Feedback informed care: co-creating treatment success

Eve Sandler

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ABSTRACT

This qualitative research was conducted in order to answer the question: What factors do patients think are most useful in therapy? Feedback was collected from a sample of 630 participants from The Community Psychiatry Program (CPP) at Johns Hopkins. Respondents were asked to complete a written survey answering two questions: 1. How do you know when you are getting better? and 2. What are the most important aspects of (CPP)?

This study collected data from both patients and caregivers. Brief responses for each question were coded using a general inductive approach, which revealed multiple themes and subthemes. One significant finding which was generated from patient responses was the importance of the therapeutic relationship as an indicator of treatment success. This finding correlates with a relational theoretical framework and with previous Feedback Informed Care studies. This research study suggests many implications for incorporating patient feedback into clinical social work practice.
This paper is based upon secondary data. Data were collected by Daniel Buccino, LCSW-C, BCD and Michael Van Wert, LCSW-C, MPH at Johns Hopkins Bayview Medical Campus. The secondary data were then analyzed and discussed below by Eve Sandler. It was submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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CHAPTER I
Introduction

This study was conducted in hopes of gaining more insight into how patients experience treatment in an adult outpatient therapy setting. Providing patients with the opportunity to evaluate their practitioner has been a commonly used practice in the medical field (Jamtvedt, Young, Kristoffersen, Oxman, & O’Brien, 2010). Ideally, practitioners will utilize the feedback they have received in order to modify the care and treatment they are providing. This process is known as Feedback Informed Care.

This study was conducted within the context of the Community Psychiatry Program (CPP) at Johns Hopkins Bayview Medical Campus. The CPP staff have been working to improve their patient outcomes by introducing different methods of feedback informed care. The current study is based on their most recent research from March of 2016. Patients in CPP were asked multiple quantitative questions, along with two qualitative questions in a patient feedback survey. Previous researchers have analyzed the quantitative data, but there has been no analysis on the qualitative questions before now.

The purpose of this study is to answer the following question: What factors do patients think are most useful in therapy? In order to answer this research question, participants were asked to give short responses to complete the following two statements: 1. “I know I am doing better when…” 2. “The most helpful things CPP provide for me are...” These questions aim to provide more information into the patient’s experience in treatment. This survey could give insight into best practices for therapists based on real patient reports.
CHAPTER II

Literature Review

The following chapter will focus on previous research on the various factors that may contribute to successful outcomes in psychotherapy. After reviewing the traditional factors that have been objectively assessed—therapist factors, patient factors, and the therapeutic alliance—we will look at the therapist’s subjective view, and finally, the viewpoint of the patient. What do patients think is most useful in therapy? Although this study aims to explore patients’ experiences specifically at Johns Hopkins Community Psychiatry Program (CPP), this literature review will provide a general understanding of Feedback Informed Care. For purposes of this study, Feedback Informed Care or Feedback Informed Treatment will be understood by the definition of “...soliciting and responding to client feedback to inform the therapeutic process.” (Tilsen & Mcnamee, 2015)

This literature review will cover the history and importance of feedback informed care. This review will describe previous studies and indicate the importance of the proposed study. It will also examine previous research on what therapists find most useful in treatment. As therapy is considered a collaborative approach between therapist and patient, it is important to understand both perspectives of the therapeutic process. Considering this, it is useful to understand the proposed study within the context of relational theory.
Theoretical Framework

Feedback Informed Care implies that the patient’s experiences and opinions are essential to a successful outcome in psychotherapy. A suitable framework for such a view can be found in relational theory. There are different interpretations of relational theory in practice, so for the purposes of this study, it will be understood according to the following description. Although relational theory derives from classical psychoanalysis, this approach includes many key differences from Sigmund Freud’s original idea of therapy (Wachtel, 2008). Freudian psychoanalysis is considered a one-person approach, meaning that the therapist interprets what the client is saying, but does not engage in an ordinary interactive conversation between two people. In relational theory, a two-person approach, the therapist communicates very differently. In this approach, the therapist is no longer considered the expert who interprets the patient’s internal psyche. This approach emphasizes the importance of the relationship being built in the present moment between the patient and therapist (Wachtel, 2008). Relational theory recognizes that this relationship can give insight into patterns and themes seen in other relationships in the patient’s life. Still utilizing Freud’s ideas of the unconscious, this relationship also provides the therapist with examples of unconscious feelings or desires that are manifesting in their interactions. Rather than interpreting these manifestations, the therapist will invite the patient to help deconstruct them together.

According to Wachtel (2008), this theory is often misunderstood as an opportunity for therapists to excessively self-disclose; some would also see a risk of encouraging a codependent relationship. In actuality, he suggests that this theory merely brings more awareness to the importance of a collaborative approach in which the patient is considered an equal part of the therapeutic process (Wachtel, 2008).
This theoretical framework helps in conceptualizing the process of Feedback Informed Care. Since this theory emphasizes the impact the patient can have in this relationship, it seems intuitive to provide them with the opportunity to give feedback. Goldstein, Meihls, and Ringel spoke to this collaborative approach in 2009 when they wrote, “Thus, therapists must be self-scrutinizing about the impact of their attitudes, belief systems, and actions on the assessment process and cautious in forming conclusions about the client without the client's active involvement” (pg. 85). At its core, Social Work has always valued the collaborative effort between the therapist and client. In this statement, Goldstein et al. are emphasizing how crucial it is for therapists to allow the patient to be actively engaged, rather than presenting themselves as “experts.” If therapist and client are considered equal members of this relationship, according to relational theory, then the client must feel that their perspective of therapy is being considered and valued. Although social workers have historically valued this perspective, the use of Feedback Informed Care provides the patient with a formal setting to voice their experiences.

Since the days of Sigmund Freud, many derivatives have been created of his classical psychoanalysis. In many styles of modern day therapy, the voice of the patient has become more and more influential. These two-person approaches include relational, client centered, constructive, narrative, and solution-focused therapy. Bohart and Tallman (1999) stated that in their approach to therapy, the “Patient is treated as an equal collaborator” (pg. 141). Social workers have always emphasized the importance of this collaboration, but these modern approaches are creating a formal platform for patient feedback.
Predicting Success

This literature review will begin with an overview of previous research on predicting patient success. The current study aims to understand how patients explain their own treatment success. Before addressing the patient’s perspective, though, this chapter will review which areas have been previously studied as factors contributing to patient success.

Researchers are constantly trying to understand why certain patients succeed in psychotherapy while others fail. Many categories have been researched as possible factors contributing to success. While some members of the field are now turning towards patient feedback to understand success, it is important to understand attempts by previous researchers to predict positive outcomes.

Below is a review of the most common areas of focus in this research, including therapist factors, patient factors, and the therapeutic alliance as predictive factors of patient outcomes. Another theme that is not included below is the therapist's theoretical background and specific techniques used with patients. Researchers have done in-depth studies considering, for example, different psychodynamic practices versus behavioral techniques. Theoretical backgrounds are mentioned in a few studies below, but were not researched in detail for this thesis. Such research has an important place in the larger conversation about treatment success, but goes beyond the scope of the current relationally based, study.

Therapist factors. Therapist factors is one area of psychotherapy that has been researched as a possible predictor of patient outcomes. In 2005, Wampold and Brown conducted a study to explore the role that the individual therapist plays in patient outcomes. Their study aimed to find how important were therapist factors in the therapeutic relationship. They created a 30-item self-report questionnaire for patients based on the Outcome Questionnaire 45 from
Lambert, Gregersen, and Burlingame in 2004.

This version of the Questionnaire was narrowed down to 30 questions, as opposed to the original 45. Wampold & Brown (2005) renamed their version of this classic questionnaire as the Life Status Questionnaire (LSQ). This instrument considers three main areas of the patient’s life: self-reported discomfort, interpersonal relationships, and social roles. These are scored throughout their time in treatment as markers of progress. Along with patient’s self-reported questionnaire, researchers also evaluated the patient’s mental status and condition at the beginning of treatment and at the end. This was an important measurement in order to accurately assess the patient’s progress during treatment.

These researchers included participants who were 18 years or older who had been in treatment with a therapist for at least six months (Wampold & Brown, 2005). This study included 6,146 patients who were being seen in the context of managed care by 581 different therapists. The therapists were considered a random factor during this study. The researchers were not aiming to evaluate any particular therapists’ outcomes, but rather engage in a broader investigation of the field. They did obtain information about the therapist’s age, gender, degree, and years of experience. These data were collected anonymously and considered as a possible predictor of the patient’s outcome (Wampold & Brown, 2005).

Therapists from this study were categorized as “best” or “worst” based on their success rates with patients. Their caseload was then followed to examine if their personal success was consistent and could be predictive for their future patient’s success. Wampold and Brown (2005) analyzed the data to see if a therapist’s success with previous patients can predict their success with future patients. Their study found that approximately only 5% of a patient’s outcome from treatment is due to the therapists themselves (Wampold & Brown, 2005). This study is not alone
in indicating that therapist factors do not play a significant role in predicting patient outcomes.

A similar study was conducted in 2007 in a psychotherapy outpatient context. This study found results in support of Wampold and Brown’s 2005 results. Lutz, Leon, Martinovich, Lyons, & Stiles (2007) focused their attention on therapist demographic factors. These results indicated that approximately 8% of the total variance in patient outcomes is related to therapist demographics. Their results for patient success was higher, indicating that approximately 17% of variance in patient success was attributable to therapist demographic factors (Lutz, et al., 2007).

