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## The Co-Occurring Disorder Patient: Effects of Stigma, Perception of Care, and Treatment

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The Co-Occurring Disorder Patient: Effects of Stigma, Perception of Care, and Treatment

Lauren A. Giglia

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**Abstract**

The topic of stigma as it relates to the mentally ill and chemically addicted population has recently become more prominent in clinician discussion than it has been in the past. Patient's perception of care regarding this topic has also been amplified in discovering more information about stigma. This article will provide insight from a program evaluation that looks into the topics of perception of care, stigma, as well as implications for treatment.

**The Co-Occurring Disorder Patient: Effects of Stigma, Perception of Care, and Treatment**

The topic of stigma as it relates to the mentally ill and chemically addicted population has recently become more prominent in clinician discussion than it has been in the past. Treatment facilities want to know more about patient's experiences with stigma in order to address their emotional and mental states more effectively. Recently, hearing the opinions of patients in treatment settings have been recognized as being more useful to understanding their perceptions of the care they are receiving. Ignoring stigma is currently the subconscious approach most clinicians and treatment facilities in general adhere to, creating a society of those in recovery that are left wounded with feelings of anger, shame, sadness, and fear based on feeling stigmatized. These feelings expressed by patients who are currently in treatment propose that stigma is a steady barrier to recovery and treatment of addiction and mental illness, otherwise known as co-occurring disorders. Remaining ignorant to stigma may only perpetuate addiction and mental illness, resulting in unsuccessful healing through attempts at recovery. This remains a problem not only for those seeking treatment in addiction and mental illness, but also the entire field of healthcare workers who treat co-occurring disorders (mental health counselors, doctors, nurses, social workers, etc.). The importance of patient's perception of care is a driving force in understanding their needs in treatment. Utilizing patient insight can provide information regarding the treatment center's approach to addressing stigma, as well as many other concepts in patient care.

According to literature, stigmatization of those who experience addiction, mental illness, and/or recovery affects one's personhood (Corrigan, 2005). These effects are known to cause perpetuating vicious cycles of health concerns (Earnshaw, Smith, & Copenhaver, 2012; Corrigan, 2005). These concerns, usually affecting physical and mental health, can be addressed

if the person seeks help through a mental health treatment facility. Yet those who experience stigma solely based on their addiction and/or mental illness often encounter multiple barriers to success in treatment (Earnshaw et al., 2012; Corrigan, 2005). These barriers include, but are not limited to; a lack of support due to disheveled relationships, incapacity to trust others, and lowered self-esteem (Earnshaw et al, 2012; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Perlick et al., 2001). This review will discuss literature about how these barriers have been shown to be directly related to the individuals' experience with stigma. This review consists of material from studies and research done within the area of understanding the effects of stigma on addicts and the mentally ill, as well as their ideas on satisfaction of treatment. For the most part, addiction and mental illness will be looked at separately since co-occurring addiction and mental disorders as well as the effects of stigma have not yet been studied, thoroughly. The literature emphasizes effects on relationships, trust, and self-esteem which will be comprehensively discussed. These three concepts have also been identified and explored in the current research on the subject and will be discussed.

## **Review of the Literature**

### **Stigma Defined**

Stigma is a socially constructed generalized term that involves devaluing someone based solely on their behavior or attributes (Earnshaw et al., 2012; Corrigan, Kuwabara, & O'Shaughnessy, 2009). This term is usually used to describe what is known as public-stigma (Sanders, 2012). Public stigma refers to the impact that social discrediting due to an attribute or behavior (also known as stereotyping) has on that individual (Corrigan et al., 2009). Self-stigma is a term that explains the phenomenon of internalizing public stigma (Corrigan et al., 2009). The



concept of stigma contributes to the phenomenon of the socially constructed addict. Due to stigma people think, feel, and react differently about individuals who experience addiction and mental illness. This creates a particular negative social view of these individuals. For instance, common words used to describe addicts are; “junkie”, “crack head”, “pothead”, “drunk”, and “pill popper”. These potentially hurtful terms have been solidified and socially accepted as synonyms for the word addict.

### **Sources of stigma.**

Stigma is regularly associated with concepts such as prejudice, stereotypes, and discrimination. These three concepts are important when discussing enacted stigma and anticipated stigma. “Enacted stigma involves experiences of prejudice, stereotypes, and discrimination from others in the past; and anticipated stigma involves expectations of experiences of prejudice, stereotypes, and discrimination from others in the future” (Earnshaw et al., 2012, p. 112). Those who experience prejudice due to their addiction or mental illness feel negative emotion from other individuals. These emotions can be expressed as anger, fear, disgust, and shame. Some stereotypes that are associated with individuals who are addicted to substances or are mentally ill is that they are “out of control” and non-compliant (Earnshaw et al., 2012). These stereotypes evolve from opinions made by groups of people about one individual, which then becomes affiliated with the group that individual associates with. In this case, one person with mental illness may act in a way where another person would identify all mentally ill people with the same characteristics. Discrimination transpires when individuals react behaviorally through prejudice. This can happen when an addict or mentally ill individual is gossiped about or is fired from their job, for example. In most cases, prejudice towards people with addiction or mental illness derives from health care workers (Earnshaw et al., 2012). There

are other ways people can experience stigmatization such as through the media which will be discussed in the next section.

### *Media.*

Another aspect of stigma that those who experience addiction and/or mental illness might encounter is public humiliation. The media is known as a “significant social force in creating stereotypes” (Sanders, 2012). Reality television of celebrities in recovery, commercials portraying drug use negatively as a means of harm reduction, as well as stories on the news are all examples of displaying addicts and the mentally ill in a stereotypical matter. Most recently, celebrities in recovery such as Lindsay Lohan have engrossed celebrity media regarding her struggle with addiction and relapse. Other celebrities such as Philip Seymour Hoffman and Cory Monteith have unfortunately lost their lives due to drug overdose and have been judged throughout the media based on their drug use. For instance, Debie (2014) writes on the death of Hoffman;

“Whenever someone famous dies, there seems to be this immediate attempt by far too many people to make their life and death insignificant, as though the death of a celebrity somehow negates the death of all the other people who died on that given day. People attempt to place more value on the lives of some people, less on others, claiming that the celebration of the death of a celebrity is a misplaced outlaying of our efforts. I argue the opposite, obviously, particularly in situations like this one where there is so much opportunity for us to learn about addiction, about mental illness, about why lives end this tragic way.

The opportunity is there, without question. The issue is whether we, as a society choose to seize

it, or whether we chalk this loss up to drug use and wave it off indifferently as another selfish life wasted.”

Debie (2014) engages us to think critically about the judgment placed on those who lose their lives from drug overdose. Not only does Debie acknowledge that society stereotypes a drug user as “selfish,” but the writer mentions that we as a society accept selfishness as the conclusion and ignore any other meaning behind the death of an overdose.

### ***Public and self-stigma.***

Similarly to the idea of public humiliation, public stigma also has a grand effect on those that are stigmatized. These are important aspects of understanding stigma because we are unable to truly understand the effects stigmatization might have on a person without fully comprehending all forms of stigma. The concept of public stigma is defined as “the impact that members of the general population have when they endorse negative stereotypes” (Corrigan et al., 2009, p.140). Public stigma is often related to the media because the general population receives information regarding stereotypes through this venue. According to Corrigan et al., (2009), due to public stigma those who experience mental illness and addiction often are unable to enjoy certain aspects of a meaningful life such as a satisfying career, intimate relationships, and the comfort of a home. This study looked at the impact of public and self-stigma on those who experience mental illness and addiction and found that individuals felt more stigmatized by their addiction than their mental illness (Corrigan et al., 2009). For instance, those with substance use dependencies were viewed more negatively than those with schizophrenia who then were viewed more negatively than those with depression (Corrigan et al., 2009).

### **Relationships.**

Support of family and friends, as well as significant others are a large part of recovery and treatment for addiction and mental illness (Corrigan, 2005). Those who are able to maintain healthy relationships are thought to succeed at higher rates than those who do not have healthy, stable relationships. In some cases, relationships can be dismantled in active addiction causing shifts in the addict's stability of maintaining relationships with others. This section will look at the effects that stigma has on relationships with the addict or mentally ill person.

