CLINICIAN IMPACT ON CONSUMER DECISIONS REGARDING PSYCHIATRIC ADVANCE DIRECTIVES

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CLINICIAN IMPACT ON CONSUMER DECISIONS REGARDING PSYCHIATRIC ADVANCE DIRECTIVES

by

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Dedication

To Steve, Nora, and Amanda
Without your love and support I could not have done this.

Abstract

This dissertation examines associations between clinician attitudes both towards Psychiatric Advance Directives (PADs) and towards coercive intervention with consumers' decisions regarding PADs. In addition, it examines associations between characteristics of clinician/consumer relationships and consumers' PAD decisions. The research is grounded in the Health Beliefs model expanded to include the theory of relational autonomy. A secondary analysis of data from a randomized trial of Facilitated PADs (N=469) was completed. Multilevel logistic regression analyses examined whether clinician characteristics and attitudes were significant predictors of PAD completion by consumers and whether consumers valued PADs more highly for proscriptive purposes. Multivariate logistic regression analyses examined whether characteristics of the clinician/consumer relationship were significant predictors of these same dependent variables. Results showed that neither dependent variable was significantly associated with clinician characteristics and attitudes. PAD completion was significantly more likely if consumers were older, demonstrated greater PAD understanding, valued treatment for relational purposes, and reported having a friend; it was significantly less likely if consumers reported medication satisfaction, victimization, or if consumer and clinician were discordant on PAD attitudes. Valuing PADs as a proscriptive tool was significantly more likely if consumers were white, had experienced involuntary hospitalization, reported treatment dissatisfaction, or reported having no one to trust, and showed a trend towards significance if the consumer reported avoiding treatment for fear of forced treatment; it was significantly less likely if consumers reported not knowing enough about PADs, reported avoiding treatment for fear of being put in seclusion, agreed that consumers should talk with their provider about PADs, and if neither consumers nor their clinicians agreed that people should have a PAD to protect them from hospitalization. Findings suggest that consumers make decisions regarding PAD completion and purpose based on: 1) prior experiences with treatment; 2) perceptions regarding treatment benefits/barriers; 3) understanding of PADs; and 4) the relational context in which they make decisions. Due to the exploratory nature of the study and limitations of a secondary data analysis additional research is needed to understand the dynamics of these factors in greater detail.

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And the only wisdom there is, is the wisdom of humility.
Humility is endless.
T.S. Eliot

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Chapter 1 Introduction

Individuals with serious mental illnesses (SMI) may episodically have times of psychiatric crises and as a result experience coercive interventions such as involuntary hospitalization. Though justified by providers as necessary for the prevention of harm, these interventions are often described as frightening and traumatic times by the individual with SMI. One possible way to prevent or reduce the need for coercive intervention is through the use of Psychiatric Advance Directives (PADs). PADs are legal documents that allow individuals, when well, to document their wishes for care during times of psychiatric crisis (Joshi, 2003). With a PAD an individual may continue to receive the treatment they prefer even when they have lost capacity to express their wishes. They thus have the potential of increasing autonomy, decreasing the need for coercive intervention, and may enhance the connection and levels of trust and communication between the individual with SMI and the treatment system. Despite this potential, little is known about how individuals make decisions regarding whether to create a PAD or whether PADs are more valuable for proscriptive or prescriptive purposes. The factors potentially associated with these decisions, such as prior coercive experiences, relationship with mental health providers, and attitudes towards mental health treatment, are not yet fully understood.

This dissertation describes research examining the creation of Psychiatric Advance Directives (PADs) by individuals with serious mental illnesses (SMI). More specifically, this research examines the association between clinician attitudes towards PADs and towards coercive intervention in mental health care and the decisions individuals with SMI make regarding PAD creation and the purposes they wish the PAD to serve. In addition, the research examines the association between characteristics of the relationship between the clinician and individual with SMI and individual's decisions regarding PAD creation and purpose. Specific aspects of the relationship examined include the working alliance between clinician and individual, the concordance between clinician and individual ratings of the working alliance, and concordance on views regarding PADs and regarding coercive interventions in mental health treatment.

This dissertation begins by providing an overview of the research including a rationale for the study, followed by the study's specific aims, specific research questions, and hypotheses. This is followed by a comprehensive review of the relevant literature, including the literature on autonomy and coercion in the treatment of individuals with SMI, the theoretical and empirical PAD literature, the literature on clinician attitudes regarding PADs, and literature on the impact of the working alliance between clinician and individual with SMI on clinical outcomes. This literature is used to provide a theoretical and practice context within which to conceptualize the research questions, demonstrating the study as a relevant and logical next step in the field.

The dissertation next provides an original synthesis and conceptualization grounded in the literature, resulting in presentation of a framework and conceptual model for the research. Using this model the dissertation then provides a description of the methodology used. Since this study engaged in an analysis of secondary data, this description includes a discussion of the purposes and design of the original study from which the data are derived. Discussion of the methodology includes a description of the statistical analyses completed as well as a power analysis demonstrating that the data set was of adequate size for the purposes of the analyses. The dissertation then provides the results of these analyses. The document concludes with a discussion of the findings, of potential study limitations, and of the implications of the findings for practice, teaching, and an ongoing research agenda.

1.1 Definition of Terms

Before entering a detailed discussion of this study, it is important to ensure clarity of the key concepts in the research. To that end I provide the following definitions and brief discussions of key terms as they are used in this study.

1.11 Psychiatric Advance Directive (PAD)

Psychiatric Advance Directives (PADs) are legal documents that may be created by competent individuals, that is, individuals able to understand, appreciate, make, and communicate mental health care decisions (Appelbaum, 2004). PADs allow individuals to express their wishes for mental health care and to communicate relevant information regarding their condition at a future time when, because of SMI relapse, they may lack capacity and no longer be able to do so (Appelbaum, 2004; Backlar, McFarland, Swanson, & Mahler, 2001; Geller, 2000). PADs allow competent individuals to state their preferences for mental health care through two mechanisms: advance instructions and health care power of attorney. Advance instructions (AIs), can include statements of consent for or refusal of certain medications or other treatments such as electroconvulsive therapy, provision of information regarding actions to occur if hospitalized (e.g. contacting a family member, caring for a pet), and advance informed consent for hospitalization. Health Care Power of Attorney (HCPA) allows individuals to appoint a proxy decision maker for times when they are no longer capable of making treatment decisions (Backlar et al., 2001; Geller, 2000).

1.12 Serious Mental Illnesses (SMI)

For the purposes of this work I define serious mental illnesses as mental disorders which include schizophrenia, schizoaffective disorder, psychotic disorder Not Otherwise Specified, or mood disorders with psychotic features. These disorders interfere significantly with functioning and usually require psychiatric hospitalization at some point in the individual's life (American Psychiatric Association, 2000). Throughout this work I refer to those who experience these illnesses as "individuals with SMI" or "consumers."

1.13 Clinician

For this study a clinician is defined as a professional providing and/or overseeing mental health assessment and treatment for an individual with SMI. When the individual has multiple mental health service providers, the clinician is defined as the person who knows the most about the individual's mental health treatment, as identified by the consumer.

1.14 Working Alliance

The working alliance is the relationship between clinician and individual receiving mental health services, usually thought to include both a collaborative agreement between clinician and individual regarding mental health treatment goals and specific tasks within treatment, as well as the affective bond between the clinician and individual (Bordin, 1976).

1.15 Autonomy

The term autonomy is derived from the Greek *auto*, self and *nomos,* law, i.e., having one's own laws. The term, when applied to an individual, is defined as the liberty to follow one's will, or personal freedom (The Philological Society (Ed.), 1933). Two conditions are thought to be essential to autonomy: independence from controlling influences; and competence, or capacity for intentional action (Olsen, 2003). Intentional action involves both the ability to identify a course of action based on information regarding options and consequences and the ability to operationalize the chosen course (Reinardy, 1999). Autonomy thus requires independence, the ability to reason, the ability to choose an action, and the ability to act.

1.16 Relational Autonomy

Relational autonomy is a term used to describe an alternative conception of what it means to be an autonomous person. It expands autonomy beyond a conceptualization of independent free agent to include a consideration of the relational context in which the individual is embedded (Christman, 2004). The construct of relational autonomy is used in a wide range of literature, including feminist and constructionist works (Nedelsky, 1989). However, it is used in a variety of ways, some broader and others narrower in scope. At its broadest, relational autonomy considers the individual's embeddedness in both social relationships and the wider net of socially structured determinants of identify, such as race, class, and gender (Oshana, 1998). However, for the purposes of this research, the construct relational autonomy will more narrowly refer to a conceptualization of the individual as a social being whose decisions and identity are shaped by and connected with his/her interpersonal relationships.

