et al. (2006) found that support group participation is more likely when people believe there is something to gain from joining the group. Being part of a group where goals are created helps instill inspire and motivate the individual. When an individual is able to change his or her behavior because of the social influence, the group becomes a positive aspect of that individual's life (Grande et al., 2006).

#### 2.9.1.2 Problem Areas

Previous studies found negative perceptions that individuals have toward support groups keep them from participating (Christie et al., 2008; Grande et al., 2006; Simoni et al., 2007). The main reasons many individuals did not participate in a support group included feeling uncomfortable talking in a group setting about their personal problems and feeling they did not have time to fit the meetings into their schedule. Some individuals did not join because they felt their condition was under control, felt they received sufficient support at home, and/or believed dwelling on the issue was not healthy for them (Christie et al., 2008). In addition, parents of diabetic children claimed their child was not interested in support group participation because the child was not interested in speaking about their condition (Christie et al., 2008). Grande et al. (2006) found in a study of cancer patients participants of the support group had more support about participating in a support group compared to participants who were not part of a support group. Transportation was an issue for many in which it was either due to distance or lack of availability (Grande et al., 2006; Simoni et al., 2007).

#### 2.9.2 Online Support Groups

The Internet has opened up many channels for businesses, organizations, and personal use. Currently, more than 1 trillion people worldwide use the Internet (Internet World Stats,

2007). Besides social networking, online shopping, and e-mail, many people go online to research and retrieve information. Interest in online support group participation has been dominantly driven by health issues (Davison et al., 2000). Research has show that as many as 93 million of adult Internet users have searched online for health information and 36 million people in the United States said they were members of an online support group (The Pew Internet Research Institute, 2005) This movement toward online communication has become a worldwide phenomenon, creating hundreds and thousands of groups, reaching a large number of people from many diverse regions. Online support groups exist for chronic conditions such as asthma or heart disease to diseases such as mental illness or AIDS.

Online support groups are similar to face-to-face support groups in the sense that people who join online support groups are all dealing with a specific situation or condition. They are built on the premise that people with a particular condition can benefit by interacting with others who are dealing with similar issues. Online support groups exist in many forms including e-mail, chat rooms, instant messages, discussion groups or boards, forums, blogs, and social networks. Taylor and Luce (2003) reported that 28% of Internet users have participated in an online support group for a medical condition or a personal problem for at least one occasion. Although support groups can sometimes become misconstrued as a form of therapy, Barak, Boniel-Nissim, and Sule (2008) explained the difference between therapy and online support groups:

...the purpose of a support groups is basically to offer relief and improved feelings rather than therapeutic change in the emotions, cognitions, or behaviors of participants...they may operate without a leader or manager or have a nonprofessional administrator, whereas therapy groups always have trained professionals who lead t them....(p. 1868-1869)

The authors added support groups help individuals cope and deal with their emotions, offering a place where individuals can achieve personal strength, which adds value to standard therapy.

Many studies have examined participants' attitudes toward support groups and the effectiveness of online support groups in a number of contexts such as HIV/AIDS (Bar-Lev, 2008; Rier, 2007), trichotillomania (TTM) (Bruwer & Stein, 2005), depression (Houston, Cooper, & Ford, 2002) suicidal patients (Barak & Dolev, 2006; Gilat & Shahar, 2007), cancer (Klemm, Reppert, & Visich, 1998), Huntington's disease (Coulson, Buchangan, & Aubeeluck, 2007), caregivers of a condition or illness (Peron, 2002) and the overall effects and feelings of participants of online support groups (Barak et al., 2008).

#### 2.9.2.1 Benefits

The Internet allows people to receive information and support who may have economic, geographic, physical, or other restrictions that keep them from participating in face-to-face services. Taylor and Luce (2003) reported computer and Internet-based programs, treatment, communication, and even therapy is cost effective and just as beneficial as face-to-face interaction. They also claimed Internet support groups can have advantages over face-to-face interaction by providing help to rural residents and people who are chronically ill or not physically able to attend a face-to-face group. Individuals who participated in online support groups said they received emotional support and felt that others understood what they were going through (Barak et al., 2008; Bruwer & Stein, 2005; Coulson et al., 2007; Houston et al., 2002; Rier, 2007; Shaw, Hawkins, McTavish, Pingree, & Gustafson, 2006). For some, the online environment was comfortable for people to talk about their problems and online participants said they gathered useful information from support groups (Bruwer & Stein, 2005; Colvin, Chenoweth, Bold, & Harding, 2004). Participants in a support group for trichotillomania, felt the group were helpful in terms of learning about symptoms, ways to treat trichotillomania, and tips on how to decrease hair pulling (Brewer & Stein, 2005). Another benefit of online participation was that it tended to lower participants stress levels (Barak & Dolv-Cohen, 2006; Shaw et al., 2006) and for patients with breast cancer, the online messages helped to alleviate negative emotional reactions to cancer-related thoughts or questions (Shaw et al., 2006). When looking at online support groups for people with HIV/AIDS, participants preferred online

communication because it was a place where they could debate moral dilemmas such as when is the right time to tell your partner or someone you are dating about your HIV status (Bar-Lev, 2008; Rier, 2007).

One of the main appeals of online communication is the ability to remain anonymous during interpersonal exchanges (Barak et al., 2008; Colvin et al., 2004; Houston et al., 2002; Finfgeld, 2000; Sansone, 2001; Tate & Zabinski, 2004). Staying anonymous allows individuals to keep their social and demographic information hidden and provides a safe haven for people who are fearful of opening up to others. The online community is also seen as a nonjudgmental atmosphere, which encourages participation (Colvin et al., 2004). The Internet provides safety net for stigmatizing conditions because it protects individuals from shame and embarrassment, while making it easier for them to discuss sensitive topics (Wright, 2002). Barak et al. (2008) found participants are willing to take a bolder stance in the group because they feel comfortable saying things online they would not be able to say in a face-to-face environment.

Communicating online is also seen as convenient for participants (Colvin et al., 2004; Houston et al., 2002; Peron, 2002; Sansome, 2001). The asynchronous aspect of online communication makes certain ways of providing support more popular such as e-mail, bulletin boards, and discussion boards. Unlike face-to-face communication where all participants must listen to everything that is discussed from all individuals, others prefer the asynchronous form of communication because they can contribute to the group only when they want and are not limited to the topics brought up by other members of the group (Colvin et al., 2004; Peron, 2002). Online support is also convenient for *lurkers*, who are people who read information posted in support groups without providing any feedback or contributing their thoughts. Research has found the ability to lurk can be therapeutic because individuals who are not interested in interacting can still find a way to gain information and understanding (Colvin et al., 2004; Finfgeld, 2000).

Chatting online can be a positive experience and therapeutic for people who like to share their opinions and feelings in writing (Harvard Medical School, 2002; Finfgeld, 2000;

Peron, 2002) and it is excellent for people who are impulsive or irrational, allowing them to write their thoughts out before expressing them to others (Finfgeld, 2000).

Houston et al. (2002) found individuals suffering from depression who were part of an online support group preferred online support groups over face-to-face. Participants who preferred this method of communication tended to have lower amounts of social support in their lives compared to individuals with depression who were not part of an online support group.

#### 2.9.2.2 Problem Areas

Online support groups also have disadvantages and complications not found in face-to-face communication. One of the most common problems with online communication and support is the lack of nonverbal physical, visual or auditory cues (Colvin et al., 2004; Hillan 2003; Klemm et al., 1998). In such cases, misunderstanding, misinterpretation, and confusion among messages can occur due to lack of physical and nonverbal cues. Because the Internet serves as a barrier between sender and receiver and does not allow for individuals to project nonverbal cues, the communication may be less effective. Participants involved in online support groups have expressed that they wish they were able to touch (e.g., hug) or physically acknowledge (e.g., make eye contact) other participants to show that they are empathetic toward the other person (Colvin et al., 2004). DiMatteo and Hays (1981) added that touch and other nonverbal cues are comforting tools to use to support a distressed patient and are an important factor during empathic communication.

Another potential disadvantage to online communication is the chance the individual seeking help could develop an addiction to the Internet (Madara, 1997). Individuals who have OCD or obsessive tendencies, for examples, may begin to develop habits directed towards Internet use rather than using it merely as a helpful tool for support.

Compared to the face-to-face environment, the online world may lack formal guidelines or rules (Finn, 1996). Because some online areas may not have moderators or professionals monitoring the messages, inappropriate, inaccurate, misleading, or harmful remarks may be

exchanged. Taylor and Luce (2003) recommended using Web sites that are sponsored by nonprofit organizations because they are reliable.

Online communication can have a time lag in between messages, which can be a problem for people who are looking for immediate feedback and not all messages are addressed (Zate & Zabinski, 2004). Wright (2002), discovered cancer patients who used online support reported the most frustrating aspects was delayed feedback, not being able to hear the person's voice they were communicating with, and the off topic or hostile remarks.

### 2.10 OCD and Support Groups

As previously discussed, support groups exist for a variety of health conditions and health contexts. As online communication is on the rise, online support groups have expanded in the last few years (Pew Internet Research Institute, 2005).

While limited research has been conducted on OCD and support groups (Black & Blum, 1992), several previous OCD studies have focused on the effects of group therapy (Fineberg et al., 2005; Himle et al., 2006; Himle et al., 2003; McLean et al., 2001; O'Connor et al., 2005).

Although support is different than therapy, many individuals with OCD use support groups to motivate them to continue their therapy (Barak et al., 2008). It has been noted that group interaction is more beneficial to the patient regardless of the type of therapy used (Fineberg et al., 2005; Himle et al., 2003). O'Connor et al. (2005) discovered shared social support and the motivational effects of peer feedback helped to determine group therapy participation. Because OCD has many forms and types, it is difficult to determine which form of therapy or which support setting would be most beneficial to any individual sufferer.

Limited numbers of studies have focused on OCD and social support. Black and Blum (1992) studied the effects of face-to-face support groups for people with OCD that provided education and emotional support and found they had many benefits for the patients. They discovered that the group helped patients gain the knowledge about their disorder to seek proper treatment, allowed for patients to discover some of their symptoms as "universal," which helped combat loneliness, and helped patients re-establish social connections. Although the

researchers were concerned about patients taking on new obsessions and compulsions, they found that not to be the case. It was also stated that many participants had a supportive family (e.g. family member driving the patient 150 miles to the meeting). Prior research has not looked into OCD sufferers' perception and motivational factors when determining which form of support or treatment they choose.

Kenwright, Marks, Graham, Frances and Mataix-Cols (2005) examined individual computer-aided self help for OCD and found when patients participated in phone support over along with a computer-aided self help program, their symptoms significantly improved. Bruwer and Stein (2005) focused on online support for people who suffered from trichotillomania, which is obsessive hair pulling, a condition linked to OCD, and found that online support groups were helpful in teaching participants about their symptoms and how to treat and decrease hair-pulling. No research has been found on online supports groups and non-trichotillomania OCD patients.

Many people with OCD find it difficult to see themselves as "normal" and have difficulty associating themselves with others who they feel are normal. This social isolation can become very depressing and stressful for an OCD sufferer and an increase in stress can lead to a worsening of their symptoms. Being able to disclose with others has been known to lessen the sense of anxiety and isolation that was once a common threat to them (Spiegel, 1995). The goals and purpose of a support group should be viewed as a place that promotes education and shares victories (K. Norris, personal communication, August 16, 2008). Kathleen Norris (2008), a licensed professional counselor and supervisor of a face-to-face support group for OCD, explained that the support group she runs is not allowed to discuss medication or be promoted as a therapeutic group because of potential legal liability issues and regulations. Therefore, a support group must promote education, awareness, and encouragement; not seen as a place of treatment.

However, OCD patients also have negative perceptions and feelings toward group participation. When studying individual versus group therapy for patients of OCD, Connor et al.



(2005) found patients reasons for not wanting to participate in the group therapy included: anxiety toward sharing their feeling with others, a need for more personal attention, and fear of obtaining new obsessions and compulsions by listening to others experiences. If not run properly, support groups can become a place where the individual sufferers can become sicker because of griping and negative comments (K. Norris, personal communication, August 16, 2008). This negativity can lead to making the individual feel more depressed and drop out of the group (Black & Blum, 1992). Norris (2008) also noted that sometimes individuals stop attending because someone they have gotten close to has quit the group, and the group may no longer be as interesting.

Through her experience, Norris (2008) explained how the leaders of the support group she advocates are dedicated and have remained loyal with the group for a long period of time. For participants, the support group is seen more as a pathway to recovery, and once they feel their condition has improved, they do not feel the need to continue. K. Norris (2008) remarked:

Over time, support group runs its course for people. As they start to get well, the group is not as much of a priority. For example, Monday night football did not matter when they were that sick. But now that they have a spouse, life is going on, and they are healthier, the group is not as important. Members of the group forgive the people that outgrow the group because it is a part of getting well.

Support groups tend to be seen as a form of temporary help for some patients. Once that patient feels better, they do not feel they need to return. Black and Blum (1992) agreed and noted support groups tended to be most beneficial to the patient during transitional phases, which are periods of adjustment or stressful moments in an individuals' life. Norris (2008) suggested some individuals choose not to return to the group because they can be reminded of how sick they once were.

Norris said she believed although Internet communication can be helpful, if the site does not have a moderator, the patients can be harmed by intercepting bad advice or wrong information. She said if the group is not run properly, patients can make themselves worse

because of inaccurate information, negative comments, and too much griping. She said she feels any online site needs someone to step in every now and then to clear up any misinformation that is posted.

While a few studies have looked at OCD and support groups, none have focused on why individuals with OCD participate in face-to-face or online support groups. In order to determine the effectiveness of support groups, one must uncover individuals' attitudes, beliefs, and perceptions toward support groups in general.

### 2.11 Theoretical Background

Two theories may help researchers to understand why OCD patients do or do not participate in online or face-to-face support groups: the Health Belief Model (HBM) and the Theory of Planned Behavior/Theory of Reasoned Action (TRA/TPB). HBM suggests an individual's participation in a preventative health behavior is influenced by five factors: perceived susceptibility to a threat, perceived severity of the threat, perceived barriers in performing the behavior, perceived benefits in performing the behavior, and cues to action (Janz & Becker, 1984). The TRA/TPB is also used to examine the likelihood an individual's will engage in a specific health behavior. Fishbein and Ajzen (1980) proposed an individual's behavior can be predicted by their intentions, which are determined by the attitude toward the behavior, and the subjective norm, which are the views that important others have toward the behavior. In this study, both models are used to explore individual's attitudes and beliefs behind a health behavior -- participating in a support group -- and to discover what factors influence OCD patients' attitudes about participating in support groups. Although the theories have different elements, they both explain the combination of factors that may influence an individual's attitudes toward a health behavior.

#### *2.11.1 Health Belief Model*

The Health Belief Model (HBM) has been in existence since the 1950s when U.S. Public Health Service social psychologists, Godfrey Hochbaum, Irwin Rosenstock, and Stephen Kegels, developed a framework to determine why an individual would or would not participate in

a desired health activity or behavior (Galloway, 2003) along with discovering the determinants of voluntary health-related actions (Becker et al., 1977). The HBM is a value-expectancy theory that contained two concepts: (1) the value to avoid an illness or to get well and (2) the belief a specific health behavior will prevent illness. The HBM hypothesized individuals would not seek preventative health care measures unless they viewed themselves as vulnerable to the health condition (susceptibility), saw it as a threat (severity), were convinced that the actions necessary are helpful (benefits), and did not see the action as difficult to enact (barriers) (Rosenstock, 1974). Over the years two more elements, cues to action (internal or external events that prompt a desire to make a health change) and self-efficacy (the ability to make a health-related change) were added in order to analyze motivating factors, determine the decision-making process and other influences on the behavior (Becker et al., 1977).

Perceived susceptibility and perceived severity both deal with the individual's state of readiness to take action. The HBM suggests an individual is ready to take action if the individual perceives it is likely that he or she will experience a health threat and that the threat is of great magnitude. Janz and Becker (1984) looked at severity in terms of medical consequences, including death, disability, and pain, and social consequences, including effects on work, family, and social relationships. If individuals believe the threat to the condition is serious but do not believe that they are at risk, they will ignore the threat. If they believe they are at risk for severe consequences, they will be motivated to take proper actions to preventing the threat from occurring (Murray-Johnson & Witte, 2003).

Janz and Becker (1984) determined although perceived susceptibility and severity to a health condition appeared to have influence on an individual's behavior, it did not define the course of action chosen. Two elements, perceived benefits and perceived barriers, were more predictive of whether people engaged in a specific health behavior. The model proposed an individual weighs the potential benefits of taking the recommended action against the costs. While benefits are seen as good outcomes, barriers can be physical, psychological, or even financial. These elements of the model deal with the overall individual's evaluation of the health

behavior in terms of seeing if there are benefits to reducing the severity or susceptibility (Becker et al., 1977). Once the individual believes that benefits outweigh the costs, then they will take the preventative measures.

Cues to action are messages that gain the individual's attention. Murray-Johnson and Witte (2003) identified cues to action as an important component that helps trigger motivation and the cost-benefit analysis. Becker et al. (1977) suggested the stimulus can be either internal, including a particular state of health, mood, or feeling, or external, including interpersonal interactions, mass media communication, entertainment programs, or educational material. Both internal and external cues may increase an individual's perception of threat, motivating an individual to engage in the recommended response.

Self-efficacy is defined by Murray-Johnson and Witte (2003) as "The perceived ability to achieve an outcome through one's own action," (p. 481). When looking at health preventative measures and actions, an individual must have the ability to perceive themselves as capable of completing the action. When the barriers affect the individual's beliefs and self-efficacy, the motivation level can decrease (Murray-Johnson & Witte, 2003).

The HBM has evolved into a theory that attempts to discover and better understand the determinants of voluntary health behavior. Although it was originally developed to study preventative health actions, it has grown to explain illness and sick role behaviors as well (Becker et al., 1977).

#### 2.11.1.1 Studies Using the HBM

Previous HBM research has not examined OCD, although some studies have examined HBM and mental illness (e.g., Adams, 2000; Corrigan, 2002; Nageotte, Sullovan, Duan, & Camp, 1997; Saleeby, 2000; Souza, 2002). One area of concern in research is medication compliance with mentally ill patients. Investigators use the model to determine which factors are associated with medication and treatment compliance or non-compliance (Adams, 2000; Corrigan, 2002; Nagoette et al., 1997; Souza, 2002). By using the HBM, researchers were able to examine value expectancies related to health. Corrigan (2002) concluded, "...Health Belief

Model views humans as rational beings who behave in ways that diminish perceived threats (disease symptoms) and enhance perceived benefits (including adherence to treatments),” (p. 244). Individuals with a diagnosed mental illness believed if they did not take their medication regularly, their health would become worse, ending up in the hospital (Adams, 2002) and saw themselves as vulnerable to the adverse health outcome (Nagoette et al., 1997). Highly compliant patients viewed their condition as being controlled by external influences.

Along with outside influences, the cues to action element also played a significant role because the patients felt being able to recognize symptoms that suggested the onset of an episode determined their readiness to act (Adams, 2002). This study found that the perceived severity of illness and perceived benefits of treatment determined medication adherence.

Other studies focusing on mental illness and health behavior did not use the entire HBM, but instead studied a particular element. Previous research examined perceptions of the severity of illness (Bellon, Delgado, & Lardell, 1999, and perceived benefits (Coorigan, 2002) and barriers to seeking help (Baur, Williford, McBride, L., McBride, K., & Shea, 2005; Coorigan, 2002; Craske et al., 2005; Sareen et al., 2007). Previous studies found that the greater the perceived severity, the more frequently patients sought primary health care services (Bellon et al., 1999). Common barriers to seeking treatment included: the desire to solve their problem on their own (Sareen et al., 2007), fear of being stigmatized (Craske et al., 2005; Sareen et al., 2007), difficulties with transportation (Bauer et al., 2005), lack of knowledge as to where to get help (Craske et al., 2005), conflicts between work and home commitments (Bauer et al., 2005), and financial issues (Craske et al., 2005). Although there has been a wealth of studies looking at HBM and mental illness, no previous HBM studies examined OCD and support groups.

### *2.11.2 Theory of Reasoned Action/Theory of Planned Behavior*

The Theory of Reasoned Action (TRA) was developed by psychologists Ajzen and Fishbein in the late 1960s and early 1970s. The model attempted to explain how and why an individual's attitudes impact health behaviors. It claimed an individual's behavior is determined by his or her intention to perform the behavior. The TRA examined two components to

determine the intention: the individual's attitudes toward the behavior and the subjective norm. The attitude toward the behavior refers to the individual's personal judgment that performing the behavior is good or bad, helpful or unhelpful. The subjective norm is the individual's perception of what others think about performing the behavior. It deals with the opinions and attitudes of people the individual sees as significant, such as family and friends. Ajzen and Fishbein (1980) discussed how the theory predicts and understands behavior: "The first step toward this goal is to identify and measure the behavior of interest. Once the behavior has been clearly defined, it is possible to ask what determines the behavior," (p.5). The TRA assumes that the individual has control over the action and the individual's intention to perform, or not perform, a behavior is relatively easy to predict. Even though the TRA looks at an individual's attitude toward the behavior, one of its main limitations is that it does not take into account behavior that is not in the control of the subject. It only deals with volitional behavior. In order to address this issue, Ajzen and Driver (1991) proposed the Theory of Planned Behavior (TPB). It contains the same elements as the TRA but added a third component: perceived behavioral control. Basically the theory states behavioral intention is influenced by the perceived difficulty of the task and the perceived control over the behavior. Therefore the theory proposes that an individual's behavioral intention is influenced by the attitude toward the behavior, the subjective norm, and the perceived behavioral control. The TPB is used in many health communication contexts and researchers have used them to determine likelihood of achieving a health goal.

#### 2.11.2.1 Studies Using the TRA/TPB

Unlike the HBM, no research has been found on TPB with mental illness or OCD. However, limited research has been conducted on the TPB and cancer support groups (Grande, et al., 2006; Voerman, Visser, Fischer, Garssen, Andel, & Bensing, 2007). Grande et al. (2006) surveyed cancer patients who were part of a support group while Voerman et al. (2006) surveyed men with prostate cancer about their views on support group participation. Both studies discovered an individual's interest in participating in a support group resulted from positive attitudes toward participation along with a lack of support from important others. The

studies differed in that Grande et al. (2006) found that the subjective norm was the most significant factor to participation while Voerman et al. (2007) did not find the subjective norm relevant at all. However, it was evident that perceived behavior control was also a determining factor for participation (Voerman et al., 2007). Barriers to participating included lack of awareness (Voerman et al., 2006) while others claimed to not know their doctors opinions of support group participation (Grande et al., 2006). In the end, both studies agreed the individual's attitude plays a significant role in behavioral intention.

### 2.12 Research Questions

In this study, two theoretical frameworks: the Health Belief Model (HBM) and the Theory of Reasoned Action (TRA)/Theory of Planned Behavior (TPB) are used as to determine what factors might influence or suggest reasons people with OCD choose to participate or not participate in a face-to-face or online support. The review of literature provided sufficient information suggesting people with OCD suffer from stigma (Fennell & Liberato, 2007; Knapp et al., 2002; Simmonds & Elliot, 2001) and most of the time self-stigma (Fennell & Liberato, 2007). Therefore, stigma must be considered because when people feel stigmatized, they can have a fear of being involved in a group setting (Craske et al., 2005; Sareen et al., 2007). This factor alone can determine reasons for participation or nonparticipation status for both face-to-face and online support groups.