### *Friends and family.*

In a qualitative study where individuals who are addicted to substances were interviewed about their experience with stigma, about 30% of the statements were related to stigmatization from friends and/or family (Earnshaw et al., 2012). Families were more stigmatizing than friends, and in particular, parents were the most stigmatizing. Participants specifically spoke about a "lack of caring or warmth" from family members (Earnshaw et al., 2012, p. 115). The stereotype of being untrustworthy was the most predominant from family in this study. Participants discussed their feelings about being viewed as "untrustworthy" from their parents and other family members. One participant stated (Earnshaw et al., 2012):

"Even though now that I'm clean, I'm in recovery, my mom and dad rarely even talk to me. Every time they see me, they have in the back of their mind, 'Is he clean?', 'Is he gonna steal from us again?', 'Is he a changed individual?' It seems like my mother and father wouldn't give me the benefit of the doubt."

Here, this participant explained the phenomenon that family and friends may never trust the addicts in their lives again. This feeling is not based on their current behaviors in recovery, but past ones in active addiction (Earnshaw et al., 2012). Participants also went on to articulate that

they felt as though their families did not understand addiction and they often believed the addicts would end up using again (Earnshaw et al., 2012).

### *Healthcare professionals.*

Healthcare professionals involved with treating addiction and mental illness include doctors, nurses, counselors, and other professionals. As stated earlier, healthcare professionals are noted from those who experience addiction as being the most prejudiced (Earnshaw et al., 2012). This means that the participants have described feeling the most negative emotion from healthcare professionals than any other category of people in this study (Earnshaw et al., 2012). Once again, participants explained that healthcare professionals treated them as untrustworthy. In this sense, participants explained that they felt as though healthcare professionals “did not care about their well-being” and would not help them treat pain in some cases due to skepticism that the participants were “drug seeking” (Earnshaw et al., 2012). In many cases, participants explained noticing a difference between speaking with healthcare professionals before and after disclosing their past use of substances.

In other cases, participants explained differing feelings among healthcare professionals. Some explained that they felt opposite feelings from nurses than they did from doctors. For instance, one participant explained how a nurse may be frustrated with someone in active addiction, but does not act towards them with negative emotion (Earnshaw et al., 2012):

“They do get frustrated with having to see the same people over and over and over again, or a young kid come in that’s overdosed because, to them, they’re trying to save lives and they’re [the patient are] just doing something stupid and being selfish and stuff, like, you

know, being reckless with their lives...and it's frustrating to them [the nurses], but they don't have a hate or an anger."

The difference explained here is that participants feel negative emotion such as rudeness or coldness from doctors, yet not always from nurses. Some participants stated that they thought nurses were more understanding. They also explained "that nurses were more likely than doctors to be empathetic and non-stereotyping" (Earnshaw et al., 2012).

### *Perception of care.*

As mentioned above, receiving opinions and insight from patients themselves can be very powerful and influence the procedure of treatment. According to Connors (2009), "the concept of 'patient satisfaction', defined as the subjective result of expectations and experiences within health systems, has gained prominence over the past several decades and is now recognized as a central component to effective addiction treatment models." Often times asking for the patient's opinion on their services can foster improvement in treatment facilities by recognizing gaps in patient needs. For instance, a study conducted by Connors (2009) proved that patients in a methadone maintenance treatment program stated that they desired less group therapy services and more focus on organized recreational activity at the treatment center, as well as involvement in leisure activities outside of the facility. These patients also included that they would like to have their families more involved in psychotherapy (Connors, 2009). Overall, this study found that according to consumer satisfaction improvement needed to be made most with individual and recreational services (Connors, 2009). In another article, Deering, Horn, & Frampton (2012) describe how overall patients are satisfied with the care they receive in addiction treatment centers. The authors include that limitations to satisfaction involve restrictions placed on patients

due to specific day to day changes in their lives. These changes are associated with opiate replacement therapy, such as methadone, that requires patients to come into treatment on a daily basis, for example.

### **Trust.**

Those who experience addiction are not easily trusted by friends, family members, and healthcare professionals based on their past behaviors and not current ones (Earnshaw et al., 2012). These stereotypes, prejudices, and in some cases discrimination lead others to not trust those who experience addiction or mental illness based solely upon factors of stigma. The paradoxical effect that occurs when an addict is not trusted by others perpetuates untrustworthiness and therefore the addict does not trust their friends, family members, and healthcare professionals either.

### ***Anonymity.***

The concept of remaining anonymous is one that has been important in addiction and recovery for many years. Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) both explain this importance in their 12 traditions, whereas tradition numbers four, ten, and eleven all pertain to the idea of remaining anonymous. For instance, tradition four of AA states, “each group should be autonomous except in matters effecting other groups or A.A. as a whole” (Alcoholics Anonymous, 1935). Just recently, a film called “The Anonymous People” looks at this new phenomenon of remaining anonymous in addiction contributing to stigmatization based on lack of communication about the subject. For instance, it is thought that because addicts and alcoholics want to remain anonymous, that they are not speaking about their feelings with the people who are judging them. The concept of wanting to protect one’s image by remaining

anonymous also contributes to the stigma that addicts and alcoholics endure. Remaining anonymous also provides the subconscious mindset that addicts and alcoholics can only self-disclose to other addicts and alcoholics and that it is not permissible to discuss their addiction with anyone else.

### **Self-Esteem.**

According to Rodrigues et al., (2013), those who experience co-occurring disorders also experience lower self-esteem due to relapse and noncompliance to treatment. More specifically, acceptance of stereotypes, disengagement of treatment, the possibility of relapse, as well as the likeliness of unsuccessful recovery all attribute to low self-esteem in those who experience stigma due to co-occurring disorders (Corrigan, Watson, & Barr, 2006; Livingston & Boyd, 2010; Lysaker, Tsai, Yanos, & Roe, 2008; Watson, Corrigan, Larson, & Sells, 2007; Yanos, Roe, Markus, & Lysaker, 2008; Corrigan, 2007; Fung, Tsang, & Corrigan, 2008; Marlatt & Gordon, 1985; Link et al, 2001; Perlick, et al, 2001; Sirey, et al., 2001). Corrigan (2005) states that if society judges a person negatively, that person is more likely to think negatively of themselves. Feelings of guilt, shame, and disgust stem from these negative cognitions which then foster lower self-esteem and feelings of worthlessness and hopelessness which are sometimes worse than the addiction or mental disorder originally being treated (Corrigan, 2005).

Some believe that one way to extinguish stigmatizing those who are addicted and mentally ill is to explore the biological cause and effect of the diseases which may in turn help the public better understand how they are treated (Sanders, 2012; Schomerus, et al., 2012). This idea has been evidenced by the treatment, education intervention, and decreased stigma of HIV and AIDS (Stangl, Lloyd, Brady, Holland, & Baral, 2013). Along with this same concept, other theories about overcoming stigma involve the idea that once the public becomes more



knowledgeable and understanding of addiction and mental illness reasons for stigmatization will decrease (Schomerus et al., 2012). According to Boysen and Vogel (2008), the best ways for others to better understand the mentally ill is through education intervention.

Understanding the experience of those feeling stigmatized could better educate healthcare professionals in order to work more effectively with stigmatized populations. In turn, this could improve patient's perception of care. Individuals who experience addiction as well as mental illness will be discussed as well as reports of feelings of stigmatization from friends, family members, healthcare professionals, as well as the media and public in general. Patient satisfaction has also been explored with ideas on how to better work with those who are in treatment. Self-esteem as well as the ability to trust and be trusted, is also affected by feelings of stigmatization. In summary, this literature represents a beginning foundation of being able to better understand concepts of how stigma affects those who experience addiction and mental illness, as well as patient's opinion on services. The present study will determine further how individuals who experience co-occurring disorders are affected by stigmatization through a qualitative survey. This study will also examine through a Perception of Care Survey the satisfaction of treatment in a chemical dependency treatment facility in Western New York. Specific research questions include: If you are a person in recovery have you been stigmatized? If you are a person with mental illness have you been stigmatized? If you are prescribed methadone have you felt stigmatized? If yes to the previous questions, how did you feel? And, what do you think should change in order to reduce stigma among those who are in recovery, mental illness, and/or methadone? Information from the study will then be utilized within a chemical dependency treatment program to include aspects of working with stigma, as well as improving patient care, if needed.