Although therapist demographic information and therapist success rates are important in this research, other factors about the individual therapist have also been considered as possible markers for a patient’s predicted outcome. In consideration of relational theory, a therapist’s interpersonal skills is one of the most important therapist factors to consider. One specifically notable study on therapist interpersonal skills was conducted in 2009 by Anderson, Ogles, Patterson, Lambert, & Vermeersch. This study followed 25 therapists who collectively saw 1,141 patients in an outpatient college counseling setting. Just as Wampold and Brown (2005) used a modified version of the Outcome Questionnaire-45, these researchers used one as well to rate participant’s success. Patients took this questionnaire at the beginning of every session over a 45-month time span. Not all patients were seen for 45 months, but that is the length of time that the therapist’s caseload was followed (Anderson, et al., 2009).

Also utilized in this study was The Social Skills Inventory (SSI; Riggio, 1986). This is a 90-question survey given to the therapists who participated in the study. The survey was created to assess a person’s interpersonal skills including expressivity, sensitivity, and their control in social and emotional settings. These researchers then examined the results of the therapist’s interpersonal skills in comparison to their patient’s success. Their findings suggest a correlation
between the therapist's interpersonal and social qualities, and the patient’s treatment outcomes (Anderson, et al., 2009).

To ensure they were really finding a correlation between these two variables, researchers also received information about the therapist's age, sex, the percentage of their work that was dedicated to clinical hours, and the therapist's theoretical orientation. Out of these factors, this research indicated that age was the only significant factor which correlated with patient success. Upon further analysis, researchers suggested that their outcomes show a correlation between age and higher SSI scores. Anderson and colleagues concluded that a therapist’s interpersonal skills increase over time in the field, which in turn shows a correlation between age and patient success. They supported the notion that the patient’s success rates are more likely correlated with the therapist's interpersonal skills, rather than simply due to the age of the therapist (Anderson, et al., 2009).

From the above research, it is clear that an individual therapist has some effect on the patient’s outcome, although the exact amount of that influence is still unclear. In the context of relational theory, it is important to also consider the impact that the patient has on their own success.

**Patient factors.** Literature on predicting success in patient treatment also considers the patient’s influence on treatment. In 2012, Joutsenniemi and colleagues conducted a study to understand the influence that patient factors (i.e. age, gender, education, employment status, marital status, and living arrangement) have on treatment outcomes. This socio-demographic information was obtained at the start of treatment. This study included 326 participants in outpatient treatment who had been diagnosed with a mood or anxiety disorder. Participants were randomly assigned to be in either short-term or long-term psychotherapy to account for the
variance in length of treatment (Joutsenniemi, Laaksonen, Knekt, Haaramo, & Lindfors, 2012). In the follow-up “success” questionnaires, the researchers’ hypothesis was supported: patient socio-demographic factors correlated with different treatment outcomes. For example, their study found that participants who were categorized as less advantaged (i.e. homemakers, single parents and divorced patients) had different responses to treatment than their demographic counterparts. These “less advantaged” categories of participants either did not benefit from treatment or only benefited from long term psychotherapy (Joutsenniemi, et al., 2012). Although this is just one study, and it cannot be generalized, it does indicate some evidence supporting the role that patient demographic factors may play in treatment outcomes.

Research has now suggested that both patient and therapist factors can influence the outcomes of treatment. In consideration of the proposed study, this literature review will now turn towards the therapeutic alliance. If therapist and patient are considered equals in this relationship, then we must understand how these two participants interact with one another and collaboratively create treatment outcomes.

**Therapeutic alliance.** For purposes of this literature review, the therapeutic alliance will be understood as the bond that forms between the patient and therapist during their collaborative work in treatment (Krupnick, et al., 1996). In 1994, Luborsky conducted a meta-analysis of data from 18 different studies (from 1976-1994) on this subject. He was determined to find out if the therapeutic alliance affects the patient’s ability to succeed in treatment. After analyzing these previous studies, he did indeed find a correlation between the two (Luborsky, 1994). At the end of his write up, Luborsky endorsed an “enlarged perspective” indicating the large-scale importance of this research. He stated:

“A primary benefit of the enlarged perspective is the ability to see that the trend of the
correlation between the alliance and outcome measures is not strictly confined to measures of the alliance; it is also true for other positive relationship qualities, particularly from the patient’s point of view” (pg. 46). This statement made in 1994 seems to hold true today. There are many areas of psychotherapy which may predict a patient’s success, and one critical factor is the patient’s individual perspective and experience in therapy.

In 1996, the effects of the therapeutic alliance were examined again by Krupnick and colleagues. This study followed 225 patients receiving different styles of treatment (Krupnick, et al., 1996). Researchers monitored the patient’s progress in therapy and assessed the therapeutic relationship that was built. This study indicates a couple notable findings. First of all, this study found that the style of therapy does not influence the ability to form a strong therapeutic alliance. Secondly, these researchers found evidence in support of the therapeutic relationship influencing the patient’s success in treatment. This association was significant whether it was compared to one single session or to treatment over a longer span of time. This last finding may be important in conceptualizing a patient’s length of treatment. Krupnick and colleagues (1996) suggest that a patient’s early ratings of the therapeutic alliance should correspond with their progress in treatment.

Each of these areas that have been studied carry significant importance in the field, but they are often still missing the critical perspective of the client. In an attempt to address this gap, the proposed study aims to understand patients’ perspectives of therapy and what factors they experience as corresponding to their treatment success or treatment failures. The proposed study attempts to give a voice to patients’ perspectives of effective treatment so as to gain a better understanding of their experiences. In previous studies on predicting success, the therapist’s view is often the main perspective that is considered. Below is a review of some data on therapist
perspectives of treatment.

**Psychotherapists Feedback**

This increasing interest in patient feedback must be understood within the context of previous research conducted with psychotherapists. Previous researchers, such as Tasca, et al. (2014), have examined which aspects of therapy that therapists find most important in treatment for their patients’ success. This study included 1,019 participants, the majority being practicing clinicians. It is important to note that this was not a self-evaluation, but rather an evaluation of what makes therapy successful in general. In this study, researchers utilized focus groups to categorize areas of research that therapists find important to their practice. This open dialogue, guided by some questions, aimed to find what therapists think is most important in therapy and therefore what they think needs to be researched more heavily within the field (Tasca, et al., 2014).

All focus groups were recorded and later listened to by a group of coders who diligently created themes heard in the therapist's narrative. From their findings, four main categories were found: 1. Therapeutic Relationship/ Mechanisms of Change. This included alliance building, empathy, and the process of rupture and repair. 2. Professional Development. This theme included how therapists were trained and were continuing to inform their therapeutic approach (ex: supervision), 3. Therapist Factors. This refers to the individual therapists’ beliefs, demographics, and life story, and 4. Client Factors: These were the same as the therapist factors and the two were also considered in how they interacted in the relationship (Tasca, et al, 2014). It is notable that these categories fall in line with previous research on what factors may predict success in treatment (Tasca, et al, 2014). These categories will be beneficial in analyzing the data from the proposed study. It is important to understand the therapist's perspective in comparison
As indicated above, therapist feedback is important, but it also only provides researchers with half of the story. Only hearing one perspective in this dyad can be problematic. In 2015, a study conducted at the International Center for Clinical Excellence in Chicago provided an excellent example of this problem. This study indicated that the perspective from therapists might not be giving an inclusive and accurate depiction of therapy (Miller, Hubble, Chow, & Seidel, 2015). In this literature, Miller, et al. (2015) discussed many ways that therapists work to improve the care they provide for patients, including supervision and receiving continuing education credits. They suggest that although therapists endorse a belief that these tools make better therapists, there is little research to support that notion. Miller et al. (2015) discuss previous research on this subject and report that “after reviewing a century of the literature and research on supervision, Watkins (2011) concluded: ‘We do not seem any more able to say now (as opposed to 30 years ago) that psychotherapy supervision contributes to patient outcome’ (p. 235) (Miller, et al. 2015).

Although there is research to support clinical supervision as a useful tool for therapists, it has not been connected to concrete measures of success for patients. Overall, Miller and colleagues (2014) found that in the quest to make “better therapists,” research has largely failed. These authors suggest that a turn to routine outcome monitoring (ROM), a style of feedback informed care, may be the next step in developing this profession to best meet the needs of its clients (Miller, et al. 2015).

**Feedback Informed Care**

The conversation now turns towards how to most effectively receive feedback from clients. As mentioned above, social work has historically been a field which honors the patient’s perspective.
role in therapy. Feedback informed care indicates the necessity for a more formal, reliable, and empirically based form of feedback.

**Instruments used.** When considering utilizing feedback from patients, it would be greatly beneficial for therapists to know what surveys or questionnaires yield the most useful feedback. Specifically, notable in this section is the difference between overall patient feedback and patient satisfaction feedback.