Studies have shown reasons people participate in support groups are because of gaining helpful information and receiving advice on treatment (Black & Blum, 1992; Brewer & Stein, 2005). Feeling alone was another reason people participated in a support group (Black & Blum, 1992).

Studies have also discovered people do not participate in support groups because they felt uncomfortable speaking in front of others (Christie et al., 2008; Grande et al., 2006; Simoni et al., 2007), they felt their condition was under control (Christie et al., 2008) and they did not know of support groups available to them (Grande et al., 2006; Simoni et al., 2007).

Because online communication is prevalent, the study will also address online support group participation. Research has shown people who participate in online support groups enjoy the anonymity (Barak et al., 2008; Colvin et al., 2004; Houston et al., 2002; Finfgeld, 2000; Sansone, 2001; Tate & Zabinski, 2004) and convenience the Internet provides (Colvin et al., 2004; Houston et al., 2002; Sansone 2001). Wright (2002) explained that people who are stigmatized prefer communicating online because it feels safe to them. However, others have discovered people do not like online communication because it lacks nonverbal cues (Colvin et al., 2004; Hillan, 2003; Klemm et al., 1998) and formal guidelines (Finn, 1996).

Researchers have discovered when looking at the elements of the HBM perceived benefits (Coorigan, 2002) and barriers (Baur et al., 2005; Coorigan, 2002; Craske et al., 2005; Sareen et al., 2007) were important elements when determining support group participation while cues to action also determined readiness to act (Adams, 2002).

The TRA/TPB also was used when looking at support group participation. The most common factor discovered was the attitudes of the individual (Grande et al., 2006; Voerman et al., 2007). Participation is likely when the individual has a positive attitude toward joining the group. While not all studies found the subjective norm and the perceived behavioral control to be significant findings, when looking at the current study, they both have the ability to influence why people with OCD participate in a support group. The attitudes and opinions of others can shape and effect the individual's perception.

Based on the literature reviewed, four research questions have been posed in order to determine what elements of the HBM and TPB help determine whether or not individuals with OCD choose to participate or not participate in either a face-to-face support group or an online support group for OCD.

**RQ 1:** Why do individuals with OCD participate in face-to-face support groups?

**RQ 2:** Why do individuals with OCD not participate in a face-to-face support groups?

**RQ 3:** Why do individuals with OCD participate in online support groups?

**RQ 4:** Why do individuals with OCD not to participate in online support groups



CHAPTER 3  
METHODOLOGY

3.1 Introduction

This chapter will describe the methods of data collection and data analysis used in order to answer the research questions posed in studying sufferers of obsessive compulsive disorder (OCD) and support groups. The study involved 29 participants, which included 10 males and 19 females. 29 participants were sufficient enough to reach saturation and additional participants did not add new information to the study. A quantitative method would be difficult in gathering data for the types of questions stated because the study is looking into individual's attitudes and perceptions and conducting a random sample of the general population would not allow the researcher to find people who know the most about OCD and support groups: OCD sufferers. Qualitative research on the other hand, is a more effective way to answer the research questions because it allows for the researcher to "Examine people's words and actions in narrative or descriptive ways more closely representing the situation as experienced by the participants," (Maykut & Morehouse, 1994, p. 2). Since this study focus on descriptive and detailed analysis of participant's experiences and perceptions toward their OCD and support groups, a qualitative approach was used to gather data. In order to determine why individuals with OCD participate or do not participate in face-to-face or online support groups for their OCD, the researcher's methods included: in-depth individual interviews, focus groups, and open-ended online questionnaires. The Glaser and Strauss (1967) constant comparative method, also know as the grounded theory and analytic induction, was used as a method of data analysis.

### 3.2 Sampling, Recruitment, and Participant Selection

This study used a combination of non-probability and snowball sampling methods in order to recruit people who had OCD. Snowball sampling is effective because of its efficacy in finding people whose attributes are central to the problem studied (Lindlof, 1995). The method uses a person as a source for locating other people who in turn nominate other individuals who are eligible to participate. Since the study focused on individuals with OCD, a snowball sampling method allowed for the researcher to use credible sources such as psychologists, OCD sufferers, and contacts made through the OC Foundation's annual conference as a means of obtaining referrals for possible participants. In quantitative research, most sampling techniques result around probability sampling where there is a chance for every population element to be selected (Lindlof, 1995). In qualitative research, the researchers are not interested in sampling just the general population (Lindlof, 1995; Maykut & Morehouse, 1994), they are more interested in purposeful selection (Patton, 1990), in which each participant is selected because of their expertise and experience with the issues being studied. Therefore, a random sample of the general population of Dallas-Fort Worth would not have been appropriate to this study because it would have been less likely to acquire participants who knew something about OCD or had personal experience with the condition. Therefore, a non-probability sampling was used by recruiting participants through two advertisements made by the researcher. The responses were directed from an advertisement published in the OC Foundation Newsletter (see appendix A), an organization strictly for OCD patients and experts, and an advertisement published on the OCD Tribe Web portal (see appendix B), an online social network for people with OCD. Because OCD is a stigmatized condition and many people who have OCD keep their condition hidden, it was important to the study to find experts in the field in order to recruit the necessary subjects. The publication chosen by the researcher goes out to people who have OCD and experts in the field who work with OCD patients or study

OCD. People who discovered about the study through these advertisements contacted the researcher, informing them of their interest to participate or referred someone they knew had OCD.

The constant comparative method introduced by Glaser and Strauss (1967) is a data-analysis method used in many qualitative research studies that suggests the importance of grouping data in categories and themes. Glaser and Strauss recommend the researcher must select participants who vary in terms of the main selection characteristic in order to generate as many properties of the categories as possible. Using selection criteria based on experience with support groups, several types of participants with OCD were included: people who were currently in a face-to-face support group (n=5), people who were currently members an online support group for OCD (n=5), people who were currently participants of both face-to-face and online support groups (n=4) and people who were currently not in any type of support group (n=15).

### 3.3 Methods of Data Collection

Three methods were used throughout this study: in-depth individual interviews, focus groups, and online questionnaires. Because this study examines reasons behind a specific health behavior, in-depth interviews help to see the daily life and experiences of the individual being interviewed (McCracken, 1988) while focus groups allow for the researcher to observe group interaction and obtain information quickly about the topic of interest (Morgan, 1997). Open-ended online questionnaires are a convenient way of reaching a population that could not be studied in a face-to-face manner, especially when looking at members of an online social network (Wright, 2005).

#### *3.3.1 In-depth Interviews*

In-depth interviews are one-on-one interviews that pertain to a particular topic of interest (McCracken, 1988; Lindlof, 1995). Lindlof (1995) explained the purpose of interviewing:

In qualitative research, one interviews people to understand their perspectives on a scene, to retrieve experiences from the past, to gain expert insight or information,

to obtain descriptions of events or scenes that are normally unavailable for observation, to foster trust, to understand a sensitive or intimate relationship, or to analyze certain kinds of discourse. (p. 5)

In this study, in-depth interviews were used to understand non-support group participant's perspectives on support groups. When deciding on the number of in-depth interviews to conduct, McCracken (1988) stated his first principal, "less is more," and by having less, "It offers an opportunity to glimpse the complicated character, organization, and logic of culture," (p. 17). He goes on to explain the sample size in qualitative research is not meant to represent some part of the larger world. Unlike quantitative research where the number of individuals share similar characteristics is usually a significant factor, the purpose of the interview is to obtain insight on how one culture views and construes the world (McCracken, 1988). Although the author did recommend eight in-depth interviews, four interviews were able to be completed in the current study, which consisted of three males and one female. This was due to a limited amount of willing participants in the Dallas/Fort Worth area. Six participants expressed interest, yet four followed through. Three were referred through snowball sampling while one contacted the researcher after reading the OC Foundation advertisement. Four interviews are sufficient to the research because views from 12 other non-support group members were gathered through online questionnaires. The researcher met all participants at a neutral site and the interviews lasted between 45 minutes and 1 ½ hours.

Several people responded to the ad in the OC Foundation newsletter who did not live in the Dallas-Fort Worth area. In order to obtain a larger sample size from the non-support group population and to include participants who were geographically too remote for a face-to-face interview, OCD sufferers who were not in any form of support group and lived outside the DFW area (n=12) were given an open-ended online questionnaire, which covering the same questions as the face-to-face in-depth interviews. Having this population complete an online questionnaire allowed for the researcher to use subjects of who lived at a geographical distance, making it more convenient for both parties (Taylor, 2000). Since research has shown

people with OCD suffer from self-stigma (Fennell & Libereto, 2007) and stigma in mental illness can lead to secrecy or withdrawal from society (Link and Phelan, 2006), an online questionnaire also was a successful way to reach people who would not be willing to admit to suffering from OCD in a face-to-face situation.

### *3.3.2 Focus Groups*

Focus groups are interviews among small groups that concentrate on topics of interest addressed by the researcher. It is the researcher's interest that drives the discussion and the data obtained comes from the group's response and interaction where their experiences on particular topics can surface (Morgan, 1997; Linlof, 1995). One of the main advantages is they allow for the researcher to observe a great amount of discussion in a limited amount of time (Morgan, 1997). Interviewing a focus group for individuals who are in a support group was an effective way to gain information and perspectives about the group because the researcher can observe participant's reactions and responses. This setting allows for the moderator to observe the interaction of the group as a whole.

For focus groups, the basic rule of thumb is to have three to five focus groups with six to ten participants in each group (Morgan, 1997). Group sizes smaller than six may not generate enough discussion while larger groups may get off topic easier and not allow all participants to contribute (Morgan, 1997). Although three to five groups are recommended, the goal is to achieve "saturation," (Glaser & Strauss, 1967). With saturation, the goal is to collect data until the researcher has reached a point where collecting additional information will not achieve new understanding. Saturation was reached in the current study when the data obtained became repetitive. The number of groups used tends to vary between studies. Another issue with the group size is the amount variability the participants provide (Morgan, 1997). More groups are needed when the participants have diverse experiences in order to gain a "coherent set of opinions and experiences," (Morgan, 1997, p. 44) from participants.

In the current study, three focus groups were initially planned in order to interview OCD sufferers who were currently members of a face-to-face support group, yet one group was

interviewed. One support group that was initially identified as a potential focus group source was not an active support group but rather an educational and awareness group, which contained new participants each week. Another group refused to be audio or videotaped, and could not be used as a focus group because the refusal to be taped would have caused several problems with accurate data collection. The support group that did participate in a focus group contained eight participants: seven were regular attendants of the group while one was attending for the first time. The group contained three males, five females, and the focus group lasted for 1 and ½ hours.

Because OCD is a unique disorder where participants' responses could be affected by the type of OCD they have, knowing their OCD symptoms help understand their attitudes toward support group participation. Among all eight participants, two had contamination issues, three were hoarders, two had morbid obsessions, and the one that with no previous support group experience was a checker, repeatedly checking objects such as doors, locks, or the Off settings on household appliances. It is important to note that although each individual diagnosed with OCD is grouped into a specific category of OCD, many had overlapping symptoms due to the fact OCD is not usually a one-symptom disorder and can evolve over time (OC Foundation, 2008).

Morgan (1997) suggested one group can be problematic to the study because there is no comparison of one group to the next and it can be difficult to determine if the discussion is reflecting the unusual makeup of the group or if it is the "dynamics of that unique set of participants," (p. 44). In this case, data discovered from the focus group will be compared to the in-depth interviews and online questionnaires in order to gather a better understanding of the OCD community and support groups.

### *3.3.3 Open-Ended Online Questionnaires*

Data for the study also was conducted through online, open-ended questionnaires. The online questionnaires included participants who could not be interviewed face-to-face and participants who were members of an online support group that was part of the OCD Tribe

online community. The researcher joined the OCD Tribe network and created a profile page where the description of the study and a link to the online questionnaire was posted. The participants could click on a link that took them directly to the questionnaire. The questionnaire was created through [www.surveymonkey.com](http://www.surveymonkey.com), a free online questionnaire site. Participants were recruited through the messages on the researcher's profile page and through individual messages sent to participants' in-boxes. Five members of the OCD online support group agreed to participate.

Originally, online questionnaires were developed only for participants of the online social networking support group. However, Survey Monkey was also used to create an open-ended online questionnaire for non-support group participants who lived outside the Dallas/Fort Worth area. Twelve interested subjects, who were recruited mostly through the OCD Foundation newsletter, contacted the researcher via e-mail or phone and expressed interest in participation. The researcher then e-mailed them the link to complete the questionnaire. One main advantages of conducting online questionnaires is that it allows for a diverse range of people with OCD, including those who are hesitant to meet face-to-face (Wright, 2005). This method also uses the Internet, including people who would be difficult to reach through other means (Garton, Haythornthwaite, & Wellman, 1999). Open-ended online questionnaires were deemed to be an important method when gathering data because many people with OCD are ashamed and embarrassed (Link & Phelan, 2006; Hindshaw, 2005) and people who communicate online enjoy being anonymous during interpersonal exchanges (Barak et al., 2008; Colvin et al., 2004; Houston et al., 2002; Finfgeld, 2000; Sansone, 2001; Tate & Zabinski, 2004).

Other reasons for conducting the questionnaire online included: online support groups and communication was a topic interest to the researcher and members of the OCD Tribe were recruited through cyberspace. Perron (2002) suggested "Qualitative approaches can provide insight into the online experience of participants and their feelings and attitudes toward the online community," (p. 76). This ability for people to participate in online questionnaires allows

for the researcher to research populations of interest and not be restricted to certain populations because of barriers to face-to-face interviews.

### *3.3.4 Question Guide*

A total of four question guides were developed: one for in-depth interviews with non-support group participants (see appendix C), one for focus groups with face-to-face support group participants (see appendix D), one open-ended online questionnaire with online support group members (see appendix E) and one open-ended online questionnaire for participants who could not be directly interviewed by the researcher (see appendix F).

All question guides contained questions designed to elicit participant description of: their perceptions about face-to-face and online support groups, their experiences with OCD and their struggles with the disease, their efforts to control their OCD, their experience and perspectives on social support, their use of the Internet in terms of their OCD, and their perceptions of societal views of OCD. The questions were categorized in a way that answered all four research questions and addressed elements of the Health Belief Model (Janz & Becker, 1984) and Theory of Planned Behavior (Ajzen & Fishbein, 1980).

In order to answer the first research question about why individual with OCD participate in face-to-face support groups, the researcher asked participants in support groups questions such as:

- What motivates you to attend the group?
- Why do you choose to participate in the group?
- Why do you feel others participate in support groups?

For the participants who were not in support group, they were asked to discuss:

- Why do you think other people with OCD attended support groups?

In order to answer the second research questions about why people do not participate in face-to-face support groups, the researcher asked the individuals who did not attend questions that pertained to their reasons for nonparticipation, along with past experiences in participation. For



the participants who were in a support group, the researcher asked them to discuss reasons why they thought other people with OCD did not attend support groups.

In order to answer the third research question about why people with OCD participate in online support groups, all participants were asked:

- Why do you feel people choose to participate in online support groups?
- What are the notable differences between an online support group and a face-to-face support groups?

In order to answer the fourth research question about why people with OCD don't participate in online support groups, the question guides asked:

- Why do you choose not to participate in an online support group? (non-participants)
- Why do feel others do not participate in online support groups? (all participants).

Questions that derived from the HBM derived around the four major elements of the model explained by Janz and Becker (1984): perceived severity, perceived benefits, perceived barriers, and cues to action. Example of questions provided by the researcher included: What do you think support groups have to offer for someone with OCD? Why would support groups be difficult to attend? And to what extent does OCD affect your daily life?

Questions under the TRA/TPB (Ajzen & Fishbein, 1980) revolved around the three elements of the theory: attitude toward the behavior, perceived behavioral control, and subjective norm. Questions included: How do others feel about support groups? Do you feel that support groups can have an affect with controlling your OCD? How do you feel the media portrays OCD and support groups? Describe what a support group is like? This last question asked participants to describe what a support group is like in order for the researcher to understand their attitude toward support groups.

Other questions not addressed in the research questions or theory elements pertained to participant's views on their experience with OCD and their struggles with the disease.

Because OCD is a disorder that varies in terms of symptoms and OCD may differ in terms of experiences, it is important to examine their disease experiences.

All research methods and questions used were reviewed and approved through the University of Texas Institutional Review Board. All participants had to consent to the terms and conditions of the interview and were allowed at any point to withdraw from the study without penalty. None of the participants were offered or given rewards for their participation.

### *3.3.5 Data Collection*

Data was collected in three ways: through an audio digital recorder, a video camera, and written material. The researcher used an audio digital tape recorder for in-depth interviews and the focus group. The video camera was also used for the focus group in order for the researcher to effectively and accurately transcribe and match all participants with their responses. The camera allowed for nonverbal communication to be observed, which in turn allowed the researcher to more accurately capture meaning and nuance. For online participants, the data was collected online through Survey Monkey where it was in text format. The audio and video data was transcribed into text. However, because the online data is automatically generated into text, it was analyzed in the format generated by Survey Monkey.

### *3.3.6 Method Validation*

During any type of research, the methods chosen are a key aspect to the study. In this study, three types of participants were chosen in order to understand and discover sufferers' reasons for participation or nonparticipation in a support group for their OCD. By studying people in a face-to-face support group, an online support group, and no support group may reveal similarities or discrepancies among answers to common questions. These answers helped determine what factors play into their decision making regarding support groups. The three methods used are significant because they give the researcher a variety of material to compare and contrast rather than having one uniformed method of collecting data. Triangulation is significant to the study because it allows the data to be mapped out and explained in more

detail. This method of checking, “gives a more detailed and balanced picture of the situation,” (Altritcher et al., 1996, p. 117).

### 3.4 Methods of Data Analysis

Analyzing qualitative data is best seen as a continuous process through the entire study (Lindlof, 1995). In qualitative research, rather than looking at predetermined variables, the data analysis takes an inductive approach in which the important data to analyze emerges from the raw data itself (Maykut & Morehouse, 1994). When analyzing qualitative data, an approach called the grounded theory, otherwise known as the constant comparative method (Glasser & Strauss, 1967), was used to make sense of the 77 pages of transcriptions and the 33 pages of online questionnaires. Lindlof (1995) describes four stages to data analysis and theory development: data analysis, data reduction, explanation, and theorizing.

#### *3.4.1 Process of Analysis*

In order to analyze data in qualitative research, the researcher must play an active role throughout obtaining and interpreting the data (McCracken, 1988). This requires reading through all the transcripts obtained from the study. It is through the researcher's interpretation that themes and discoveries are made, allowing for the data to be enriched and theories to be established. The analyst looks for key concepts in the data through coding, a process that allows the researcher to take notes while reading the transcripts and determining commonalities and differences in order to form categories of interest (Lindlof, 1995). The researcher codes each incident into as many categories of analysis as possible. It is important to remember, “While coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category,” (Lindlof, 1995, p. 106). As the researcher gets deeper into the analysis, he or she notices more themes emerging and uncovers underlying meaning in the text, which he or she then compares to the categories that have already been developed. This cyclical process allows for the researcher to intensively analyze important areas (Lindlof, 1995). These methods of inductive reasoning allow for categories to begin with specific incidents and evolve into more general categories and themes.

### *3.4.2 Data Reduction*

The reduction of data is a stage all researchers experience. In qualitative research, reducing data involves reduction at both the physical and conceptual level (Lindlof, 1995). This process allows for the researcher to only gather relevant information to the study and compare it with other data along the way.

Because most qualitative research acquires such a large amount of data, it would be nearly impossible to contain and analyze it all. Therefore, physical reduction allows for the researcher to categorize, sort, and prioritize data according to themes that have emerged in the process (Lindlof, 1995). Referring back to the constant comparative method, Glaser and Strauss (1967) used inductive category coding combined with simultaneous comparison to gain all emerging themes. As each new concept is selected for analysis, it is compared to previous concepts, categorized, and coded by grouping together similar concepts and weeding out unnecessary data. Conceptual reduction involves, “an interaction between the kinds of action noted in the field and the theoretical ideas with which the analyst began the study,” (Lindlof, 1995, p. 217). This process allows for the researcher to take previous literature and studies and apply it to current data, rejecting or accepting parts in order to create a better understanding. The literature review in Chapter 2 of this study is a wealth of information compiled by the researcher that helps create a basis for the researcher to recognize and determine the necessary data to use for theorizing and developing conclusions.

### *3.4.3 Explanation*

Explaining the concepts discovered through the data analysis process in a way that makes sense and is understandable is a crucial element to analysis. In this process, the researcher takes the first transcript and reads each and every word of the text to form as many categories as possible. Notes and ideas are gathered in order to make sense of these categories discovered from the first transcription. By continuing this method of categorizing and grouping together important elements found from the transcriptions, the researcher is able to begin gathering an understanding of the participants' attitudes and meanings (Lindlof, 1995).

The analyst asks questions of “how” and “why” these discoveries have occurred and what it means to the current study. The researcher makes sense of the way the participants makes sense of their own attitudes, beliefs, and behaviors (Lindlof, 1995). This process of internalizing the data allows for observers to understand the combination of what the researcher experienced and how he or she made sense of the data observed.

#### *3.4.4 Theorizing*

By following the constant comparative method, the researcher is able to draw conclusions and make inferences related to established theory. Through comparing incidents, the researcher is also able to see his categories in terms of, “their internal development and their changing relations to other categories,” (Glaser & Strauss, 1967, p. 114). A theory is explained by Lindlof (1995) as, “an ever evolving construction that depends on the comparison of cases,” (p. 218). It is through the intense study of a single situation that justifies how and where a theory can be applied (Lindlof, 1995). It is the application of the theory to connect to concepts learned that enables the researcher to draw conclusions that support or reject the theory. The theory that emerges from this process should be able to relate to the data in a way that is easily understandable (Strauss & Corbin, 1990).

#### *3.4.5 Credibility, Transferability, Confirmability, and Dependability*

When analyzing qualitative data, it is important that the researcher is careful about what and how information is reported. In all research studies, the truth and validity of the research itself is a key concern (Mackey & Gass, 2005). It is crucial the researcher demonstrates that the findings are credible and applicable to the research population. One way to enhance credibility is by collecting data in many different contexts and situations, which helps to create a clear and direct conclusion (Fraenkel & Wallen, 2003).

Transferability refers to the context of the research. In qualitative research, the findings are not usually directly transferable between contexts. Therefore, a method described by Mackey and Gass (2005) as “thick descriptions” helps to determine the similarity between

contexts. This process results in using multiple participants' perspectives to help explain insight discovered in the study.

Confirmability is a concept that maintains the researcher fully explains and interprets the data (Mackey & Gass, 2005). Other researchers should be able to understand and interpret the study in the same manner and compare their findings with previous research. The findings may either confirm or reject the statements made on the first researcher's discoveries. Although the concept of replicability is an essential part of quantitative research (Mackey & Gass, 2005), it is also used in qualitative research where researchers analyze, repeat and adjust the way in which they conduct their studies based on previous research studies in the area.

Dependability refers to the consistency of the conclusions drawn by the researcher. In order to ensure that the findings are not only consistent but valid, the researcher must maintain that all personal biases and assumptions are not hindering the discoveries made. Therefore, it is suggested that researchers use participants to review patterns found in the data (Mackey and Gass, 2005). Because there was only one group studied, the researcher decided to conduct "member checks," in which participants of the support group that could not be audio or video taped would be presented with the study's findings and themes in order to achieve validation and clarification. This method suggested by Marshall and Rossman (1995) allows for the researcher to explain the results of the study and collect a final understanding on the themes and connections found. The participants that were presented this information were in the same study population (n=2) which allows for the researcher to see the similarities and discrepancies from the findings. Member checks are good to use to help the researcher understand the key concepts learned from the study.