## **Methods**

### **Setting**

This program evaluation took place in an outpatient chemical dependency and methadone maintenance program in the Northeastern United States of America. Services at this clinic include individual and group therapy, as well as opioid replacement therapy such as Methadone and Suboxone, in an outpatient environment. This treatment center is located in a hospital setting, in an urban surrounding. This clinic serves 598 patients amongst the chemical dependency and methadone programs. 335, or 56%, of the clinic population identify as male while 263, or 44%, of the population identify as female. Two patients identify as Alaska Native, one patient identifies as American Indian, two patients identify as Asian, ninety-six patients, or 16% of the clinic population, identifies as Black/African American, 69% of the clinic population, or four hundred and eleven patients, identify as White, one patient identifies as Pacific Islander, 12% of the population identify as Puerto Rican, one patient identifies as Mexican, one identifies as Cuban, while eight patients identify as another Hispanic race that has not been listed. 77% of the population name English as their primary language. One patient identifies French as their primary language. Thirty-six patients name Spanish as their primary language. One patient identifies Hindi as their primary language. While three patients state that Sign Language is their primary language. Participants were presented with the option to provide data while in a group therapy room or while waiting for their methadone dose in an open waiting area of the treatment center.

### **Participants**

This research project used a purposive sampling procedure. This program evaluation was open to all patients at the clinic. Both Stigma and Perception of Care Surveys were advertised to all patients within the clinic. Participants chose whether or not they would respond to the surveys. 114 out of 300 patients responded to both the Stigma and Perception of Care Surveys.

Participants ranged in age from 21 to 55 and over. 39% of participants acknowledged ranging in the ages of 25-34. Another large age group identified is from 45-54, with 31% of participants. 56 % were male, while 44 % identified as female. 8% of participants identified as Hispanic, 3.5% as American Indian/Alaska Native, 76.3% as White, 13.2% as Black/African-American, and 4.4 % identified as “other”, and 2.6% did not answer the question about race. 53.5% of respondents report their primary reason for receiving services to be for both mental illness and substance use. 44.7% identified solely with substance use, while .9% or 1 respondent said they were receiving services only for mental illness. For the purpose of this program evaluation, respondents who identified with co-occurring disorders (therefore 53.5% of respondents) will be analyzed in the results section.

### **Measurement Instruments**

Two surveys were utilized in this program evaluation. The first survey was administered in April 2014 and asked questions based on stigma. It consists of five short answer questions regarding the concept of stigma. The survey was created by the researcher and was approved for the purpose of a program evaluation by the research investigator and the program’s director. These questions include:

- (1) Have you ever felt stigmatized being a person in recovery or active addiction? If so, please explain.
- (2) Have you ever felt stigmatized being a person with mental illness? If so, please explain.
- (3) If you are currently prescribed Methadone or Suboxone have you ever been stigmatized by others (i.e. peers, doctors, professionals)? If so, please explain.
- (4) What changes do you believe need to be made in order to reduce stigma towards people in addiction, recovery, people with mental illness and/or people currently prescribed Methadone or Suboxone?

This survey was analyzed through a qualitative lens by which themes among responses were collected. These themes were then interpreted into multiple aspects of stigma that will be discussed later on. The validity of this instrument is deemed to be high based on reviews from the director and research

investigator of this program evaluation. Reliability is also deemed high from the same two persons mentioned previously, as well as other experts in qualitative research.

The second survey was administered in August 2014 and represented the patient's perception of care. This survey, "Perception of Care Survey", is developed by the Office of Alcoholism and Substance Abuse Services (OASAS). This survey consists of 16 different questions among 3 different parts. These parts are broken down into three different concepts. Part 1 consists of demographics of participants and asks about age, gender, race, and length of time in the current program. Part 2 is entitled "What kind of services are you receiving?" This section asks questions pertaining to specific services within the fields of substance abuse and mental health counseling. In Part 3 participants are asked to rate their services with the use of a rating scale utilizing answers such as disagree, somewhat agree, agree, and strongly agree. This part is named, "What do you think about the services you received?" Participants are also asked to provide their written opinion about what they believe the program is doing right and what they believe could be improved. Descriptive statistics were utilized when analyzing the data, and frequencies were performed in order to better understand the opinions of the co-occurring disorder patients.

### **Procedure**

Measurements were administered to participants in two separate occasions. The stigma survey was distributed in April of 2014 to the entire treatment center in a group therapy setting. Participants were given 15 to 20 minutes to fill out the survey and hand them back to the researcher. The Perception of Care Survey was distributed in the same fashion, yet took place in August 2014. Each survey was distributed over a span of three weeks. The researcher was available in most rooms in which the surveys were administered. Oftentimes, the researcher was a nonparticipant in the room while surveys were administered. Other staff members from the treatment center such as counselors, nurses, and doctors were also involved in distributing the surveys.

### **Data Analysis**

The stigma survey was analyzed through a qualitative lens by which the researcher typed all of the responses in a word document. Statements were then separated based on themes related to the prevalence of stigma in their lives. These themes are addiction, self-esteem, family/friends, healthcare, and career. These topics will be further discussed in the upcoming Results and Discussion sections.

Questions 1 through 13 on The Perception of Care Survey were analyzed quantitatively with the use of SPSS. The last three questions of the survey were analyzed through a qualitative process. The researcher typed all of the responses into a word document and separated them by question. A limited number of themes were then pulled from the answers provided. Themes pulled from this survey are compassion, accountability, sobriety, group therapy, individualized care, Methadone, and gratitude. These concepts will be further discussed in the following sections.

## **Results**

### **Perception of Care**

As mentioned previously, 53.5% of respondents report that their primary reason for services is to attend to both mental health and substance use. For the purpose of this program evaluation, these participants will be looked at in great detail in order to better understand the co-occurring disorder needs according to perception of care, as well as effects of stigma.

Participants were asked to use a scale including the terms disagree, somewhat agree, agree, and strongly agree to answer multiple questions regarding their care. When asked to disagree, somewhat agree, agree, or strongly agree to the statement, “As a result of the program services I have received, I am less bothered by my symptoms”, 24.6% of co-occurring patients reported to strongly agree, 39.3% said to agree, 32.8% somewhat agree, while 1.6% disagree. Please note Figure 1.1.