1.17 Coercive Treatment

Coercion is derived from the Latin *coercere* meaning to shut in, restrain, or confine. The definition of coercion includes the concepts of constraint, restraint, or the application of force to control the action of a voluntary agent (The Philological Society (Ed.), 1933). In mental health care, coercive assessment and treatment are justified on the principles of nonmaleficence (the prevention of harm) and beneficence (doing good for the individual). Nonmaleficence can be used to justify actions to prevent harm either to the individual or to others (Hoyer et al., 2002; Wettstein, 1987). Beneficence can be used to justify actions such as forced mental health treatment for individuals who have limited capacity to understand their situation and refuse treatment that would be of benefit to them (Verkerk, 1999).

1.2 Background

In the United States, about 2.6 percent of the adult population has a diagnosis of a SMI (*Mental health: A report of the Surgeon General*, 1999), and of these individuals about 30 percent experience a crisis resulting in hospitalization during a year's time (R. Coffey et al., 2001). Many of these hospitalizations involve coercive treatment such as involuntary commitment or forced medication. Though mental health providers argue that coercive interventions are done under the principles of beneficence and nonmaleficence, to protect or prevent harm to the individual or to others (Blecher & Blank, 1989; Munetz, Galon, & Frese, 2003), some individuals with SMI and some advocates have countered that involuntary treatment may be in itself harmful and should be avoided whenever possible (Hoge & Grottole, 2000). In addition, they argue that support for coercive intervention is based in stigmatizing perceptions of individuals with SMI as being highly dangerous or having "bad character" (Watson, Corrigan, & Angell, 2005).

Involuntary treatment, particularly involuntary hospitalization, has been described by individuals with SMI as frightening, dehumanizing, and as a barrier to recovery (Marsh, 2000). Involuntary commitment may result in iatrogenic psychosocial effects such as increased stigma in the community, loss of housing or employment during confinement, as well as physical harm through side effects from medication that may be forced during hospitalization (Bentley, 1993; Rogers, 1999). Though results are mixed and additional studies are required (Salize & Dressing, 2005), some research suggests that positive outcomes of long term hospitalization may be reduced if the individual perceived the hospitalization as coercive (Kaltiala-Heino, Laippala, & Salokangas, 1997).

In addition to direct harmful effects of involuntary treatment, fear of future forced intervention may decrease individuals' willingness to seek out mental health treatment. One study found that 28 percent of individuals with SMI surveyed reported avoiding mental health treatment because of fear of hospitalization, and 26 percent because of fear of forced medication. This fear and resultant treatment avoidance was significantly associated with prior involuntary hospitalizations and with repeated warnings and pressure regarding medication compliance from providers (Swartz, Swanson, & Hannon, 2003).

Given the potential negative impact of involuntary treatment, it is of benefit to individuals with SMI to identify alternative strategies for provision of mental health care which may minimize the need for coercion. One such strategy is the use of a Psychiatric Advance Directive, or PAD. PADs are legal documents that allow individuals with SMI to express their wishes for care and communicate relevant information regarding their condition during a time when they are capable and psychiatrically stable, so that at a future time, when they may be in crisis and no longer able to express their wishes, their preferences are clear to providers. They may include both statements of acceptance or refusal of certain treatments as well as provision of information regarding actions that would be of help during a crisis or hospitalization. In addition, PADs may designate a surrogate healthcare decision maker (Joshi, 2003; Ritchie, Sklar, & Steiner, 1998; Swanson, Tepper, Backlar, & Swartz, 2000). PADs are created or revoked when an individual is presumed to be competent and capable of making mental healthcare decisions, and go into effect only at such time as the individual is determined to have lost this capacity. (Joshi, 2003; Swartz, Swanson, & Elbogen, 2004; Widdershoven & Berghmans, 2001).

PADs have the potential to decrease the harmful effects of involuntary treatment by identifying medications the individual knows are tolerable and effective and thus reducing the risk of side effects and need for forced medication. In addition, PADs can document needed actions to prevent psychosocial harms such as lost housing or employment. PADs may also prevent involuntary hospitalizations by providing emergency mental health workers with information that may be used to resolve crises without hospitalization. Finally, with a PAD in place, individuals with SMI may be less reluctant to seek out mental health care for fear of coerced treatment. Increased engagement in treatment may in and of itself decrease crises and thus the need for coercive intervention (Swanson, Tepper et al., 2000).

Despite the promise of PADs, there are concerns that they may not be utilized to the benefit of individuals with SMI. Individuals may refuse to create them, seeing PADs as either unnecessary or as futile in a system that does not listen to their preferences (Backlar et al., 2001; O'Connell & Stein, 2005). Providers express concerns that PADs will be used as a way to refuse all care [which was, in fact, the initial intent of Thomas Szasz when he first proposed them (Szasz, 1982)], or that PADs will be so proscriptive that their ability to guide treatment effectively is minimal (Appelbaum, 2004; Srebnik & Brodoff, 2003; Srebnik et al., 2005). For PADs to have maximal impact, increasing consumer voice, decreasing involuntary treatment, providing useful clinical information, and increasing consumer engagement in treatment, I would argue that two conditions are necessary: a) the individual must create a PAD; and b) the PAD should have at least a balance of proscriptive and well as prescriptive elements, so that practitioners are given guidance in what *to do* as well as what *not to do*, in order to best provide effective care for the individual in a respectful manner.

There are a number of factors that may influence an individual's decision to create a PAD, and their view of the PAD as useful for predominantly proscriptive or prescriptive purposes. These could include the individual's demographic characteristics, their understanding of and attitudes towards mental health treatment, and their prior experiences with coercive mental health treatment. Preliminary studies support these factors; a survey of over 1,000 individuals with SMI at five sites found that interest in a PAD was higher for individuals who were non-white, female, had a history of self harm, and who had experienced coercion via arrest or pressure to take medication. Individuals in this study who reported already having a PAD were more likely to have higher insight into SMI and higher experience of external pressure to be in treatment from the criminal justice system or those controlling the individual's finances (Swanson, Swartz, Ferron, Elbogen, & Van Dorn, 2006) Though not specific to PADs, a relevant related study found that the desire of individuals with schizophrenia to be involved in treatment decisions was positively associated with prior involuntary treatment, younger age, and negative attitudes to psychotropic medications (Hamann, Cohen, Leucht, Busch, & Kissling, 2005).

In addition to characteristics and experiences of the individual with SMI it may be important to consider characteristics of the individual's clinician and of the clinician's relationship with the individual with SMI as influential factors in PAD decisions. Specifically, it is of interest to examine the clinician's support for PADs and attitudes towards coercive intervention. In addition, within the clinician/individual relationship, it is important to examine the working alliance between clinician and individual, and the concordance between the clinician's and individual's attitudes towards coercive treatment. The literature supports examination of this area. In the PAD-specific literature, a study completed by Srebnik and colleagues (2003) found that the interest of individuals with SMI in completing a PAD was significantly associated with their case manager's support for PADs (Srebnik, Russo, Sage, Peto, & Zick, 2003). A recent study by Swartz and colleagues (2006) found that individuals reporting that they trusted their psychiatrist were more likely to value PADs as a prescriptive tool to access treatment rather than proscriptive tools to avoid treatment (Swartz, Swanson, Van Dorn, Elbogen, & Shumway, 2006). In the broader mental health literature a positive working alliance between clinician and individual with SMI has been associated with longer engagement with treatment (Frank & Gunderson, 1990), more positive attitudes towards medication (Day et al., 2005), and increased medication compliance (Weiss, Smith, Hull, Piper, & Huppert, 2002).

Based on these studies one can argue that both clinician attitudes towards PADs and the quality of the relationship between the clinician and individual may shape individuals' willingness to create a PAD. In addition, these variables may shape individuals' view of treatment and, by extension, their view of PAD utility. However, to date there has been no extensive examination of the impact of the characteristics of clinician, individual, and clinician/individual relationship upon the decision of the individual with SMI to create a PAD and his/her valuing of PADs as useful for proscriptive or prescriptive purposes. This study address these questions, as outlined in the specific aims discussed below.