In 1999, a meta-analysis was conducted in an effort to understand the reliability of patient reports of satisfaction (Sitzia, 1999). This study identified 195 previous studies which examined patient satisfaction in treatment. These studies were collected from multiple broad health care journals, and therefore these findings are not specific to mental health treatment. This information is still important in understanding the reliability of patient feedback. John Sitzia (1999) considered many different areas of these studies including their content, criterion, and construct validity. He also examined their internal consistency and stability of the test used and the test results. This included a consideration of studies using both old/unmodified tests and studies which created new/modified tests. Sitzia (1999) found that in 60% of the studies which used new instruments, there was no valid or reliable data found from these patient questionnaires. He also found that old tests had significantly higher percentages on validity and reliability testing than new/modified versions of these tests. This 1999 analysis was created in hopes of understanding previous research and to create a path forward in patient feedback. The findings indicate that patient satisfaction data is not reliable and that our most effective tests are the old and unmodified versions.

These data are important in understanding the proposed study. Since patient satisfaction data seem to be unreliable, the current study does not aim to evaluate this. Instead, the current
study aims to understand a patient’s experience of treatment, whether that is positive or negative. The short questions asked in this study are open-ended and intentionally not guiding the patient’s narrative.

Other aspects of patient feedback have previously been studied and are worth considering. In 2016, Seidel, Andrews, Owen, Miller, and Buccino conducted a study comparing three popular patient feedback scales: The Rating of Outcome Scale (ROS), Outcome Rating Scale (ORS), and the Outcome Questionnaire. The ROS and ORS are ultra-brief well-being measurement scales, respectively consisting of 3 and 4 items, while the OQ is a longer, 45 question Likert-type scale questionnaire. During this study, clients were administered all three of the scales for 1-3 sessions. This study was conducted with 279 patients, 86 of them completing all three surveys for each of the three sessions. These participants were receiving a combination of psychotherapy and psychiatric medications. This total is based on the number of patients who attended all three of their sessions. Each of the 279 participants completed all three surveys at least once. Both the ORS and ROS showed good reliability as brief measures of change in client outcomes, while the OQ seemed to be a less reliable form of patient feedback (Seidel, et al., 2016). The current study utilized a similar one-time, brief measurement scale. It was concise and in line with the current research about the most effective feedback forms.

**Effectiveness.** In 2001, a study was conducted by Lambert, Smart, Nielson, Whipple, Hawkins, and Vermeersh to better understand the effect that patients’ feedback has on their own treatment. This study included 609 patients who were assigned to one of two groups. Patients were assessed and then categorized as either expected to be “treatment failures” or expected to “succeed” in treatment (Lambert, et al, 2001). The participants in both groups were then randomly assigned to either an experimental group or the control group.
All participants were administered the same weekly Outcome Questionnaire, but the results were only given to therapists in the experimental groups. The therapists who participated had some clients in both the experimental groups and the control groups in order to control for the influence of therapist factors (Lambert, et al, 2001). All results were graphed, so the therapists and patients could have a tangible representation of the course of treatment over time.

For patients expected to be “treatment failures,” twice as many patients in the experimental (feedback) group showed statistically significant improvement than in the control group. Also, patients in this experimental (feedback) group were coming to treatment more consistently and for a longer period of time. There were also significant results for the group of patients expected to succeed in therapy. For this experimental (feedback) group, patients were able to decrease the number of necessary sessions while still increasing their positive outcomes (Lambert, et al, 2001).

Similarly, in 2014, Davidson and Bell performed a critical analysis of existing research to better understand the implications of patient feedback. These researchers found 10 studies from 1990-2013 that met their inclusion criteria. This was done via an electronic database search. Each of the studies examined short-term results of treatment. A wide range of therapeutic techniques were used with the patients from these studies, including cognitive-behavioral, interpersonal, and humanistic therapy approaches (Davidson & Bell, 2015).

After analyzing and comparing the data from these 10 studies, the researchers found some mixed results. For patients with mild symptoms, Feedback Informed Care resulted in more successful therapy. Receiving feedback from patients with more severe symptoms had no influence on their treatment outcomes (Davidson & Bell, 2015). Although these results may suggest a lack of effectiveness of Feedback Informed Care for certain categories of patients, it is
important to read these results within the context of the study. It was not specified how therapists were utilizing the feedback, and the use of patient reports was not monitored (Davidson & Bell, 2015). This study may have provided more substantial results if conducted with more constraints on the study.

**Conclusion**

Considering a relational approach to therapy, the therapist and the patient should each play a significant role in the patient’s treatment outcomes. The above research gives some insight into the therapist's perspective of that relationship and the aspects they find to be most significant. This literature review also provides some examples of the effectiveness of Feedback Informed Treatment. Although the majority of literature indicated that feedback from patients is beneficial, there has been little research done that actually uses the verbatim feedback from the patient.

The proposed study aims to analyze the feedback patients have provided about what they experience as most helpful in outpatient psychotherapy. In the Tasca, et al. (2014) study, mentioned above, therapists suggested four main categories they found to be most influential for treatment outcomes. There is not a significant amount of current research indicating similar findings from a patient’s perspective. In the current study, patients gave open-ended feedback about their treatment at CPP. After coding this data, the patient’s feedback was compared to therapist’s results in previous studies. Since therapy relies so heavily on the relationship and alliance formed between the client and therapist, it is crucial to consider these results in comparison to the current study on patient results. These categorized short answers from patients help us to form a more complete understanding of the factors which contribute to “treatment success” from both the patient and therapist perspectives.
CHAPTER III
Methodology

The purpose of this study was to answer the following question: What do patients think is most useful in therapy? In order to achieve this, participants were asked to give short responses to complete the following two statements; 1. “I know I am doing better when…” and 2. “The most helpful things CPP provides for me are...” This was an exploratory study to provide patients the opportunity to give open feedback. This study emphasizes the importance of the patient’s voice in attempts to make the therapeutic working relationship more collaborative. Ideally, these data will assist the field in creating best practices that incorporate the therapist and patient's perspective of “successful” therapy.

Although this secondary research analysis is focused on the two qualitative questions stated above, an understanding of the full study is necessary to conceptualize the results. This study was created in tandem with a study on the therapist’s perspective which was conducted at Johns Hopkins in February 2015 (Mistry & Venner, 2016). This patient study had two primary goals: 1. to understand a patient’s perspective of therapy 2. to understand the patient’s perspective on integrating feedback-informed care into practice. These researchers wanted to know patient preferences in therapy along with their attitudes, exposure, and comfort with providing feedback to care providers. This study consisted of five sections of demographic information, an outcome-rating scale, therapy interventions, exposure to feedback informed care,
and comfort with giving feedback (Mistry & Venner, 2016).

Previous students at Johns Hopkins have already analyzed the data on the patient’s experience with providing feedback. Therefore, the current study is focusing on the patient’s actual feedback, which comes from the section on outcome-ratings and therapy interventions. These sections both consisted of two questions, one open-ended question, followed by one multiple choice/ranking question. For example, under the outcome-rating section, patients were first asked to finish the sentence “I know I am doing better when…” They were provided a few lines to describe how they evaluate their own progress. They were then asked:

I know I am doing better when: (Rank by importance from 1 to 4, 1=most, 4=least). Each option should have a DIFFERENT ranking.

__ I feel less depressed, less worried, sleep better, hear fewer “voices,” [my symptoms] … (I experience fewer symptoms)

__ I enjoy life more, feel safer, am more comfortable with myself, am more satisfied with my relationships, etc…(my quality of life is better)

__ I can handle things better when they go wrong (my coping skills have improved)

__ I am able to do better at work or school, get along better with family/friends, I get around more easily, I stay out of the hospital, etc… (I function better)

(Buccino & Van Wert Study, 2016)

These four categories- symptom reduction, quality of life, coping skills, and functional improvements- were based on results from the therapist study conducted in February 2015. These researchers intended to see if there were similarities in what therapists and patients use as markers of therapeutic success (Mistry & Venner, 2016). Similarly, in the second section on Therapy Interventions, patients were first prompted to give a short answer response to “The most
helpful things CPP provides for me are...” They were then given the same question with four answers to rank:

These are most helpful to me: (Rank by helpfulness from 1 to 4, 1=most, 4=least). Each option should have a DIFFERENT ranking.

__ Getting help with finances, jobs, food, housing, social services, transportation, etc.
__ Learning skills to help me handle things when they go wrong.
__ Having a trusting relationship with my healthcare provider, feeling understood by her/him, she/he working with me well.
__ Having the right medications.  

(Buccino & Van Wert Study, 2016)

These answers fell into the following categories: Case management tasks, coping skills, the therapeutic relationship, and medication management. Again, these categories were derived from the original study conducted with therapists at CPP (Mistry & Venner, 2016).

As seen in that example, patients were first asked to answer an open-ended question and then asked to answer the same question with guided answers. This format was intentionally used, so that the researchers’ four categories did not influence the patient’s qualitative responses. This mixed methods study provides participants with an opportunity to indicate if there are other important categories that the researchers did not include. In the current analysis, the focus will be solely on the qualitative portion of this research.

This type of study also gives insight into the importance of qualitative research. It is reasonable to assume that those four categories chosen for the multiple-choice questions do not encapsulate every patient’s experience in outpatient therapy. An open-ended question allows for a more complete and thorough understanding of their answers. With the purpose of the current
study being to answer: “What do patients think is most useful in therapy?”, it is important to provide the space for different experiences to be acknowledged.