**Figure 1.1**

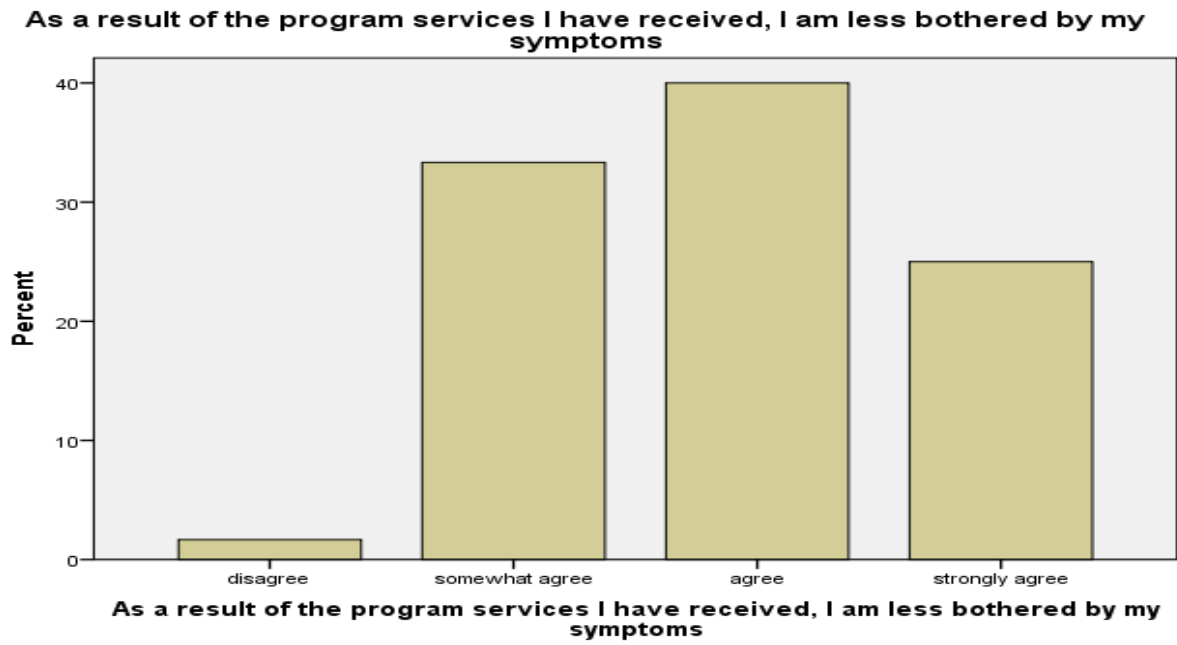


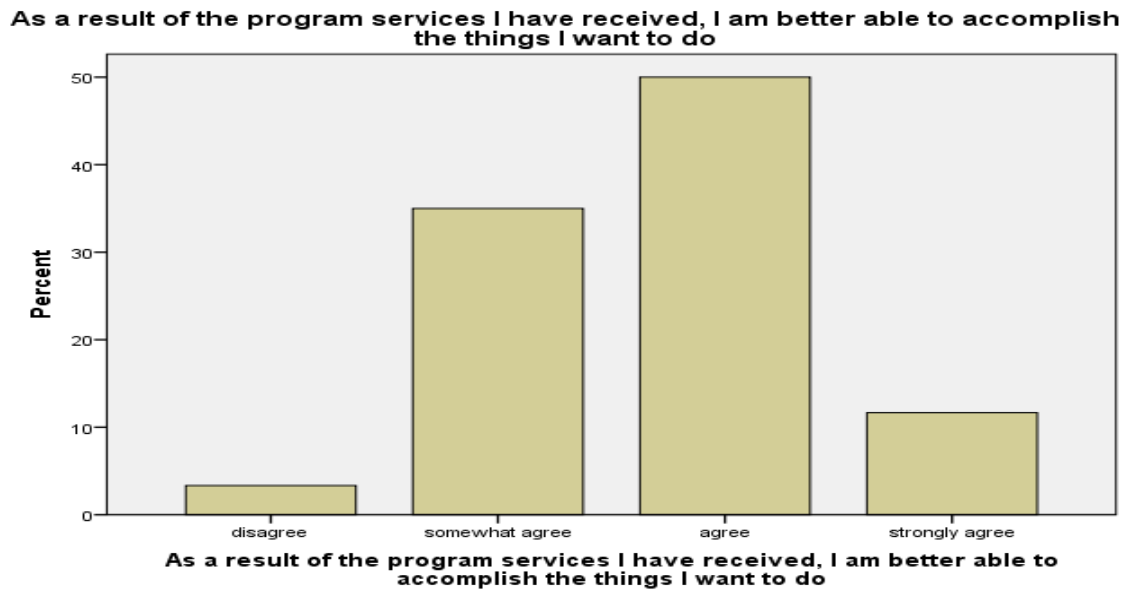
Figure 1.2 shows that when participants responded to the statement, “As a result of the program services I have received, I am better able to cope when things go wrong” 3% disagreed, 31% somewhat agreed, 38% agreed, while 26% strongly agreed.

**Figure 1.2**



According to Figure 1.3, “As a result of the program services I have received, I am better able to accomplish the things I want to do”, 3% disagreed, 34% somewhat agreed, 49% agreed, and 12% strongly agreed.

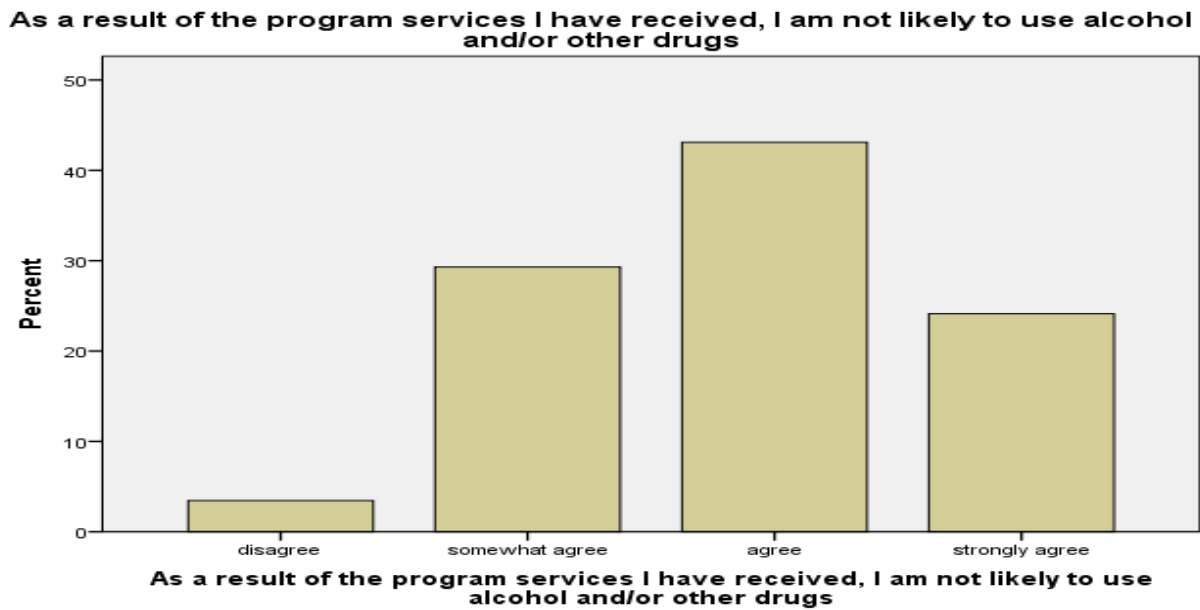
**Figure 1.3**





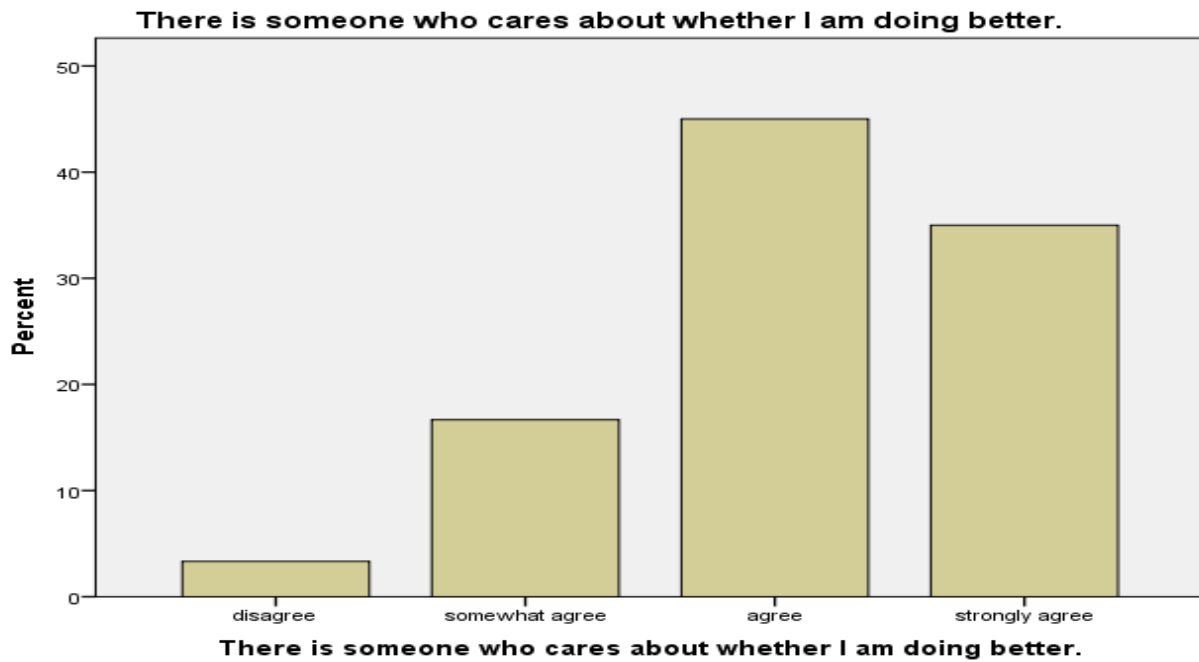
When discussing patient's progress in treatment specifically regarding their use, they answered questions based upon their likelihood to use alcohol or other drugs. In Figure 1.4, participants stated that 3% disagreed, 28% somewhat agreed, 41% agreed, and 23% strongly agreed that are "not likely to use alcohol and/or other drugs" as a result of the program services.