1.3 Specific Aims, Research Questions, and Hypotheses

1.31 Aim 1

To examine the association between clinician attitudes regarding PADs and PAD completion by individuals with SMI.

Research question 1. Is clinician support for PADs a significant variable in a predictive model of PAD completion by individuals with SMI?

Hypothesis 1a. Individuals are more likely to complete a PAD if clinician support for PADs is high.

Hypothesis 1b. The impact of clinician support on PAD completion will be moderated by how well the clinician knows the individual; clinician knowledge of the individual will be based on self-report.

1.32 Aim 2

To examine the association between clinician/individual concordance in views on their working alliance (including the elements of agreement on goals and tasks, and affective bond in the relationship), in PAD attitudes, and in views on coercion in mental health treatment on PAD completion by individuals with SMI.

Research question 2.1. Is clinician/individual concordance on the working alliance a significant variable in a predictive model of PAD completion?

Hypothesis 2.1. PAD completion is significantly associated with concordance in the working alliance between clinician and individual, and with whether both rate the alliance as positive.

Research question 2.2. Is clinician/individual concordance in PAD attitudes a significant variable in a predictive model of PAD completion?

Hypothesis 2.2. PAD completion is significantly associated with concordance in PAD attitudes between clinician and individual (no direction to hypothesis.)

Research question 2.3. Is clinician/individual concordance in views on coercion in mental health treatment a significant variable in a predictive model of PAD completion?

Hypothesis 2.3. PAD completion is significantly associated with clinician/individual concordance in views on coercion in mental health treatment (no direction to hypothesis.)

1.33 Aim 3

To examine the association between clinician views on coercion in mental health treatment and the individual's valuing of the PAD as a proscriptive tool.

Research question 3. Is clinician support for coercion in mental health treatment a significant variable in a predictive model of the individual's valuing of PAD as a proscriptive tool?

Hypothesis 3a. Individuals are more likely to value PADs as a proscriptive tool if clinician support for coercion in mental health treatment is high.

Hypothesis 3b. The impact of clinician support for coercion in mental health treatment on the individual's likelihood of valuing PADs as a proscriptive tool will be moderated by how well the clinician knows the individual; clinician knowledge of the individual will be based on self-report.

1.34 Aim 4

To examine the association between clinician/individual concordance in views on their working alliance and in views on coercion in mental health treatment, on the individual's valuing of PADs as a proscriptive tool.

Research question 4.1. Is clinician/individual concordance on the working alliance a significant variable in a predictive model of the individual's valuing of PADs as a proscriptive tool?

Hypothesis 4.1. Individuals are less likely to value PADs as a proscriptive tool if there is concordance in the working alliance between clinician and individual and both rate the working alliance as positive.

Research question 4.2. Is clinician/individual concordance in views on coercion in mental health treatment a significant variable in a predictive model of the individual's valuing of PADs as a proscriptive tool?

Hypothesis 4.2. Individuals' valuing of PAD as a proscriptive tool is significantly associated with clinician/individual concordance in views on coercion in mental health treatment (no direction to hypothesis.)

Chapter 2 Literature Review

The belief in the importance of client self-determination and the desire to respect client choice often come into conflict with the perceived need for coercive intervention in mental health treatment; tension is seen between the wish to support autonomy and to prevent harm. This is particularly true in mental health services for individuals with SMI, where symptoms may decrease an individual's capacity for sound judgment and safe behavior. Controversy about coercive interventions has reached new heights in the past decade, with a recovery-focused consumer movement emphasizing the need for partnership and choice in treatment conflicting with high profile media coverage of acts of violence committed by individuals with SMI and with an increased ability to involuntarily treat individuals through legal tools such as involuntary outpatient commitment.

Psychiatric Advance Directives (PADs) have been proposed as a mechanism to reduce the need for coercive mental health treatment and strengthen autonomy in individuals with SMI. If PADs are to be effective they will require the support of clinicians, both in creating them and in honoring them during times of crisis. In addition to this direct role, clinicians may also play an indirect role in the creation of PADs through their influence upon and relationship with the individuals with SMI whom they serve. Thus, in order to examine the issues of interest to this investigation, which are: 1) associations between clinician characteristics and the individual's decisions regarding PAD creation and the purpose they wish the PAD to serve; and 2) associations between the relationship of the clinician and individual with SMI and PAD creation and purpose, it is essential to ground the discussion within the broader conceptual and empirical frameworks of both issues of autonomy and coercion in mental health care and clinician/client relationship.

This literature review therefore begins with an examination of autonomy and coercion in the treatment of individuals with SMI, including both theoretical debate and empirical studies. Next this review synthesizes the existing PAD literature, discussing the legal contexts of PADs, the conceptualization of PADs as tools to increase autonomy and decrease coercion, and summarizes the existing empirical studies on PAD creation, content, and effectiveness. Given the important direct and indirect roles clinicians may play in PAD creation, the review next examines what is known about clinician views and attitudes regarding PADs. The review then includes an exploration of the concept of the working alliance and how the clinician relationship with the individual with SMI may shape the individual's ongoing engagement with and desire for mental health treatment, treatment adherence, and clinical outcomes. In closing, this section describes my conceptual model for the dynamics of an individual's decisions regarding PAD creation and purpose that was tested by this research.

2.1 Autonomy and Coercion in the Treatment of Individuals with SMI

2.11 Autonomy and Coercion: Ethical Debates

It has been suggested that PADs may be tools that can increase the autonomy of individuals with SMI and decrease their need for coercive intervention. To understand the importance of this claim it is essential to ground our PAD discussion within the larger context of the struggle between autonomy and coercion in the treatment of individuals with SMI.

Autonomy is an ethical principle across contemporary clinical medicine, including mental health practice (Jonsen, Siegler, & Winslade, 2002). In social work a client's right to self-determination, which is the exercise of autonomy, is emphasized throughout the ethics literature (Lowenberg, Dolgoff, & Harrington, 2000; Reamer, 1993). Social workers' responsibility to support this client right is articulated in their codes of ethics, including the Preamble of the Canadian Association of Social Workers Code of Ethics (Canadian Association of Social Workers, 2005), and the code of the National Association of Social Workers (NASW, 2000). As stated in Section 1.02 of the NASW Code (p. 7) "Social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals."

Given the importance of the ethical principle of autonomy, why is it such a challenge in the treatment of individuals with SMI? The answer is due in part to the link between autonomy and reason. Autonomy requires both liberty and capacity, and capacity requires the ability to reason and to act (Reinardy, 1999); thus it could be argued that individuals with SMI have less right to autonomy because their disorder limits the ability to reason. However, the issue is more complex, since individuals with SMI often experience fluctuating symptoms, may be asymptomatic for extended periods of time, or have symptoms such as lack of energy or lack of ability to experience enjoyment, which do not result in loss of capacity (American Psychiatric Association, 2000). Thus it is not simply a question of "Should individuals with SMI have a right to autonomy in their mental health treatment decisions or should they not?" but the more complex question "What level of capacity to make treatment decisions does an individual with SMI have at this time and should his/her right to autonomy be limited as a result?"

When considering ethical justifications for overriding the autonomy of individuals with SMI, two principles are usually invoked (Rothman, 1998). The first is nonmaleficence, the prevention of harm. This can include both actions to stop a harmful event such as suicide, homicide, or fire-setting, as well as interference with actions that may have permanent harmful consequences, such as refusal to eat or drink (Sasson, 2000). In these cases coercive actions prevent harm to the individual or to other individuals (Hoyer et al., 2002; Wettstein, 1987) or are necessary for the protection of the larger society (Rogers, 1999).

The second principle invoked is beneficence, doing good for the individual by providing beneficial treatment. It has been argued that individuals who have limited capacity to understand their situation may refuse treatment that would be of benefit to them. In these cases, coercive interference to force individuals to accept treatment would be for their own good, a form of individual paternalism or "compassionate interference" (Belcher & Blank, 1989; Davis, 2002; Monahan, Swartz, & Bonnie, 2003). Without involuntary treatment during times of poor judgment it will be impossible for individuals to ever move towards recovery and their health and lives may be at risk (Belcher & Blank, 1989; Fuller Torrey, 2004; Munetz & Frese, 2001; Munetz et al., 2003). By violating autonomy now, the individual may over time gain greater autonomy through the benefits obtained from treatment, and may ultimately be appreciative of the coercive intervention (Verkerk, 1999).