Having member checks ensures that the data found is not biased toward one group and other participants have the opportunity to explain their views on the matter. This method of triangulation is important because it helps ensure the validity of the study (Mackey & Gass,

2005). Triangulation allows the data to be explained in more detail and the researcher is able to compare data in multiple ways.

In the current study, theoretical (using multiple perspectives) and methodological (using multiple methods) triangulation was used.

The current study used the methods of analysis previously discussed. Many views and opinions about support groups were collected from participants with various types of OCD and the participants were interviewed in a variety of contexts (focus groups, in-depth interviews, and open-ended online questionnaires). By using multiple methods, the researcher is able to obtain a broader perspective on the findings as a whole while specifically connecting recognizable similarities and differences to the contexts studied (Mackey & Gaass, 2005). The study also had a trained coder review the transcripts and themes discovered by the researcher in order to determine the commonalities or discrepancies that existed between interpretations. As previously mentioned, member checks were also used to help determine the validity and consistency of the themes found from participants.

Chapter 4 will discuss the findings developed from the data collection methods explained in chapter 3.

## CHAPTER 4

### FINDINGS

A total of 29 OCD patients participated in the study during a four month period. The focus group that was studied consisted of eight participants. Four in-depth interviews were conducted for people with OCD who were not in a support group, while 12 non-support group participants completed online questionnaires. Five online questionnaires were collected from people who were members of the online support group, the OCD Tribe. Many themes were discovered during the data collection.

Participants were broken down into categories based on their current and past experience with face-to-face and online support groups (see table 4.1). The study found participants fit into the following categories: current face-to-face participants (5), current online participants (5), current participants of both face-to-face and online (4), past face-to-face participants (3), past online participants (1), past participants of both face-to-face and online (3), no participation experience (6), current online with past face-to-face experience (1), and first time participant in a face-to-face support group with no past experience (1). Out of the 29 participants studied, 15 were currently participating in some type of support group for their OCD while 14 were not. The types of OCD among participants varied in the study. These types consisted of: washers and cleaners, hoarders, checkers, orderers, pure obsessionals, and people with scrupulosity (see table 4.1 for more details).



Table 4.1 OCD Participants

	sex	age	area	OCD type	current f-t-f	current online	past f-t-f	past online
focus group								
1	M	50-59	TX	washer	Y	Y	N/A	N/A
2	M	40-49	TX	checker	N	DNA	DNA	DNA
3	F	50-59	TX	hoarder, OCPD	Y	N	N/A	N
4	M	18-29	TX	washer	Y	N	N/A	N
5	F	18-29	TX	pure "O"	Y	Y	N/A	N/A
6	F	60-69	TX	hoarder checker	Y	N	N/A	N
7	F	50-29	TX	hoarder	Y	N	N/A	N
8	F	18-29	TX	pure "O"	Y	N	N/A	N
in-depth interview								
9	M	18-29	TX	washer counter	N	N	N	N
10	F	30-39	TX	checker counter	N	N	N	N
11	M	40-49	TX	washer	N	N	Y	Y
12	M	40-49	TX	pure "O"	N	N	Y	N
online questionnaire								
13	F	30-39	OK	checker, orderer, pure "O"	N	N	N	N
14	F	18-29	FL	pure "O"	N	N	N	N
15	F	40-49	TX	pure "O"	N	Y	Y	N/A
16	F	40-49	MI	orderer, scrupulosity	N	N	N	N
17	F	18-29	WY	washer, pure "O", scrupulosity	N	Y	N	N/A
18	M	18-29	FL	washer, cleaner, checker	N	N	Y	N
19	M	18-29	OH	pure "O"	N	N	N	N
20	F	18-29	OH	pure "O", checker	N	N	N	Y
21	F	18-29	WI	washer, checker	N	Y	N	N/A
22	F	18-29	PA	orderer	N	N	Y	N
23	F	18-29	NJ	checker, counter, hoarder, washer	N	N	Y	Y
24	F	18-29	CO	pure "O", orderer	N	N	Y	Y
25	F	18-29	LA	washer, pure "O"	N	Y	N	N/A
26	F	18-29	UK	pure "O"	N	Y	N	N/A
27	M	50-59	TX	washer	Y	Y	N/A	N/A
28	M	18-29	TN	pure "O"	Y	Y	N/A	N/A
29	F	18-29	DNA	pure "O"	N	Y	N	N/A

## 4.1 Research Questions

### *4.1.1 RQ 1: Why do individuals with OCD participate in face-to-face support groups?*

In this study 11 participants were current face-to-face support group members and 18 were non-members. The main reasons subjects either participated or felt that others participated were to improve their condition, seek advice and help from others, and reassure themselves they were not alone. Through these results, five themes were discovered: identity and reassurance, education and help, hope and encouragement, mentoring and camaraderie, and nonverbal communication.

#### 4.1.1.1 Identity and Reassurance

The most common theme that emerged from this study is the need for people with OCD to connect and relate with others who understand what they are going through. Many study participants claimed they felt alone in the world and no one really understands what they are going through. This feeling of loneliness was a reason to want to identify with others.

*Participant 22* (past face-to-face participant): I think other people with OCD participate in support groups to know that they are not alone and that they can get better. I think people with OCD participate in support groups so that they can be around people who understand their problem. OCD is so misunderstood and can be difficult to explain. I imagine people also like knowing they're not alone.

The need to reach out and associate with other people who have the same problems was a way of combating loneliness. The majority of participants claimed they feel misunderstood, which is a reason they feel the need to hide from society. Another participant said:

*Participant 11* (past participant of both): I think that we really need to talk to someone who really understands more and is more compassionate than someone saying, "Well, just do it!" We need someone to say, "I understand. I feel the same way." But at the same time, be able to say, "You have got to do this to help."

While many non-participants agreed and gave similar responses others talked about how a support group can give them a sense of confidence.

*Participant 12* (past participant of face-to-face): There is a power that comes with networking with people and hooking up with people, a feeling of confidence that comes with that. When you get together with a group of people that have the same problems as you and you walk out that door and you go back into the real world, you feel rejuvenated, like you have been strengthened a little bit.

Many non-participants also claimed they would participate to hear what others have to say and be able to tell their story and feelings to others. This form of identifying with others seemed to be prevalent among support group members and nonmembers. *Participant 6* (current face-to-face participant) explained how her first time in a support group she asked the group if anyone else had trouble reading. She discussed she was surprised to see the number of people who had the same issue. It was ability to connect with others who were going through similar situations that influenced her to stay in the group: "That was one of the things that really hooked me in the support group because it was the first time I was really able to relate to somebody and they understood what I was went through." Through this connection she was able to learn methods that others used to help them read. Participants of a support group explained it did remind them they were normal, functional people that just have some issues they are trying to overcome.

*Participant 8* (current face-to-face participant): It's almost like validation that, "I'm not really a loon." I just have something I have to deal with like everyone else has got their baggage.

While both participants and non-participants claimed they did not feel normal in their everyday life, they agreed the reassurance that they are not alone and there are others like them encouraged participation. *Participant 28* (current participant of both) explained how after participating in the face-to-face group, he does not feel as lonely as he use to. This need for

identity and reassurance is something participants felt that face-to-face support groups can offer for people with OCD.

#### 4.1.1.2 Education and Help

Another reason for participation was the need for help. Many participants felt their condition was a definite problem and they needed a place to go to get help and information. While this was a common answer among non-participants, it also rang true for participants. *Participant 2* was a first-time participant in the support group studied by the researcher. After explaining what his struggles with OCD were and how his condition has gotten worse he admitted his reason for attending: "I am getting kind of sick of it so I figured I would come to a support group to see what it is all about." He explained he wanted advice from others and help from others about what things they were doing to help fight their OCD. For many non-participants, the chance of bettering themselves would be a reason to participate. *Participant 11* (past participant of both) believed a reason to join is, "The possibility of being cured or improved. That off chance...This can be something positive in my life for me, because having OCD is such a negative turn in your life, you need something more positive."

*Participant 27* (current participant of both) how he became part of the group: "I'm a member of a group. I joined the group as a way of getting help. It was at the same time I started CBT [cognitive behavioral therapy] and started medication."

Support groups were also explained in a way that could help a person control their OCD. *Participant 22* (past face-to-face participant) stated, "I think support groups can help people find new coping strategies. I think support groups could help me control my OCD by teaching me about new coping strategies and available treatments."

#### 4.1.1.3 Hope and Encouragement

One of the benefits of face-to-face support groups is the sense of hope and satisfaction the group can provide. Because OCD is a constant battle and sufferers are never completely cured, participants felt the group could help provide the strength and motivation to continue to

fight the battle against OCD. *Participant 1* (current participant of both) talked about his reasons people choose to participate in support groups:

I didn't know what to expect, and come to find out it's a group or people who are a lot like me, who just have this issue to deal with. To see other people who were dealing with it and seeing them make progress and how they are able to control their lives, really gave me a sense of hope that I can go down the same path.

The need for encouraged was important because many people revealed they do not have a lot of faith or self-esteem at times. Hearing others share their experiences about their lack of control can help them feel better about their weaknesses.

#### 4.1.1.4 Mentoring and Camaraderie

One of the most popular reasons for ongoing participation in support group among current members was the camaraderie and friendships that have been established. In the same vein, current members want to mentor new members. *Participant 8* (current face-to-face participant) discussed her reasons for maintaining group membership:

I come primarily now because I remember how scared I was 4 years ago. So I come now because it breaks my heart to see people dealing with this, they don't know where to go, and they finally figured it out, they come to the support group. With morbid obsession OCD, and I am not saying its worse than any other OCD but it is scary, scary, scary, and when you think that you are going to hurt somebody you love and you don't know why and all you can do is think about it, it is the worst feeling that I have ever known in my whole life. I think a lot of people who decide to come to an OCD support group go through some morbid obsessions or repetitive bad thoughts whether they are sexual or horrific...just terrible. I feel like for me, I am the token, person that has to deal with that too and I like to be like, "Hey dude, I've got it and I got my stuff together and you can live with it."

*Participant 3* (current face-to-face participant) of the same group agreed and discussed her reasons for maintaining the relationships established in the group:

I guess with me when I first came, I thought I had OCD, but it didn't take me long to realize I didn't have the same thing. But I still kept coming because I liked the camaraderie and I kept seeing other people who came in who were like me. I come more to help other people who come in who really are the OCPD [Obsessive Compulsive Personality Disorder], and they have no idea.

*Participant 27* (current participant of both) shared his reason for joining and being involved in the face-to-face group:

I like the group very much. I have been associated with it for over 6 years now. I like the companionship of others who are going through the same problems. I also enjoy being there to support new members, to offer them comfort and to answer their questions.

Most of the group explained they feel it is important to be a mentor and help others who are lost and need support because they remember when they were at that point in their lives needing others to pull them through. They also claimed it is through the group they have maintained camaraderie and close relationships, which they believe helps to make the group stronger.

#### 4.1.1.5 Nonverbal Communication

Along with the benefits to participating in a support group, participants expressed a reason why face-to-face groups would be better than online groups. One of the reasons people preferred face-to-face communication is because of the ability to physically see the person you are talking to.

*Participant 28* (current participant of both): I think talking with a person face-to-face gives you a better sense of who they are than just seeing what they type on the screen.

It's kind of weird getting to know someone over months and months in the chat room and never see them in person.

Participants also felt not being able to hear the person's tone of voice, read their body language, or touch the one another could make the communication more difficult. Through online communication, participants felt it could be harder to express their emotions. It was also noted that face-to-face support has a better chance in helping with people's OCD symptoms because group members are able to watch you progress and hear your success stories at group meetings. People believed this ability to see the person rather than just a computer screen allows for participants to gain more encouragement from others.

*Participant 12* (past face-to-face participant): Live face-to-face is better because seeing and talking to another living human being is a lot different. I talk to a lot of people online but I still have to get out of the house. I get depressed if I just sit in there and email and IM. There is no substitute for being with someone in real life. So the kind of boost of confidence I was talking about 15 minutes ago, probably to get that you would need to talk to real people.

When asked which type of group he preferred, *Participant 1* (current participant of both) said:

I think I get more out of the face-to-face support groups. The face-to-face groups have the advantage of more intimacy. You can look at the person you are speaking to, you are not just receiving their words, but you hear their tone of voice, you see the expression on their face, and you see the body language. It just seems to be more gratifying.

All participants who felt face-to-face communication was better said it was because of the nonverbal communication and the ability to see the person when communicating. The ability to be able to reach out and hug or touch someone if they start crying or if they are feeling down was something they felt would be more encouraging and a stronger form of support. Last, they

expressed how face-to-face communication made a big difference in how they interacted with others as well.

#### *4.1.2 RQ 2: Why do individuals with OCD not participate in face-to-face support groups?*

The study found many reasons why people did not participate in a face-to-face support group for their OCD. The most significant themes discovered were: lack of knowledge and awareness and lifestyle, social anxiety and OCD barriers, previous unsatisfactory experiences, and attitude.

##### *4.1.2.1 Lack of Awareness*

Many participants claimed the reason they are not currently in a support group is because they do not know where one is in their area or said the closest support group is too far away.

*Participant 24* (past participant of both): I live in a major metropolitan area, yet there is no OCD support group near me. In order to reach a group, I would have to take a bus ride that is an hour or more each way -- not an easy thing to do on a weekday evening after I get off work.

*Participant 20* (past online participant) said: "I have never been to a face to face support group for OCD. There are no support groups in my area for OCD. None."

For others, they weren't even aware of support groups for OCD. They seemed interested in the idea but said it never occurred to them to join a group. *Participant 19* (non-participant) explained how she did not know about support groups: "I hadn't really been aware of them. I imagine there is a great deal of talk therapy, talking about an individual's obsessions and compulsions as well as counseling and ways of improving and overcoming it."

Many who were interested said they would go if they knew where one was. *Participant 25* (current online participant) said, "I have no idea what it would be like, but if they had one in my area, I would try and go." It appeared people believed they would go if they knew about them but many said they were unaware if there was a support group in their area.



Many participants felt they did not have time in their life to participate in a support group. Participant 9 (non-participant) was working full time and going to college in which he felt he was busy enough already and did not have time to go to a support group. Participant 10 (non-participant) felt overwhelmed and was too busy because of parenting duties including taking her children to extra-curricular activities. The support group leader of the face-to-face group interviewed by the researcher (participant 6, OCD sufferer) explained how the time of the year can have an effect on the group size. During the summer months many people take off for vacation and sometimes the meetings may have two people in them.

#### 4.1.2.2 Social Anxiety and OCD Barriers

One common theme regarding barriers found throughout this study is that fear that prohibits some people with OCD from participating in a face-to-face support group. All populations studied described barriers they felt kept people from participating in support groups. Most of the barriers had to do with social anxiety, their OCD conditions, and fear of taking on new obsessions and compulsions.

Revealing personal information is potentially difficult for anyone, but some people with OCD have a severe fear of face-to-face communication. Many participants expressed they had a fear of opening up to other people in a face-to-face environment about their problems and issues. Some claimed it would be difficult for them to open up to others in a group setting as well. Participant 1 (current participant of both) described how he has talked to other OCD sufferers online and discovered many people do not attend support groups because they have the fear of face-to-face communication. He explained how he understands their reasoning because he always had a little bit of social anxiety and attending the meeting for the first time was a challenge for him. Other participants that do not attend support groups agreed with this concept. *Participant 20* (past online participant) discussed her reasons for not participating:

I think support groups can be difficult for people who are shy (like me) and introverted and not comfortable in group settings (like me also). It is hard enough to talk to a

therapist about OCD symptoms let alone a whole group of people. I think it would be challenging to open up to people about something so personal.

Not only is a group setting difficult for most, but revealing the strange obsessions and ritualistic behaviors that have become part of their lifestyle is challenging for some OCD patients. *Participant 26* (current online participant) noted, "I couldn't bring myself to do this. I'm far too uncomfortable around others, even loved ones." *Participant 13* (non-participant) said, "It may be difficult to reveal to others some activities or thoughts you have. It's tough when you are asked to accept a challenge and then be held accountable. I am not certain if they could be helpful."

Many that do not attend a face-to-face support groups explained they would never attend because they keep their OCD hidden and they cannot get over the fear of going. *Participant 16* (non-participant) said, "It is easier to pretend there's nothing wrong with me." *Participant 29* (current online participant) added, "I would never participate in a face to face setting. I hide my OCD." For many, opening up in a face-to-face setting is not ideal because of the stress and anxiety they feel it will cause them.

All the participants said that their condition creates much stress and major coping challenges for them. Although the type of OCD varies from person to person, sometimes it is the OCD itself that can be a reason for not seeking help. *Participant 4* (current face-to-face participant) suffers from contamination OCD and described his feelings about barriers that can get in the way of him participating: "For some people there is a problem. For people who have the contamination fear, getting in their cars is a challenge; you don't even want to go outside." Other contamination sufferers agreed with these same challenges and even added the location can play an effect as well.

*Participant 11* (past participant of both): Location like [name of town] is in a hospital, you don't want to go there, depending on what your OCD is. Hoarders probably wouldn't have a problem with it. I can only speak for my condition. I would be more worried about the people. You don't know what kind of chairs you're sitting in, the

cleanliness of the place. That is something that can really cause you anxiety and you wouldn't want to go.

In such examples, OCD sufferers felt they can become their own enemy when it comes to determining whether or not to participate.

With OCD, uncertainty is something that causes problems for patients. Because sufferers' do not know what the group is like or what is exactly going to happen, they tend to make negative predictions and assumptions about the group. *Participant 24* (past participant of both) said:

If you think you are alone, going to a support group could be very scary (seriously, what if it's just you and two other people?). The very nature of OCD could also make it difficult. OCD is so centered around uncertainty. Not knowing where the group is located, what to expect, how many people will be there, whether or not you'll be expected to participate, etc. are all things that could make someone with OCD not take that first step to attend a group.

For others, being around other people with OCD, could be a major problem in itself. The idea of sitting next to others who have problems that others are unaware of could be stressful for the OCD patient. *Participant 16* (non-participant) said:

The reason boils down to fear and self-loathing. I have an innate sense of being a "freak" although I function normally and have worked hard not to define myself by this disorder. I am afraid that if I get in a room with a bunch of twitching, counting, repetitive touching people, I will collapse. Being under stress is a huge trigger for my symptoms, and being around a group of people who are talking and demonstrating the horror I've lived with all these years would be the ultimate stress.

#### 4.1.2.3 Gaining Obsessions and Compulsions

Many people expressed a fear that by listening to other people with OCD talk about their problems they would acquire new obsessions and compulsions. Participants in the study not in a support group were especially concerned about this aspect.

*Participant 16* (non-participant): I can spot people in daily life who seem to have OCD symptoms and it triggers mine. So sitting through a meeting could be difficult. Also, seeing and hearing about the pain these people deal with everyday could be debilitating. It's like the rape victim listening to other's talk about their assaults. It's comforting to know you are not alone, devastating to relive the emotions involved.

Reliving these emotions and experiences could be a challenge for someone with OCD because they are thinking about other people's obsessions and compulsions and they feel that could plant new ideas into their minds. *Participant 14* (non-participant) added: "I would think that it would be a terrible combination of people to get together because they could all mooch off of each other's obsessions and just end up worse than before." Although this is a serious concern for people who are not in support groups, others who participate in support groups do not feel the same way. *Participant 6* (current face-to-face participant) said:

We had a couple of people that wouldn't come because they were afraid if they came in, they would hear about somebody else's OCD and they would get it. It doesn't work like that. It's not the power of suggestion either. It's what is in our own little brain that we conjure up all these little goofy things.

While OCD participants of the face-to-face group could see how people's OCD conditions might keep them from participating, they did not agree that group participation could give them new obsessions and compulsions. Only non-participants expressed fears of "catching" new OCD rituals.

#### 4.1.2.4 Previous Unsatisfactory Experiences

For those who are not currently in a face-to-face support group, their reasons for not being involved was due to previous unsatisfactory past experiences with a group and the negative perceptions they have toward them.

*Participant 24* (past participant of both): I have been to a support group one time. I felt that I didn't relate well to most of the people in the group--they were all older adults, no one really in my peer group. They also seemed to have somewhat different experiences with their OCD than I did; they seemed to have it less under control, or less willing to attempt to control it. Maybe it was just that they felt more comfortable about expressing their shortcomings in their struggle with OCD. Regardless, I didn't feel any sense of overwhelming relief of being among people who could relate to my problem.

Another area of concern is the atmosphere of the group. Others felt the group was more negative than hopeful and optimistic.

*Participant 11* (past participant of both): They didn't seem like they were in that kind of an atmosphere for change, they were just mostly complaining about what they had. The guy who organized it was talking about how he lost his house; he lost his job, stuff like that. It was not positive, it was more negative.

Most participants claimed they are looking for something positive because every day they are focused on the negative. Therefore, hearing negativity from a group might deter them from returning. *Participant 23* (past participant of both) had a similar experience:

One problem I have with support groups, as I've experienced online, is the constant one-upmanship. I don't want to be in a room full of other people just like me, telling horrible OCD tales in the hopes of having the most pathetic story.

Others felt the group was not run professionally. *Participant 15* (current online participant/past face-to-face participant) claimed there were people in the group that weren't even officially diagnosed with OCD and were not even sure if they had it.

I found an OCD group and did not like the way it was run or the people who ran it. Some people in the group thought they had OCD but were not ever officially diagnosed. I didn't think they should be there unless they knew or were in treatment of some sort. I went once.

Past participants of a support group felt the support group was no longer helpful for them because the group provided more education about OCD than support and that they heard the same stories over and over.

#### 4.1.2.5 Attitude

Another reason people with OCD do not attend support groups is their attitude toward their condition. *Participant 22* (past face-to-face participant) discussed her feelings about not wanting to be involved in a support group currently:

I am not ready to make a commitment to change drastically (for example, by cleaning my room and ceasing to hoard). However, about 4 yrs ago when I was in college, I attended one meeting of the mental health awareness group out of curiosity regarding whether it would help my OCD. The meeting ended up being like a peer support group for people with various mental illnesses. There was at least 1 other person in the group with OCD, and he had similar symptoms. I didn't attend any other meetings since I thought I was too busy, and I felt kind of embarrassed.

*Participant 9* (non-participant) said:

It is kind of like trying to get an alcoholic to get help. You know you have a problem but you have lived with it for so long you are like, "Why should I change?" That really kills me with the OCD because I don't like change a lot. Once things change, my anxiety gets real bad.

One participant said he did not feel that a support group would help him. *Participant 12* (past face-to-face participant), suffers from what is called pure “O” (obsessions) in which he has no ritualistic behaviors; the condition is strictly all in his mind. He believed support groups are not ideal for people who suffer only from obsession like himself because they have no physical behaviors for them to modify. He said:

The people who participate in a support group, their OCD is probably going to be somewhat less mental than the way mine is. I am not a real group person. I do well one on one. If the person is not talking directly to me and someone else, I zone out. That happens to me real bad. I would get real anxious and either have to dominate the conversation or not say anything at all. Someone who has specific ritualistic OCD as opposed to this pure obsessive stuff, yeah a support group would be good for them.

#### *4.1.3 RQ 3: Why do individuals with OCD participate in online support groups?*

Many of the participants claimed they participate or would participate in an online support group for many of the same reasons mentioned earlier for face-to-face groups. Talking to others who are going through similar struggles, learning information and strategies to help with their condition, and wanting to help others are all themes that were found in the data. Reasons for online participation in particular included the desire for anonymity and overcoming social anxiety, identity and curiosity, education and help, and convenience.