**Figure 1.4**



Next, some of the results found in the perception of care survey that marry the concepts of the stigma survey will be shown. In Figure 1.5, the statement “There is someone who cares about whether I am doing better”, is presented. 3% disagreed, 16% somewhat agreed, 44% agreed, and 34% strongly agreed.

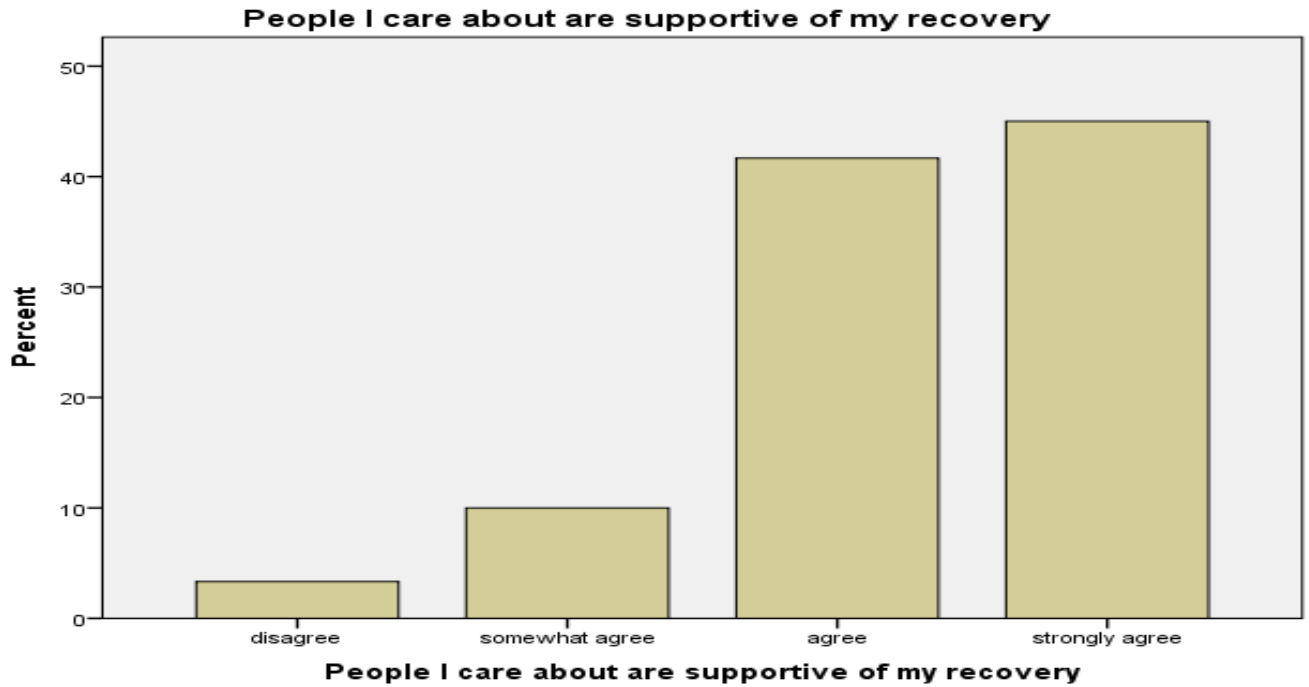
**Figure 1.5**



The next question asks participants to respond to, “People I care about are supportive of my recovery.” 3% disagreed, 10% somewhat agreed, 41% agreed, and 44% strongly agreed.

These results are presented in Figure 1.6.

**Figure 1.6**



The next questions address patient's opinions regarding returning to and recommending the program to others. When asked to decipher if they would return to the program in the future, there were not any respondents that disagreed. 5% of participants somewhat agree, 43% agree, while 53% strongly agree. These responses are displayed in Figure 1.7.

**Figure 1.7**

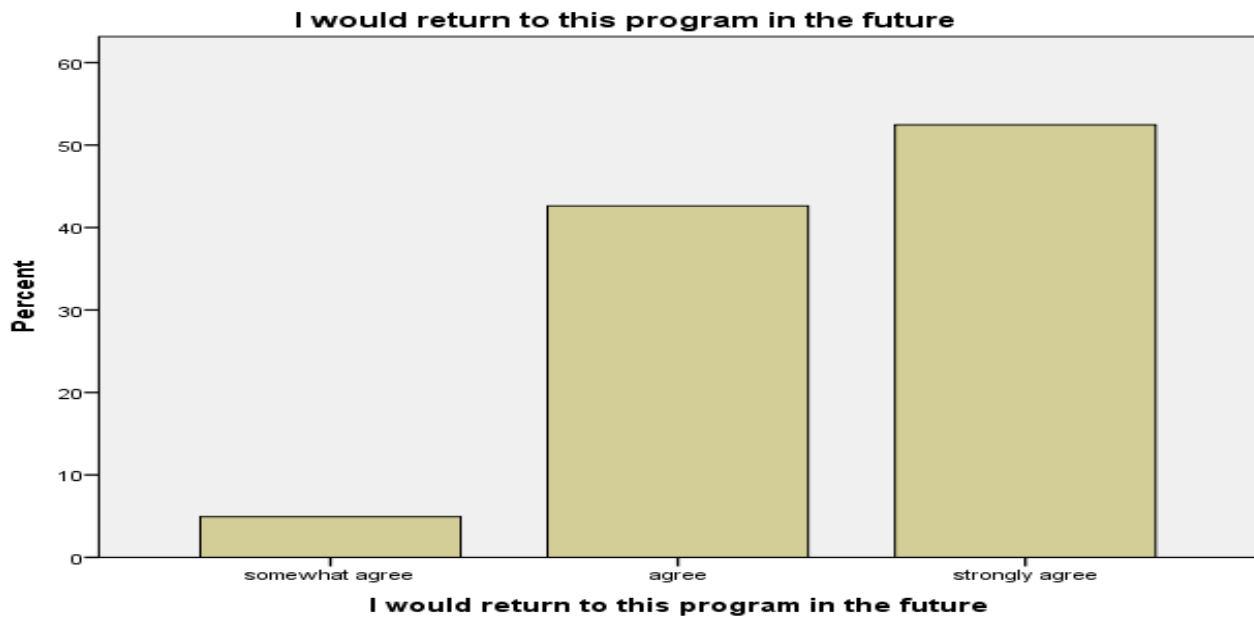
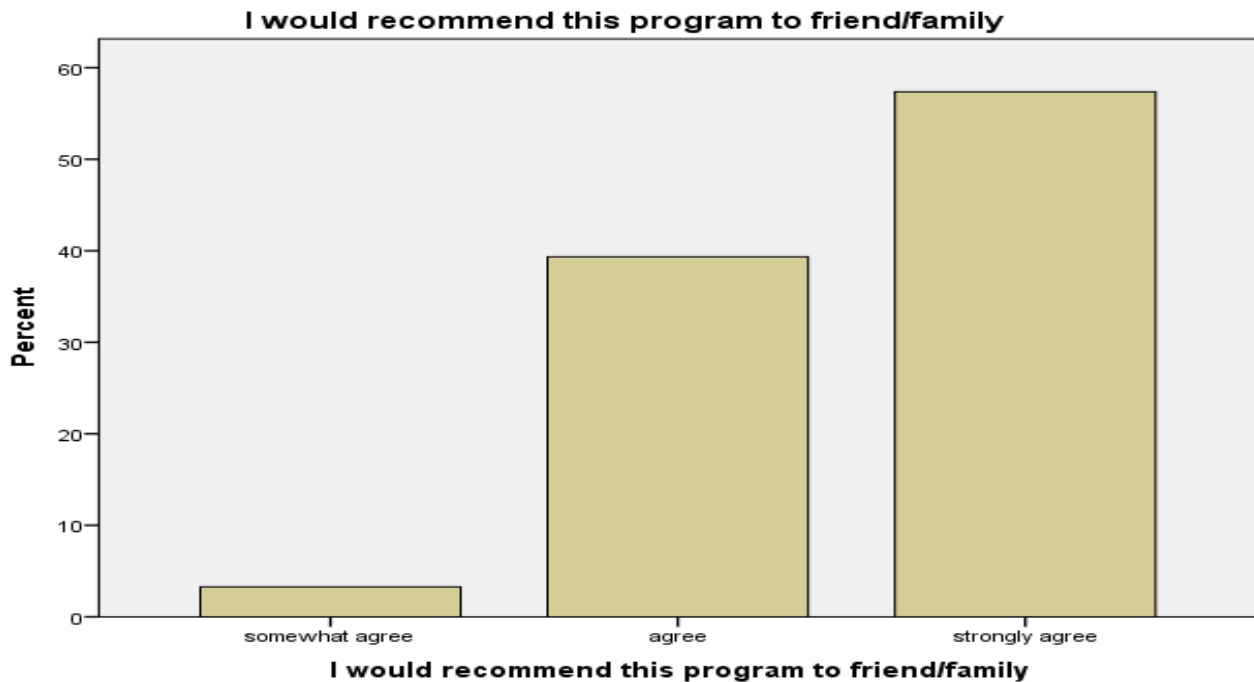