Since the goal of these two short answer questions was to receive unguided answers from participants, this writer used a general inductive approach for coding these data. David Thomas (2006) wrote about this style of coding, saying “the primary purpose of the inductive approach is to allow research findings to emerge from the frequent, dominant or significant themes inherent in raw data, without the restraints imposed by structured methodologies.” (pg. 2) This style of coding allowed for the responses received to be organically categorized, as to not miss any important data.

Sample

There were 630 participants who completed this study. The majority of the participants were patients in the adult outpatient program. Since this study was conducted in the general outpatient waiting room, some participants were parents of children who received treatment in the child outpatient program.

Out of the 630 participants, 479 were patients themselves, 136 were caregivers of children or adults who were patients, and 15 of them did not answer this question. The patients were also asked to self-identify their gender for demographic information in this survey. This section resulted in three categories of patient responses: female, male, and gender-fluid. There were 394 females, 224 males, and 5 participants were gender-fluid. Finally, there were 7 participants who did not answer the question regarding their gender. Patient’s age was also part of the demographic information received. According to the original data analyzed by Mistry and Venner (2016), 136 of the patients were below 18 years old, which corresponds with the number of caregivers who filled out the survey for their children receiving treatment. They categorized
the rest of the patients who answered this question as either an adult or an older adult. They received 403 questionnaires from adults, 67 from older adults, and 25 participants did not indicate their age.

Participants were then asked to identify the program in which they were receiving treatment, along with the number of years they had been in that program. Mistry and Venner (2016) stated that 86.4% of participants were being treated in the General Outpatient Program, which included both adult and child outpatient services. The other programs made up much smaller portions of the patient demographic: 18.4% were in the Psychiatric Rehabilitation Program, 12.2% Intensive Outpatient Program, 5.9% Case Management, 5.1% Mobile Treatment, 4.3% School and 3.0% Creative Alternatives. These programs are not mutually exclusive, and many participants were in multiple programs which explains the overlap in percentages (Mistry & Venner, 2016).

In terms of years in treatment at Johns Hopkins, 14% of the population had been seeking treatment for less than a year, 21% for 1-3 years, 35% for 3 years or more and 30% were unknown. The unknown category included people who did not answer this question and people who reported they did not know their length of treatment (Mistry & Venner, 2016).

Safeguards and Ethics

Confidentiality. This study was conducted from April-June, 2016, and the writer did not begin working at Johns Hopkins until September, 2016. Considering this, the writer/coder had no exposure to the participants during the study. This, along with the fact that all data are de-identified, ensures that the participant’s identity is not at risk of being exposed. The data were received through a private excel sheet and stored on a password protected computer for the duration of the data analysis. Any demographic information that was collected was utilized to
give context to the participant pool as a whole and not to describe individuals who took part in
the survey.

This study was previously expedited through the Johns Hopkins Internal Review Board
(IRB) because it was considered an Internal Quality of Care study. The previous researchers
have grandfathered the writer under that approval, as a Johns Hopkins Intern. Since this was
considered a quality of care study, it was not required for this writer to take the Johns Hopkins
IRB training.

**Risks and benefits.** The risks of participating in this study were minimal in comparison
to the expected benefits. Patients were given a clear description of the purpose of the study. The
title of the survey read: “Help us improve your care at the Johns Hopkins Bayview Community
Psychiatry Program (CPP) by doing this anonymous survey. Your opinion is important!” Patient
identities were not at risk of being exposed. This study was de-identified, and all questions were
answered at the patient’s discretion. Patient records or other medical information were not
obtained for purposes of this study, so their privacy was not at risk. The risk of psychological
harm due to the content of these questions was minimal. These questions did not include
triggering content and had a very low risk of increasing a patient’s symptoms. Patients were
offered the option of taking this survey with the help of their therapist or discussing it with their
therapist afterwards. Although this was not a formal debriefing, it provided them the opportunity
to consult with someone about any possible triggering questions.

The obvious benefit of this study is that participants have the chance to give open
feedback to their treatment team. Participants were able to voice their experience of therapy in a
constructive format, which may have felt more comfortable than telling their team in person. A
possible benefit of this is that their therapist would have more insight into their practices and
modify their approach to create the best outcomes for individuals.

Another benefit for patients is that taking a more active role in their health care treatment can feel empowering. For some patients, this may have helped negate some feelings of helplessness. This study gave them a platform to take charge of their treatment and guide their own recovery. These patients may have felt this would benefit their own treatment, and they may have also taken pride in being able to contribute to the mental health field. Participating in any study can give participants a feeling of purpose.

**Data Collection**

This study was designed by a group of therapists at the Johns Hopkins Community Psychiatry Outpatient Program in Baltimore, Maryland. The Johns Hopkins Internal Review process was expedited for this entire study because it was completely de-identified and was considered a quality of care study. This survey was given in the waiting room of the clinic and was administered by the front desk staff. This was a voluntary survey handed out in the CPP waiting room to patients. This survey was administered for approximately three months, from April until June of 2016.

This survey included multiple choice questions along with two short answer questions for the patients to answer openly. The survey was created by Daniel Buccino, LCSW-C, BCD and Michael Van Wert, LCSW-C, MPH in parallel with a therapist’s perspective study conducted in February, 2015. The quantitative research was analyzed in May, 2016 by two students from The University of Maryland, Reema Mistry, MHS and Shani Venner, MBBS, MPH. This thesis used secondary data, i.e., qualitative responses collected from the same survey.
Limitations

The major limitation to this study was the method by which it was administered. There were a significant number of patients who skipped one or more questions on this survey, providing us with incomplete data. In the context of the full study, only 36% of the surveys received were completely filled out (Mistry & Venner, 2016). In the context of the two short answer questions, the number of incomplete surveys was also significant. For the first open ended question, we received 110 surveys with no response and 32 answers that did not fit the question. For the second question, we received 142 no responses and 29 answers that did not fit. These numbers are very important to consider as a limitation to the study.

One explanation for this, of course, is that the patient simply did not want to answer the question, and therefore the method of administering it may not have made a difference. Another important possibility to consider is that many patients may not have understood the question as it was asked.

Johns Hopkins Community Psychiatry often works with patients who have a very low level of education. For many patients, the wording of these questions may have been too complicated for them to provide accurate feedback. For example, using the prompt “I know I am doing better when…” many patients responded with an answer such as “I am better”. If this study had been administered differently, there may have been an opportunity for those patients to clarify how they know when they are better. For example, if these questions had been asked in an in-person interview, we may have seen different results. By asking the questions face-to-face, the researcher could have ensured each patient understood the questions and asked follow up questions to yield more substantial responses. Having so many respondents not answer, or answer in a manner that did not fit the question, may skew the overall findings for this sample of
patients.

Also in consideration of the education level of these patients, some patients had difficulty reading the survey or otherwise completing it on their own. In some of these cases, their therapist assisted them in understanding the survey. This may have skewed the data from those specific participants, and it also decreases the anonymity of their answers. Therapists may have prompted a patient to help them answer the question. This may have caused the response bias known as “social desirability”, meaning patients may have felt influenced to answer the question to “please” the therapist, rather than giving honest feedback.

Although this may have influenced their answers, it is important to note that those therapists did not analyze the data. Therefore, this may have influenced the responses, but the coding was not influenced by the therapist’s knowledge of the patient’s responses.

**Data Analysis**

During the coding process, I began by looking for common themes in the qualitative data. These data were coded using a general inductive approach. As briefly described above, this style of coding takes the raw data and puts it in categories based on similar themes. The general inductive approach has five steps according to Thomas (2006): 1. Preparation of raw data files (“data cleaning”), 2. Close reading of text, 3. Creation of categories, 4. Overlapping coding and uncoded text, and 5. Continuing revision and refinement of category system.

The secondary data that I received had already gone through the “data cleaning” phase. The previous students working with these data had already entered the data on an excel spreadsheet in a coherent format. I began my analyzing process with an extensive read through of the data, originally just familiarizing myself with the content. On my second read through of the data I began to create themes from the patient’s responses. At first, I created many narrow themes to
make sure that every piece of the patient’s response was recognized. In step four I searched for answers which overlapped or could otherwise not be coded. It is important to make note that with this style of coding, answers can fit into multiple themes and sections of answers may not be included at all, if they do not fit the context of the study (Thomas, 2006).

An example of a response which fit in many themes was one participant who wrote “I know I’m doing better when… other people point it out to me. I start to smile and laugh more--become more talkative--sleep less, take better care of myself physically, become more social”. If the goal were to only code every answer once, a significant amount of the patient’s perspective would be lost. Using this response as an example, it could fit into a multitude of response themes.

Finally, I created larger themes which encapsulated the responses in my original, narrow themes. During this final step, I was conscious of answers which exemplified the findings of this study and later used the verbatim patient responses in my findings section to further explain each theme. Although in the final step I condensed these themes, I did not want to lose the wide range of responses. Therefore, in my findings section I have included my first narrow categorizations and titled them as “subthemes” under my broader themes.
CHAPTER IV

Findings

The purpose of this study was to answer the following question: What factors do patients in outpatient treatment think are most useful in therapy? In order to answer this question, researchers at Johns Hopkins Community Psychiatry Program asked patients in a written survey to evaluate their experience of therapy by completing two statements 1. “I know I am getting better when…” and 2. “The most important thing CPP provides for me is…”. The respondents’ answers were rich with information about how patients perceive their own treatment success. This chapter will report on the findings from this Feedback Informed Care survey.