##### *4.1.3.1 Anonymity and Social Anxiety*

Discussing personal struggles in front of others tended to be a concern with participants who did not attend a face-to-face support groups. Social anxiety was a barrier for face-to-face participation. Therefore, one of their main reasons for participation online is the feeling of anonymity; being able to hide who they are behind the computer screen makes them feel safe and more confident.

*Participant 11* (past participant of both): Online you are bolder or more confident. People who are afraid of speaking in public don't have to worry about it on the

Internet. In person or face-to-face, you have to talk about it face-to-face and openly with other people listening.

Some participants would rather keep their condition hidden. *Participant 23* (past online participant): “I think online, you may feel more anonymous and be more open about your problems. You’re also communicating with people across the country rather than people in your own community that you may run into outside the support group.”

For some who were not part of an online support group, the idea seemed appealing and interesting. *Participant 16* (non-participant) expressed how fear is the reason she is not currently in a face-to-face support group.

I would definitely consider an online group; in fact, I think it would be the best of both worlds for me. The comfort of being anonymous....as you can tell, I'm not having a hard time opening up to you in this forum! I could read what others had to say in the safe environment of my own home, and if it got too stressful, I could log out and take a break. Why don't I participate already? I don't know of any, and I haven't looked for any.

Participants also expressed the fear of being judged by others. Many people felt being online was safe because other people were not able to judge them and they felt equal to everyone else. They felt being in a face-to-face group was more intimidating for them than an online group. Participants commented about this concept:

- *Participant 26* (current online participant): I’ve been a tribe member for two months, and have never been happier. Because of my social problems, talking online to other OCD sufferers is a godsend to me. It’s so nice that I can be open with people who don't judge me. When I feel especially bad, I’m only a blog away from genuine support, and can also give advice to others with similar problems.
- *Participant 26* (current online participant): “It’s the only time I feel socially equal to everyone else.”



#### 4.1.3.2 Identity and Curiosity

Participants in face-to-face support groups said they joined because of the need to identify with others with similar conditions. Online participants also expressed this desire to talk to other OCD sufferers about their experiences.

*Participant 17* (current online participant): I participate on an online forum at this point, and it helps a lot to share your experience with others: what your OCD is like, how you deal with it, etc. Also helps to know that you are not alone.

The need to identify with others also helped them overcome their feeling of loneliness. One participant shared her feelings about the OCD Tribe:

Participant 28 (current online participant): I love the site! I joined on August and I am sooooo glad I did. It was something I used for about 2-3 hours a night when I first found it. It made me realize there are other sufferers of OCD, not just me. I think that had a positive effect on the way I felt about myself. I get on the site still almost every day, although I don't chat as much as I used to. I think I will be logging on for the rest of my life!

Other reasons people with OCD choose to participate in online support groups was because of curiosity and the need to identify with others similar to them. Many participants said they were interested in seeing what the online world was about and see if they enjoyed it.

*Participant 20* (past online participant) said: "I wanted to join because I wanted to hear what other people had to say and see if it was similar to my own behaviors." Not knowing what it was like or what it had to offer sparked interest in participants. For *Participant 27* (current participant of both) the combination of his curiosity and the desire to help others were reasons he began participation, "I have been a member since Sept. 2007. Curiosity, and wanting to provide support to others- I like the friendships."

#### 4.1.3.3 Education and Help

Learning medication tips and treatment method options are usually areas of concern for people with OCD. Most participants in the study said they have used the Internet to find information about OCD and searched for ways to help their condition. This need to get better was common reasons why people participated in online support groups as well. *Participant 15* (current online/past face-to-face participant) said he joined two online forums two months. “I had hoped hearing what kind of treatments/medication people are on could be helpful and learn how they dealt with their OCD.”

*Participant 25* (current online participant) said:

I have been on the OCD Tribe for a few months, and I joined as a place to look for help. I needed people to talk to that understand what I'm going through. I can post blogs about my problems.

Although this participant discussed reasons she does not like some forms of online support groups and does not believe the online support group used in this study is a support group, she does feel the need to participate to help educate and clarify any false information. People also felt the need to participate online provide help to others. *Participant 14* (non-participant) said, “I would participate in order to help others who are at that desperate stage of self-loathing that I was once at.”

#### 4.1.3.4 Convenience

Finally, the reason some people participated in online support groups was the convenience online communication offers to people with OCD. Many participants enjoyed being to communicate in their own home at any time of the day. *Participant 11* (past participant of both) said, “The good thing about online is that you can do it anytime, even if it's by e-mail. You can get on any time of the day or night.” For others, it was convenient because they can choose when they start and stop participation. For some, discussing their OCD symptoms and problems can cause their anxiety to increase. Therefore, being able to manage the length of

time they participated was important. *Participant 5* (current participant of both): “I started out in a chat room before I ever went into therapy and attended groups because it felt safer. If I started feeling anxious I could close the window and be done with it.”

Others felt online participant allowed for people to participate more frequently. *Participant 20* (past online participant) noted, “Face-to-face groups may meet once a week or once a month, but an online support group could be easily open everyday.”

Along with feeling safe and being in control, online communication was also viewed as being easy to find someone to talk to. Another participant mentioned there are more people online, which allow more opportunities to hear other people’s experiences.

*Participant 1* (current participant of both): The online group is nice because you can almost always find some one to chat with, and you have a pretty wide audience, with the opportunity to get a wide variety of opinions and experiences.

#### *4.1.4 RQ 4: Why do individuals with OCD not participate in online support groups?*

While several participants have used or are currently online support group, several participants do not like this form of support. Themes about non-participation in online support groups included: a lack of knowledge or resources, lack of trust, lack of nonverbal communication, previous unsatisfying experiences, and OCD-based barriers.

##### *4.1.4.1 Lack of Knowledge of Resources*

Some participants said they were not aware of existent face-to-face support groups, a lack of knowledge also seemed to be an issue with online as well. Participant 14 (non-participant) said, “I have not participated in an online support group because it has never occurred to me.” Another barrier to participation was not having resources (e.g., a computer, or an Internet connection) that would enable people to participate. Several participants in the face-to-face group said they did not own a computer. *Participant 6* (current face-to-face participant) owned a computer but said she was a poor typist.

I don't go online with a group because we really didn't have a good computer, we are dial up, and I read really slow. I don't know how to type and it would have taken me forever. We have updated our equipment and I just peck along. Needless to say, that wouldn't be my forte at all.

Barriers like these can prevent people with OCD from even using the Internet and thus an online support group.

#### 4.1.4.2 Lack of Trust

Participants said that because personal information is shared in a support group, they want to feel they can trust the other person receiving the information. Because you are unable to see the person with whom you are communicating online, it is difficult from some study participants to trust the person with whom they are communicating.

*Participant 11*(past participant of both): You can't trust the person on the other end. That goes with other chat rooms. You could be chatting with someone you thought was 30 years old and they are a 10 or 12 year old and you do not know. There was this one girl from England; she was supposedly a cutter, cut her arms. It seemed like she wasn't getting anywhere, still doing it. But she said she was; that's the bad thing about the Internet. You can't see face-to-face, you can't see the scars. I have seen several pictures of her but she didn't send any pictures of her arms.

This participant was not the only one that felt uncomfortable talking with someone they didn't know. *Participant 13* (non-participant) said: "I am not comfortable revealing so much of myself to an online forum." *Participant 8* (current face-to-face participant) said she did not want to throw her "goods" out on the Internet.

*Participant 21*(current online participant): I visit ocdtribe.com as well, mostly to provide education for others. Some consider that site a support group, I consider it a Web community for those with OCD. I like it overall but I dislike that it is not run by professionals in the field to prevent incorrect information from being posted and that

many post about treatments that have not been proven to be efficacious, which may steer others in the wrong direction if they are looking to obtain treatment for the first time.

Several other participants also said that online groups would be better if they could be monitored.

#### 4.1.4.3 Lack of Nonverbal Communication

Online communication can be difficult when trying to gauge people's emotions about the context of the conversation because people cannot see the other person's facial expressions or hear their tone of voice. This barrier can be a reason people choose not to participate in online support groups. *Participant 13* (non-participant) said: "They are different in that when not face-to-face it can be difficult to understand someone's tone, and it's impossible to read body language." The lack of nonverbal cues can make the communication less effective and more difficult to understand, making online support groups less appealing.

#### 4.1.4.4 Previous Unsatisfactory Experiences

Some past participants in online support groups believed the online group did not meet up to their expectations or give them what they were looking for. *Participant 24* (past participant of both) said online groups are good for people who are just realizing they have OCD.

I was much more active when I joined it, participating in discussions that helped me see others who were dealing with similar situations that I was. I got information about some good books from that group, which I went on to read. I no longer participate much because there doesn't seem to be any more in-depth support that happens through the group. It seems like a great resource for those who are just realizing they have OCD or just being diagnosed with OCD and looking for peers and information. However, I don't find it especially helpful for those who already have learned a lot about their disease and the methods to deal with it, but need continued support in that struggle.

Participants also commented that the majority of online participants wanted to receive support rather than give it to others.

*Participant 23* (past participant of both): I didn't think I could get the support I was looking for from people with my problems. Everyone there was pretty much looking to get support, not give support. And there were a few people on there who, again, were constantly trying to have the saddest, most pathetic story. There was one woman who I was pretty sure was making most of her problems up as she went along.

In her situation, it was not just the fact that there was not much support being given, it was the belief that no one could give her the support she needed.

#### 4.1.4.5 OCD Barriers

Finally, one of the barriers to participating in online support groups is concerned with the participant's condition itself. As with face-to-face support groups, sometimes people's particular OCD symptoms can get in the way of their participation. For *Participant 6* (current face-to-face participant), she said part of her OCD is struggling with reading. Along with not having an up to speed computer or the ability to type fast, her OCD itself is a barrier to participation.

With OCD a lot of people have trouble reading because they feel they have to remember everything they have read, understand completely and if DOUBT creeps in they have to start over till they get it right so you reread and reread the same page. The more you read the more anxious you get so in my case it was easier not to read. So when I did take a typing class I read real slow and had to look at the keys to make sure I hit the right one once again it was easier to quit than put my self through the anxiety.

## 4.2 Other Findings

In addition to answering the research questions, the study investigated participants' beliefs about and perception of stigma, social support, and control over OCD. Stigma seemed

to be a passionate topic for participants. They felt society and the media do not portray OCD accurately. They also said they believe that OCD or support groups do not get enough news media exposure, which is why many people do not know much about them. Participants felt support is something that is very important for people with OCD to have in their lives. They described a variety of sources from which they receive their support and discussed their feelings about the amount of support in their life. When talking about their control over OCD, participants' answers ranged from having hardly any control to having much control. All expressed their amount of control over their condition varies based the situation they are in and what stressors they are dealing with at the time. Stress seemed to be a common feeling for people with OCD in a way when their stress level increases, their condition worsens.

#### *4.2.1 Stigma*

Most participants felt other people who do not have OCD do not understand or act empathetic toward OCD sufferers. Participants said they felt as if people saw them as weird or crazy. It is because of these stigmatized feelings people with OCD are not completely open to others about their condition.

*Participant 16* (non-participant): I have not told any friends, and only one boyfriend, because of the stigma. I mean, OCD sounds freakish, it IS freakish, and it's practically impossible to describe accurately. I do not want people thinking I'm a weirdo or dangerous, and I surely don't want them watching me closely to "catch" me in the process of an abnormal movement. I'm not a lab rat, or a lunatic. I want to be considered a "normal" woman!

The feeling of shame is a common feeling for people with OCD. Participants discussed how it is difficult to explain their condition to someone who does not have it.

*Participant 12* (past face-to-face participant): It is impossible to explain because it is so deeply abstract. When I was a younger, I could stare in the dark and I know I turned the lights off, anyone would know the lights are off, but I had to stare to make sure they

were off even if I knew they were off. That is impossible to explain to someone. It is the most bizarre, abstract thing. There is no logical connection at all and people who do not have OCD don't get it.

Participants felt that other people who do not have OCD do not understand the shame and embarrassment they experience. *Participant 18* (past face-to-face participant) said: "One of the most difficult things for those without OCD to understand is the feeling of shame that comes with the disorder."

The study found people with OCD felt society was not very accepting of them and they feel that society does not promote enough knowledge and awareness about OCD. They feel if more information was made available to the public, others might be more understanding.

*Participant 20* (past online participant): I honestly do not think there is enough education and awareness of OCD and anxiety disorders in our society. There is much awareness in my community about causes like cancer, epilepsy, autism, diabetes, etc, but hardly any about anxiety disorders. Therefore I feel there is a negative social stigma associated with OCD.

Many participants expressed how their job can be very stressful, which tends to make their condition worse. They said it is difficult to work with others who do not understand what they are dealing with because others are not empathetic. Some participants have experienced stigma in more personal ways such as being treated as different or being teased at work for their condition. Two participants shared their experiences with feeling stigmatized at their job.

- *Participant 11* (past participant of both/ washer & cleaner): I have some guys at work, one guy in particular; he picks on everyone and he's always saying, "Get down on the floor and do that." When I answer the phone I use the speaker and he's like, "Pick up the phone. Put it to your ear."
- *Participant 12* (past face-to-face participant): The problem for people with OCD is they are stuck in a unique world. You are put in a category with people who don't have the



same problem you have. The job I work in, just to give you an example, is a piece mill job. I doubt I am even making \$3 an hour; they pay you by the piece. Most of the people around are mentally retarded or physically handicapped. I am the only person there that is quote on quote normal. It's kind of humiliating. When I was trying to cut plastic loose from a plastic container a lady said, "Supervisor! Supervisor! Clients can't have a knife!" Here I am, I work with tools, I build things, I sell them on e-Bay at home, and here I am at work and they won't even let me use a knife without a supervisor's permission? By the way, I will say employers will encourage, not discourage, OCD. How many times have you ever worked for a boss that said, "You're too clean, you're too careful, you are doing too much." You aren't going to find that. So a person with OCD is going to get on a job and it's going to snowball.

Portrayals of OCD in the entertainment media are another area where the OCD community feels stigmatized. As previously mentioned, many participants felt they do not understand what they are going through and most claimed the media's portrayal of OCD is not accurate. Terms like "it's a joke" or "a comic event" were used when explaining how the media shows people with OCD. They also felt there was not enough news media coverage on OCD or anxiety disorders.

*Participant 29* (past online participant/ pure obsessional): The media doesn't get it. If I went on a talk show and said I have disgusting thoughts out of the blue about touching my son, I'd be locked up and he'd be taken away from me. DESPITE the fact I'd never hurt my baby. The media doesn't even begin to understand the shame we face.

Others said they believed the entertainment media does not accurately show the struggles people with OCD experience. They feel like it is seen as a condition that can be easily overcome.

*Participant 28* (current participant of both): I think the media could do a better job of portraying the complete angst of it. OCD is not a fun thing to have, sure it can maybe

cause funny situations to occur but it is horrible to have. Maybe a focus on the struggle it causes and knowing just because someone overcomes a compulsion doesn't mean that the chemical deficiency that causes OCD isn't completely gone after that. It is something that will always be there to some extent. OCD isn't something someone can just get over."

Some feel OCD cannot be effectively explained because it is difficult to express the immense amount of fear that OCD patients experience daily. *Participant 8* (current face-to-face participant) said, "You can't demonstrate or show someone the fear you have inside, when you are dealing with OCD." Since OCD is a mental illness, participants felt the entertainment media portrays it in a negative way because television and movies show people with mental illnesses as violent and unstable.

*Participant 15* (current online/past face-to-face participant): Most of the media, I feel, distorts any of the diseases and shows the most negative side of it. Like saying most murderers or killers have a mental health issue like bi-polar [disorder]. That certainly is not the case but they easily put a label on things like this.

Participants discussed the TV show "Monk" and many believed the character of Monk was a "joke" and portrayed OCD in a comical sense. They feel the series has brought attention to only certain types of OCD (such as the washing, checking, ordering) and forgets about many people who suffer from disturbing obsessions.

*Participant 26* (current online participant): I think there is a common misconception that all people with OCD flick light switches on and off, or scrub their hands a lot. I know a lot of people are like that, but the public seem not to know about pure-O. They seem to think we're all like Monk.

However, one participant said she enjoys the show and believes it portrays OCD in a positive light.

*Participant 20* (past online participant): I think shows like “Monk” and “The Odd Couple,” movies like “The Aviator” and “Melvin and Howard,” are excellent in that they take on a sensitive and important subject and portray it in a positive way. “Monk” is an amazing show and offers sufferers like me with a sense of hope that there are others out there who appreciate and respect and trying to understand what we go through every day. “Monk” also portrays Tony Shaloub’s character as a brilliant detective who is a master of his craft because of his OCD. It makes him who he is. I think this is very important.

As far as support groups are concerned, most participants felt the entertainment media does not show support groups at all or even care to portray them on television.

#### *4.2.2 Social Support*

When it comes to social support, participants felt their family, friends, doctors, and other OCD sufferers were all people they expected to provide them with support. While many claimed they received support from these people, others did not feel they had support in their lives. While the sources of support were different between participants, their individual perceptions about support were also different. Participants explained support in different contexts and some felt that support did not have to revolve around OCD. In essence, people felt they can receive support from others without discussing their condition and problems.

##### *4.2.2.1 Sources*

The majority of participants felt support came from their family (spouse, parents, and siblings), therapists and doctors, and other people with OCD.

Most participants saw their family as a primary mean of support. While they saw their families as supportive, they still did not feel that their families understood what they were going through; nor could their family members relate to their struggles. Most participants of the face-to-face support group said they believed their family was supportive of them being in the support group and said their family is supportive of whatever they feel they need to do to get better.

- *Participant 5* (current face-to-face participant): I think my family was like, “OK, she’s got someone else to talk to now.”
- *Participant 8* (current face-to-face participant): I think my friends think its weird but my family is really supportive. I think my friends are kind of like, “Why are you doing that?”

Even though family seemed to be positive about most people participating in support groups, others expressed their families were not so supportive.

- *Participant 7* (current face-to-face participant/hoarder): Not everyone has a supportive family. My naming what I had, it divided my family. When I got treatment for eating disorders it divided me and my sister. She went once to a support group with me and refused to go back. I had an eating disorder for years before I had OCD. She watches a lot of TV, where these people go in and clean up somebody’s apartment on the weekend and she thinks if they can do it, I can. I am more terrified of her than I have ever been because of how she feels about taking care of me.
- *Participant 14* (non-participant): My mother would laugh if I ever joined a support group. They think “it’s all in your mind” and you just need “will power.”
- *Participant 16* (non-participant): My family would wonder why I was participating because they don’t think there is anything REALLY wrong with me. I’m just too emotional and a sucker for a doctor with a prescription pad. My mother tried for years to convince me that my physician was giving me my drugs in order to make me an addict and make lots of money off me.

*Participant 29* (current online participant) said her husband feels that she sometimes receives too much support. “My husband has been with me long enough; he knows what to do when I need him. He is happy with the support group; however he thinks I am on here too often.”

Overall, participants expressed that they feel their family does not truly understand and even though they are supportive, they are only supportive to a certain extent. Many struggle communicating with their family because of their family's attitudes about OCD.

Participants also mentioned that their doctors give them support. Many participants thought highly of their doctors and felt they received a great amount of help and support from them.

*Participant 16* (non-participant): My therapist, mainly. I see her once a month, down from once a week. She helps me think through situations that would be simple for someone with a healthy brain. We work very hard on self-esteem issues as well. She's a godsend.

Other participants, on the other hand, did not see their doctor in such a beneficial way and had mixed feelings about the lack of support they provide.

- *Participant 4* (current face-to-face participant): I have talk to numerous shrinks, psychiatrists, psychologists, been on an off meds, nothing has worked for me. Unless you have it, you aren't an expert. Even the experts aren't experts because they don't have it.

Support group participants felt people who have OCD were a major source of support. The participants in the face-to-face support group studied by the researcher all agreed they were there for one another and they were their biggest means of receiving support because they do understand what they are going through. Other participants agreed as well.

*Participant 28* (current face-to-face participant): I think the people who help me out the most with my OCD are other suffers. When people tell me of their experiences with OCD it is like they are taking the words right out of my mouth. It's so nice to relate!

#### 4.2.2.2 Perceptions of Support

Although many participants discussed various sources of support, they all identified people who gave them support and people who did not. People with OCD tended to have

different perceptions of support. These differences resulted in their views about feeling supportive, what support is, and how to receive support from others.

*Participant 23* (past participant of both): I have a wonderful network of support. Everyone at work knows about my OCD. I don't keep it a secret, and they are as understanding as possible. I have a therapist who is also supportive, a psychiatrist who works with me to find the best medicine combinations, and friends I can vent to if need be. Just by being there for me and listening to my problems, and trying to distract me, my friends support me. I think pretty much everyone in my life gives me the support I need.

Others feel support can be a form of enabling. Enabling is when someone who does not have OCD help the sufferer out by doing things for them they are not able to do or will not do (e.g., opening the door for an OCD washer). *Participant 11* (past participant of both), spoke about how people with OCD can sometimes see support as enabling them.

We make a mistake and accept support as people doing things for us that we should be doing. That is wrong because that is being enabled or babied. The biggest thing for support is to not laugh at a person or joke with a person or reach out and touch them.

On the other hand, one participant explained the he prefers to receive support from his friends whom he shares a common interest with. He does not feel that support has to be focused on his OCD.

*Participant 12* (past face-to-face participant): I think we support each other in that we find a hobby that we are able to succeed in and it makes us feel good about ourselves even though we can't succeed in the real world, and in the hobby world it makes us feel good about ourselves.

He said the people he shares his hobby interest with do not have OCD, but they all have some form of condition that keeps them from functioning in the real world. They use each other as support but do not really communicate about their issues with their condition.

#### 4.2.3 Control

Perceived level of control over OCD also varied from participant to participant. The feelings of whether or not they felt their OCD was under control went from almost total control to hardly any control. The majority of participants claimed they had the least amount of control when they were feeling stressed. Participants discussed how stress decreases their ability to control their OCD.

- *Participant 10* (non-participant): I guess the biggest thing I noticed is when I get stressed out it gets a hundred times worse.
- *Participant 9* (non-participant): I would try to eliminate the stress in your life. The more stress in your life, the worse it gets.

Participants expressed when they are not busy and have a lot of time to think, their OCD gets worse. In that sense, many prefer to stay occupied because it keeps their mind focused.

- *Participant 23* (past participant of both): I have the most control when I am not alone enough to focus on my own thoughts, when I take my medication, and when I participate in therapy.
- *Participant 9* (non-participant): When I am by myself, it is really hard. When I have someone else there to play video games, talk, watch TV with, it keeps my mind away from it all.

Since OCD is all about control, participants expressed how it tends to wax and wane over time. Several of the support group participants felt their control level was better now than it use to be. Many other participants claimed they feel they have a good amount of control.

- *Participant 27* (current participant of both): I think I'm probably in control 90% of the time.
- *Participant 17* (current online participant): Most of the time I feel like I have total control. This means basically that I can "let the thought go" or it doesn't mean anything—what I understand people with OCD experience. I do believe that CBT [cognitive behavioral

therapy] and other talk therapy helps, but also that I need the medication to “take the edge off.”

On the other hand, there were many participants that felt they had little or no control over their obsessions and compulsions.