In contrast, two major arguments against coercive intervention are often seen. One position, taken particularly by individuals with SMI and some advocates and thinkers with a more civil rights perspective, is the deontological, or rights-based, argument that coerced treatment for an individual not declared legally incompetent is wrong, cannot be justified, and is the result of the social control efforts of the state (Arrigo & Williams, 1999; Hoge & Grottole, 2000; MadNation, n.d.; Szasz, 1970). If individuals with SMI have harmed someone they should be incarcerated just as other citizens, but dangerousness does not justify forced treatment (Giordano, 2000). Slightly more moderate forms of this position argue that it is wrong to take away the liberty of an individual based on what they *may* do in the future, particularly given our empirically proven poor predictive powers regarding who may become dangerous (Dallaire, McCubbin, Morin, & Cohen, 2000; Holloway & Szmuckler, 2003). Also, it is argued that it is wrong to take away an individual's rights because of something that is the fault of the larger society, i.e., if there were sufficient service capacity and if services were provided in acceptable ways involuntary treatment would not be necessary (M. Allen & Fox, 2001; Brown, 2003).

Opponents to coercive intervention take issue with the assumptions that treatment is not harmful, and that coercive treatment is effective. Treatment, particularly psychotropic medication, has serious and sometimes lethal side effects (Carpenter, 2002). Hospitalizations can result in the loss of the individual's home, job, and social supports, and put him/her at risk for abuses in institutional settings. Coercive processes, such as being physically restrained, are traumatizing and may result in reactant anger or learned helplessness. A coercive experience may disrupt the therapeutic alliance or make individuals reluctant to return to treatment for fear of additional coercion (M. Allen & Fox, 2001; Hoge & Grottole, 2000; Rogers, 1999; Stastny, 2000). The use of coercion may also reinforce stigma, labeling individuals with SMI as so dangerous that they must be forced into care, and thus increasing the social rejection of people with SMI. A final argument offered is that there is no definitive evidence that coercive interventions such as Involuntary Outpatient Commitment (IOC) are broadly effective, thus they cannot be justified (M. Allen & Fox, 2001; Carpenter, 2002).

It is clear from this literature that the ethical debate between autonomy and the need for coercive intervention looms large in the mental health field. One of the promises of PADs is that they may be a tool that can decrease the struggles surrounding this debate. By allowing the individuals' wishes to be heard during crises, PADs may reduce or obviate the need for coercive intervention during crises for many individuals with SMI while ensuring that they obtain needed and effective care.

2.12 Autonomy and Coercion: Empirical Studies

Beyond ethical rhetoric, recent research has attempted to answer some of the questions raised by the arguments between autonomy and coercion in mental health treatment, with conflicting results (Salize & Dressing, 2005). Several studies in the United States, Canada, and Australia have examined the effectiveness of Involuntary

Outpatient Commitment (IOC). IOC is a commonly used form of court ordered community based mental health treatment; a study of five communities in the United States found that between 12 and 20 percent of consumers surveyed reported experiencing IOC at some point in their lives (Swartz, Swanson, Kim, & Petrila, 2006). Results were mixed, suggesting that if IOC is effective in decreasing psychiatric crises, it may be so primarily for subsets of individuals with SMI (Kisely, Xiao, & Preston, 2004; O'Brien & Farrell, 2004; Swartz et al., 2001). The largest randomized controlled trial of IOC demonstrated positive outcomes (e.g. fewer days in hospital) in post hoc analyses for individuals with psychotic disorders who received IOC for more than 180 days and received intensive case management as a part of their treatment (Kisely et al., 2004; O'Brien & Farrell, 2004; Swanson, Swartz et al., 2000; Swartz et al., 2001). A time-series analysis of the same data demonstrated a significant effect for IOC on hospitalization irrespective of diagnostic category (Swartz, Swanson, Wagner, Burns, & Borum, 1999). A recent review by the Cochrane Collaboration (Kisely, Campbell, & Preston, 2007) pointed out the lack of a strong evidence base for IOC, identifying only two randomized trials of the intervention. The Collaboration's review combined data from the two studies and found "little evidence for the effectiveness of compulsory community treatment in any of the main outcome indices: health service use, costs, social functioning, mental state, quality of life, or satisfaction with care. We were only able to establish a statistically significant effect for one outcome, social functioning (victimization)." (p.9). These criticisms have been refuted by the researchers who conducted the large IOC trial, who reiterated their positive findings of decreased hospital admission for individuals in the IOC arm of the study (Swanson & Swartz, 2007). Clearly the effectiveness of IOC remains a controversial topic.

When reviewing these studies it must be remembered that subjective benefit as experienced by the individual may be different than objectively measured outcomes. The randomized trial discussed above found that IOC increased quality of life for individuals, but that this effect was significantly moderated by the individual's level of perceived treatment coercion (Swanson, Elbogen, Wagner, & Burns, 2003). A study of individuals with SMI under IOC found that only 27.6 percent personally endorsed benefits of IOC after completion; this increased to over 50 percent endorsing IOC if they personally had benefited from the IOC (Swartz, Swanson, & Monahan, 2003)

Research exploring the effectiveness of coercive hospitalization has shown interesting results. A recent literature review concluded that involuntarily admitted consumers showed substantial clinical improvement over time, that 39 to 75 percent subsequently viewed their hospitalization as necessary, and that 39 to 81 percent reported benefiting from the hospitalizations (Katsakou & Priebe, 2006). However, studies comparing voluntary and involuntary hospitalizations had somewhat different findings. Three studies found that individuals hospitalized involuntarily did not have significantly different clinical outcomes or post-discharge compliance from voluntary controls (Cournos, MacKinnon, & Stanley, 1991; Rain, Williams, Robbins, & et al., 2003; Steinert & Schmid, 2004) and do suggest that involuntary hospitalization is no less effective than voluntary care. However, another study found a negative correlation between involuntary hospitalization and self-reported treatment adherence one month post-discharge (Rain, Steadman, & Robbins, 2003). In addition, a survey of the impact of involuntary treatment on engagement found that 28 percent of individuals with SMI reported fear of coerced treatment as a barrier to seeking mental health care, and found this was significantly associated with prior involuntary hospitalizations as well as compliance pressures from community based providers (Swartz, Swanson, & Hannon, 2003).

Surprisingly, research regarding coercive intervention and individuals with SMI has demonstrated that voluntary or involuntary status is only loosely associated with coercion as perceived by the individual and is more closely associated with individuals' perceptions of how they were related to and treated by others, termed procedural justice, during the coercive process, as well as the timing and number of coercive interventions experienced (Hoyer et al., 2002; McKenna, Simpson, & Coverdale, 2003; Monahan et al., 1999). One study showed that individuals perceived longer IOC to be more coercive, but that this effect was mediated by the way they were treated by their case manager, specifically by the case manager's verbal warnings and reminders of the outcomes of noncompliance (Swartz, Wagner, Swanson, Hiday, & Burns, 2002). Other studies have shown that multiple coercive interventions applied together may be experienced as coercive, even if the interventions are not seen as coercive individually (Elbogen, Swanson, & Swartz, 2003; Swartz et al., 2006). However, even studies using perceived coercion as an independent variable have shown no consistent results in outcomes (Bindman, Reid, Szmukler, & et. al, 2005; Kaltiala-Heino et al., 1997).

The current research in this area provides no clear guidance in resolving the tensions between autonomy and coercion in the treatment of individuals with SMI. It does, however, suggest that the experiences of individuals and their perceptions of process and interaction are central to the issue; context and relationship influence perceptions regarding coercion. If this is the case, one can argue that context and relationship may also influence perceptions regarding autonomy, that is, an individual thinks about and exercises autonomy while considering and influenced by the relationships within which s/he is embedded. This contextualized concept of autonomy is sometimes referred to as "relational autonomy" by feminist ethicists and those interested in structural and cross cultural ethics (Clifford, 2002; Furlong, 2003a, 2003b). Similar to Foucault's conceptualization of power (Foucault, 1980), relational autonomy is seen as created through process with others rather than the exercise of isolated and independent choice by an individual. Autonomy is thus a process grounded in a relationship among people. PADs, which support the autonomy of individuals with SMI, should therefore be considered in the context of relationships, particularly relationships with clinicians.