Findings will be reported in three different categories. As this survey was administered to patients in multiple different programs, participants were asked to acknowledge if they themselves were the patient or if they were a caregiver to a patient. Those who marked “caregiver” may have been the parent of a child in the child outpatient program. They may have also been a caregiver to an adult in a more structured program for adults who are unable to live independently. When considering a survey “from the patient’s perspective” it is crucial to recognize that the caregiver responses may not be the actual words from the patient.

After considering this, the coder decided to report these findings separately to differentiate between the patient’s voice and the voice of a caregiver. There is also a third response category to include the voice of participants who did not answer if they were a caregiver or a patient. This respondent category is much smaller, but nevertheless provides more
information about the sample as a whole.

The coding process for all surveys was done simultaneously, and therefore each participant subgrouping has the same categories of responses. In Tables 1 and 2, the coder has clearly identified the percentage of responses from each respondent group that falls into each coded theme. These responses are reported separately to clarify the section of the sample giving the response.

This findings section will first describe the themes and subthemes found for question number one. Themes will be illustrated with direct quotes from participant responses. The examples given were chosen because they best exemplify the response theme.

Following the description of each theme is Table 1, fully detailing the percentages of respondent answers which fell under each theme. These percentages are shown within the respective patient category (patient, caregiver, or unidentified). Included under the chart is a summary of which themes emerged as the most prevalent indicators of treatment improvement that were identified by patients. This same organization is repeated in reporting the findings from the second question which was asked in this feedback survey.

Section One: “I know I am doing better when…”

This section of the chapter begins by reporting data from the first survey question: “I know I am doing better when…” The answers to this question were coded into five themes, each with multiple subthemes in order to preserve the richness of individual responses. The five main themes are as follows: 1. Change in symptoms, 2. Functional changes, 3. Use of treatment, 4. Social impact, and 5. Answers which could not be coded. Below are explanations of each theme and their respective subthemes along with direct quotes from responses.
Change in symptoms. The theme of Change in symptoms was used to include participant responses which identified a change in a symptom that was being targeted in therapy. Below is a description of each subtheme:

1. Change in mood: This subtheme included participant responses that acknowledged a change in participant mood as an indication of their improvement. This included answers such as: “I am able to be happy again” and “I feel enthusiastic, calm and can focus”.

2. Decreased symptoms: This subtheme included participant responses that specifically identified an absence of a symptom for which they were receiving treatment. For example, many reported: “I am less depressed”.

3. Decreased hospitalizations: A few responses acknowledged that the participant particularly knew they were doing better when they were less frequently admitted to the hospital. An example of these responses was: “I have stayed out of the hospital for over 4 years.”

4. Change in thoughts (process and content): This subtheme included participant responses which referenced a cognitive change. An example of this change was: “I think about negative thoughts and I know they're not true”.

5. Change in self-image: This subtheme was similar to the change in thoughts subtheme, but differed in that the responses were specific to the individual’s self-image or self-talk. For example, one respondent stated: “when I start feeling good about myself, when I'm feeling confident, when I have posotive (positive) thoughts, when I have "can do" attitude".
**Functional changes.** This theme included different ways that respondents marked their progress based on how they were functioning in their everyday life.

1. Daily functioning: This subtheme highlights patient responses which identified a change in their daily tasks. Many of these patients remarked: “I can get out of bed in the morning” or “I’m able to go to work.”

2. Achieving goals: These responses identified a treatment goal participants had reached which fell under the theme of Functional changes in their life. An example of an achieved goal response was a participant stating: “completed all my goals for last 3 years”

3. Coping: This subtheme included responses which were broader in scope. Some responses referring to changes in functioning did not mention daily tasks or goal achievement, and therefore the subtheme of Coping was developed to best capture that data. Some examples of this subtheme included participants simply stating: “I’m coping better”, while others were able to identify how “coping” impacts their functioning. A more specific example of this was: “I see different obstacles (obstacles) and I'm able to cope and get through smoothly”.

**Use of treatment.** Responses were coded under this theme when they indicated that participants were able to recognize their own progress based on their adherence to treatment.

1. Using therapy/doctor appointments: These survey responses recognized that the individual was seeing progress when they were showing up more consistently to sessions or when they were more actively engaged in treatment. This subtheme was seen in responses such as: “I keep my appointments with my therapist” and “I attend more often and communicate.”
2. Using skills/tools: These participants identified that they are doing better when they are more active in treatment specifically by doing their therapy “homework”. Many identified being more equipped to cope or de-escalate themselves through the use of these tools/ skills. An example of this subtheme was the response: “I’m able to use my coping skills”.

3. Medication: This subtheme included responses that identified medication adherence and being better organized in taking medications. The majority of these answers were short and direct such as “medication” or “medication maintenance”.

4. Physical health improvements: A few responses acknowledged a connection between physical health improvements and mental health improvements. An example of this was: “...take better care of myself physically…”

Social impact. This theme included responses indicating participants’ desire to socialize. This also included responses which acknowledged how an individual’s progress in treatment impacts others. These subthemes encapsulate a variety of ways the patients were able to recognize their own progress in connection to socializing.

1. Socializing more: Responses were coded under this subtheme when they indicated that participants marked their own progress based on an increase in their socialization. This subtheme also includes responses from patients about isolating less or reaching out to friends for support. An example was one response saying: “...When I take my meds or take a brisk walk or get together with friends and family”

2. Someone else noticed/ change in outside appearance: responses fell under this subtheme when respondents were able to identify their own progress based on someone else’s report. This included family members, friends, and their treatment team recognizing a
change in the patient. One example was from a caretaker response saying: “No complaints from his job/supervisors”. This subtheme also included broad statements about a change in an individual’s outside appearance being a tool for recognizing change; for example, a patient saying “I smile more”.

3. Expressing-self to others: This subtheme included participants reporting they are doing better when they are more able to verbally express themselves. This included responses about being clearer headed and therefore able to verbalize their thoughts. This also included responses about learning more effective communication styles. An example from this subtheme was “Stand up to my kids or other people. When I can say no and mean it”.

**Could not be coded.**

1. No response: Patients left this section blank.

2. Patient is not better: There were a handful of patients who reported no progress or even that they feel they are getting worse in treatment. For example, one participant acknowledged, “Well I have not got better because of trust issues with my therapist and I am not happy with her.”

3. Answer doesn’t fit: This subtheme was created for participant answers that either did not have enough substance to be coded or answers that simply did not make sense. An example of an answer in this subtheme which was quite frequent was a patient answering, “I know I am doing better when… I am better.” In this instance, the patient did give a response, but it did not have enough content for the coder to properly categorize it. With responses similar to this, the coder chose to categorize it as an answer that “did not fit” rather than possibly inaccurately analyze what the patient meant.
Table 1
*Percentage of Responses for Question 1 Based on Respondent Categories*

<table>
<thead>
<tr>
<th>Themes and Subtheme</th>
<th>Patient (n=479)</th>
<th>Caregiver (n=136)</th>
<th>Unidentified (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in Symptoms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Mood</td>
<td>19</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>2. Decreased symptoms</td>
<td>15</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>3. Decreased hospitalizations</td>
<td>.6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4. Change in thoughts</td>
<td>5</td>
<td>.7</td>
<td>0</td>
</tr>
<tr>
<td>5. Change in self-image</td>
<td>4</td>
<td>.7</td>
<td>0</td>
</tr>
<tr>
<td>Functional Changes</td>
<td>26</td>
<td>23.7</td>
<td>7</td>
</tr>
<tr>
<td>1. Daily functioning</td>
<td>20</td>
<td>21</td>
<td>7</td>
</tr>
<tr>
<td>2. Achieving goals</td>
<td>2</td>
<td>.7</td>
<td>0</td>
</tr>
<tr>
<td>3. Coping</td>
<td>4</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Use of Treatment</td>
<td>22.8</td>
<td>28</td>
<td>7</td>
</tr>
<tr>
<td>1. Using therapy/doctor’s appointments</td>
<td>13</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>2. Using skills/ tools</td>
<td>7</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>3. Medication</td>
<td>.8</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4. Physical health improvements</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Impact</td>
<td>15</td>
<td>12.7</td>
<td>0</td>
</tr>
<tr>
<td>1. Socializing more</td>
<td>8</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>2. Someone else noticed/ change in their outside appearance</td>
<td>5</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>3. Expressing self to others</td>
<td>2</td>
<td>.7</td>
<td>0</td>
</tr>
<tr>
<td>Answers could not be coded</td>
<td>23</td>
<td>31</td>
<td>47</td>
</tr>
<tr>
<td>1. No response</td>
<td>16</td>
<td>23</td>
<td>40</td>
</tr>
<tr>
<td>2. Patient is not better</td>
<td>1</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>3. Answer didn’t fit the question</td>
<td>6</td>
<td>5</td>
<td>7</td>
</tr>
</tbody>
</table>
Table 1 has provided the percentage of responses from the total sample which fell under each theme and subtheme for question number one. Below is a summary of the major findings detailed in Table 1. The percentages from the unidentified participants will not be expanded upon because they provide such little insight on the patient’s perspective of psychotherapy.

**Summary Findings for Question 1**

Changes in symptoms was the most frequent theme found in responses from patients themselves. Patients and caregivers reported under this theme that a noticeable change in the patient's mood was the best factor for recognizing their progress in treatment. Both categories of participants also recognized a decrease in symptoms as an important marker.