- *Participant 25* (current online participant/washer & cleaner): I have almost no control. If I don't wash my hands or soon, I feel like I'm having a heart attack, like the whole world is gonna come crashing down if I don't find a way to calm my thoughts, and the only way to do that is through the compulsions.
- *Participant 20* (past online participant): I have very little control over the obsessions and compulsions. I often cannot keep the thoughts from coming.
- *Participant 24* (past participant of both): I find the compulsions most easy to control when it is a concrete action that I can resist, such as how I used to need to have my shoes lined up next to each other, with at least some part touching. By physically resisting the urge to re-arrange them after I'd kicked them off, I was able to overcome that compulsion and, for the most part, the obsession. Also, when the compulsions are mental exercises, it is very difficult to control-- it's like telling yourself to not think about white elephants (of course you're going to then think about white elephants).

#### *4.2.4 Member Checks*

The researcher performed member checks, which allowed the researcher to review the study's findings with participants in a second support group. The participants agreed mostly with the findings from the study but added insight to why people might or might not participate in a support group for their OCD.

Overall, they felt people participate in support groups for many of the same reasons mentioned in the study (provide help, advice, support, hope, encouragement, etc.). However, one participant explained how her doctor help introduce her to the group and was very encouraging about participating in a support group. Others also believed if the individual does



not have the desire to improve, there would be no reason to seek support. One participant explained the people that tend to come to face-to-face support groups are those whose conditions fluctuate in the middle. The participant noted that if the person's symptom severity was too great, that could keep them from participating. On the other hand when people perceived their symptoms as mild, they probably feel they have their condition under control and do not need to attend.

The member checks participants, who are all part of a support group run by a lay person, said they thought that more people would be willing or interested in participating if the group was run by a professional, This aspect would enhance the credibility of the group and could possibly get a better turn out.

The leaders of the member check support group identified two reasons that people stop coming to support groups: because the participant does not think they need the help anymore and their schedule has become too hectic. They also expressed how each meeting is different because of who shows up and what is discussed. Therefore, they suggested that people should give the meeting more than one shot because more than likely the first meeting is going to feel a little awkward. They also expressed the need for good advertisement because many people are not even aware of the groups that exist.

When asked about the fear of participants taking on new obsessions and compulsions, support group participants expressed they do not feel it was possible to take on other obsessions and compulsions. During the member checks, the participants also felt this was true. They explained that listening to others share their experiences would not influence new obsessions and compulsions into their minds. They expressed this has never happened to them.

When discussing online support group participation, they agreed with the results saying that online support groups can be beneficial to sufferers because it can allow them to be more confident and express themselves in ways that they may not be able to do in a face-to-face

group. One participant in the member checks expressed how she had trouble reading and typing and that she would not be able to participate because of the amount of time it takes her to compose and read messages. This finding was similar to a participant in the face-to-face support group interviewed. The participants of the member checks agreed with the majority of these results. However, they felt that a main reason why people do not participate in an online support group is because they may already be a member of a face-to-face group and are already receiving the support they need.

One of the major differences noted between the groups was the discussion about family. While not all participants in the focus group felt their family was supportive about them being in the group, the participants of the member checks felt their family promotes the idea of them coming. In addition, they expressed how they often have family members come to the group as well, where the focus group did not have any family members present. They expressed how having family members or others who do not have OCD come to the group is good because it allows the family to learn more, which can help enhance the relationship between the sufferer and the non-sufferer.

Chapter 5 will discuss the implications of the study, limitations, and direction for future research.

## CHAPTER 5

### DISCUSSIONS, IMPLICATIONS, LIMITATIONS, AND FUTURE RESEARCH

The purpose of Chapter 5 is to discuss the overall research findings described in Chapter 4. This chapter will also explore specific theoretical and practical support group implications as they connect to the findings, describe limitations to the study, and provide directions for future research.

#### 5.1 Specific Findings and Discussion

This study examined why people with OCD choose to participate or not participate in a face-to-face or online support group. The theoretical frameworks of the Health Belief Model (HBM) and the Theory of Reasoned Action (TRA)/Theory of Planned Behavior (TPB) helped the researcher make connections and organize the research. The theories proposed in the current study are used simultaneously in order to provide a framework that helps the researcher understand phenomena of support group participation and provide explanations for the health behavior. The theories helped the researcher determine what factors may be noteworthy in OCD participants' decisions to participate or not participate in a support group. The elements and factors of the HBM and TRA/TPB helped the researcher gain a better understanding of this issue.

##### *5.1.1 Reasons for Participation*

Participants of the current study proposed many reasons why they choose to take part in a support group for their OCD. One of the universal reasons for participation is people with OCD feel it is easier to communicate with others who could relate and understand what they are going through. This finding supports previous research indicating exchanging emotional support and information with others who were going through similar experiences was a key benefit to participating in a support group (Barak et al., 2008; Bruwer & Stein, 2005; Coulson et

al., 2007; Houston et al., 2002; Rier, 2007; Shaw et al., 2006). This study also found participants saw the group as a place where they received encouragement from others. This finding supports previous literature claiming support groups offer emotional support and encouragement for the individual (Harvard Medical School, 2006; Spiegel, 1995). Both face-to-face and online support groups also helped people combat loneliness, allowing participants to connect with others who are like them. This finding relates to Pilsuk and Parks (1980) findings that support groups for health-related conditions create a sense of belonging for the individual and help them avoid feelings of isolation and loneliness. This need to reach out to others for advice and help tended to be a key interest for both face-to-face and online support group participation as well. Support group participants said methods they learned from the group have been helpful in how they deal with their OCD. Participants of both types of groups said they joined a support group to gain information that could help them with their condition and non-participants said that help and ideas from others would be a reason they might choose to participate. These findings supports previous research that revealed people participate in support groups because they can learn information about their condition, gain coping methods, and express emotions (Harvard Medical School, 2006, Christie et al., 2008, Endler and Park, 1994, & Spiegel, 1995).

The study also found people felt support groups gave them a sense of hope and confidence. Similarly, Christie et al. (2008) and Peterson et al. (2008) concluded that support groups can improve confidence and self-esteem. One theme that emerged from the data was that face-to-face and/or online support group members said they enjoyed the friendships they made as a result of the group communication and those friendships were a reason they remained in the group. This supports previous research that indicated support groups provide an opportunity for others to meet new people and make new friendships (Christie et al., 2008; Harvard Medical School, 2003; Peterson et al., 2008).

Although people describe similar reasons for participating in face-to-face and online support groups, the study found differences between the two communication channels. People said they felt online they could be bold and confident when expressing their experiences, struggles, and feelings about their OCD because they did not have to reveal their identities. The ability to participate anonymously was important to participants because they felt they could be more open with others than in a face-to-face context and would not be judged for what they said. Participants online also felt socially equal because the lack of interpersonal cues makes it difficult to determine social status. These findings support previous research stating one of the main appeals of online communication is the ability to remain anonymous during interpersonal exchanges (Barak et al., 2008; Colvin et al., 2004; Houston et al., 2002; Finfgeld, 2000; Sansone, 2001; Tate & Zabinski, 2004). It also supports Colvin et al.'s (2004) research, which found the online community is a safe place because it allows people to communicate in a nonjudgmental atmosphere and Barak et al. (2008), who determined online members take a bolder stance in the group because they are able to say things online they would not be able to say in a face-to-face environment. In looking at OCD support group participation online, this study discovered that online support groups reduced social anxiety issues for some participants and allowed them to manage their fears enough to participate in support groups.

The study also learned online support groups appealed to members because of the asynchronous and user-driven nature of the Internet. Participants said they could communicate any time of the day in the comfort of their own home. They felt online was preferable to face-to-face because they can start and end participation at any point they choose, something they have no control over in a face-to-face group. This finding supports previous research that noted online communication is convenient for the participant (Colvin et al., 2004; Houston et al., 2002; Peron, 2002; Sansone, 2001).

However, the study also discovered that support groups could be good for people who have some form of social anxiety or OCD barriers to participation. This is because OCD is a

disease that revolves around lack of control. Many participants in therapy learn how to overcome their fears through cognitive behavioral therapy (CBT) or exposure response prevention (ERP) therapy. In ERP therapy, a therapist will encourage the patient to do something that they normally wouldn't do because their OCD prevents them from doing it (e.g., a patient who is a washer may be asked to touch a trashcan and not be allowed to wash his/her hands). Support groups can encourage OCD patients to overcome fears and complete tasks that the OCD makes difficult such as being in a new environment that could not be clean to the individual, listening to others talk about their problems, or typing and reading information on the Internet.

#### *5.1.2 Initiation versus Continuation*

While research question one and three deal with reasons for face-to-face and online support group participation, the study found there tended to be reasons to initiate participation and benefits to continuing participation. For face-to-face support groups, the need to identify with others who are similar to them, reassure themselves they are not alone, education, and help were reasons for initiation into a support group. Reasons people continued participation in the support group was because of the ability to mentor others and the friendships that were made through the group.

For online support group participation, people initiated membership into the group because of the ability to communicate and remain anonymous, being curious of what exists online, and the fact using the Internet can be a convenient way of communicating. Furthermore, people tended to continue participation because of the ability to remain anonymous and the group being convenient to the user. While these themes were found in the study, they showed the benefits sought from being in the group varied between initiation and continuation.

#### *5.1.3 Reasons for Non-participation*

Participants of the current study proposed many reasons why they choose to take part in a support group for their OCD. One of the universal reasons for participation is people with

OCD feel it is easier to communicate with others who could relate and understand what they are going through. This finding supports previous research indicating exchanging emotional support and information with others who were going through similar experiences was a key benefit to participating in a support group (Barak et al., 2008; Bruwer & Stein, 2005; Coulson et al., 2007; Houston et al., 2002; Rier, 2007; Shaw et al., 2006). This study also found participants saw the group as a place where they received encouragement from others. This finding supports previous literature claiming support groups offer emotional support and encouragement for the individual (Harvard Medical School, 2006; Spiegel, 1995). Both face-to-face and online support groups also helped people combat loneliness, allowing participants to connect with others who are like them. This finding relates to Pilsuk and Parks (1980) findings that support groups for health-related conditions create a sense of belonging for the individual and help them avoid feelings of isolation and loneliness. This need to reach out to others for advice and help tended to be a key interest for both face-to-face and online support group participation as well. Support group participants said methods they learned from the group have been helpful in how they deal with their OCD. Participants of both types of groups said they joined a support group to gain information that could help them with their condition and non-participants said that help and ideas from others would be a reason they might choose to participate. These findings supports previous research that revealed people participate in support groups because they can learn information about their condition, gain coping methods, and express emotions (Harvard Medical School, 2006, Christie et al., 2008, Endler and Park, 1994, & Spiegel, 1995).

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remained in the group. This supports previous research that indicated support groups provide an opportunity for others to meet new people and make new friendships (Christie et al., 2008; Harvard Medical School, 2003; Peterson et al., 2008).

Although people describe similar reasons for participating in face-to-face and online support groups, the study found differences between the two communication channels. People said they felt online they could be bold and confident when expressing their experiences, struggles, and feelings about their OCD because they did not have to reveal their identities. The ability to participate anonymously was important to participants because they felt they could be more open with others than in a face-to-face context and would not be judged for what they said. Participants online also felt socially equal because the lack of interpersonal cues makes it difficult to determine social status. These findings support previous research stating one of the main appeals of online communication is the ability to remain anonymous during interpersonal exchanges (Barak et al., 2008; Colvin et al., 2004; Houston et al., 2002; Finfgeld, 2000; Sansone, 2001; Tate & Zabinski, 2004). It also supports Colvin et al.'s (2004) research, which found the online community is a safe place because it allows people to communicate in a nonjudgmental atmosphere and Barak et al. (2008), who determined online members take a bolder stance in the group because they are able to say things online they would not be able to say in a face-to-face environment. In looking at OCD support group participation online, this study discovered that online support groups reduced social anxiety issues for some participants and allowed them to manage their fears enough to participate in support groups.

The study also learned online support groups appealed to members because of the asynchronous and user-driven nature of the Internet. Participants said they could communicate any time of the day in the comfort of their own home. They felt online was preferable to face-to-face because they can start and end participation at any point they choose, something they have no control over in a face-to-face group. This finding supports previous research that noted



online communication is convenient for the participant (Colvin et al., 2004; Houston et al., 2002; Peron, 2002; Sansome, 2001).

However, the study also discovered that support groups could be good for people who have some form of social anxiety or OCD barriers to participation. This is because OCD is a disease that revolves around lack of control. Many participants in therapy learn how to overcome their fears through cognitive behavioral therapy (CBT) or exposure response prevention (ERP) therapy. In ERP therapy, a therapist will encourage the patient to do something that they normally wouldn't do because their OCD prevents them from doing it (e.g., a patient who is a washer may be asked to touch a trashcan and not be allowed to wash his/her hands). Support groups can encourage OCD patients to overcome fears and complete tasks that the OCD makes difficult such as being in a new environment that could not be clean to the individual, listening to others talk about their problems, or typing and reading information on the Internet.

#### *5.1.4 Face-to-Face versus Online Participation*

Although the researcher discovered both face-to-face and online support groups had emerging themes, the study discovered there were themes that existed in only one type of support group when determining reasons for support group participation and non-participation.

Both types of support groups found identity, education, and help were all reasons why people participated. For reasons why people did not participate in either group was due to lack of awareness and knowledge, previous unsatisfactory experiences, and OCD barriers. Both face-to-face and online support groups tended to have similar reasons to participate and not participate.

However, there were also significant differences that emerged in the study. For face-to-face support group participation, themes such as reassurance, hope and encouragement, mentoring and camaraderie, and nonverbal communication were all reasons why they participated. These themes did not exist among reasons people participated in online support

groups. On the other hand, there were also existing themes found among online support group participation that was not discovered among face-to-face support group participation. These themes were: anonymity and social anxiety, curiosity, and convenience. For example, people who preferred online participation liked the fact they could communicate anonymously and it was seen as a convenience to them in their everyday life. These were two themes that did not exist among face-to-face support groups.

Reasons for non-participation in either group were also different between face-to-face and online groups. While not participating in a face-to-face support group resulted from social anxiety and attitude, reasons for not participating in an online support group was due to a lack of trust and lack of nonverbal communication.

## 5.2 Theoretical Implications

In order to understand why people with OCD participate or do not participate in face-to-face or online support groups, this study looked at the Health Belief Model (Janz & Becker, 1974) and the Theory of Reasoned Action/Theory of Planned Behavior (Ajzen & Fishbein, 1980). Both models examine the psychological and sociological elements that influence health behaviors and both models were used to develop questions to determine what other elements may play a role in whether people participate in face-to-face and/or online support groups. The study also looked into other concepts such as stigma and social support in general. Both of these concepts were important to the study because looking at people's perceptions of how society and important others view OCD and support groups may affect an OCD sufferer's feelings toward support group participation.

### *5.2.1 Health Belief Model*

The Health Belief Model (HBM) was used to develop questions for this study to determine which factors of the model could be important when looking at why people with OCD participate or do not participate in a support group. The model proposes six elements that can affect a health behavior: perceived susceptibility, perceived severity, perceived benefits,

perceived barriers, cues to action, and self-efficacy (Janz & Becker, 1984). Because study participants already were diagnosed with OCD, perceived susceptibility was not studied. The study found that the advantages to joining the group (benefits), the costs and problems to joining (barriers), the need to get help and get better (severity), and how society portrays OCD and support groups (cues to action) were all relevant and explained why people with OCD did or did not participate in a support group.

Previous research has found two elements of the HBM are more predictive of health behaviors: perceived benefits and perceived barriers (Janz & Becker, 1984). Grande et al. (2006) said support group participation is more likely when people believe there is something to gain from joining the group. In the current study, people with OCD see support groups as a safe place where they can connect with others who understand what they are dealing with, gather information and knowledge that can help them with their condition, gain a sense of hope and encouragement from others, gain friendships, and help others. For online support group participation, participants felt the ability to remain anonymous and the convenience of the Internet were seen as benefits to joining the group. However, a significant barrier kept people from participating in a support group such as a lack of awareness of existent groups, previous unsatisfactory experiences with support groups, suffers from social anxiety, and has OCD symptoms that prohibit them to attend. Additional barriers to online support group participation include a lack of trust, a lack of professionalism, and a lack of necessary technological resources.

People with OCD said they felt stigmatized and this represents another important potential barrier to participation. They said they believe that society does not understand OCD, and they feel they are societal outsiders. These feelings of being stigmatized have resulted in OCD sufferers keeping their condition hidden. This finding supports previous research that states the most devastating effects of stigma is feeling ashamed and embarrassed (Link & Phelan, 2006; Hindshaw, 2005). Goffman (1963) said when people become a victim of stigma,

they hide who they are and present themselves to others as how they believe they ought to be seen. According to Goffman (1963) they would not want others to know about their stigmatizing condition, and the support group would represent a threat to the “normal” social identity they wish to project. Fennell and Libereto (2007) found people with OCD suffer from self-stigma, a process where individuals recognize their symptoms and diagnosis themselves as being different from others before an official diagnosis is made (Fennell & Libereto, 2007). For an individual who feels stigmatized, the resulting feelings of self-doubt and unworthiness represent a barrier to participating in social activities such as joining a support group.

The Health Belief Model posits that the patient’s perceived severity of an illness can help predict whether the patient will engage in certain health behaviors. The more severe a condition is perceived, the more likely it is that a person will take action to prevent that condition, according to the model. Some study participants said they joined support groups because they felt their condition was becoming uncontrollable and their OCD was having a serious impact on their ability to function. Participants said they joined support groups or were interested in joining support groups in order to get help from other people in managing their OCD symptoms. In the focus group, a first time support group attendee said his reason for coming to the support group was because his condition had become a serious problem and he had come to the group to seek help and advice. Support group advocate Kathleen Norris and the leader of the leader of the face-to-face support group studied, both said support group participants come and go because once they feel they have a grasp on their condition, they do not feel the need to continue participation. The patient’s perceived severity of their OCD symptoms may be a prompt for them to become members of support groups.

In the HBM, cues to action are messages that gain the individual’s attention about the health behavior (Janz & Becker, 1974). Becker et al. (1977) suggested the stimulus can be either internal (e.g., a particular state of health, mood, or feeling) or external (e.g., interpersonal interactions, mass media messages, entertainment programs, or educational material). Both

internal and external cues can increase an individual's perception of threat, motivating an individual to engage in the recommended health behavior.

Internal cues in this study were found to be the participant's symptoms and their feelings toward being able to control the symptoms. Participants did not join the group because they recognized their symptoms as abnormal; it resulted from how severe they felt their symptoms were. The study found that external cues such as interpersonal interactions with others motivated participants to join support groups. However, participants reported it was their perceptions about their disease or their ability to cope with the disease that prompted them to join a group. They expressed their family and friends were supportive of them participating but they did not influence them to seek participation in the first place.

Other potential external cues include media prompts in form of news reports, health promotion campaigns or entertainment content. Almost all participants in the study felt the media does not really portray OCD or support groups accurately, if they portray them at all. They also agreed they have never seen the media promote or mention an OCD support group. Although the television series "Monk" was discussed in positive and negative ways, no participants said viewing the show prompted them to join a support group. It can be argued that because of the lack of support group portrayals in the shows and movies devoted to OCD, people might not even be aware of them and therefore uninterested in participating.

The last element of HBM model is self-efficacy, which are people's beliefs that they can perform the behavior. When looking at support group participation, people must have the ability to perceive themselves as capable of completing the action. Participants of the study did not participate because they suffered from social anxiety or had OCD symptoms that prohibited them from participating. In this case, self-efficacy was a factor because participants did not believe they could bring themselves to overcome this fear and attend the support group. This element of the model conceptually relates to perceived behavioral control of the TRP (Ajzen &

Fishbein, 1980). A more detailed analysis of perceived behavioral control appears in the Theory of Reasoned Action (TRA)/ Theory of Planned Behavior (TPB) section of this chapter.

### *5.2.2 Theory of Reasoned Action/Theory of Planned Behavior*

The Theory of Reasoned Action (TRA)/Theory of Planned Behavior (TPB) (Fishbein & Ajzen, 1980) was used to develop questions to determine what factors may influence the study participant's behavioral intention to join a support group. The theory states three factors influence an individual's behavioral intention: the individual's attitude toward the behavior, which can be positive or negative; the perceived subjective norm, which is the individual's beliefs about how important others view the health behavior, and perceived behavioral control, which is the individual's perceptions of the difficulty the task and his or her ability to perform the behavior. The study found that all three factors of the TRA/TPB model may influence whether OCD patients seek to join support groups.

The theory posits that in order for people to intend to engage in a health behavior, they must have a positive attitude toward the behavior. If the participants' attitude was positive toward support groups, the chance for participation would be greater than if the attitude toward support groups was negative, according to the TRA/TPB. Participants who had a positive attitude toward support groups saw them as a place where they could share their feelings with others who can relate and understand; get help with and information about their condition; and gain hope and encouragement from others. Positive attitudes toward online support group participation included: being able to remain anonymous while interacting with others about their condition and the convenience of communicating online. However, study participants, especially those that were not currently in a support group, also expressed negative attitudes towards participating in a support group. These negative attitudes resulted, in part, from previous unsatisfactory experiences with support groups such as: participants were not able to relate to the group, the group appeared to be more negative than positive, there was a lack of professionalism, and the group was more educational than supportive. Negative attitudes

toward online support groups included perceptions that online support lacked trust, nonverbal communication, and professionalism. People with positive attitudes seemed more likely to be in support groups or to express a desire to become part of a support group.

Another significant part of TRA/TPB is the level of perceived behavioral control. The theory states behavioral intention is influenced by the perceived difficulty of the task and the person's perception that they will be able to complete or control the behavior. Study participants who do not believe they have control over their ability to control their reactions and behaviors in a support group do not participate in an either type of support group. People with OCD who have contamination issues or suffer from social anxiety, for example, believed their OCD conditions would not allow them to participate. This finding supports Voerman et al. (2006) conclusion that attitude and perceived behavioral control were determining factors for face-to-face support group participation. For online participation, people also mentioned that checking behaviors made typing and reading text difficult for them. Because their OCD symptoms focused on perfectionism, they were not able to participate in an online support group. For both face-to-face and online support groups, participants expressed they believe their lack of control over their symptoms would prevent them from becoming part of a support group.

Along with OCD symptoms, stigma also affected participants' perceived behavioral control. Participants said they felt stigmatized as OCD sufferers and explained they felt the need to hide their condition because they were ashamed. Having self-doubt and feeling unworthy is a common feeling for people with OCD. Participants who suffer from self-stigma (Fennell & Liberato, 2007) do not feel they are capable of attending meetings, admitting their problem, or seeking help.

The subjective norm looks at important others who are connected to the individual (e.g., family and close friends) and how their views on the health behavior affects that individual's behavioral intentions. The theory states the perceived attitudes of important others can influence the attitude of the individual. If the subjective norm has a positive attitude toward

participating in a support group, chances are the individual's attitude will be positive as well. Research participants were asked who gives them support in their life, how those people support them with their OCD, and how their significant others feel about support group participation. The data suggests the perceived social norms of family members and friends play an important role in the decision to join support group. The majority of the members of the face-to-face support group expressed their family was very supportive when it came to support group participation. Although this was common in the study, it was not true for all face-to-face support group participants. One participant of the face-to-face group explained being involved in the group has divided her and her sister. She explained not everyone has a supportive family when it comes to OCD and support group participation. This finding was unusual compared to her peers in the support group.

Participants of the study who were not in any type of support group tended to feel that they had a lack of support and their family would not be supportive of them participating in a support group for their OCD. They also explained they tended to hide their condition from their family so they were not sure of how their family feels about support groups. These findings suggest that people with OCD who do not perceive family support for support groups may not join them. These findings support Grande et al. (2006) research that determined the most relevant factors for participating in a cancer support group were the beliefs about support groups and other's views on support groups.