2.2 Psychiatric Advance Directives: What Does the Literature Tell Us?

2.21 Definition and History

PADs, as described previously, are legal documents that allow individuals with SMI, when capable, to express their wishes for care and communicate relevant information regarding their condition at a future time when they are in psychiatric crisis. The historical origins of PADs are twofold. First, in the 1980s Thomas Szasz developed the idea of the "psychiatric will" as a way for individuals to refuse all psychiatric treatment and stay free of (in his view) psychiatric oppression (Swanson, Tepper et al., 2000). Second, a series of cases in the United States, most notably the Cruzan and Quinlan cases, highlighted the issue of decision-making regarding life-prolonging treatment when an individual has lost competence and is not expected to recover. The Cruzan case in particular stimulated interest in documenting patient preferences, an impetus for the development of the medical advance directive. Though medical advance directives were intended to be used primarily in end of life situations rather than for conditions of fluctuating capacity such as SMI, the idea of the advance directive was adopted within the mental health community as a way of maintaining individual autonomy during times of psychiatric incapacity (Ritchie et al., 1998).

PADs have extensive legislative support; twenty five states in the United States have some specific PAD legislation (Swanson, 2007). In addition PADs are supported by the U.S. Patient Self-Determination Act of 1990, which mandates that health facilities ask patients if they have an advance directive, including a PAD, and provide them with information regarding advance directives upon request (Backlar, 2004; Backlar & McFarland, 1998). However, individual state laws also allow PADs to be overridden in a number of situations, including involuntary commitment and conflicts with physician opinion of standard of care (Swanson, McCrary, Swartz, Van Dorn, & Elbogen, 2006). This override has been successfully challenged in federal appellate court under the Americans with Disabilities Act in Hargrave v. Vermont, where it was argued that since there is no such override for medical advance directives, having an override in psychiatric advance directives is discriminatory. Therefore the future of a physician's ability to legally override a PAD is not yet clear (Appelbaum, 2004). This ambiguity in the power of providers to override PADs may contribute to the ambivalence providers express regarding their endorsement of PADs, as is discussed later in this section.

2.22 Conceptualization of Benefits of PADs

An extensive literature describes the potential benefits of PADs; it has been proposed that PADs have the potential to increase autonomy, decrease coercive hospitalization and forced medication, and promote recovery. Discussions have focused on both improved clinical outcomes as well as the enhanced sense of empowerment individuals may experience as a result of PADs. These conceptual discussions can be sorted into two areas: the benefit of *creating* a PAD and the benefits of *invoking* a PAD.

It has been suggested that the process of creating a PAD may be of benefit in a number of ways. First, it provides the individual with an opportunity to voice his/her lived experience and knowledge gained from having a SMI and to have that knowledge valued and used in the development of crisis plans (Widdershoven & Berghmans, 2001). Through the process of creating a PAD the individual can more directly shape his/her treatment, and may also talk with a provider to gain greater understanding of treatments and make better informed treatment choices (Backlar, 1995; Srebnik & LaFond, 1999). This increased sense of choice, of being listened to and respected, and of ownership of a plan may result in the individual's increased willingness to engage in and adhere to treatment, and may also increase some individuals' sense of self-efficacy and hope for recovery (Backlar & McFarland, 1998; Miller, 1998; Winnick, 1996). By examining past crises and discussing lessons learned for future care when preparing a PAD, the individual may also gain increased self-awareness regarding his/her SMI and its patterns, and may be able to identify preventive actions, coping skills, and self-management techniques s/he can use in the future, thus reducing future crises and the need for coercive intervention (Backlar, 2004). Since work by Swartz and colleagues (2003) has shown that 28 percent of individuals with SMI report avoidance of mental health treatment because of fear of coercion, individuals creating a PAD may have less anxiety and concern about the potential for coercion and be more willing to come for mental health treatment, again improving chances for positive outcomes and recovery. From this discussion it seems likely that PADs may be of clinical utility even if never invoked; PAD creation in and of itself may be a positive intervention.

During times of crisis, it has been posited that invoking a PAD may be of great benefit to an individual with SMI. With a PAD the individual is able to continue to have his/her choices honored during a time of incapacity, receiving the treatments s/he knows from experience are most effective and having a say in crisis management (Howe, 2000). Similarly, a PAD can provide mental health professionals with valuable psychosocial information regarding the individual in crisis (Backlar, 2004). A PAD with informed consent for hospitalization or medication can obviate the need for a court commitment and coercive care (Backlar, 1995), and if clear instructions on crisis management and hospital diversion strategies are included, may decrease hospitalization rates (Backlar, 2004).

2.23 Empirical PAD Literature: Demand, Creation, Content, Effectiveness

Despite the growing interest in PADs over the past fifteen years, and despite the existing debate about their effectiveness and appropriateness for use with individuals with SMI, surprisingly little empirical research had been completed on PADs (O'Connell & Stein, 2005) prior to the mid-2000s. The research discussed here falls into four categories: studies of interest in PADs by individuals with SMI; studies regarding PAD creation; studies of PAD content; and randomized controlled trials of PAD (or similar tool) effectiveness.

Studies exploring views on PADs among individuals with SMI have found little knowledge of but substantial interest in PADs. One study interviewing individuals with SMI and multiple hospitalizations found that when introduced to the concept 53 percent were interested in creating a PAD. Reasons given for interest in PADs included a desire to prepare for future crises and to ensure that preferred treatment was obtained (Srebnik et al., 2003). Similar results were found in another study; when individuals with SMI were asked about the utility of PADs in a range of situations between 74 and 90 percent saw PADs as useful in at least some settings (O'Connell & Stein, 2005). A large study of five urban United States sites (N=200 at each site) found that though only between four and 13 percent of individuals with SMI had completed a PAD, between 70 and 83 percent were interested in doing so when introduced to the concept. This interest was higher for individuals who were non-white, female, had a history of self harm, and who had experienced coercion via arrest or pressure to take medication (Swanson, Swartz, Ferron et al., 2006; Swartz, Swanson, Van Dorn et al., 2006).

In addition to an examination of the latent demand for PADs among individuals with SMI, efforts have been made to begin to understand the reasons an individual may have for wanting a PAD, i.e. how individuals with SMI see a PAD's usefulness and purpose. In a randomized trial of a facilitated PAD process at Duke University a baseline survey found that participants placed the highest value on using PADs prescriptively to specify treatment recommended by their doctors (median value 8.5; 1-10 scale), with lower value placed on proscriptively avoiding unwanted treatment (median value 7.0) and identifying surrogate decision makers (5.0). Researchers also found that those individuals wishing both the Advance Instruction (AI) and Health Care Power of Attorney (HCPA) parts of a PAD were most interested in continuing recommended care during crises and enabling surrogate decision making, while individuals wishing only an AI were most interested in using the PAD to avoid unwanted treatment (Swartz, Swanson, Van Dorn et al., 2006).

PAD creation can be a challenging process for individuals with SMI, with barriers such as lack of awareness and understanding of PAD law as well as lack of resources to complete, notarize, and submit the actual document (Swanson, Swartz et al., 2003). However, research has demonstrated that with support individuals with SMI are capable of completing a PAD. One research team has demonstrated that an interactive software package can effectively assist individuals in successful completion of a PAD (Srebnik et al., 2005). The Duke randomized trial has demonstrated the effectiveness of facilitation using a standardized process to help individuals complete PADs (61 percent PAD completion vs. 3 percent in control group) (Swanson, Swartz, Elbogen et al., 2006). In this study researchers also examined variables associated with actual PAD completion and found that actual completion of a PAD for those in the intervention arm was positively associated with older age, and higher scores on an independent help seeking scale, an adverse medication experience scale, and a scale measuring ability to reason about PADs, as well as negatively associated with recent violent victimization (Swanson, Swartz, Elbogen et al., 2006). No variables related to clinician characteristics or clinician/consumer relationships were examined in this study.

Three studies have examined the contents of PADs created by individuals with SMI. No study found that the PAD was used exclusively to refuse all treatment. However, PADs were used for both proscriptive and prescriptive purposes. Most frequently PADs were used to provide information about specific treatment wishes, including specific medications requested or refused, actions professionals should engage in or avoid to de-escalate crises, and individuals that providers were asked to or prohibited from contacting during crises (Papageorgiou, Janmohamed, King, Davidson, & Dawson, 2004; Srebnik et al., 2005; Swanson, Swartz, Elbogen et al., 2006). Two of these studies also examined these PADs for clinical utility, defined as the degree to which PADs were clinically feasible, useful, and consistent with standards of care. In one study of 469 individuals with SMI 90.5 percent of PADs were found to have clinical utility (Swanson, Swartz, Elbogen et al., 2006), and another study of 106 individuals found that 95 percent of PADs met these criteria (Srebnik et al., 2005). Neither of these studies, however, examined closely the level of proscriptiveness versus prescriptiveness in PADs, nor predictors of more heavily proscriptive or prescriptive PADs.