Functional changes were also an important indicator of improvement for both participant categories. Changes in the patient's daily activities was the largest subtheme within this theme.

Use of Treatment had the highest percentage of responses by caregivers which indicates its significance in caregivers’ assessment of whether the patient is doing better. Specifically, both caregivers and patients reported that therapy and doctor’s appointments were most important in the “use of treatment”. This included responses about more consistently coming to appointments and engaging with treatment. The second most prevalent subtheme under the Use of Treatment was the use of medication.

Social impact was the smallest theme for all participants in this sample. Patient responses which fell under this theme most consistently fit in the subtheme of Socializing More. Instead, caregivers most consistently reported that they recognized a change in outside appearance or that someone else noticed an improvement, for example, doctors, teachers, and friends.

This difference in response percentages makes logical sense based on the participant
categories. It is reasonable that caregivers would have an easier time recognizing the patient is doing “better” based on outside perspectives; while the patient is better able to recognize their own progress based on individual changes in socializing.

Answers that could not be coded was a very large theme for both participant samples. In fact, more caregivers left this question blank than writing comments which fit in any other theme. Within this theme, the most consistent subtheme was participants not responding at all. The frequency of no responses is important to consider when understanding the findings of this patient feedback survey. This factor will be expanded upon in the discussion section of this paper as it possibly speaks to many things, including the sample and the style of administering the survey.

Section Two: “The most useful thing CPP provides for me is…”

The first question asked participants to broadly consider treatment and reflect on how they notice patient progress. In the second question “the most useful thing CPP provides for me is…” participants were asked to identify, specifically how this outpatient program helps the patient to make that progress.

This question yielded a multitude of different perspectives, and therefore will also be reported in terms of major themes and subthemes. First, these themes will be described below with examples from each subtheme to illustrate the responses. Then the percentage of participant responses will be reported in Table 2. Just as seen in the coding of question one, responses will be presented in three categories of respondents: patients, caregivers, and unidentified participants. This table will provide a detailed quantitative report of the coder’s findings. A summary of these findings will then be provided. The reports from the patient and caregiver perspectives will be emphasized over the unidentified respondents. As recognized previously, the
unidentified responses provide less context in understanding participant feedback on the Community Psychiatry Program. The four main themes that emerged in analyzing responses to the second question are: 1. Treatment, 2. Interventions, 3. Outcomes, and 4. Answers that could not be coded. Below are explanations of each theme and their respective subthemes along with direct quotes from responses.

**Treatment.** Patient responses that fell under the Treatment theme include many different aspects of this program. These respondents identified the most important aspects of their treatment at CPP.

1. Therapeutic relationship: Participants whose responses fit in this subtheme identified the most useful part of CPP as creating a therapeutic relationship with their team. An example of these responses was “...caring providers who listen, who see and accept me as I am”. Responses in this subtheme specifically mentioned the relationship to a provider (doctor, therapist, etc.)

2. Safe space: These responses focused on the importance of the emotional space of a therapy session. These responses emphasized the comfortability and familiarity. An example of this was “Safe place to divulge my secret feelings...”

3. Support: This subtheme acknowledged the emotional support patients can receive from their care team. This subtheme was broad and included many responses that simply stated “support” as the most important thing CPP provides for them. Longer responses from this subtheme are illustrated with this example: “Just being there for me. Help me to remember who I am”.

4. Specific staff members: These responses were similar to the subtheme of the therapeutic relationship, but these respondents provided a more specific example. These responses
included the names of the care providers who were most helpful to the individual (therapist, psychiatrist, or front desk staff).

5. Consistent Care: This subtheme was created to include responses which were broader in scope. Some responses regarding Treatment could not accurately fit into the subthemes above. For example, some responses simply stated “care” or “mental health care” as the most useful aspect of treatment. This subtheme also included more specific comments, such as the program they were in or an aspect of that program. For example, some participants wrote “PRP” (a program at Johns Hopkins), while some responses identified a particular support such as “help with housing”.

Interventions. In many ways, responses under the Intervention theme were similar to the Treatment theme, although these answers were slightly less expanded upon. Many responses in this theme were concrete and short such as patient’s responding “meds”.

1. Medication: Many responses highlighted medication maintenance as the most important thing CPP provided for them.

2. Therapy: Many responses in this subtheme were vague such as “therapy” or “talk-therapy”. Also considered in this subtheme were responses which acknowledged their therapist’s theoretical background or specific style of therapeutic interventions. One response identified: “Exposure therapy, individual therapy, great PTSD therapy”.

3. Skills: This subtheme was for participant responses that reported particular therapeutic homework or concrete skills that the patient could use at home. One response in this theme was “Coping skills, ways to maintain calmness…”

4. Advice/concrete help: This subtheme recognized the usefulness of a therapist giving more direct advice, which differed from the concrete skills mentioned above because it
focused on concrete advice or suggestions from the therapist. For example: “...She has helped me to prioritize and devise plans to follow through on goals.”

**Outcomes.** Participant responses in the “outcomes” theme were responses which highlighted a result of treatment.

1. **Change in self-talk or self-image:** In these responses, participants identified the most useful thing CPP provided was a change in their internal dialogue. This included responses about an increase in the individual’s self-esteem or self-worth. Two examples of this subtheme were a patient’s statement that “My team reminds me to find strength in myself” and a caregiver reporting: “To have more confidence in themselves, to have more security in the things they do, to have more respect…”

2. **Resolving their past:** This subtheme included reports that CPP health professionals have helped to resolve/address issues from the patient’s past. One patient who recognized this psychodynamic work stated: “The outlet to explore my feelings and resolve back matters that keep me from functioning properly”.

3. **Functional changes:** Similar to this subtheme for question one; participant responses in this subtheme stated that this program has helped them to be able to complete their daily tasks. For example, one response in this subtheme was: “Getting my life back. I was unable to do any normal activity”.

4. **Change in symptoms:** This subtheme primarily focused on a decrease in reported symptoms. An example from a caretaker’s point of view was a parent stating: “My child takes Concerta and he's not as hyper like jumping and not constantly moving”.

5. **Physical health:** Some responses acknowledged the most important aspect of Community
Psychiatry for them was actually the physical health component. An example of subtheme was a patient saying “Mental and physical help”.

Could not be coded.

1. No response: Participants left this section blank

2. Does not help: There were a handful of participants who reported no progress. There were also two patients in this subtheme who self-identified as new patients and acknowledged they hadn’t been in the program long enough to answer this survey fully.

3. Answer does not fit question: This subtheme is the same as for question number one. Many of these responses did not have enough substance to be coded. For example, one patient wrote the most useful part of CPP for them was “back stopping”. This coder could not identify or assume what that meant. Other responses in this subtheme made sense, but did not answer the question. For example, one participant critiqued “wish I had a better selection (selection) of times to meet with my counselor”. This may be useful feedback for the clinic, but does not help to identify the most useful thing CPP provides for its clients.
Table 2.
*Percentage of Responses for Question 2 Based on Respondent Categories*

<table>
<thead>
<tr>
<th>Themes and Subtheme</th>
<th>Patient (n=479)</th>
<th>Caregiver (n=136)</th>
<th>Unidentified (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Therapeutic relationship</td>
<td>22</td>
<td>12</td>
<td>29</td>
</tr>
<tr>
<td>2. Safe space</td>
<td>9</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>3. Support</td>
<td>7</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>4. Specific staff members</td>
<td>8</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>5. Consistent care</td>
<td>7</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td><strong>Interventions</strong></td>
<td>36</td>
<td>47</td>
<td>7</td>
</tr>
<tr>
<td>1. Medication</td>
<td>12</td>
<td>18</td>
<td>0</td>
</tr>
<tr>
<td>2. Therapy</td>
<td>10</td>
<td>14</td>
<td>0</td>
</tr>
<tr>
<td>3. Skills</td>
<td>8</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>4. Advice/ concrete care</td>
<td>6</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
<td>18.8</td>
<td>21</td>
<td>0</td>
</tr>
<tr>
<td>1. Change in self-talk/ self-image</td>
<td>3</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>2. Resolving their past</td>
<td>.4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3. Functional changes</td>
<td>11</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>4. Change in symptoms</td>
<td>4</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>5. Physical health</td>
<td>.4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Answers could not be coded</strong></td>
<td>22</td>
<td>30.7</td>
<td>73</td>
</tr>
<tr>
<td>1. No response</td>
<td>17</td>
<td>30</td>
<td>73</td>
</tr>
<tr>
<td>2. CPP does not help them</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3. Answer didn’t fit the question</td>
<td>4</td>
<td>.7</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 2 provides a detailed report of the percentage breakdown for each theme and subtheme based on the respondent categories. Consistent with the report on question number one, a summary of the major findings from caregivers and patients follows. The 15 participants
who remained unidentified are not included in the summary.

**Summary Findings for Question 2**

In analyzing responses from patients, themselves, Treatment emerged as the most important thing CPP provides for them. The therapeutic relationship was the aspect of treatment that was reported most frequently by both patients and caregivers.

Caregivers identified Interventions as the most useful aspect of the services offered by CPP. Under the broad theme of interventions, medication was mentioned as most useful by both caregivers and patients. The subtheme of medication was closely followed in frequency by the subtheme of therapy.