Stigma perceptions also are related to the TRA/TPB's perceived subjective norm. Some of the participants in the study felt they were being stigmatized and stereotyped by co-workers, family members, friends, and even the entertainment media. The overall perception of societal norms is that "normal" do not attend support groups – only "abnormal" people attend focus groups. Participants admitted to hiding their OCD from their family and friends. One study participant who is not currently in a support group said her family would laugh at her if she joined a support group. Goffman (1963) said people hide away and present themselves as they



wish to be seen. People who self-stigmatize assume that people would react negatively to learning about the stigmatizing characteristic and assume that people around them would react negatively. Fear of being stigmatized may lead patients to believing that their significant others would react negatively toward the health behavior.

The findings suggest that non-participation in support groups can be a result of stigma. This finding supports research claiming people with a mental illness do not comply to take medication when there is a lack of social support and perceived stigma (Corrigan 2002). Although Corrigan looked at medication adherence and not support group participation, being in a support group is viewed as a form of treatment or bettering oneself and when the individual experiences stigma, the chances of them seeking support or help may be less likely.

### 5.3 Support Group Implications

Study findings have several implications for health practitioners or OCD advocates interested in establishing either an online or face-to-face support group. Starting a group is not an easy task. Support group advocates said the keys to a good support group are effective advertising, a dedicated leader, and an encouraging environment.

The study found people do not participate in support groups because they are not aware of any in their area nor do they know where they can go to find more information. Therefore, the first step to starting a support group is to raise awareness about the group. Effective promotion is the first key concern for starting a support group. Advertising targeted to local doctors and therapists and even hospitals is important but reaching the online community may be one of the most effective ways to reach people in the OCD community. Because OCD is a stigmatized condition, people with OCD do not reveal their condition to even close friends and family, but people with OCD use the Internet regularly and visit Web sites devoted to OCD and mental illness. Study participants expressed they frequently visited Web sites such as [www.ocfoundation.org](http://www.ocfoundation.org), [www.ocdtribe.com](http://www.ocdtribe.com), [www.stuckinadoorway.org](http://www.stuckinadoorway.org), [www.ocdonline.com](http://www.ocdonline.com), [www.ocdhope.com](http://www.ocdhope.com), and [www.nami.org](http://www.nami.org). It would be helpful to contact those Web sites and

other sites concerned with OCD or mental illness. The OC Foundation has a support group section on their Web site where people can advertise group meetings. Also, support group leaders should consider developing a Web site for their support groups in order to provide a place where interested OCD patients can get more information and/or submit questions about the group. Providing information about the groups goals, functions and moderator may reduce some of the anxiety that study participants said they felt when they did not have sufficient information.

Since people with OCD fear communicating face-to-face or may have symptoms that prohibit them from attending a face-to-face meeting, it may be helpful to start an online support group first and then develop a face-to-face group as the participants become more comfortable with one another. Once an interpersonal network is established online, participants would get to know one another and become comfortable sharing their experiences and feelings. Over time, the group could meet face-to-face because the group members already have established friendships and disclosed personal information in an online environment. Therefore, starting a face-to-face group may involve first establishing a group in cyberspace. However, barriers to face-to-face participation found in the current study included geographic isolation, a desire for anonymity, and a lack of time. Because these factors could all be barriers that would keep people from participating in the group, it might be effective to maintain an online group even once the group begins face-to-face interaction so others can continue participating in the way that is most comfortable and convenient for them. Because the group found that many people with OCD tend to have different types of OCD and a variety of experiences, the online group could create different threads based on different types of OCD (e.g., checker, washer & cleaner, pure obsessional, hoarder). The study discovered people that no longer participate in support groups are because they feel that they were not able to connect with anyone in the group because they all had different symptoms than them. Having different threads posted can help individualize the group in a way where discussions can occur about a particular type of OCD.

This would be beneficial to participants because they can communicate about their specific problems. There would also be a general discussion board that would be directed toward all types of OCD. By having the site organized and specific, it would appeal to the participants' interests and needs.

When starting a face-to-face support group, the setting and location is crucial. By talking to the members first online, the group leader could get a feel for what type of setting is comfortable for everyone. Maybe the group could meet at a recreational center, a church, or even a coffee shop. The key is to have it in a casual setting so participants feel comfortable and do not feel as if they are being analyzed and tested, a common complaint when the support group meets in a hospital. The study found that people with contamination issues felt that the location of the support group could prohibit them from coming. For example one participant noted that hospitals would not be a good place to have them because people with contamination issues do not like going into a place where sick people enter and exit. Geographic proximity is also a key component. The meeting should be held at a location central to the majority of the participants. If they see it is too far to commute to, they will not attend. One participant of the study explained how the closest support group was over an hour away and she did not have the time or money to travel that far. While it is impossible to make the setting convenient for all members, it must be convenient for the majority. For people who would not be able to travel the distance, the online group would be more beneficial for them.

The time of the meeting is also something leaders should discuss with potential members. Although some people with OCD are not able to work, people with OCD do hold full-time jobs. Having meetings during business hours would not be ideal because the chances of a good turnout are slim. Either a weeknight or on the weekends was preferable to study participants. People with OCD in the current study said the weekends are difficult for them because their days are less structured over the weekend and they have significant free time. Free time is not beneficial for people with OCD because it gives them an opportunity them to

think about the things which provoke anxiety and to dwell on their obsessions and compulsion. Participants from the study said since OCD is a thought-based condition, when they have a lot of time to think, their symptoms become hard to control. Therefore meeting on the weekend might be better for the members because it would give them a way to manage their free time.

Once the location, day, and time have been established, the next step is to determine who will be the group leader. Typically, group leader selection is important because that sets the tone for the group. People with OCD said they like feeling relaxed and need to not feel stressed or anxious in a support group. For some, having a leader who is a psychologist or doctor would cause anxiety. Participants in the study described negative experiences with doctors and several said they felt medical professionals were not helpful. The support group that participated in the focus group was led by a woman who had OCD herself. She had been a member for 12 years, and the people in the group felt comfortable around her because they knew she could relate to what they were going through. People with OCD felt that people without OCD, even their doctors, did not truly understand what they are going through. Therefore, having an individual who actually has the condition would be ideal for the leader. They have to be someone that can be counted on and who has had experience in a support group before.

However, other participants from the group preferred groups that were run by professionals. In this case, therapists would be appealing and add credibility to the group. The member checks participants explained how they feel their support group would be larger if it was run by a professional because it would give the group more credibility. They explained that having a therapist run the group can become expensive, which is why many groups do not have one. The study found that people with OCD might prefer two different types of leaders, so it would be important to consider involving both and maybe have the professional leader attend less frequently. This way the group is promoting an atmosphere that is both credible and comfortable.

Study participants identified a negative atmosphere as one of the reasons why they stopped going to support groups they had attended in the past. The support group that participated in the focus group seemed to promote this positive atmosphere. The group discussed topics such as their personal lives, recent challenges, and shared victories. The group believed shared victories are important because they instill hope in others. A positive focus allows participants to brag about themselves and share with the group something they have done to overcome a challenge with their OCD. Because of these findings, it is clear that a support group should have a positive atmosphere and focus on accomplishments, encouragement, and help others set and maintain personal goals.

#### 5.4 Limitations

This study employed qualitative research methods to gather and analyze thick, descriptive data. The purpose of the study was to determine the reasons why people with OCD participate or did not participate in face-to-face or online support groups. Because the nature of the study was qualitative, the sampling consisted of snowball and non-probability sampling in order to identify and recruit the most qualified participants. However, because this study did not use random sampling, the results cannot be generalized to a larger population of people with OCD or a larger population of support group participants.

A non-probability sampling was used by creating a flyer in the OC Foundation's newsletter and by posting an advertisement on the researchers profile page of the OCD Tribe. From the research participants, the researcher learned about other online social networks and online support groups that exist for OCD (e.g., <http://www.stuckinadoorway.org/>). If the researcher had known this at the outset of the study, the researcher could have advertised through other online networks besides the OCD Tribe and perhaps recruit members of other online support groups.

Another limitation to the study was the number of focus groups and in-depth interview participants. The study used a combination of in-depth interviews, a focus group, and online

surveys. Morgan (1997) recommends conducting three to five focus groups because interviewing one group does not allow the researcher to be able to compare and contrast the findings of that group. Because the researcher only conducted one focus group, the data collected about participants in OCD support groups may not represent the full range of face-to-face support-group experiences. Because of the limited number of focus groups, the researcher conducted member checks as a method of validation. Through the member checks, the researcher found that the one support group studied did indeed give accurate information about face-to-face support group participation. The study also discovered that several of the participants who completed the online questionnaires were current and former face-to-face support group participants and they provided the researcher with additional first-hand information about support group participation. The researcher was able to compare the online questionnaire results to the focus group result and gathered more data than originally anticipated.

Another limitation to the study is the number of in-depth interviews conducted. Several potential interview subjects were recruited but did not follow through with an interview. While the study conducted four in-depth interviews, McCracken (1988) suggested having at least eight in-depth individual interviews. However, McCracken's ballpark figure of eight interviews is a recommendation for studies that use interviews as the only method of data collection. This study also looked at data from online questionnaires, in-depth interviews and a focus group. The researcher did not anticipate the amount of interest received from the advertisement in the OC Foundation's newsletter. Because the newsletter is national, people all over the United States expressed their interest to participate in the study. Therefore, the researcher was able to collect more in-depth information from non-support group participants through open-ended online questionnaires for the people who did not live close enough for face-to-face in-depth interviews. The resulting 29 participants in the study were sufficient to research the saturation necessary for qualitative research.

Online surveys were also conducted for people who were members of the OCD Tribe, an online social networking site for people with OCD. Finding an online support group for people with OCD was challenging. Many OCD Web sites the researcher visited were more informational than support focused. The researcher eventually discovered the OCD Tribe, an online social network for people with OCD. The researcher noticed it was designed like MySpace and determined through reading people's profiles and comments that it was a form of support for people with OCD. However, it was discovered in the results some people do not feel the OCD Tribe was a support group, rather it was noted as an online Web community for people with OCD. While the participants did not elaborate on this aspect, the researcher felt it was an important issue. The study consisted of five OCD Tribe members that filled out the online questionnaire. Other ways the researcher could have had a more efficient size could have been from participating in online chats with members rather than sending them personal messages in their "inbox" or "wall." This could have allowed potential participants to ask any questions they had about the questionnaire in a synchronous format. As previously mentioned, the researcher discovered from the participants of the study other possible online support groups that could have been used when recruiting and studying online support group participants.

The focus groups were videotaped and audio-recorded for transcription purposes. This was a barrier in the research because one support group would not participate due to videotaping or audio-recording. The support group that did participate in a focus group had three members who did not participate because of their fear of being videotaped. While the people who did not want to be videotaped preferred to observe, the researcher could have possibly interviewed the three separately to avoid their fears of video recordings.

The participants in the study had different types of OCD. While this created a unique population, it also made it sometimes difficult for the researcher to compare data between the participants. Although many of the participant's answers were similar on certain issues, their

type of OCD seemed to affect the way they responded to the questions, making it challenging for the researcher to compare data. For example, participants who suffered from pure obsessions tended to have a different outlook on support groups compared to participants who were hoarders. Another challenge was the participants had varying past experiences with both support groups and therapy. These past experiences may have shaped their attitudes toward support group participation. For example, some participants may have had bad experiences with doctors, medication, therapy, or support group participation, which could have shaped their overall attitude about support groups and even their attitudes about participating in a study about support groups.

#### 5.5 Directions for Future Research

Conducting research is a very detailed and intricate process. The researcher has to make many decisions about methods, population, sample size, and theoretical approaches. The current study had many limitations but offers directions for future research. Researchers learn from previous studies in order to determine how to make the next study more effective. This section will discuss the directions for future research suggested by this study.

Because this study used two theoretical frameworks: the Health Belief Model (HBM) and the Theory of Reasoned Action (TRA)/Theory of Planned Behavior (TPB), the researcher has a variety of approaches to study the phenomena. When looking at the TRA and why people with OCD participate or do not participate in a support group, the perceived subjective norm seemed to be a significant factor. Therefore, a future study could focus on the perceived subjective norms views on support group participation, interviewing patients and their significant others, comparing the patients perceived subject norms to the actual attitudes of their family and friends. Also when looking at the perceived subjective norm, it would be important to look into health care providers opinions of support group participation as well. Research participants in the current study suggested their physician or psychiatrist was someone they turned to for advice and support.



Fennell and Liberato (2007) discussed a concept called self-stigma. People who suffer from mental illness tend to stigmatize themselves. Future research could examine the role self-stigma in an OCD sufferer's perceptions of support groups. Because OCD is a thought-based condition, self-stigma may influence the way in which OCD patients perceive themselves and other OCD patients. If they do not hold themselves or other OCD sufferers in high regard, they may not believe that a support group would be an effective way to gather information, seek advice or exchange emotional support.

A lack of perceived behavior control also seemed to be a significant factor in why some non-participants did not join a support group. Several participants said they felt that their specific obsessions and compulsions kept them from participating in support groups. Future research could look into different types of OCD (e.g., washers, orderers, hoarders, pure obsessionals, etc.) and see if the type of OCD a patient has affects the patient's perceived behavioral control. By breaking up the study by types of OCD, the researcher could also compare which type of support group, face-to-face or online, seems more potentially beneficial for the individual sufferer.

Previous studies indicated online support group participation lowered participants' stress levels (Barak & Dolv-Cohen, 2006; Shaw et al., 2006). Since people with OCD expressed how stress makes their condition worse, it would be beneficial to study a group of nonparticipants of a support group, have them participate in an online or face-to-face group, and see if being involved in the group affected their perceived stress levels.

One final suggestion for future research would be to compare the different types of support groups. The current study found support groups may differ in terms of how it is run, whether it is more of an informational group or an emotional support group, where the meetings are held, and what types of personalities participate in the group. Therefore researchers could compare different types in order to determine the strengths and weaknesses of the group. Another important reason to compare different support groups is that each group may have a

unique set of rules and procedures they follow. In order to compare and contrast the cohesiveness and supportiveness of the group, it is important to look at the makeup of each participant and the attitudes and attributes they bring to the group.

APPENDIX A

ADVERTISEMENT PUBLISHED IN THE OC FOUNDATIONS NEWSLETTER

Graduate Research Study  
Obsessive Compulsive Disorder and Support Groups

**Reason for the Study**

I have an uncle who was diagnosed with OCD about seven years ago. When he informed me he had OCD and was receiving medical help for his problem, I had no idea what OCD was or what he was dealing with. It is because of the struggles I have seen him go through, I have decided to become a supportive family member and be there for him as he may need me. The purpose of this study is to learn as much as I can about OCD so I can help him find new ways and methods to help make his life and the lives of OCD patients easier. Through talking with many people who have OCD and through my research, I have discovered that OCD is a daily battle. Each day is a challenge and although some days may be easier than others, this is a battle many have to deal with for the rest of their lives. After attending the OC Foundation seminar last summer, I learned that social support is a communication method many people with OCD turn to.

**How You Can Help**

I am interested in interviewing people who have OCD and fit in one of the following categories:

1. People who are participants of a face-to-face support group.
2. People who are participants of an online support group.
3. People who are not participants of any type of support group.

All questions will be based on your experiences with OCD and your view on support groups in general. Interviews will be recorded in order for me to transcribe them for my study. Your name and identity will be kept confidential at all times. You only have to give information that you feel comfortable giving. I want to hear how your opinions and learn about your experiences.

If you are interested please contact:  
Allison Davis  
Graduate Student  
The University of Texas at Arlington  
Email: \_\_\_\_\_  
Phone: \_\_\_\_\_  
Appendix A content goes on this page.

APPENDIX B

ADVERTISEMENT PUBLISHED ON THE OCD TRIBE

<http://www.ocdtribe.com/user/?P=allian11>  
Graduate Research Study  
Obsessive Compulsive Disorder and Support Groups

I am a graduate student working on my Master's degree in Communication. I am studying the role online support groups can play for people who have OCD. I have an uncle who has struggled with OCD and have seen all the challenges he has faced. Over the last few years I have learned so much about OCD and I really want to learn as much possible about his condition so I can be a supportive family member, and give him the support he needs. Although he is the motivation of my study, I have discovered people who do not have OCD, do not realize the struggles that you deal with and hardly know anything about what OCD is. I want to interview people who are a part of an online support group. If you have been officially diagnosed with OCD, communicate on the OCD Tribe, and use it as a communication and connection tool or for support from others, then you are eligible! I want to see what role the OCD Tribe plays in terms of your OCD. The questionnaire is online; all you have to do is copy and paste this link into your web browser.

[http://www.surveymonkey.com/s.aspx?sm=x870HN69agSokej63jGvhg\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=x870HN69agSokej63jGvhg_3d_3d)

Once you are finished with the questionnaire, it will automatically be sent to me. All questions pertain to your experience with OCD and the role the OCD Tribe plays with your OCD. Your identity will remain anonymous. Throughout this study, if you have any questions please email me at \_\_\_\_\_.

Thank you,  
Allison

APPENDIX C

QUESTION GUIDE FOR IN-DEPTH INTERVIEWS

## PEOPLE WHO ARE NOT IN A SUPPORT GROUP

### Introduction

Good afternoon. My name is \_\_\_\_\_, I am a graduate student at the University of Texas at Arlington. I am currently working on my thesis and plan to graduate with a Master's in Communication this December. I am also a high school speech and debate teacher where I take students all over the East Texas areas and help them learn how to become confident when it comes to public speaking and voicing their opinion.

I have an uncle who was diagnosed with OCD about seven years ago. He is 47 years old and has always been someone I looked up to. When he informed his family he had OCD and was getting medical help, I had no idea what OCD was nor did I understand what he was dealing with. It is because of the struggles I have seen him go through that I have decided I want to become a good family member and be there for him as he may need me. My uncle is not married and does not have any children. Therefore, I feel it is my duty as his niece to learn as much as I can about his condition so I can help him find new ways and ideas to make life easier. From what he has told me, OCD is a daily battle. Each day is a challenge and some days are easier than others but in the end, this is a battle he and many others have to face for the rest of their life. It is for these reasons why I am so interested in this study. My goal is to promote OCD awareness among others who are not aware of the condition or how they can help. After attending the OC Foundation seminar last summer, I learned that social support is a communication method many people with OCD find effective with their condition.

One of the things I am especially interested in hearing about is your feelings toward support groups along with your experiences with OCD. Because there are many different forms and types of OCD, it is important to learn about your condition and your feelings toward support groups. I would like to hear your thoughts and stories from you in this hour that we have together. I will be asking you questions today about your experience with OCD and your opinions about support groups.

There are no right or wrong answers to any of the questions – I just want to hear how you feel and want to learn from you and your experiences. Everything that you say today will remain confidential and no one will have your name matched up with your words.

Thank you for your participation and willingness to commit to this project.

Allison Davis  
Graduate Student, The University of Texas at Arlington



## Questions

### Discussion Starter

Tell me a little bit about yourself and your OCD.

- Prompt: How would you describe your OCD?
  - For example, how severe is it to you and explain what your struggles are.
  - To what extent does your OCD affect your daily life? (Please describe)
  - Is there any thing that you feel restricted from doing because of your OCD?
- How much control do you feel you have over your obsessions and compulsions?
- When do you feel like you have the most control? (Please describe)

### Interview Questions

#### **Experience and feelings toward support groups**

- Have you ever participated in a face to face support group?
  - **Follow up questions for people who have participated**
    - What was it like? (Describe what you experienced)
    - What did you like and dislike about it?
    - Why did you stop attending?
    - What prompted you to join the support group?
      - Prompt: family, physician, friends, OCD severe
  - **Follow up questions for people who have not participated**
    - Why have you not joined a support group for your OCD?
    - Describe what you think an OCD support group is like? What goes on in the meetings?
  - **Follow up questions for people who both participants and non participants**
    - Would you consider joining a face-to-face support group? Why or why not?
    - Describe any conflicts that sometimes get in the way of you participating in a support group.
      - Prompt: scheduling, emotional, family issues, not enough time
    - What would motivate you to begin attending a support group?

#### **Opinions toward support groups**

- Why do you think others with OCD participate in support groups?
- What do you think motivates people with OCD to choose to participate in support groups?
- What do you think people get from attending support group meetings?
- What do you think support groups have to offer for people with OCD?
- How do you think support groups can affect people's OCD?
  - Prompt: How it can affect their daily life along with their condition?
- Describe how support groups could be difficult to attend for people with OCD?
  - Prompt: Discuss things that could make a support groups challenging.
- How long would you say it is necessary for people to stay in a support group?
- Do you feel that support groups could have an affect with controlling your OCD? How so?

#### **Social Support**

- Who do you feel gives you support with your OCD?  
Prompt: Drs, friends, family, spouse, etc.
- Describe the kind of support they give you?

Prompt: physical - Drs. Appointment, picking up medicine; emotional - listening; help with ERPS

### **Online and Internet Use**

- Describe what ways (if any) you use the internet in terms of OCD?  
Prompt: Researching information, communication (email, myspace, facebook, IM, etc.)
- Have you ever participated in an online support group for your OCD?
  - Follow up questions for people who answered yes to the previous question
    - What did you like and dislike about the group?
    - What motivated you to join and participate?
    - Do you continue to use an online group for support?
    - (For people who have also participated in a face-to-face support group)
      - How is an online support group different than a face-to-face group?
      - Which do you prefer? Why?
    - (For people who have not participated in a face-to-face support group)
      - How would you image an online support group is different from a face-to-face support group?
      - Prompt: In terms of communication, creating relationships, physical differences, etc.
  - Follow up questions for people who answered no to the previous question.
    - Why do you not participate?
    - Would you consider joining an online support group? Why or why not?
    - How would you image an online support group is different from a face to face support group?
      - Prompt: In terms of communication, creating relationships, physical differences, etc.
  - Follow up questions for both
    - Why do you think other people participate in online support groups?
    - Why do you think others do not participate?

### **How people that do not have OCD view OCD**

- How do you feel that people who do not have OCD view people who do?  
Prompt: List some words, stereotypes, or images that comes to mind.
- How do you feel others view support groups in general?
- How do you feel the media portrays people with OCD?  
Prompt: fictional portrayal (such as Monk) & news media portrayal
- How do you feel the media portrays support groups in general?
- How do the people that are important to you feel about OCD?  
Prompt: What are their feelings and attitudes toward your condition?
- How the people that are important to you feel about support groups?  
Prompt: Do they promote the idea?  
What are their feelings about your involvement with a support group?

Thank you for participating and giving your honest feelings. Now as addressing someone who does not have this condition and wants to learn more in order to help society and others who do not have OCD try to understand, what would you want me to know the most about this topic today?

Prompt: What information would you want me to leave with and share with others.

- Is there anything else you would like to add or discuss?

End of Interview

APPENDIX D

QUESTION GUIDE FOR FOCUS GROUPS

## Introduction

Good evening. Thank you all for participating in this discussion about obsessive compulsive disorder and support groups. My name is \_\_\_\_\_ and I will be the moderator for this interview.

One of the things we are especially interested in hearing about is your feelings toward support groups and how it affects your OCD. Because there are many different forms and types of OCD, it is important to learn about your condition and what support groups do for you. We would like to hear as many different opinions and stories from all of you in this hour that we have together.

There are no right or wrong answers to any of the questions – we're trying to explore how you feel and want to learn from you all.