A few studies have looked at the impact of PADs on individuals with SMI. A qualitative study conducted in New York, where state-wide training on PADs has occurred, found that participants reported the PAD creation process required a review of painful experiences and current resources but that it was meaningful and provided both a sense of empowerment and security (Amering, Stastny, & Hopper, 2005). A small study of 40 individuals invited to complete PADs found that 30 agreed to do so, that the majority (87 percent) endorsed PADs, and that most said having a PAD gave them a feeling of empowerment. In follow-up interviews eight to ten months after baseline, 46 percent of consumers expressed concern or dissatisfaction with PADs, particularly regarding provider lack of education on PADs and lack of willingness to honor the PAD (Backlar et al., 2001). A qualitative study interviewing consumers with a PAD after a crisis event also found that individuals with SMI saw PADs as tools for empowerment and self-determination, but were concerned about providers' lack of knowledge about PADs and the difficulty in communicating with providers regarding their PADs (Kim, Van Dorn et al., 2007).

Only two randomized controlled trial of PADs and one of crisis cards, which are clinical, non-legal documents similar to PADs but created through a process involving provider, facilitator, and individual with SMI, have been published to date; several additional studies are in progress. One PAD study, completed in 2002, randomly assigned 156 individuals with SMI being discharged from a psychiatric hospital to PAD or control group and followed them for one year. No significant differences were seen between groups in involuntary readmission rates, days spent in hospital, or satisfaction with psychiatric services (Papageorgiou, King, Janmohamed, Davidson, & Dawson, 2002). A study of 160 individuals randomized to crisis cards or control group were followed for fifteen months; here researchers found a significantly lower rate of involuntary hospitalization in the crisis card group (13 percent vs 27 percent,) and lower number of involuntary bed days (14 vs. 31), perhaps due to the providers' involvement in and awareness of the crisis card process. There was also a trend towards lower rates of hospitalization overall (30 percent vs. 44 percent), but no difference in overall days in hospital between the two groups (Henderson et al., 2004).

Results from the Duke randomized trial suggest benefit to consumers in PAD creation. At one month follow up, individuals with SMI who had completed PADs had a greater working alliance with their clinicians than those in the control group, and those with improved working alliance were more likely to report receiving the mental health treatment that they believed they needed (odds ratio=2.45, $p<0.05$) (Swanson, Swartz, Elbogen et al., 2006). At six month follow up after completing a PAD individuals with SMI experienced fewer crises (odds ratio=0.66, $p<0.05$), mediated by an improvement in the working alliance with the individual's clinician at one month (Swanson, 2007). At twelve months consumers who completed PADs reported significantly greater increases in perceived self-determination in treatment compared to the control group, particularly among individuals who had good understanding of PADs (43 percent vs. 24 percent) (Elbogen et al., 2006).The existing empirical evidence thus suggests that PADs are infrequently utilized but there is high latent demand for them among individuals with SMI, that individuals wish to use PADs for differing purposes (i.e. proscriptive or prescriptive), and that with support individuals are capable of making clinically useful PADs. In addition, research indicates that PADs hold promise as a beneficial intervention, that PADs can have a positive impact on clinical outcomes, and that this impact may be in part mediated by improvement in the working alliance between clinician and consumer. Given individuals' need for support for successful PAD development, and the link between alliance and PAD impact, the evidence thus also suggests that the clinician may play a pivotal role in PAD creation and effectiveness. Thus clinicians' knowledge of and support for PADs and the clinician/individual relationship are important elements to consider in PAD research, and are discussed below.

2.24 Clinician Views and Attitudes towards PADs

The dramatic difference between PAD prevalence and PAD demand suggests that PAD awareness is low, not simply among individuals with SMI, but among providers as well. Studies examining provider awareness of PADs have found this to be true; a survey of mental health professionals, law enforcement, general healthcare providers, clergy, and individuals with SMI and their families found that less than 11 percent reported that they were very familiar with PADs (O'Connell & Stein, 2005). A recent survey of mental health social workers in North Carolina found that only 5 percent reported that they were very familiar with the Advance Instruction (AI) portion of PADs and 15 percent with the Health Care Power of Attorney (HCPA) portion of PADs (Scheyett et al., in press-b).

However, lack of awareness regarding PADs may not be the only provider related factor associated with low PAD prevalence. In addition to lack of awareness, there may be lack of support for PADs among the provider community. This lack of support may stem from multiple sources. First, providers may have concerns that, because of the symptoms of SMI, an individual may not have the level of insight and capacity needed to exercise autonomy and create an appropriate PAD. In addition, they may foresee times when the individual's PAD may hinder the provision of needed service, and when a psychiatric crisis would require coercive intervention. Finally, PADs shift the traditional power structures in the provider/patient relationship, moving to a greater level of partnership with and autonomy for the individual with SMI, and decreasing the authority of the traditional provider role; a shift which may be uncomfortable for some clinicians. Ambivalence regarding the benefits of voluntary versus involuntary treatment is common among front line mental health professionals (Scheyett et al., in press-a). As a result, even if aware of PADs, some providers may not be willing to inform individuals with SMI about them, to work with them in PAD development, or to honor PADs during times of crisis (LaFond & Srebnik, 2002).

A number of studies have surveyed mental health providers' views on PADs, and have found great ambivalence and widely varied levels of support, ranging from 20 to 75 percent (Atkinson, Garner, & Gilmour, 2004; Backlar et al., 2001). In the majority of reports about half of those surveyed endorsed PADs (Amering, Denk, Griengl, Sibitz, & Stastny, 1999; Elbogen et al., 2006; Kim, Scheyett et al., in press; Swartz et al., 2005). Interestingly, several studies have found PAD endorsement to be significantly associated with correct knowledge of PAD law, particularly knowledge regarding clinician ability to override PADs (Elbogen et al., 2006; O'Connell & Stein, 2005; Swartz et al., 2005). This suggests that clinicians may be more comfortable with PADs when they do not feel their "hands are tied" by the document.

Clinicians also have been found to differ in their support for the two elements of a PAD. One study compared clinician endorsement of the AI and HCPA elements of PADs across psychiatrists, psychologists, and social workers. In all three disciplines providers more frequently supported HCPAs than AIs. This suggests that clinicians may be more comfortable supporting empowerment of a surrogate decision maker than the individual's choices via the AI, perhaps seeing these proxies as more reasonable arbiters of treatment decisions than an AI (Elbogen et al., 2006). From the literature it is clear that lack of PAD knowledge, and ambivalence about PADs and the power shift they represent are present among mental health clinicians. The impact of this lack of knowledge and ambivalence on PAD creation and the purposes for which PADs are used by individuals with SMI has yet to be determined.

2.3 The Relational Context: Clinicians, Individuals with SMI, and the Working Alliance

To date, characteristics of the individual have been the primary variables examined when exploring factors associated with PAD decisions. However, these decisions have not been contextualized within the clinician/individual relationship or working alliance, the focus of this research. It is therefore important to explore the literature regarding the relationship between individuals with SMI and their clinicians and its impact, both on clinical outcomes in general and PADs in particular.

2.31 Working Alliance In Mental Health Treatment

Since the 1970s there has been a growing literature exploring the relationship between provider and client, the working alliance, which might in part account for positive outcomes in mental health treatment. The most well-known and widely used formulation of the concept of alliance was developed by Bordin, who proposed that the working alliance was a real relationship between the client and clinician, grounded in a collaborative process that contains three aspects: agreement on goals, agreement on tasks, and affective bond grounded in positive regard and trust (Bordin, 1976). Examining research in this area, recent literature reviews have found statistical evidence for a link between therapeutic alliance and improved outcomes (Hewitt & Coffey, 2005; Howgegi, Yellowlees, Owen, & Meldrum, 2003). Two meta-analyses have been done to attempt to synthesize this literature and identify underlying patterns, an earlier work by Horvath and Symonds (1991) and a more recent work by Martin (2000). The Horvath and Symonds study reviewed 24 studies, and found an average effect size of .26 between quality of alliance and clinical outcomes (Horvath & Symonds, 1991). The more current work analyzed 79 clinical studies; here the author found a similar modest effect size of .22 between quality of alliance and outcome, and saw that this relationship seemed to be consistent regardless of the many variables which differed among the studies, including different alliance scales, type of outcome measures, type of outcome or alliance rater, time of alliance assessment, type of treatment, or publication status of the study (Martin, 2000).