Outcomes was found to be the least important theme for all participant responses to this question. Within this theme, both categories of respondents most frequently referenced a functional outcome from therapy.

Similar to question number one, in this question, a significant number of participant responses could not be coded. The most frequent reason why an answer was unable to be coded is because the participant left it blank. For both questions one and two, the reasons for this low response rate will be elaborated upon in the discussion section of this paper.

**Conclusion**

These data come from 630 patient feedback surveys which were read and then coded for consistent themes. The findings from this chapter suggest different ways by which patients at Johns Hopkins Community Psychiatry notice they are getting better and what aspects of this program contribute to their success. Although responses were unique, many consistencies were found in coding these responses which provide insight to a patient's experience of outpatient psychotherapy. The following chapter will elaborate on these findings, connect the findings to
previous literature on the topic, address the study’s strengths and limitations, and provide implications for future studies and implications of this study for social work practice.
CHAPTER V

Discussion and Conclusion

The purpose of this study was to answer the following question: What factors do patients in outpatient treatment think are most useful in therapy? In order to answer this question, researchers at Johns Hopkins Community Psychiatry Program asked patients in a written survey to evaluate their experience of therapy by completing two statements 1. “I know I am getting better when…” and 2. “The most important thing CPP provides for me is…”.

This chapter will review the major findings from this study and offer a comparison of these findings to previous research noted in the literature review. This chapter will address limitations and strengths, considered retrospectively, to the current study. Lastly, before concluding this research study, the writer will provide recommendations for future research, and what implications can be drawn from this study for Social Work Practice and Policy.

Summary of Major Findings

The coding process for all participants (patients, caregivers, and unidentified participants) was the same, but findings were reported within the self-identified participant categories. During the coding process for question number one, five main themes were found in responses from each participant category. These themes were: 1. Change in symptoms, 2. Functional changes, 3. Use of treatment, 4. Social Impact, and 5. Answers which could not be coded.

Patient responses to question one most frequently recognized a change in symptom and the subtheme of a change in their mood as being reflective of their individual progress in
treatment. Responses from the other participant category, caregivers, provided different insight from their experience of treatment. These responses most frequently acknowledged the theme of treatment and the subtheme of the patient’s use of therapy and doctor’s appointments as a marker of the patient “getting better.”

For question number two, “the most useful thing CPP provides for me is…”, four themes were discovered during coding for all participants. These themes were: 1. Change in symptoms, 2. Functional changes, 3. Use of treatment, 4. Social Impact, and 5. Answers which could not be coded.

For this short answer question, the most prevalent theme in patient responses was in regard to CPP providing patients with Treatment. Most notable in these responses was the subtheme of the importance of the Therapeutic Relationship. The responses about CPP from the caregiver perspective most often acknowledged the Interventions used by the treatment team, and the most notable subtheme was the Intervention of prescribing medication.

**Comparison with Previous Research**

Comparing the themes found in patient feedback from this study with the findings from the previously mentioned Tasca, et al. (2014) study, in which similar research was conducted with therapists, gives a broader context for understanding the current findings. Naturally, the themes found in these two studies were different for a multitude of reasons, most importantly is that the samples were different and the surveys were different. In the current study, caregivers and patients were asked their experience of psychotherapy, while the Tasca et al. survey was conducted with therapist participants.

In the Tasca et al. (2014) study, therapists were asked to report on which areas of the therapy they found most important and therefore what areas they felt needed to be researched
more consistently to inform our Evidence Based Practices. Even considering the differences in methodology, the answers from the two perspectives in this dyadic relationship provide a more inclusive depiction of how this collaborative work can be done most effectively. Since the theoretical framework for this study is based on the relationship between patient and therapist, the caregiver perspective will not be further expanded upon in this discussion.

When coding the therapist feedback on their experience of therapy, Tasca et al. (2014) found four main themes: 1. Therapeutic Relationship/ Mechanisms of Change. This included alliance building, empathy, and the process of rupture and repair. 2. Professional Development. This theme included how therapists were trained and were continuing to inform their therapeutic approach (ex: supervision), 3. Therapist Factors. This refers to the individual therapists’ beliefs, demographics, and life story, and 4. Client Factors: These were the same as the therapist factors and the two were also considered in how they interacted in the relationship (Tasca, et al, 2014).

Although these themes do not directly coincide with the themes found in the current study, the significant overlap and discrepancies are worth unpacking. In comparing these two studies, patients and therapists seem to agree that the most important piece of therapy is relationally based. In the Tasca et. al (2014) study, therapist responses named the therapeutic relationship as the most important factor, while in the current study, the most frequent patient response theme was labeled “treatment”. Patient responses in this study paralleled the clinical language of Tasca’s therapist subthemes: “alliance building, empathy, and the process of rupture and repair”. The current study categorized these same notions in the subthemes of the therapeutic relationship, safe space, emotional support, and consistent care. Within this theme, a number of patient responses even named specific staff with whom they felt this alliance. As seen in this overview, the prioritization of the relational aspect of treatment is seen in both perspectives.
While the specific themes of “therapist factors” and “client factors” are unique to the Tasca et al. (2014) study, similar content arose in the current patient feedback survey, especially in regard to the interaction of both of the individual’s factors. The therapist’s ability to relate to the patient and express commonalities was a crucial component in many responses from the patient’s perspective. These relationship dynamics remained important to both patient and therapist.

There was some notable patient feedback which was not consistent with therapist feedback. For example, in the current study, patient responses also recognized medication and specific therapeutic interventions as an important piece of their treatment in CPP. This indicates that patients and therapists may have varying perspectives on what creates an environment that fosters treatment “success”. This difference in opinions highlights the necessity of more feedback informed modalities.

Comparing the findings from Tasca, et al. (2014) study with the current findings, gives us a foundation to consider the importance of both perspectives. This is not the only literature which corresponds with the findings from this study though. Luborsky (1994) as well as Krupnick et al. (1996) conducted very different studies, but both found similar evidence, supporting the importance of the therapeutic relationship in treatment success.

Luborsky's (1994) meta-analysis emphasized the importance of the therapeutic alliance from the patient's perspective, just as the current study does. This study, conducted 23 years ago, specifically noted that the patients were acknowledging a dire need to focus on the relational aspects of therapy. This recommendation is supported by the findings from current patients at Johns Hopkins.

The Krupnick et al. (1996) research also has a significant place in this conversation. These researchers studied the effects of the therapeutic alliance on patient outcomes. Results
from this study indicated a correlation between the strength of the relationship and the patient’s progress in treatment. This was not conducted with patient feedback, but researchers suggested in their discussion of these findings that a patient’s early ratings of the therapeutic alliance should correspond with their progress in treatment.

Another important study to compare to the current findings was the Anderson, et al. (2009) research. This study did not directly look into the therapeutic relationship, but focused on one component of this relationship. These researchers found a correlation between the therapist's interpersonal and social qualities and patient treatment outcomes. Comparing this to the current findings, suggests that patients experience therapy differently depending on their therapist’s interpersonal skills and ability to create an alliance with them.

Comparing these two studies also supports the move towards Feedback Informed Care. Patients who are allowed the opportunity to offer feedback to their therapist, may be able to verbalize their experience of the therapist’s interpersonal skills and help to co-create a stronger alliance. Furthermore, this could address, in some cases, the dropout rate of patients in therapy. Therapists who can provide a safe space in which feedback from patients is welcomed can help patients practice their ability to be an active agent of change.

Limitations

The main limitation in this study was the high level of no responses, and responses which did not fit the question as it was posed. For question one, 23% of patient responses and 31% of caregiver responses could not be coded. Similarly, for question two, 22% of patient responses and 30.7% of caregiver responses could not be coded. These large numbers may be indicative of some other limitations in this study.
One possible explanation for this response rate is related to the sample pool. The average education level of the patient population at The Community Psychiatry Program is lower than a high school diploma. This information suggests patients may have had difficulty reading and completing this survey on their own.

This patient demographic information corresponds with another limitation of this study. This study was administered by the front desk staff, and patients were asked to complete it in the waiting room while waiting for their appointment. Considering the reading level of many patients at CPP, this method of conducting this research may not have been the most efficient. I believe these factors are indications for revisions of this research in future Feedback Informed Care studies. It may provide better insight for a researcher to ask patients in a one-on-one interview about their experiences of psychotherapy. This methodology would give opportunity for clarification and follow-up questions to gain a better understanding of the patient’s perspective.

There were additional limitations related to the coding process and the use of secondary data. As the sole coder for both open-ended questions, I may have been unaware of biases I introduced into the results. Although I was grateful to be able to join this research project and allowed the opportunity to work with this data, this also created some tensions in the writing process. This research was created as an internal Quality Care Study for the Johns Hopkins Results Committee. The researchers created it to gain general information from their patients, and therefore this thesis question was created after the study was complete. Another complication of using secondary data is that I had very limited information about the original study conducted between April and June of 2016. At times, this posed as an obstacle in my ability to contextualize these research findings.
Strengths

Because this study was conducted in a large hospital setting, the data collectors were able to reach a significant number of participants. Having 630 respondents in a study gave a large range of perspectives and provided many themes and subthemes to consider when deconstructing “successful” treatment. I believe this also speaks to how many patients want to be invited into this collaborative process.