There are a few things we would like you to keep in mind. Please take turns speaking and please do not speak to another individual while someone else is speaking. This is important because it will help us as we are reviewing the interview later. We encourage you to talk to one another—ask questions if you have any about something someone else is saying. If you would like to add follow up comments to something someone else is mentioning, please feel free. This is an open discussion and we want you all to feel comfortable and share your feelings.

Everything that you say today will remain confidential and no one will have your name matched up with your words. We just want to get opinions from people with OCD and learn as much as we can.

The purpose of this study is to learn how support groups affect people who have obsessive compulsive disorder. Through this study, I plan to discover your feelings toward support groups. I want to learn what role support groups play in your life and hear about your experiences.

Thank you for your participation and willingness to commit to this project.

Allison Davis

Graduate Student, The University of Texas at Arlington

## Questions

### **Ice Breaker & Discussion Starter**

Let's go around the room and introduce ourselves. Tell us a little bit about you like your first name, career, family, and what type of OCD do you have.

- How would you describe your OCD?  
*Prompt: For example, how severe is it to you and explain what your struggles are.*
- To what extent does your OCD affect your daily life? (Please describe)  
*Prompt: What restrictions have you made for yourself because of your OCD? What can you not do because of this?*

### **Focus Group Questions**

- How long have you attended a support group for OCD?

***Some people attend support groups regularly and others attend periodically.***

- How would you describe your attendance and why?
- What prompted you to join a support group?  
*Prompt: What influenced you to join? (spouse, family, friends, doctor, yourself, your condition)*
- How long do you feel it is necessary for you to continue attending these meetings?

*Prompt: How long do you see yourself as a part of a support group?*

***I hear many people say that another person helped motivate them to attend.***

- What role does this person play in your life? What is your relationship like with him or her?
- Who do you feel gives you support with your OCD in your life?
- Describe the kind of support they give you?  
*Prompt: physical - Drs. Appointment, picking up medicine; emotional - listening; help with ERPS*

***Now let's move on to why you attend the meetings and what you receive from them.***

- Why do you choose to attend?  
*Prompt: What do you get out of attending these meetings?*
- What, if any, were the negative factors you considered when you were making the decision to join the group?
- How do these meetings affect your day to day life?
- What would you say support groups have to offer for people who have OCD?
- How many of you have attended a support group for awhile, stopped attending, and then returned?
- For you who have experienced leaving and returning, what were your reasons for leaving?
- Why did you choose to come back to the group?
- How would you describe the process of attending a support group for OCD to others who do not participate?

*Prompt: What would you say to them about the group?*

***I hear some of you describing what you get out of the meetings, how they are helpful, and what you do.***

- Tell me more about what takes place in support group meetings.
- How has being involved in a support group affected your management of your OCD?

*Prompt: What role does a support group play in your life with your OCD?*

- Do you feel like you have control over your obsessions and compulsions? Why or why not?
- (If answered yes to the previous question)
  - When do you feel like you have the most control? (Please describe)
- Why do you think others who have OCD do not attend support group meetings?
- Is it ever difficult to make yourself attend a meeting? Please explain.
- Why do you think others that do attend meetings do so?

**You all have provided some very interesting feedback. Let's change the subject to online using the internet for your OCD.**

- Describe the ways (if any) you use the internet in terms of using it for your OCD?  
*Prompt: Researching information, communication (email, MySpace, facebook, IM, etc.)*
- How many of you have participated in an online support group for your OCD?

For those who have:

- How is it different from a live face-to-face support group?
- What did you like and dislike about the group?

For those who have not:

- Describe your reasons for not participating.

**The last thing I want to talk about is how you feel about how others view you and OCD in general.**

**How people that do not have OCD view OCD**

- How do you feel that people who do not have OCD view people who do?  
*Prompt: List some words, stereotypes, or images that comes to mind.*
- How do you feel others view support groups in general?
- How do you feel the media portrays people with OCD?

*Prompt: fictional portrayal (such as Monk) & news media portrayal*

- How do you feel the media portrays support groups in general?
- How do the people that are important to you feel about OCD?  
*Prompt: What are their feelings and attitudes toward your condition?*
- How the people that are important to you feel about support groups?

*Prompt: Do they promote the idea?*

- What are their feelings about your involvement with a support group?

**Thank you all for participating and giving your honest feelings. Now as addressing someone who does not have this condition and wants to learn more in order to help society and others who do not have OCD try to understand, what would you want me to know the most about this topic today?**

*Prompt: What information would you want me to leave with and share with others.*

**Is there anything else you would like to add or discuss?**

End of Focus Group Interview

APPENDIX E

QUESTION GUIDE FOR OPEN-ENDED ONLINE QUESTIONNAIRES  
FOR ONLINE SUPPORT GROUP MEMBERS: OCD TRIBE

## Introduction

My name is Allison Davis and I am a graduate student at the University of Texas at Arlington. I am currently working on my thesis and plan to graduate with a Master's in Communication this August.

I have an uncle who was diagnosed with OCD about seven years ago. When he informed me he had OCD and was receiving medical help, I had no idea what OCD was or what he was dealing with! It is because of the struggles I have seen him go through, I have decided to become a supportive family member and be there for him as he may need me.

The purpose of this study is to learn as much as I can about OCD so I can help him find new ways and methods to help make his life and the lives of OCD patients easier. It is for these reasons why I am so interested in this study. My goal is to promote OCD awareness among others who are not aware of the condition or how they can help.

One of the things I am especially interested in hearing about is your feelings toward the OCD Tribe and along with your experiences with OCD. I would like to see how you use the OCD Tribe in terms of your OCD.

There are no right or wrong answers to any of the questions – I just want to hear how you feel and want to learn from you and your experiences.

Everything that you write today will remain confidential and no one will have your name matched up with your words. Thank you for your participation and willingness to commit to this project. I hope to learn from your experience.

Allison Davis  
Graduate Student, The University of Texas at Arlington

(Participants will then view the informed consent document and be asked to agree that they are 18 years or older and agree to the terms of the consent form. Once they agree, the participants will be able to view and complete the survey.)



## Questions

### Part 1: Your experience with OCD

- Tell me a little bit about yourself and describe your OCD.
- For example
  - How long have you been diagnosed with OCD?
  - What type of OCD do you have?
  - How severe is your OCD to you, explain what your struggles are, and to what extent does your OCD affect your daily life? (Please describe)
  - Is there anything that you feel restricted from doing because of your OCD? (For example: socially or physically)
- How much control do you feel you have over your obsessions and compulsions? When do you feel like you have the most control? (Please describe)

### Part 2: Your experience and feelings toward face to face support groups

- Are you currently a member of a support group or have you ever participated in a live face-to-face support group? (If yes, please state which one applies to you.)

For people who answered yes to question three.

- What prompted you to join the support group? (For example: family, friends, physician, problems with OCD, etc.)
- What was it like at the support group meetings? (Describe what you experienced) What did you like or dislike about it?
- If you have stopped attending, what were your reasons?

For people who answered no to question three.

- Describe what you think an OCD support group is like? What goes on in the meetings?
- Why have you not joined a support group for your OCD?

### Part 3: Online Support and Internet Use

- How long have you been a member of the OCD Tribe?
- Why did you join the OCD Tribe?
- Please describe what you like or dislike about the OCD Tribe?
- Describe the ways (if any) you use the OCD Tribe for your OCD? What do you do on the website?
- How do you online support (OCD Tribe) is different than face-to-face support? (Example: In terms of communication, creating relationships, physical differences, etc.)
- In what other ways (if any) you use the internet in terms of OCD? (For example: researching information, communication (email, myspace, facebook, IM, etc.)

### Part 4: Your views on social support

- Who do you feel gives you support with your OCD? (Example: family, friends, spouse, physicians, etc.) and how do they give you support? (Example: taking you to Drs. Appointment, picking up medicine, listening to you, help with ERPS)
- How does your friends and family feel about you using the OCD Tribe for your OCD?

### Part 5: Information about the way you feel others view people with OCD

- How do you feel others who do not have OCD views people with OCD?
- How do you feel the media portrays OCD? (Example: the news, fictional T.V. shows like Monk, etc.)

Opinions toward support groups in general

- Why do you think others with OCD participate in support groups and what do you think motivates people to participate in support groups?
- How do you think support groups affect an OCD patient's life?
- What do you think keeps people with OCD from participating in a support group?

Thank you for participating and giving your honest feelings. Now as addressing someone who does not have this condition and wants to learn more in order to help teach society and others, what would you want me to know the most about this topic today? In other words, what information would you want me to leave with and share with others

APPENDIX F

QUESTION GUIDE FOR OPEN-ENDED ONLINE QUESTIONNAIRES  
PARTICIPANTS WHO COULD NOT BE INTERVIEWED BY THE RESEARCHER

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## Questions

### Part 1: Experience with OCD

- Tell me a little bit about yourself and your OCD.  
For example:  
What is your gender, age, and where do you live (city, state)  
How long have you had OCD?  
What type of OCD do you have?  
To what extent does OCD affect your everyday life?  
What restrictions do you feel that you have because of your OCD?

### Part 2: Feelings about control

- How much control do you feel you have over your obsessions and compulsions?
- Please describe when do you feel like you have the most control?

### Part 3: Experience with face-to-face support groups

- Have you ever participated in a live face-to-face support group for your OCD?  
If answer is yes:  
What prompted you to join the group?  
Describe your experience with the group (what did you do in the group, your likes and or dislikes).  
Why did you stop attending the group?  
If answer is no:  
Why have you not participated in a support group for OCD?  
Describe what you think an OCD support group is like? What goes on in the meetings?

### Part 4: Opinions toward support groups

- Why do you think others with OCD participate in support groups and what do you think people get from participating?
- How do you think support groups can affect people's OCD? (For example, how can it affect their daily life and condition?)
- Describe how support groups could be difficult to attend for people with OCD? (For example, discuss things that could make participation in a support group challenging.)
- Do you think support groups could have an effect with controlling your OCD? How so?

### Part 5: Views on social support

- Who do you feel gives you support with your OCD? (family, friends, spouse, doctor, others OCDers, etc)
- Describe the type of help and support they give you?
- Who in your life do you feel does not give you the support you need (if any)

Part 6: Use of the Internet

- How do you use the internet (if you do) for OCD? (Researching information or communication: please list websites you visit.
- Have you ever participated in an online support group for your OCD?  
If yes:
  - What was the name of the group and/or website?
  - What did you like and or dislike about the group?
  - What prompted you to join the group?
  - Do you continue to use an online support group for your OCD?If no:
  - Why do you not participate?
  - Would you consider participating in an online support group? Why or why not?

Part 7: Compare and contrast face-to-face vs. online

- Even if you might have or have not participated in a live face-to-face support group, an online support group, both, or neither, tell me what you think the similarities and differences would be between the two types of support groups?

Part 8: Society views OCD

- How do you feel others who do not have OCD view people who do?
- How do you feel the media portrays OCD? For example the news perception, fictional T.V. shows like Monk, or talk shows.
- How do you feel others and the media portray support groups?
- How do the people that are important to you in your life feel towards support groups and OCD? (For example, what are their feelings and attitudes toward your condition, what are their feelings about your involvement in a support group?)

Part 9: Other information to add

- Thank you for participating and giving your honest feelings. Now as addressing someone who does not have this condition and wants to learn more in order to help educate society and others, what would you want me to take from your experience and share with others?

APPENDIX G

SAMPLE TRANSCRIPT: FOCUS GROUP

Transcript: Focus Group Face-to-Face Support Group  
June 3, 2007  
Moderator: Allison Davis

All names were taken out to protect the participant's identities. Participant's names were replaced with their number (e.g., Participant 1). A brief description of the participant's numbers and type of obsessive compulsive disorder (OCD) they have is below:

Participant 1: washer & cleaner  
Participant 2: checker (first time participant)  
Participant 3: hoarder, Obsessive Compulsive Personality Disorder (OCPD)  
Participant 4: washer & cleaner  
Participant 5: pure obsessional  
Participant 6: hoarder, checker (support group leader)  
Participant 7: hoarder  
Participant 8: pure obsessional

Moderator: Let's go around the room and introduce ourselves. Tell us a little bit about you like your first name, career, family, and what type of OCD do you have.

Participant 1: I am (Participant 1). I've suffered from OCD of some form or another since my twenties. I am fifty now. Most of my issues has to do with contamination, chemical or germs. I have suffered other forms as well. What is called the hit and run syndrome. When you are driving and you pass someone and you think, "Oh did I hit them." or thinking that you have done something catastrophic and you feel the need to go back and check. That about sums it up in a nutshell.

Participant 2: My name is (Participant 2). First time I have been here or any support group. I am in my early thirties, I don't remember when I first noticed, it has been a couple of years. The only thing I have done is read books on it. I have a tendency to check locks, especially at work. I sometimes spend an hour making sure the door is locked even though I know its locked I keep going back. Make sure the car engine is turned off, make sure I set the alarm. Sometimes I check the alarm then the lock and we have a spare key, sometimes I think I dropped the spare key outside, so I start looking around for a spare key when I know its inside, so I have to go back and open everything up, the key is there of course, then I have to go back and lock everything. I spend like an hour and a half doing this. I try not to be the last person to leave the building. Sometimes as a joke my coworkers will say, "You got 10 minutes you gotta get out of here." I am getting kind of sick of it so I figured I would come to a support group to see what it is all about.

Participant 3: My name is (Participant 3) and I think what I have is a little different. I am a hoarder, I don't have a fear about anything, I am not afraid of germs, checking, or rituals like that and I can kind of pinpoint mine to something that was catastrophic. It happened about 20 years ago and I can kind of look at that incident and see that is the beginning when this happened. I think mine is more of a personality disorder than regular OCD. OCPD is kind of different. I have been coming to this group for four years now. It does help me, I don't think I have changed any, don't think I have gotten rid of any of my stuff particularly. But its good when somebody comes in and they have problems, they can kind of pretty much tell which group they are going to go in, if they have got personality disorder, they talk to me, if they have



contamination they talk to (Participant 1). To me, I think the thing that I have found out is the key is fear. With OCPD there is no fear. With OCD, there is a fear whether its germs or if you don't do something, something is going to happen to you or you are going to kill somebody. For me, I have just picked up that the OCPD does not have fear, at least I don't.

Participant 4: My name is (Participant 4). My main manifestation is contamination also. It is not exactly your normal fear of germs, its fear of something I create out of nothing and I have no idea what it is. It is very stagnating, I wash my hands a whole lot, I wash my body a whole lot, that's been the main gig since 1994. Before that it was more or less rituals, ritual thoughts, prayers. I am not a hoarder at all, but everything else you have read about on OCD, I have felt, its really frustrating. You have to live with it, definitely a detriment to quality of life.

Participant 5: I'm (Participant 5). I'm 18. I think I have had OCD forever, or at least it feels like it. My biggest problem is perfectionism, things have have to be straight, they have to be right and if they are not right they are wrong and they can't be wrong. I also have a lot of trouble with the intrusive thoughts. I have a nephew that is a year and a half old and for the longest time I couldn't be alone with him because I was afraid I was going to hurt the baby, I was afraid I was going to do something sexual or terrible to the baby. It has been a journey. I have been in therapy for about a year and a half and its getting better.

Participant 6: I'm (Participant 6). I am the quasi – facilitator of this group. I have had OCD my whole life, started on meds in 1987, moved from Ohio to Pennsylvania, then Pennsylvania to here and this was really the first place that had a support group that was nearby. I was real excited and called up and since 1996 I have been a member of this group, in 1998 took over as facilitator of the group. It's really interesting, as the facilitator, over the years we have always kept it at two locations, every now and then someone will kind of wander in that hasn't been here for a long time and either something good has happened in their life or something bad, but we have always kind of been here. That's why we won't change the time or we won't change the date because everyone kind of knows we're here and its where we are going to be. I was really interested in when I first came here, the one thing I asked the group was has anyone had a problem reading. Half the group raised their hands and it was one of those things where they had to reread a page, we all had the same type of thing where we all had to read everything verbatim, we couldn't get past that page. One of the guys in the group said, he was from Wisconsin, and the support group that he was in up there, it was professionally led. What the person said was you get a cheap novel, you read a page, read the other page, tear it out and throw it away and you can't reread it and train yourself to do that. I have always had that kind of in the back of my mind, subsequently have started reading for pleasure which I never did and my husband was your 60 years old and all of a sudden you're reading mystery novels and now I read one one a month. For me, to read one book in 10 years was quite a fee. And now I really enjoy it, it's really amazing. That was one of the things that really hooked me in the support group because it was the first time I was really able to relate to somebody and have them understand what I was went through, which is what we were talking about, we all had different things. One of the girls a long time ago, it was really interesting because I went to a Catholic school and she went to a Catholic school and she said she would always get in trouble because it was the desk that raised up and she said the nuns would come by because she would suppose to be reading or doing something and she said the desk would be up and she would be organizing everything and the nuns had no clue why she was doing that and they would get so frustrated, and I was like you know that was the same thing that happened to me. I guess I was in my late 40s early 50s, it took that long to find people that I could relate to.

Participant 7: My name is (Participant 7), I found out about the group maybe two years ago because they had a print out. I called (Participant 6) and spent about 20 minutes on the phone

with her. I have had this forever, as long as I can remember. I am a hoarder, also a picker, and check sometimes. Sometimes I will have the car keys in my hands and I can't close the door or the trunk. I can see the keys, I can feel them, and I can rattle them but I can close the doors to the car because I think the keys are still inside the car. When I was a child, I liked order, I liked to collect things and put them in groups. I didn't see anything wrong with that and I guess it has grown from there. I have trouble getting rid of things. I have done a little bit to control the acquiring but I have trouble with books actually. I never had a problem reading, I am an avid reader. I would go into a book store, especially half price books or a thrift store and come out of there with 20 books and now I don't go to the bookstore without a list and if the book is not on the list, I can't get it. I have to leave the store go home and put it on the list, then I can go back and get it. I have been able to leave Half Price Books three times now because they didn't have what was on my list and I didn't come out with anything else. My apartment is a mess. I have taken pictures of it but nobody wants to look at the pictures. I call it layers, when I moved in it was a layer of furnishings around and there is another layer of stuff from my mom when she died I inherited. I have a path about that wide that goes from my front door through the living room and into the kitchen and I have another path about that wide that goes from the front door to the bathroom. I'm making some progress on some papers, I have started saving part of some things instead of the whole thing. I have filled a copy paper box full of papers to get rid of, it is in my car its not in my apartment anymore.

Participant 8: I will take it off your hands if you want I'll recycle it for you.

Participant 7: Oh, I have a ton of bags to go through (everyone laughs). I have two more bags to go through then I am going to take it to work. After I came here, I had a vacation planned to Connecticut and I found. I looked them up on the same website that this group was on and found two groups in Connecticut. That was a professionally facilitated group, so that was a little different experience; it was a very large group, 10 men and 4 women. It was an educational group, not a therapy group and they had group leaders. It was interesting, I liked it.

Participant 6: (Participant 8) is our professional thought person.

Participant 8: That's me. Get that on the camera. My name is (Participant 8). I was definitely a washer as a kid. I didn't know what it was, didn't know why I was washing all the time, I thought it was normal. I thought well everyone else, that's weird because they aren't worried about germs. I went through a really long stage of being really weirded out by people with AIDS or even gay people or even the word AIDS or seeing something that said AIDS on it would freak me out because I would think, "Oh my God that means I have it or it is some sort of sign." When I say it out loud it sounds stupid. So I went through a checker stage, my mom is a hoarder. I always thought when I heard of OCD that meant organized thoughts. Unfortunately I have not been blessed with organizational OCD. (everyone laughs) My desk is a mess, it's not a "hoarding" mess, I just don't think I have any OCD toward junk. I get rid of some junk, I save some junk, I probably have things I shouldn't have but I think, "I don't want to waste it." But I have gotten better we had a thing at work the other week and I was thinking, "I want to buy a new fan for outside." and a coworker was like, "then we are going to have to store it." And so I was like, "Oh ok, lets not buy it, lets rent it." Typically would think renting it would be a waste of money for something like that. Three years ago I got very stressed out with work and started a volunteer organization. I don't know exactly why OCD waxes and wanes and stress causes it to wax or wane and I started thinking I was going crazy, I was thinking I was schizophrenic. I was thinking I was going to kill people. So that was pretty scary. At the time I was dating a guy who had a lot of guns and I started thinking what if I got a hold of the gun and killed him, and that thought just got stuck in my head over and over and I wouldn't even talk to him to him and I would try and push him away. I would tell him, "You don't understand. I am dangerous." and I

couldn't understand why no one thought I was dangerous because my head was scarring myself obviously so I ended that. So I went to a counselor, and I have been very blessed. I have very supportive family and friends. The counselor said, "You know I don't think you are crazy. I think what you have is this morbid obsession of OCD." So after reading about it, it was really interesting reading the OCD workbook and reading how this lady has a cat and she is afraid she is going to stick a cigarette in the cats eye. I was like, "Oh my God I have those same thoughts!" That was a welcome relief because I was able to read it over and over and have it sink. No matter how real these thoughts seem, a person with OCD will never act on these thoughts. When you are dealing with the thought and you have got the thought causing confusion, you don't understand that and you can't figure it out, "If I would never do this, then why am I thinking this. And if I am thinking this then maybe I want to do it, or maybe I don't even have OCD and maybe its worse than that." I went through this whole phase of, "Oh I must be crazy." That is when I found the group because at that time it was a very bad time in my life, probably the worst time ever in my life. Since then with this supportive group and why it's so valuable, I've got (Participant 1), (Participant 6), (Participant 3), (Participant 5), & (Participant 4), the regulars I guess. It's nice to go and be able to talk about it. To be honest it probably hasn't affected me at all in the last year, but I hear other people's stories and I can see where it can creep back in very easily. Oh that's a lie, I did go on a cruise with my best friend and I started freaking out cause I thought I was going to throw her overboard and I started getting all worried wondering, "Well what if she and I are alone at night." So I went on the cruise and everything was fine, she's not swimming in the ocean (everyone laughs). The funny thing is, for me the anticipation of the activity more than the activity itself. The cruise was great, I had a great time. I was drinking the whole time and I was so worried, "What if I get drunk and throw her overboard. What if I lose control, and what if I don't call the coastguard?" Just stupid stuff to where I was literally crying. It's the way the mind works and these stupid connections. When you say it out loud its like, "Dude, what are you thinking!" but in my head at the time, I would get so worried, "Well God is going to punish me." Anyway, I have been really good for the last 6 months at least. I have felt great. I haven't had that many symptoms. I still have the fleeting thought and I am like, "Dude that is stupid!" and then it goes away. As far as the washing goes, I haven't been a major washer in a couple of years. I haven't been a checker in a few years either. It's kind of nice being in the group, but when (Participant 1)'s going through his stuff with washing, I just thinking, "Oh God, I remember that." And I am able to be a little more sympathetic and for me the group helps because it makes me realize that other people dealing with the same thing and I am normal. I thought when I got here that it was going to be a bunch of people kicking their foot. I don't know what I thought, rocking back and forth (everyone laughs), but everybody's smart everybody's funny. (Participant 1) and I have hung out, (Participant 5), (Participant 4), and I have all hung out after work and I like that. It's nice to have some camaraderie with people you know are affected by the same thing you are affected by and to see them in their normal life. To have them see you in your normal life. It's almost like validation like, "I'm not really a loon, I just got something I got to deal with like everyone else has got their baggage."

Participant 6: I think one of the neatest things, (Participant 1) called me one night and said, "Did you see (Participant 8) on tv?"

Participant 8: Oh gosh.

Participant 6: I know. I have to brag on you, it's amazing. She was going down 183 and she happened to come upon this wreck. There was this little girl laying on the side of the road and blood and...how many AIDS tests have you had? A ton?