Figure 1.8 shows that no respondents disagreed about recommending the program to a friend or family member, while 3% somewhat agreed, 39% agreed, and 57% strongly agreed.

**Figure 1.8**



### **What is this program doing right?**

When asked, "What is this program doing right?" respondents answered by stating that they believed counselors were very compassionate. Participants specifically stated feeling understood by counselors, they felt "listened to", and also thought that counselors were very helpful. Another theme portrayed by patients' responses to this question was that they thought they were being held accountable, felt a better sense of responsibility, as well as were able to better manage their lives. Participants also referenced that being able to maintain sobriety and address the problems they intended to were all things this program was successfully doing. One respondent said;

I feel like this program gives each person here a chance to work on every area that they need to touch base on and work changing/improving their issues. If they aren't getting what they need or want to from this program, it's because they aren't trying to.

Another participant answers this question while addressing opiate replacement therapy;

Providing me methadone to keep me from using and craving heroin. Counseling to help deal with the wreckage of my past and also to help cope with any problems that may occur at the present time as a result of my past use.

### **What could be done to improve this program?**

When answering the next question, "what could be done to improve this program?" twenty one out of eighty nine participants simply stated, "nothing." Other participants went on to say, "I can't think of anything. To me this program is amazing. It will not do the work for you!" Another participant states, "My opinion is that this place is fine tuned."

One concept that was addressed by more than one respondent is that they would like more access to different therapy groups. Some participants asked for more group times, different specialty groups, as well as more flexible times in order to attend. One patient said, "I wish the groups were a little longer. An hour seems to go by too fast and that we do not get to finish all of what we are talking about." Another respondent answered, "More specialty groups (available times), more structured group activities (homework maybe?)." Another respondent specified wanting peer led groups, or groups that focus on mindfulness and meditation.

Another theme recognized within this area is individualized care. A respondent stated, "More resources and more better counselors. Not such a huge case load for the counselors or

team so that they can have more time for each individual. And to have daycare for moms who attend groups!” Another participant explained, “Perhaps make treatment a little more individualized. Take each person as an individual case and individual circumstances. Not a textbook ‘addict or alcoholic’-sometimes can be too ‘by the textbook.’” Some respondents also asked for more counselors; “I think maybe more people (counselors) so could have more time with them.” Another participant simply stated “more staff.”

Many respondents acknowledged the theme of there being a long wait time in order to get into treatment as being an area to improve. One respondent stated, “Long wait times for initial intake.” Another said, “Easier to get into when trying to enter. Not such a long waiting period.” A patient reported, “The waiting list to get on the program is very long.” Similar to this theme, some participants spoke about wishing they could have received medication and/or mental health treatment sooner. A respondent said, “For me I wish I could have got my Suboxone a lot sooner.”

Another theme within this area is regarding strictness. The majority of patients that spoke about strictness asked for treatment to be stricter. For instance, a participant stated, “I think an overall better way to make sure people are truly clean/sober’ in groups, more stricter urine screens, observed.” Another respondent simply said, “Continue being the same or a little more strict.” A third person reported, “Stricter consequences for non-attendance show proof of appointments. More drug testing.”

### **Is there anything else about this program you would like to say?**

When patients were given the chance to freely write whatever they would like about the program, the majority of respondents specifically attended to feelings of gratitude. Eighteen

participants specifically stated “thank you” in their response. One person stated, “This program is good for both depression and addiction. Something it would be nice to have more time when someone needs it. But most of the time they are there and listen. It has helped me personally in my struggle with things I did not know I had. Thank you.” Another said, “Just that I’m thankful to have such a professional recovery team on my side.” Some patients also expressed gratitude about their lives being saved. A respondent wrote, “I am very grateful for this program. I feel it will help me save my life.” Another patient simply said, “It saved my life and still is.”

Another theme that came from this question was complimenting the program. For instance, a respondent wrote, “Great program, five stars.” Another person stated, “It’s just a great program.” A third person exuded, “Good program!” In more detail, a person responded with, “This is a great program. It is very supportive. The counselors are very helpful and supportive as well.” Another participant writes, “Great program, just what I needed!”

Some patients went on to specifically thank their counselors. For the purpose of remaining confidential, the names of counselors have been changed. One respondent replied, “I love Laura. She is amazing and has been a huge part of my recovery.” Another person wrote, “If you want and are serious about stopping the use of drugs and no longer want to be a substance abuser, Albert is the best man for the job.” A third patient stated, “I love coming here. And Valerie always seems to understand and makes me feel comfortable.”

Conversely with the above stated, some respondents had constructive feedback for the program. A patient wrote, “Meetings are where recovery really happens. The outpatient really isn’t enough or even close to enough to keep someone clean. Knowledge about addiction is



great, but you need sober supports and friends that you spend time with to change your lifestyle. They should make actions mandatory.”

### **Responses related to stigma.**

Some respondents also answered their perception of care survey questions with themes of feeling stigmatized. For instance, a participant stated, “Treat clients (patients) like any other patient in this hospital. Not like a lower class patient by limiting their movements. Specifying exits-entrances, hallways utilized only certain hours, etc. This adds stress and compromises trust between client and doctors/counselors.” Another respondent also refers to stigma with the statement, “I don’t feel less than because of my alcoholism.”

### **Stigma Survey**

In this section, responses to the stigma survey will be presented. This section will be organized by each question on the survey, which will then be elaborated by themes and statements. Some themes will be repeated often, as well as explained through techniques about their overlap among questions. The results will be shown in order of the questions on the survey, beginning with the first one.