The research discussed above indicates that the working alliance may be a significant factor in successful outcomes of psychotherapy. However, it cannot be assumed that this is also true for the relationship between an individual with SMI and a mental health service provider. It is therefore important to examine studies specifically exploring the association between working alliance and outcomes for individuals with SMI, that is, studies not focused on alliance in psychotherapy with individuals with non-psychotic depression or neurotic disorders but rather studies examining the alliance in the context of case management and other services designed for individuals with SMI. In the range of existing studies specific to working alliance and individuals with SMI outcomes of interest varied and included symptom severity, level of functioning, quality of life, treatment engagement and adherence, violent behavior, discharge outcomes, and hospitalization rates (McCabe & Priebe, 2004). Instruments used to measure alliance also varied; one frequently used was the Working Alliance Inventory (WAI) (Horvath & Greenberg, 1989), which was shown to have good psychometric properties specifically with SMI populations (Goldberg, Rollins, & McNary, 2004; Neale & Rosenheck, 1995).

Though outcomes examined varied, multiple studies found positive associations between the alliance and a few key variables. A positive relationship was found between alliance and engagement in mental health treatment in a number of studies (D. Coffey, 2003; Frank & Gunderson, 1990; Loneck, Banks, Way, & Bonaparte, 2002), as well as between alliance and adherence to medication (Frank & Gunderson, 1990; Solomon, Draine, & Delaney, 1995; Weiss et al., 2002). Additional outcomes frequently associated with working alliance were treatment satisfaction (Calsyn, Morse, Klinkenberg, Yonker, & Trusty, 2002; Chinman, Rosenheck, & Lam, 2000; D. Coffey, 2003; Klinkenberg, Calsyn, & Morse, 1998; Solomon et al., 1995), level of functioning (J. Allen, Tarnoff, & Coyne, 1985; Clarkin, Hurt, & Crilly, 1987; Frank & Gunderson, 1990; Goering, Wasylenki, Lindsay, Lemire, & Rhodes, 1997; Neale & Rosenheck, 1995), decreased symptomatology (Frank & Gunderson, 1990; Goering et al., 1997; Klinkenberg et al., 1998; Neale & Rosenheck, 1995), improvement at discharge from hospital (Hansson & Berglund, 1992; Svensson & Hansson, 1999), decreased time in hospital (Frank & Gunderson, 1990; Priebe & Gruyters, 1992), quality of life (McCabe, Roder-Wanner, Hoffmann, & Priebe, 1999; Solomon et al., 1995), employment (Donnell, Lustig, & Strauser, 2004; Priebe & Gruyters, 1992) and less violent behavior (Beauford, McNiel, & Binder, 1997). For a summary of these studies, see Appendix A.

From this literature two relevant points can be made. First, a positive working alliance is associated with a number of positive outcomes. Second, a level of agreement, or concordance, between clinician and individual in their views on treatment, specifically treatment tasks and goals, is central to alliance. Given these findings, it is reasonable to postulate that concordance between clinician and individual views on other aspects of treatment, such as the need for coercive intervention, may also be relevant predictors of outcomes such as successful PAD completion.

2.32 PADs and Working Alliance

Little work has been done exploring the relationship between PAD creation or outcomes and the working alliance between clinician and individual with SMI. As discussed above, preliminary results from the Duke randomized trial suggests that positive outcomes associated with PADs such as increased functioning, increased treatment satisfaction, and decreased crises may be mediated by improved working alliance (Swanson, Swartz, Elbogen et al., 2006). In addition, two studies suggest that the individual's relationship with a clinician may influence decisions regarding PAD creation. A study of high service users with SMI found that 53 percent of study participants expressed an interest in having a PAD, and this interest was significantly associated with their case manager's endorsement of PADs (Srebnik et al., 2003). A recent study by Swartz and colleagues found that individuals reporting that they trusted their psychiatrist were more likely to value PADs as a prescriptive tool to access treatment rather than proscriptive tools to avoid treatment (Swartz, Swanson, Van Dorn et al., 2006). Thus the clinician's views of PADs may significantly influence individuals' decisions regarding PAD creation, and the quality of the relationship between clinician and individual may influence the purpose for which they wish to use a PAD.

In summary, from the literature above one can see that the relationship between individuals with SMI and their clinicians may impact the individuals' interest in a PAD and the type of PAD they wish to create. Since the working alliance has been associated with treatment engagement, one also can posit that a stronger working alliance may be associated with a PAD containing more prescriptive (i.e. treatment seeking) content. In addition, the level of concordance between individual and clinician on broader mental health treatment issues may influence engagement with the treatment system; one study found higher levels of engagement and satisfaction when clinicians and individuals shared a biological explanatory model for SMI (McCabe & Priebe, 2004). It is therefore logical to suppose that the level of concordance between clinician and individual on issues such as the need for coercion in mental health care may impact both the individual's interest in creating a PAD and the type of PAD they wish to develop.

2.4 Summary and Conceptual Model

2.41 Summary of Literature

There is considerable tension between support for autonomy and the need for coercive intervention in the mental health treatment of individuals with SMI. This tension is particularly high during times of crisis, where the risk of harm to the individual or others may be increased. However, there is a risk of harm in engaging in coercive intervention as well. Some individuals with SMI report that they experience involuntary treatment as hurtful and frightening, and fear of coercive intervention keeps a number of individuals from engaging with the mental health treatment system.

PADs are legal tools designed to increase autonomy of individuals with SMI by allowing them to state their crisis treatment preferences during times when they are stable and have full capacity. Creating a PAD and having it honored during crises may decrease the need for coercive intervention and increase an individual's engagement with treatment. Though few individuals with SMI have created PADs the latent demand for them is high; when provided with assistance a majority of individuals with SMI can create a clinically feasible and useful PAD. Individuals with SMI who have completed PADs have reported a resultant increased sense of autonomy and empowerment, even if the PAD is not invoked or honored (Kim, Van Dorn et al., 2007). Thus the creation of the PAD may of itself be an important intervention.

Clinicians are mixed in their opinions of PADs. Most studies indicate that about half of clinicians surveyed endorse PADs while others are unsure or have concerns that the benefits of PADs may be outweighed by the harm in having individuals refuse helpful or needed treatment. Given the demonstrated influence of the clinician and of the working alliance on individuals' clinical outcomes, this ambivalence is noteworthy for a number of reasons, among which is the possible impact of the clinician on the individual's decisions regarding PAD creation and purpose.

2.42 The Next Questions and a Conceptual Model

Within the existing research on PADs only a few studies have explored the factors associated with an individual's decision to create a PAD (Swanson, Swartz, Elbogen et al., 2006) and the factors associated with the purposes individuals wish PADs to serve—to proscriptively avoid treatment during crises or prescriptively ensure they receive specific treatments (Swartz, Swanson, Van Dorn et al., 2006). None have explored extensively how clinician views of PADs or clinician/individual relationship characteristics may impact PAD creation and content. This unexamined question is compelling, since it may affect both the broad establishment of PADs by individuals with SMI as well as the utility of the PADs that are created. If clinicians' views and relationships with individuals impact PAD creation and content, there are implications for clinician training, with the possibility of developing training interventions that help clinicians support the creation of maximally useful PADs.

In developing a conceptual model to use in the examination of these research questions, I have built upon two foundations: the Health Beliefs model (Becker & Maiman, 1975; Chen & Land, 1986) and the theory of relational autonomy (Furlong, 2003a). The Health Beliefs model is an explanatory model identifying relevant predictors of specific health behaviors. It posits that individuals engage in health behaviors based on: a) their perceptions of the seriousness of the condition the behavior seeks to address; b) their perception of the risk or threat of the condition; c) their perceived benefits of the behavior; and d) their perceived barriers to the behavior.