Participant 8: I have had my share.

Participant 6: So what did she do? And here is this kid covered in blood. She gives her mouth to mouth and tried to resuscitate her. They are interviewing her on TV and you can see the tears and when push came to shove, something inside kicked in. To this day, you never got an AIDS test have you?

Participant 8: I have had two since then.

Participant 6: But not right after that.

Participant 8: I did actually.

Participant 6: Oh you did? Ok.

Participant 8: I got one at the baseline test. The thing is, I was so OCD about it, she was worse than just blood, there was vomit, it was disgusting.

Participant 8: Sorry I know (Participant 6) is anti-vomit person (laughter). I went to the hospital afterwards and got a baseline test to make sure and they said they were going to check her too. I ended up getting her heartbeat to come back, but she ended up dying still. They said they said they were going to test her, but they never did so I got check again in six months. And they told me, "Well your test is negative," and I was like, "Well, yeah, I'm not worried about mine right now, I was worried about this other girl, so mine will be negative in six months." I also got on the AIDS drug just to make sure.

Participant 6: Oh I didn't know that?

Participant 8: Yeah and spent a lot of money on that. I was venting to a friend about it and he was like, "You know (Participant 8), you are just so blessed that you have the money to spend on it and if you need to do that, it's ok." I'm drug free.

Moderator: How long have some of you been in a support group? I know for one of you it's your first time, but for those who have been part of this group?

Participant 1: It's been about six years now, six years this past January.

Participant 8: This will be my fourth year.

Participant 2: This is my first time.

Participant 3: Well if you have been here four, I have been here six, because I her quite awhile before you.

Participant 4: I think this has been my sixth meeting, so not too long.

Participant 5: Over a year. I have been off and on out of the country.

Participant 6: Since 1996.

Participant 7: 2 months. I knew s support group would help but I didn't act on it. I had the print out. When I called I didn't think it was real. I thought the phone line would be disconnected of it someone answered it would be someone else.

Moderator: What about your first experience in a support group. What were some thoughts or feelings that were going through your mind?

Participant 1: It was a little bit nerve-racking. I really didn't know what to expect. I think I came to the support group just about the same time I started group therapy. In a lot of regards, I really didn't know what to expect. I didn't know if I was going to get better, there were a lot of unknowns. In that light though, that was one of the real benefits: it gave me a chance to sit down and talk to someone because I had never done that before. I didn't know what to expect, and come to find out it's a group of people who are a lot like me, who just have this issue to deal with. To see other people who were dealing with it and seeing them make progress and how they are able to control their lives, really gave me a sense of hope that I can go down the same path.

Participant 3: I guess with me when I first came, I thought I had OCD, but it didn't take me long to realize I didn't have the same thing. I do have a medical background but I don't have a computer so I did a lot of research and found out pretty quickly what I did have. My friend who had a computer did certain things and this OCPD popped up and out of 20 things, I had 17 of them. But I still kept coming because I liked the camaraderie and I kept seeing other people who came in who were like me. I come more to help other people who come in who really are the OCPD and they have no idea. I think it really is more to help other people. I don't think it has helped me that much. I think hoarding is very hard to get over, but the thing that has helped me the most is that clean sweep, where they go in a clean house, I see that and say, "Ew... those horrible people, ew..that looks like my house..layers and trails." Plus I have 10 dogs, I am in dog rescue, you see germs don't bother me. I would breed germs and I would get frustrated when they didn't grow (everyone laughs). I am coming from the other side of that. If someone comes in and they don't know what they have and are confused and worried one of us is going to be able to help them because they probably have the type of OCD that one of us has.

Participant 6: We have had one other lady, she is a hoarder, but she hoards like (Participant 3) does. (Participant 3) will hoard cans but then she takes them to recycling and gets money and buys bibles and stuff like that. It's not like somebody that has this fear of throwing this piece of paper away because 10 years down the line you may need that paper for something. Which is what I had a real problem with. It took me probably about 4 months to get everything completely and totally organized in our office after some 30 some odd years, 40 years. And you talk about a catharsis. It really gave me a sense of accomplishment, nobody else would probably understand that but to walk into the study and know that everything is labeled and filed and where it is suppose to be and to be able to get something out and get a number when I need it. It's just amazing. Since my husband is retired, we will go into the study and we have these two wonderful chairs its kind of like, "That's our den now!" We can sit there and turn the TV on, he plays on the computer and I rock, it's wonderful! I have maybe one other room to get to and I am done.

Participant 3: We really have seen a lot of people who come in with issues like (Participant 8)'s, serious things. Remember that girl that was afraid of those green neon lights? And the guy who patted a man on the back in Dallas and thought he brought the contamination down here.

Participant 8: I come primarily now, because I remember how scared I was 4 years ago, so I come now because it breaks my heart to see people dealing with this, they don't know where to go, and they finally figured it out, they come to the support group, and with morbid obsession OCD, and I am not saying its worse than any other OCD but it is scary, scary, scary, and when

you think that you are going to hurt somebody you love and you don't know why and all you can do is think about it, it is the worst feeling that I have ever known in my whole life. I think a lot of people when they decide to come to an OCD support group a lot of them go through some morbid obsessions or repetitive bad thoughts whether they are sexual or horrific, just terrible. I feel like for me, I am the token, person that has to deal with that too and I like to be like, "Hey dude, I've got it and I got my stuff together and you can live with it." Because I had never tried to kill myself but when I was going through that I could see why people would. I could never have even said that before. I was always the happy-go-lucky and my life was always so great and I always had an angel on my shoulder, who wouldn't want to be me, and all of a sudden, I went from on top of the world eating the biggest piece of humble pie you could get served, for me for those same people who are dealing with the same thing, feeling confident, comfortable, and good in their own skin to feeling like what is wrong with me, I am going crazy! And when you are going through that you can't talk about it enough. You feel like you have to let people know so they know I'm crazy, so they can run! And to see people go through the same kind of thing. A lot of people who come to this group have a morbid obsession.

Participant 6: That is like the girl who came last time.

Participant 8: The sexual one or whatever.

Participant 6: No. The one that just moved down here from Michigan. We were down stairs. When she called, and I should have called (Participant 8) and warned her but I didn't. But she had a lot of the same obsessional thoughts. You know that she could really relate to (Participant 8), so give (Participant 8) a call. When somebody calls like that, if you don't relate to them as well, your able to channel them to someone else.

Moderator: So what prompted you all to join the group? I am going to be interviewing some people at the end of the summer who don't attend support group meetings. But what got you involved and what motivated you to begin attending.

Participant 8: I couldn't find a shrink, in this town you can't find a shrink that can see you 6 months out. I needed as much information on it as possible. Finally I was like, I will try this support group and maybe they can turn me on. We share ideas of not only how to get over things but information on medication, good therapists, and the shrink I see now, she doesn't see new people but if I refer someone from the support group to her, she will see them.

Participant 5: I was so dysfunctional before I started. It had gotten so bad and if I got out of the house it was a good day because at the time I was dealing with headaches and I was so sure that I had a brain tumor. It seems ridiculous now, but I just started therapy, was debating about going on meds, I had never considered that before, and I needed someone that got it so I could say, "Hey I think I am going to kill my nephew, he is only 2 months old and I don't know why," and they wouldn't think I was completely off my rocker at least anymore than I did. You need someone when you are dealing with this.

Participant 3: I think it is good sometimes to bring a relative, a mother, a friend, somebody who things they're just nuts. You can say well I am kind of nuts but there is this group of nutty people and if you come you can get a better idea. I don't think any of us understand it, I think we learn how to deal with it. I think other people who hear us talk, they leave with a better idea that person is just one of many who has a problem.

Moderator: That's interesting that you mentioned relatives. Who do you feel like gives you support besides each other, but in your own personal lives who gives you support? Who do you have in your life that you feel like you can talk to?

Participant 1: My wife, I can talk to her about it to a degree but there is a point where she kind of reaches overload, she doesn't understand and after awhile, she just loses patience with it, not that I can blame her. The things that I put my family through, I wouldn't want to be put through.

Participant 4: My mom she wrote a research paper on OCD for her undergrad degree. For somebody who doesn't have it, can't really relate. They can try to understand, it's not their fault that is just how it is. She is major, major support. I have talk to numerous shrinks, psychiatrists, psychologists, been on an off meds, nothing has worked for me. I didn't think coming to a support group would be therapeutic in a curing sense, and its not. It doesn't take my OCD away. It is very therapeutic in a human sense. It is very nice to come and just relate.

Participant 6: It's kind of reassuring.

Participant 4: Yeah absolutely, and to hear other people's stories. I am very open about it with everyone, they are all pretty cool, but they don't get it. Unless you have it, you aren't an expert. Even the experts aren't experts because they don't have it.

Participant 5: I think it's really hard to know who you can trust sometimes. (Participant 8) and I, how can we go to someone and say, "I think I might kill you." I have a good friend, my nephews mother, I drug her to therapy with me. I was at her house so much and I didn't think it was very fair to her to be around it and not understand it.

Moderator: How supportive do you feel she has been?

Participant 5: She has been really incredible. She has done the work, read the books. I can't think of anyone, and even my parents are just great, but anyone else I know who would be strong enough to say, "Alright. You have vacuumed the carpets six times; now you have to stop." and that is what I need sometimes, someone to say, "Stop it, that is ridiculous!"

Moderator: Do you feel that you have someone that doesn't have OCD that you do or could talk to, when you are feeling stressed out or wanting to get something off your chest or is it just the group?

Participant 8: I talk to my sister. I have an older sister that has enough problems in her life for me to throw all mine at her. She is awesome. When I first was going through all this and I didn't know what to do, she researched the therapists for me, she was like, "We are going to get through this...Oh no, I'm coming up there...what do you need?" She lives in Houston. We talk everyday. And the blessing of this whole OCD, she is 8 years older, and we are like this now. She is hands down by best friend, my biggest supporter, and honestly I will say that the OCD has brought us closer together, we were a pretty decent close family but it has brought a new appreciation of my family to me. I guess that happens with all families you go through your ups and your downs. I always try to look at the positive in this and I think if I hadn't gone through this, maybe we wouldn't be as close as we are, and it's awesome. Even when I would go through breakdowns, she bought me these pajamas with toes on them that said totally cool all over them. It's just totally stupid. On the envelope on the outside she wrote, "I think you're" and on the inside I see these pajamas with frogs on it that says totally cool. Just the fact that she was holding my self-esteem for me and she was building me up, she would make me proud of myself and tell me someone values you. OCD really tricks with your self-esteem. It messes with

who you are inside and it prohibits you from doing things you love and creating relationships, and a lot of things. Just to have her in my corner, I think a lot and pray a lot about how wonderful I am to have her.

Moderator: Are there times you don't attend meetings? What are some negative factors that would keep you from attending them meetings?

Participant 4: For some people there is a problem, for people who have the contamination fear, getting in their cars, you don't even want to go outside.

Participant 8: I do feel bad because one time there was this girl who was afraid of Bennigans and I told her that when she does therapy they were going to make her write Bennigans in green over and over, and I do worry that maybe I scared her off because she really had this fear. Then I felt bad because I felt like I should have been more supportive because I am afraid she thinks now, "Well if I go there, that girl is really going to get my nerves going."

Participant 6: We had a couple of people that wouldn't come because they were afraid if they came, they would hear about somebody else's OCD and they would get it. I am like, "Woa, no. It doesn't work like that. It's not the power of suggestion either. It's what is in our own little brain that we conger up all these little goofy things. One of the things that I think if you listen to everyone in this group, at one time or another we have overthought everything so much, we take it down, and dissect it to the nth degree. There was this one guy who had two screws, a short screw and a long screw and he had to do these two screws in, and he got so fixated that he put the wrong screws in where they were suppose to go, so he went to his supervisor and said I think I screwed up. The supervisor said no you didn't because we have all these quality checks and it would not pass; it may get through one but not the other. So he went over his supervisor to the next guy and finally they said, "Look there is something that's not quite right here." No matter what his supervisor told him, it didn't work, he would have gone to the president. He ended up going on disability I believe and he came to the meeting a couple of times. But he said this was going to wind up in an airplane, I don't know why, and it was going to be flying over the ocean, and the plane is going to explode or fall apart because of him putting those screws in the wrong places and he was going to be responsible for all these people's death. Nobody could convince him. He was absolutely and totally locked in on this, he was traumatized to the point he wouldn't go anywhere.

Participant 5: You are just so bogged down with it. It doesn't matter what anyone says or how much sense anyone makes. It is always the worst possible scenario that it could possibly be.

Participant 6: It got him to the point where he was immobile. That is where you take OCD to the very far extreme. We have had people that have been on SSBI that cannot function. One of the NAMI groups, they had a lawyer there who was telling the group how to apply for SSBI, you can go to manic depressives, schizophrenia. The two visible examples he had was OCD. It was one with hoarders because you can visually go in a take a picture of how these people were living, not able to function, and not getting out of the house. that enabled them to fill out the paperwork and get the disability insurance because they were absolutely locked into their house and were living there 24/7.

Moderator: What would you say support groups offer for people with OCD?

Participant 8: I think what is different from this support group and most is that we are not like a 12-step program, we are more of a group that just shares and more of an intimate friendship circle, I think that a lot of people are discouraged because they think they are going to be on this



12-step program and I am going to have to get up. And here you don't have to say anything if you don't want to, you can share as much as you want, nobody is holding you to anything. The benefit of this one, that it is just merely support, there is no judging, everybody is dealing with their own stuff and we are using each other's OCD to help us get over our own OCD, the only rule is that we don't share outside of the group anybody's personal information. I can leave the group and say, "Somebody in our group has this story," without giving out their name.

Participant 5: It's an hour and a half where it is completely safe to be as crazy as you want in front of everybody else.

Nonparticipant 1: do you feel less alone?

Participant 5: Yes

Participant 8: Totally

Participant 7: I want to respond to the question about family. Not everyone has a supportive family. My naming what I had, it divided my family. When I got treatment for eating disorders it divided me and my sister. She went once to a support group with me and refused to go back. I had an eating disorder for years before I had OCD. She watches a lot of TV, where these people go in and clean up somebody's apartment on the weekend and she thinks if they can do it, I can. I am more terrified of her than I have ever been because of how she feels about taking care of me.

Moderator: Is this your sister?

Participant 7: Yeah. We are close in some ways but with my OCD we are not, that has divided us. I am terrified of being evicted. I am afraid the Fire Marshall is going to come in, look at my apartment and kick me out. They came in and installed smoke detectors and nothing happened. That has been almost a year ago, so maybe I will not get evicted but I am still terrified.

Participant 8: I'll tell you what, landlords, if you pay your rent on time, nobody cares.

(Nonparticipant 2): I'd keep those pictures to myself (everyone laughs)

Moderator: How many of you guys use the internet regularly?

Participant 1: I do.

Participant 6: I do.

Moderator: Do you ever use it to research anything for your OCD?

Participant 1: Oh yeah.

Participant 6: Absolutely.

Moderator: What sites do you find helpful?

Participant 1: The OC Foundation, I also use a social networking site. There are several out there for OCD. You said you use one for anxiety?

Participant 5: Yeah I go to a chat room.

Participant 8: (Participant 1) is great because if he gets something about morbid obsessions he will forward it to me and in my Outlook I have a little thing that says OCD and I will put it in there and when I start freaking out about stuff, I will go through and read other stories and I will say, "Ok other people are dealing with this," I haven't had to in awhile, so now they are just sitting there. I feel like it's a little tool, I can have later.

Moderator: So do you use the internet a form of communicating about your OCD with other people?

Participant 1: Uh-huh

5: Yeah, most of us are online. We use it to talk to each other too.

Moderator: How do you see that as different than this setting?

Participant 5: You saw each other yesterday and you are having a problem today I can just say, "Hey (Participant 8), I am having a real problem and I need some advice."

Moderator: I found the OCD Tribe, are any of you familiar with that?

Participant 1: Uh-huh, oh yeah.

Moderator: Well I have joined, I am a member and so is my uncle. I actually am getting people who have OCD, who are only members of the OCD Tribe and do not go to a face-to-face support group, and I am doing a survey for them via email.

Participant 1: Oh, ok.

Moderator: They will be filling out a survey for me. So I am trying to see what their thinking is in terms of how they communicate through online support versus face-to-face support.

Participant 1: The online group is nice because you can almost always find some one to chat with, and you have a pretty wide audience, with the opportunity to get a wide variety of opinions and experiences. I have gotten this from others online through the OCD Tribe. There is a fear of face-to-face.

Participant 6: Why?

Participant 1: I think I can understand that a little bit because I have always had a little bit of that social anxiety. To get there that first time was a big deal for me. I think I get more out of the face-to-face support groups. The face-to-face groups have the advantage of more intimacy. You can look at the person you are speaking to, you are not just receiving their words, but you hear their tone of voice, you see the expression on their face, and you see the body language. It just seems to be more gratifying.

Participant 5: Yeah I came that first time, had a panic attack and ran out!

Participant 6: Yeah but you came back.

Participant 5: Yeah but it was still scary.

Participant 8: I think I am on the opposite end. I like the fact that we have the group and we have trust and camaraderie opposed to throwing my goods out on the internet (everyone laughs) "Yeah so I thought about asking my boyfriend today...oh ok you want to date?"

Moderator: How many of you use the OCD Tribe?

Participant 1: I think I am the only member.

Participant 5: I do.

Participant 1: Oh ok.

Moderator: Is it easy to talk to people on there?

Participant 1: Yeah it really is.

(Nonparticipant 2: Does it take a while?)

Participant 1: It kind of takes a while to build up a little bit of network. You do on there and there is like 5,000 members. I started reading people's blogs and if I thought I had something to contribute, I would. I think I contribute more, I really don't use it as much for my own benefit, I am not a big blog writer, I don't usually use it for advice. I try to give more than I receive, I guess.

Moderator: I am very interested in it. I mean we are in this electronic media world that so many young adults and others people use this media form as a form of communication and a form of social support.

Participant 5: I started out in a chat room before I ever went into therapy and attended groups because it felt safer, if I started feeling anxious I could close the window and be done with it. Here that is not really an option, they all know me now.

Participant 6: I don't go online with a group because we really didn't have a good computer, we are dial up, and I read really slow. I don't know how to type and it would have taken me forever. We have updated our equipment and I just peck along. Needless to say, that wouldn't be my forte at all.

Moderator: The last thing I wanted to discuss how you feel about how other people who do not have OCD, view people who do? Also what is your view on the media and how they portray OCD (the TV show Monk is an example). Do you feel that it is accurate?

Participant 1: No it's not accurate at all. I don't think they really have any idea.

Participant 8: You can't demonstrate or show someone the fear you have inside, when you are dealing with OCD.

Participant 5: The thought process is such a radical....

Participant 8: And people think it's funny, which actually is better because as opposed to when people say OCD, they think, "oh they are organized or whatever" and when you say

schizophrenia they think, "oh they are crazy" So I would rather be saying, "Oh hey I have OCD."

Participant 5: Monk is hysterical though everyone loves that show. I don't know if it's all or really if its extreme but they think all people with OCD are terrified of milk.

Participant 8: I haven't seen it. I don't have cable.

Participant 1: It's pretty funny.

Participant 8: Is it?

Participant 6: One of the things, if I can figure out how to download it from my DVR to tape. Oprah had a show on OCD not too long ago and I haven't watched it yet. There are some shows out there that have been very good. I think the more that is out there the better it is. You were talking about McIngvale and when I got the brochure from the OCD Foundation I called and I was really kind of upset because I had seen her on Oprah and I think one other show. She, from what I can gather, was not on meds, I may be wrong. And she had been in the Menninger clinic I think three times. I don't understand why she was so adamant about that. I said, "you know that's giving the wrong impression", there was a real short blurb on the Oprah show when she was there where a doctor said don't discount meds, and I said, "well that was just a few seconds." So many people benefit from a combination of medicine and therapy, whatever kind it is. I said "don't overlook it; you can always stop the meds and you can start but don't discount them." There are all these things out there for the people to make available to them. That is my big deal about the support group is trying to encourage people to take advantage of all the resources that are out there whether it is the internet, or meds, or doctors, or therapy. You can't just sit there and blanket discount and say "um no don't like to take meds."

Participant 5: I can certainly understand why people wouldn't want to. There is stigma.

Participant 8: I was scared of it.

Participant 6: Yeah there is stigma but...

Participant 5: It's a popular thing to do now. You tell someone, "Oh I have an SSRI," It's almost like it isn't counted anymore because everybody has an SSRI.

Participant 6: And I will have friends that say, "What is that again? What is that PMS?" And I am like, "No it's not PMS, it's OCD!"

Moderator: That is interesting that you mentioned that the stigma. What stereotypes and stigma do you think or have you heard.

Participant 1: Well the first thing that comes to mind is when people hear OCD they think about people with contamination and they think oh its someone who washes a lot. They don't think it could be other things.

Participant 8: Well I don't leave my Paxil out on the bathroom counter if a guy comes over like I am digging through his cabinets (everyone laughs). I don't want the stigma right up front. I think whenever you are on medication, for me its like, "I'm on medication," "Oh God."

Participant 5: I know. I'm terrified to tell people. I have done temp work for (Participant 8) for about a year now, but I always take it when lunch time comes and I have to go somewhere to hide when I take these things because I feel that if they see, they will think I am insane and they will get rid of me.

Participant 6: I'm just the opposite. The more people that know about it. I did an interview for two channels, 4 & 3. I was playing golf one day and we were all upstairs eating lunch and I had people come up to me and say, "We saw you on television, we didn't know you had OCD." And I say, "Yeah. I had it all my life." And they are go, "Wow." There was no stigma to it, it was amazing. I was playing golf with one girl and she had a real bad stomach virus and had been really sick and this was her first day out. The whole time I was thinking about it and finally I said, "You know I am so sorry but, getting sick is one of the worst things", and she said "I am really ok but I understand." A few days later she called me and asked if I was doing ok and I said, "yeah."

Participant 8: No thanks I'm sick now! (everyone laughs)

Participant 6: It's not an excuse (referring to telling people). It's explaining why, I maybe sitting on the edge of the cart like this or go through 300-400 handi-wipes.

Moderator: How do people you know feel about you being in this support group? Family, whoever you live with. Do they promote the idea?

Participant 1: Oh yeah.

Participant 5: I think my family was like, "Ok, she's got someone else to talk to now.

Participant 8: I think my friends think its weird but my family is really supportive. I think my friends are kind of like, "Why are you doing that?"

Participant 4: Everyone who I talk to my OCD about is fine with it. I am even talking to dudes that are drinking beer and watching Bevis and Butthead every night. I think everyone is pretty supportive about it.

Participant 6: You don't know who Bevis and Butthead is?

Participant 3: Oh yeah, I just didn't hear what he said. I just heard butt. Oh, yeah I know who they are.

Moderator: Have y'all had problems with your insurance company?

Participant 1: Oh yeah.

Participant 5: God yes. (everyone laughs)

Moderator: Because he (my uncle) has had a lot of trouble.

Participant 1: The guy I see is not on my coverage. It's hard to find someone who it truly qualified. I get some back but it's like....

Participant 8: I just tell them point blank, "Dude I'm self pay. What kind of deal can you give me. And they well, they will cut you phat deals man!" \$50/hour compared to \$120 or whatever. Not like Mansbridge, he just likes to gouge your eyes out (everyone laughs).

Participant 6: Yeah.

- Moderator: Well thank you so much for your time. I appreciate you allowing me to come down here and interview you all.

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## BIOGRAPHICAL INFORMATION

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