#### **Question one.**

Multiple themes were found among the responses to the first question of the stigma survey. The question, “Have you ever felt stigmatized being a person in recovery or active addiction?” brought about five different themes. These themes have been identified as “Addict”, “Self-esteem”, “Family and friends”, “Healthcare workers”, and “Work.” These themes were drawn out from the data based on what participants identified as their sources of feeling

stigmatized. For instance, all answers to the first question involved sources of stigma coming from aspects of being labeled an “addict”, affected their self-esteem, came from family and friends, healthcare workers, as well as affected their careers or were work related. In this section, each theme will be thoroughly identified with statements from participants.

### *Addict.*

When answering the first question of the stigma survey, “Have you ever felt stigmatized being a person in recovery or active addiction?”, some participants answered by explaining their role as an addict. One respondent wrote, “Yes, many people believe because I am an addict (although in recovery) I can’t be trusted or that I am automatically a bad person.” Another patient stated, “Yes, because I’ve had a problem once in my life that I will always have a problem or be seen as a junkie.”

### *Self-esteem.*

Some respondents have referred to feeling “less than” or “not worthy” when answering questions on the stigma survey. These are words that are coded within the theme of “self-esteem.” For example, a patient said, “Yes I have. I feel like people look down on me and still think I’m using.” Another reported, “Yes, I have felt ‘less-than’, belittled, judged negatively, looked down upon, ashamed of myself, embarrassed, and awful about myself for it.” A third person answered, “Yes, being told this is all my fault, I am not a functioning member of society and not worthy of recovery.” Lastly, a participant stated, “I have felt negatively towards myself being an addict. I have felt like a failure.”

### *Family and friends.*

Many respondents identified their family and friends as people they were feeling stigmatized by. Here, some patients explained their experiences with stigmatization from family and friends. A participant wrote, “Yes, I feel stigmatized from other people who have never used and from my friends who still use. Like I am tainted or immoral because I was a user and also from people who still use I feel uncomfortable and judged.” Another person explained, “I have lost a lot of trust from loved ones. In recovery, my boyfriend is assumed to tell his family why I don’t/can’t have a sip of wine when we go out to dinner. He is embarrassed. I am what ‘us’ addicts are looked down upon; ‘shameful.’” A third respondent said, “Yes, when I was drinking alcohol. My ex-wife always told me I was a piece of shit and a worthless father.”

#### *Healthcare workers.*

Similar to the above theme of family and friends, multiple respondents also referred to experiences of stigmatization involving healthcare workers. A sub-theme of this area also includes chronic illness. In order to further expand on this, multiple quotes will be shared. Here a respondent explained an experience with a doctor, “Yes, especially by doctors. The experiences have left me traumatized and fearful of telling the whole truth to important people who should know it in order to not enable my active addiction.” Another participant stated, “Yes, ER doctors, my former dentist. I was accused of drug seeking.” A third person said, “Yes I have. Doctors and my family have treated me unfairly; not wanting to listen or touch me.”

#### *Chronic-illness.*

Along with the sub-theme of chronic illness, a patient explained;

“Yes, I’ve had aggressive lupus since the age of 18. This affects my skin, joints, lungs, kidneys, emotional and mental health. Until going on to the methadone program I had no issues with

doctors prescribing me countless narcotics. Now first and foremost I get treated as an active addict and have had serious trouble getting any help for pain.”

Another patient described their experience with chronic pain and stigma;

“Being a person who has chronic pain and is in recovery...I feel that I can’t go to the hospital if needed. All the doctors look at me as if I am there looking for drugs. Therefore I don’t get the treatment needed.”

### ***Work.***

The last theme found throughout the answers to the first stigma question refers to feeling stigmatized by co-workers, employers, and other areas of work. A respondent wrote, “Yes, at work people have talked down to me like I am less of a person.” Another participant explained, “In certain places especially working in the past. Most people didn’t care but others looked down on me and treated me differently.”

### **Question two.**

This section will display the results of the question, “Have you ever felt stigmatized being a person with mental illness?” This question has also been constructed into themes and statements in order to present the results. The themes recognized for this question are “Labeled” which is also broken down into three sub themes, “Insane”, “Crazy”, and “Scary.” Here, patient’s identified feeling labeled as a means of stigmatization of their mental illness. Oftentimes, participants identified being labeled as either “insane”, “crazy”, and/or “scary.” The second theme is “Self-esteem.” Once again, an aspect of self-esteem has been identified as an effect of stigma.

***Labeled.***

Participants identified feeling “labeled” by their mental illness as an aspect of stigmatization. Some ways these patients identified as being labeled involves being seen as “insane”, “crazy”, and/or “scary.” One respondent has expanded on this concept, “Yes, I’m crazy, looking for attention, faking and should be locked up forever.” Another respondent wrote, “Yes, at the doctor when I am sick they think it is all in my head and that I am not really sick.” A person also stated, “Yes, people are afraid.” Another patient shared, “Yes, my voices tell me to cut myself and my bipolar tells me to hurt other people. So when I am around people who don’t have mental illness like me or even in the same category they look at me as if I am stupid, sick in the head, or a menace to society.”

***Self-esteem.***

Participants also spoke about their effects of mental illness stigmatization on their self-esteem. A respondent explained, “I have thought negatively about myself for having a mental illness, because at times it feels like I’m broken.” Another person said, “Yes, I’ve felt ashamed, hurt and sorry for myself.”

**Question three.**

When participants were asked, “If you are currently prescribed Methadone or Suboxone have you ever been stigmatized by others?” three themes were recognized. The first theme is, “Recovery” with a sub-theme of “AA/NA & Peers.” The theme of “recovery” is represented by statements about feeling stigmatized by others in recovery due to Methadone or Suboxone utilization. The sub-theme of “AA/NA & Peers” delves deeper into the “recovery” theme by

explaining the stigmatizing effects upon relationships in recovery with AA or NA members, as well as peers in recovery. The next theme is “Healthcare Workers”, and then “Self-esteem.” These two themes are stated again as a means of showing continuity among each area of stigma, while representing the same themes as previous sections. Each theme will be described further by statements from participants.

### ***Recovery.***

Some respondents explain that they believe they are judged and stigmatized by other people in recovery for utilizing opiate replacement therapy such as Methadone or Suboxone. A patient reported, “Yes, I am judged by people in recovery, they say I am not ‘really clean’ and doctors don’t treat me like other patients because I am an addict. It makes me feel angry, hurt, and mistrusted.” In order to further describe aspects of the theme of “Recovery”, another sub-theme of “AA/NA & Peers” is used. Another participant deepened the idea of “recovery” being a factor in stigmatization of Methadone and Suboxone maintenance with the statement, “I haven’t been stigmatized by others but I also have not disclosed that I take a ‘maintenance’ drug to the NA/AA community because they think that if you take these drugs you aren’t completely clean. I don’t like it, but it is the way it is. The general public knows little about mental health and addiction.” More respondents explained in greater detail, “Yes, my sponsor in NA said and feels that I am not clean if I am taking Methadone. It makes me feel less than.” And, “Yes, even by those in recovery. Methadone/Suboxone are seen by some as just another drug to numb out with- I felt judged, demeaned, dismissed, hurt, offended, angry and ashamed.” This particular statement is also identified with the theme of “Self-esteem.”

### ***Healthcare workers.***

The mention of healthcare workers, especially doctors, is prominent in this data. Doctors continue to be identified in this area of stigmatization regarding Methadone and Suboxone. A patient expressed,

I feel very stigmatized by physicians because I take Suboxone. I absolutely do not get the same amount of respect. The tone of voice, the eye contact, and the line of questioning all change the minute I mention that I am a recovering addict on Suboxone. It makes me feel like I have done something wrong and am a bad person, that I have no right to pain control. I suffer from very severe migraines and have fibromyalgia and the physicians just smile and say to take Ibuprofen and Tylenol. I finally found some medications that work; soon to find out that they have abuse potential and I can't have them.

Another participant elaborated on emotions that can be attached to the stigmatization of Methadone and Suboxone maintenance, "Yes, by doctors and they made it hard for me to get pain medications when I really needed them. It made me feel very dirty, low, not trusted at all, and looked at like a very sick man."