Another strength to this study was the inclusion of the caregiver perspective. These findings are unique to this body of research. This includes yet another perspective, which is neglected in a didactic relational model. Findings from caregivers give even more insight to the impact of therapy and includes the perspective of everyone who is affected by it. These findings have implications for future research as well as implications for practicing clinicians, which will be further expanded upon in the following sections.

Recommendations for Social Work Research

Feedback Informed Treatment remains an under-researched area in the field of mental health treatment. The majority of the research used to support this study was related to the importance of Feedback Informed Treatment, yet little research could be found which actually used the patient’s experience as a tool to modify interventions. Simply from comparing the current study with the Tasca, et al. study, it is clear that the patient and therapist perspectives have similarities and many critical differences. This suggests that in order to fully abide by a relational approach and value the collaborative effort of therapy, more research needs to be conducted which utilizes the patient’s voice. In this section we will consider findings from this study as well as previous research to make recommendations for future studies.
The Lambert 2001 study recognized the weight that Feedback Informed Treatment can have on patient success. This study showed that patients of therapists who were given feedback, experienced greater improvement during treatment. This suggests not only the need for future research with direct patient feedback, but the need to use patient feedback. The latter will be expanded upon in the section: Implications for Social Work Practice and Policy. Lambert’s (2001) findings recognize a direct correlation between patients giving feedback and patients succeeding in treatment. This study helps to provide evidence of the need for more research on Feedback Informed Treatments.

The Sitza (1999) findings help us to further narrow down which styles of feedback are most useful. This study suggested that patient feedback should not be collected in the form of satisfaction surveys, but rather surveys which ask about patient’s overall perspective. In the current study, we can see that using open-ended questions, at times, provided us with significant insight into the patient's experience. This suggests that allowing patients to openly discuss their experiences helps us to obtain a better understanding of their experience.

This example indicates that the path to better Feedback Informed Care is through the use of less structured, open-ended, patient feedback. From the current study, it seems that not enough structure or guidance may also have consequences on collecting useful patient feedback though. Specifically, for patients with a lower education level or whom are less psychologically minded, it may be useful to help patients verbalize their experiences.

Based on these critiques of the current study and findings from previous research, one recommendation for future Feedback Informed Care would be to use a one-on-one interview style of research. Using this technique would allow patients more time and space to fully describe their experiences. For example, consider in the current study when many patients
reported “I know I am doing better when… I am better”. Unbiased follow up questions may have helped a patient describe what “better” means to them. Interviewers could have asked for an example in order to further our understanding of what “better” looks like to each individual.

Finally, the current study suggests that more Feedback Informed Care should include the caregiver perspective, when appropriate. Findings from this study suggest that caregiver and patient experience treatment differently and have different ways of marking patient progress. More research comparing the patient and caregiver perspectives could help to understand, fully, how therapy works.

**Implications for Social Work Practice and Policy**

This patient feedback study supports the move towards Feedback Informed Treatment as an Evidence Based Practice. Currently, Evidence Based Practices are taking priority in funding over other less researched models. In honoring the relationally based work that Social Workers conduct, it is only fair to include the patient’s opinion on what styles of treatment deserve this funding, making this a *true* collaborative approach. By utilizing Feedback Informed Care, we can incorporate both perspectives of therapy into a more effective Evidence Based Practice Modality.

This naturally has many implications for practicing social workers. This study first and foremost indicates a need for more patient feedback, not just in research studies, but in actual practice. Comparing once again, the findings from this study and the Tasca et al. (2014) research, it is clear that patients, caregivers, and therapists have different experiences of therapy. For practicing clinicians this shows the relevance of inviting patients into a transparent conversation about their perceptions of therapy. Asking patients explicitly about this can be done informally in
sessions and could create a stronger alliance by recognizing the patient’s importance in the relationship.

This leads into a second implication for social workers: focusing on the therapeutic relationship. Patients in this study and therapists in the Tasca et al. (2014) study recognized the important impact this relationship has on treatment “success”. Practicing therapists should acknowledge the inevitable impact that their attunement to this relationship can have in their everyday practice.

Finally, the current study explored an aspect of Feedback Informed Care which has largely been neglected, the caregiver perspective. Although this was not the main focus of this thesis, it provides us with many suggestions for practice and future research. This study found that the voice of the caregiver does not always align with the voice of the patient. This naturally has implications for practicing Social Workers, as most professionals will interact with parents of children or adult caretakers at some point in their career. This study indicates that working with caregivers may be a complicated balance for therapists in considering how each member is experiencing treatment.

Findings from the caregiver perspective can also be very beneficial evidence for practicing Social Workers. Including the experience of a caregiver in sessions may help patients consolidate gains. As Caregivers seem to witness change in the patient differently than the individual themselves, this could be great insight to assist patients in recognizing all of their progress.
Conclusion

This study aimed to give voice to the patient's perspective of therapy at Johns Hopkins Community Psychiatry Program. The current study was based upon secondary data from a study conducted by Daniel Buccino, LCSW-C, BCD and Michael Van Wert, LCSW-C, MPH which was administered between April and June of 2016. This qualitative data was collected in the context of a longer mixed methods survey in which the quantitative research was previously analyzed in May, 2016 by two students from The University of Maryland, Reema Mistry, MHS and Shani Venner, MBBS, MPH.

The current study focused on the qualitative questions from this survey. Patients were asked to give short responses to the following two questions: 1. “I know I am getting better when…” and 2. “The most important thing CPP provides for me is…”. Coded participant responses provided us with insight into the patient’s perspective of psychotherapy. These qualitative questions gave patients an opportunity to give more complex responses which built upon the previously analyzed quantitative research.

Using all of the perspectives explored throughout this study- the therapist, patient, and caregiver (in some cases)- gives a more inclusive and accurate depiction of treatment. In order for mental health care professionals to create best practices, we must remain curious about what factors truly influence treatment “success” and treatment “failures.” Considering a relational approach, and therefore treatment as a collaborative effort, it is critical to conceptualize treatment “success” from the perspective of all members involved in the process. Furthermore, we must consider each perspective equally valid and influential in creating and modifying the course of treatment.
By inviting patients into this critical conversation, clients were further empowered to be active agents in their own treatment and to challenge their treatment team to provide the best care possible. This study has furthered the quest towards “best practices” and highlighted many under-researched opinions about treatment “success”. These participants have given a glimpse of the lived experience of being the other members of this treatment team, to not only the staff of Johns Hopkins, but to all mental health professionals.
References


Appendix A

Patient Survey

Help us improve your care at the Johns Hopkins Bayview Community Psychiatry Program (CPP) by doing this anonymous survey.

Your opinion is important!

<table>
<thead>
<tr>
<th>I am a patient at CPP:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>My gender (circle one):</td>
<td>Man</td>
<td>Woman</td>
</tr>
</tbody>
</table>

| My age: | ___________years old |
| At the Community Psychiatry Program, I have been in: (circle all that apply) |
| A. Outpatient (e.g., individual therapist, psychiatrist) | E. School-based (e.g., services in school) |
| B. Intensive outpatient program (IOP) | F. Mobile treatment |
| (e.g., comes to your house) C. Psychiatric rehabilitation (e.g., PRP) | G. Creative Alternatives |
| D. Case management (e.g., help with housing, finances) |

| I have been receiving mental health care…(circle one for each question) |
| …in my lifetime for: | Less than 1 year | 1-3 years | 3+ years |
| …at the Community Psychiatry Program for: | Less than 1 year | 1-3 years | 3+ years |

1. I know I am doing better when: (Please write below)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

2. I know I am doing better when: (Rank by importance from 1 to 4, 1=most, 4=least). Each option should have a DIFFERENT ranking.

___ I feel less depressed, less worried, sleep better, hear fewer “voices,” [my symptoms]…
(I experience fewer symptoms)

___ I enjoy life more, feel safer, am more comfortable with myself, am more satisfied with my relationships, etc… (my quality of life is better)

___ I can handle things better when they go wrong (my coping skills have improved)

___ I am able to do better at work or school, get along better with family/friends, I get around more easily, I stay out of the hospital, etc… (I function better)

4. The most helpful things CPP provides for me are: (Please write below)

________________________________________________________________________
________________________________________________________________________

4. These are most helpful to me: (Rank by helpfulness from 1 to 4, 1=most, 4=least). Each option should have a DIFFERENT ranking.

___ Getting help with finances, jobs, food, housing, social services, transportation, etc.

___ Learning skills to help me handle things when they go wrong.

___ Having a trusting relationship with my healthcare provider, feeling understood by her/him, she/he working with me well.

___ Having the right medications.

5. In the past, I have answered surveys about how I am doing, including about my symptoms, quality of life, coping skills, and functioning (circle one)

Yes  Unsure  No

Please answer #6-11 by circling one number for each:
1- Strongly disagree  2- Disagree  3- Neutral  4- Agree  5- Strongly agree
6. I am comfortable answering surveys about how I am doing

7. I am comfortable talking with my CPP healthcare providers about my answers to surveys

8. I am comfortable answering surveys with my CPP healthcare provider present (e.g., during an appointment)

9. I am comfortable answering surveys on my own (e.g., at home or in the waiting room before my appointment)

10. I am comfortable answering surveys on an electronic device (e.g., smart phone, iPad, computer, kiosk)

11. It is helpful answering surveys about how I am doing and talking about my answers with my CPP healthcare provider