### *Self-esteem.*

The last theme identified within question three of the stigma survey is "self-esteem." Many respondents identified with negative feelings towards themselves based upon feeling stigmatized because of their Methadone or Suboxone utilization. A person explained;

A lot of people don't look at the positives of Methadone/Suboxone. They look at me as if I am still using drugs, although I've been clean for 18 months. It makes me feel like crap! I've done so much hard work and been through so much pain and finally start to feel good about myself. Then others come along and knock me right down.

Another participant stated, “Yes because people think it’s one addiction to replace another and think I am being selfish and not caring about my baby. It makes me feel bad about myself.”

Conversely related to the above statements, some people spoke about their resilience based upon their stigmatization. In other words, these respondents have recognized the effects upon their self-esteem and speak about improving the effects. A respondent reported, “Yes, people call me junkie, or consider me still using. I personally don’t care what people think about me, it allows me to lead a better more productive clean life.” Another person stated, “Yes, sometimes by peers because they think it’s just another drug that can be abused. I don’t care what people say about me being on Suboxone. Everyone works their own recovery. Certain things work for certain people.”

#### **Question four.**

The results of the fourth question of the stigma survey, “What changes do you believe need to be made in order to reduce stigma towards people in addiction, recovery, mental illness or currently prescribed Methadone/Suboxone?”, will now be displayed. Three themes were identified within this section. These themes are, “Individualized care”, “Education”, and “Openness.” The theme of individualized care has been drawn from statements regarding feedback from patients explaining their experiences with stigma and wishing for care that cannot be stereotypical or “the same for each person.” Here, patients speak about their opinions on how individualized care can help foster de-stigmatization. Participants also discuss education as being the most important factor in making changes in order to reduce stigma. The next theme identified



in this area is “Openness”, which comes from the concept of remaining open to begin addressing stigma differently in order to change it.

### ***Individualized care.***

Many participants acknowledged ideas about making treatment more individualized in order to reduce stigma towards people in addiction, recovery, and mental illness. A respondent wrote, “I don’t know how to change things but I believe you should take each person on an individual basis and not put everyone together.” Another person stated, “The change has to happen individually and it is hard to change ones approval.” A third participant explained, “For the public, awareness of the amount and frequency of these problems. For doctors, they serve more ore good than bad, minus a few exceptions. So maybe more ‘individualized’ care.”

### ***Education.***

Multiple patients included the term, “education” within their response. The majority of responses revolved around the idea of educating the public about addiction, mental illness, recovery, and Methadone/Suboxone. A participant stated, “Education- people need to realize that addiction is a disease and this is our medicine.” Another patient reported, “More education and a different view for how it is portrayed in media and public.” A third person explained, “I think if people were more educated about addiction it may be less stigmatized and constantly facing negative judgment. Ignorance can really harm those who suffer and makes it an even more difficult journey.” A participant has stated, “Having things be more publicly known. Education is key. People need to know that these things are diseases and that people don’t choose them. Recovery is possible.” While another person suggested, “I think addicts like myself and others

should get up in front of a panel of doctors and medical students and explain their life story to them.”

### *Openness.*

Similar to education, participants also acknowledged the importance of openness in order to better understand and therefore address stigma within the community regarding recovery, addiction, and mental health. A respondent said;

I think instead of pre-judging, doctors and other professionals should be willing and open to ask about my addiction/mental illness so I am given the chance to explain and clarify any misgivings as related to my treatment- it would go a long way in easing the negativity brought on by the label.

## **Discussion**

The Perception of Care Survey and the Stigma Survey were both implemented in order to better understand patient’s perception of their treatment, as well as their effects of stigma.

According to the literature previously discussed, the impact of patient’s perceptions as well as input about their treatment is becoming more and more appreciated by treatment facilities. Here, it is understood that the impact of the patient’s statements both regarding perception of care and stigma are powerful as well as essential to the improvement of treatment for the co-occurring disorder population.

Consonant with the literature, the results of both surveys have concluded that overall patients are satisfied with their treatment, yet believe that change must be made about stigmatization towards addiction, mental illness, and recovery. Since using statements taken from

patients have been identified as ways to better implement change into addiction treatment models (Conners, 2009), it is recognized that data from this program evaluation can do so for this particular Northeastern American addiction treatment program. According to statements written by the participants, overall they believe they are treated well by counselors, although wish to be treated differently by other healthcare professionals such as emergency room doctors, dentists, surgeons, and primary care physicians, as examples. Statements that are represented in the results section of this document are also related to those found in the literature review section regarding patient's perception of care and stigma. As mentioned previously, patient's felt most stigmatized by family and friends, healthcare workers, and the media (Sanders, 2012; Debie, 2014; Earnshaw et al., 2012; Corrigan, 2005). Some aspects that were recognized in this program evaluation that were not mentioned in literature revolve around stigma from peers and community support groups such as Alcoholics Anonymous (AA) or Narcotics Anonymous (NA). Some literature speaks to AA and/or NA perpetuating the stigma of addiction simply by remaining anonymous ("The Anonymous People", 2013), although does not recognize the stigma within community support groups regarding Methadone and Suboxone, which is thoroughly discussed in the results section. Similarly to the results shown, literature states that overall patients are satisfied with their treatment at addiction treatment centers (Deering et al., 2012). Patients have described their satisfaction by complimenting counselors' ability to understand them, as well as remain a part of a support network needed to succeed in recovery.

Respondents have suggested that educators need to be agents of change in order to improve effects of stigma within the co-occurring disorder population. Patients have named effects upon their self-esteem, resulting in low self-worth and negative thoughts towards themselves and their diagnoses. Similar to the literature represented by multiple authors such as

Corrigan et al (2006), Watson et al (2007), and Yanos et al (2011), self-esteem was noted as a source of the patient's stigma, perpetuating discrimination, stereotypes, and prejudice. Here, the literature and the results also expand on the idea that if a person often experiences negative judgments against them, they too, will think negatively about themselves (Corrigan, 2005). The literature also states that oftentimes the feelings of shame, hopelessness, and worthlessness that coincide with low self-esteem are sometimes more challenging to overcome than an addiction or mental illness themselves (Corrigan, 2005). This is proven by what participants have mentioned, as they explain stigma as a barrier to them succeeding in recovery.

### **Limitations**

Although this program evaluation was completed abiding all ethical standards, some limitations and weaknesses have been recognized. One limitation is the sample size. The sample size was 114, while 250 surveys were dispersed, and about 598 patients are present within the program. This means that only a fraction of the population was reached, while the other patients were not included within the study. Another limitation in this study is the design in which surveys were dispersed. For instance, the stigma survey was handed out in April 2014, while the Perception of Care Survey was dispelled in August 2014. With four months in between dispersing surveys, some participants could have responded to one survey and not the other, creating inconsistencies within the responses. A third limitation suggests that since the Stigma Survey was developed by the researcher, it does not have any empirical validity or reliability. This means that the Stigma Survey has only been used this one time, and cannot be compared to any other research studies.

### **Recommendations for Future Research**

In accordance with some of the above mentioned limitations the researcher has developed recommendations for future research. One of the first recommendations is to complete another program evaluation with the Perception of Care Survey which includes more than 114 participants. A possible suggestion is to advertise the survey more in order to reach out to more patients regarding the program evaluation. Another recommendation is to follow through with one-on-one interviews with patients about their effects of stigma, in order to better understand the emotion regarding their experiences.

### **Conclusion**

There are three main take-a-ways from this program evaluation. The first is that the words of participants are the most powerful and influential in order to advocate and become agents of change, especially regarding social justice issues related to stigma. Secondly, counselors at this particular program appear to be effectively accomplishing their goals of attending to patients with co-occurring disorders, according to perception of care. Lastly, this program evaluation has given a voice to those who are stigmatized based upon their addiction, mental illness, and recovery while identifying emotional wounds based upon effects on relationships with family and friends, experiences with healthcare workers, as well as self-esteem and self-worth.



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