Applying this to PAD creation and valuing of PADs more highly for proscriptive purposes, I define the *behavior* as the exercising of individual autonomy in the creation of a PAD or valuing of PADs more highly for proscriptive purposes. This has the goal of preventing the *condition* of being coerced, losing autonomy, and receiving crisis mental health care that the individual would not choose for him/herself. The behavior the individual engages in is based on his/her perception of: a) the *seriousness* of loss of autonomy or experience of coercive intervention during a crisis; b) how high a *risk* there is for loss of autonomy or experience of coercive intervention during crises; c) the *benefits* of having a PAD and/or mental health treatment; and d) the *barriers* to PAD creation and implementation and/or mental health treatment.

This model is compelling, but does not consider the relational contexts within which individuals make their decisions. I propose, as is argued in relational autonomy theory, that we must add to this model. Relational autonomy acknowledges that autonomy and choice are not exercised in a vacuum, but in process with others. Thus a consideration of the *relational supports* (or lack thereof) to the individual's goal of preventing the loss of autonomy via a PAD or valuing of PADs more highly for proscriptive purposes must be added to the model. Do those in relationship with the individual with SMI support PAD creation and autonomy? Do their positions regarding coercive intervention and mental health treatment concur with and support the individual's position?

In this study, my specific interest is the impact of the relational support of the clinician in the PAD decision process; the clinician's support of PADs, support for autonomy or coercive intervention, agreement with the individual with SMI on PADs, on support for autonomy or on coercive intervention, and agreement with the individual's view on the working alliance. As can be seen in Figure 1 below, I examined the impact of three domains on PAD creation and valuing of PADs more highly for proscriptive purposes. First is the individual's perceptions regarding the *condition* of coerced mental health treatment, both seriousness and risk. Seriousness of coercive treatment included the individual's report of distress when experiencing coercion in the past, distress over present coercion, and overall view of the benefit of coercive mental health treatment. Risk of coercive treatment included the number of coercive experiences in the past, the number of current coercive conditions experienced, and the overall level of current perceived coercion. Second is the individual's perception regarding the benefits of and barriers to PADs and mental health treatment This included insight into the need for treatment, view of benefits/harms of psychotropic medications, motivation of mental health treatment, and overall endorsement of PADs. Barriers to PADs and mental health treatment included a series of questions specific to the issue looking at both logistical barriers to creation and barriers to utilization of PADs. Barriers to mental health treatment included a series of questions looking at the individual's views as to why s/he might not come in for mental health treatment. Finally, relational support was examined, including clinician endorsement of PADs, clinician view of the need for coercive mental health treatment, clinician concordance with (i.e. support of) the individuals' view of coercive treatment, and clinician concordance with the individual's rating of the working alliance. In addition, relational support from other sources, i.e. friends and family, was included. This model proposes that the variables in each of these three domains would predict an individual's decision to create a PAD, and their valuing of PADs for proscriptive purposes. In addition, I posit that demographic and clinical characteristics of the individual with SMI may be associated with these decisions, and that how well the clinician knows the individual may moderate the pattern of associations predicting PAD completion and valuing of PADs more highly for proscriptive purposes. More specific information regarding the nature of the data set, variables and instruments used, and analyses completed are discussed below in Methodology.

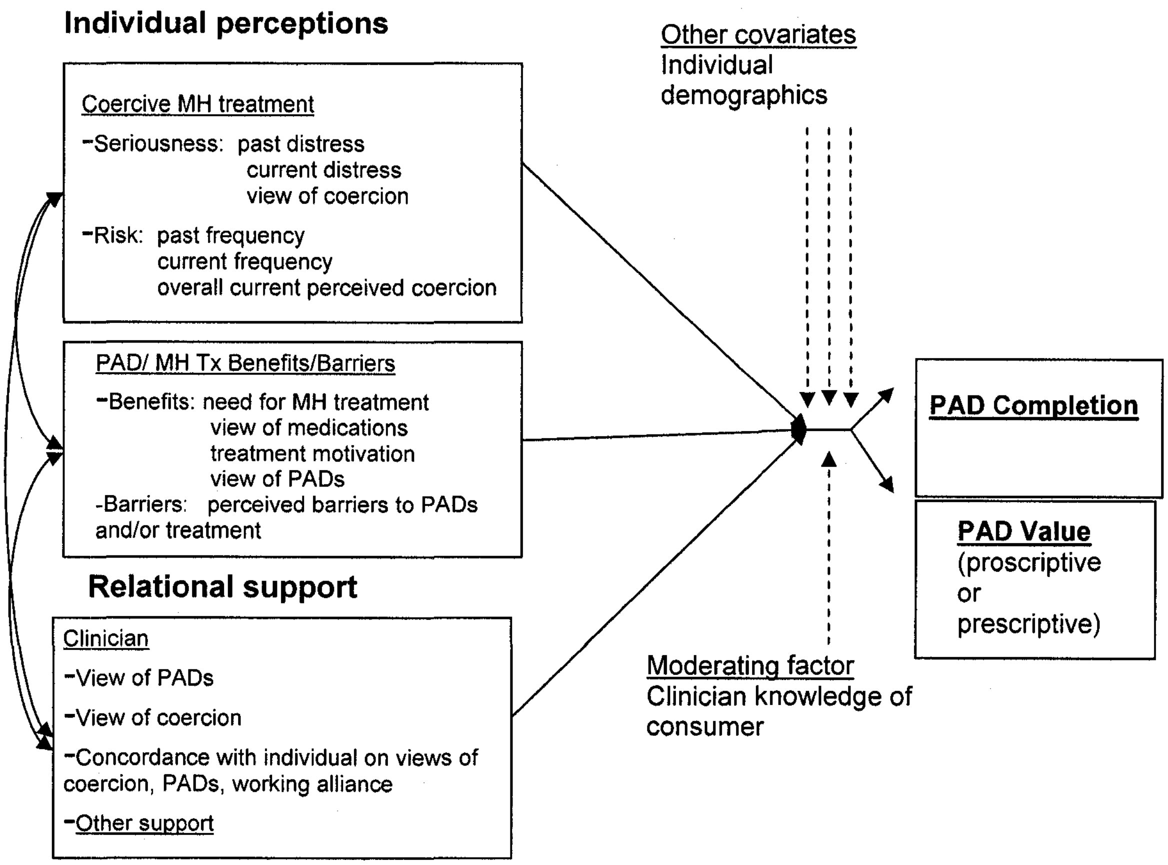

Figure 1 Conceptual Model for Study

Chapter 3 Methodology

3.1 Description of Original Study

This study was a secondary analysis of an existing data set abstracted from research conducted by Jeffrey Swanson and colleagues in the Services Effectiveness Research Program of the Department of Psychiatry & Behavioral Sciences at Duke University School of Medicine (funding dates: December 1, 2002 through November 30, 2006). The study, titled *Effectively Implementing Psychiatric Advance Directives* (NIMH RO1-MH063949), is a randomized trial of Facilitated Psychiatric Advance Directives (F-PADs), a manualized facilitation intervention to help individuals with SMI in the completion of PADs. The F-PAD manual is written for the facilitator and provides a step-by-step guide for how to facilitate the development of a PAD with a consumers. It was adapted from several medical and psychiatric advance directive planning tools (California Protection and Advocacy, nd; Hammes & Rooney, 1998) and includes an outline of how to present an introduction to PAD concepts, review past treatment experiences with the consumer, and discuss, identify, and document future treatment preferences. In the F-PAD process an individual is provided an opportunity to work with a facilitator to create an Advance Instruction, designate a Health Care Power of Attorney, or both. Study participants in the treatment arm were offered the opportunity to complete a F-PAD with a trained facilitator, and were provided assistance in witnessing and notarizing the completed document. Participants in the control arm received a brief introduction to PADs and information on consumer organizations that could help them complete a PAD if they so desired. In addition to F-PAD creation, the study had a longitudinal component, evaluating participants at one, six, and twelve months to examine the impact of the F-PAD intervention. All participants were asked to identify their primary mental health clinician. These clinicians were contacted and asked a series of questions regarding their views on the participant, their relationship with the participant, and their attitudes towards PADs and coercion.

The specific aims of the original study were as follows:

1. To evaluate the effectiveness of a manualized, pilot tested service intervention to facilitate completion of PADs;
2. To evaluate the content and structure of F-PAD documents;
3. To examine the effects of the F-PAD intervention on engagement in the outpatient treatment process; and
4. To examine the implementation of the F-PAD during mental health crises.

3.11 Recruitment and Data Collection

Criteria for eligibility to participate in the study included: a) age 18-65; b) documented diagnosis of schizophrenia, schizoaffective disorder, other psychotic disorder, or major mood disorder with psychotic features; c) currently receiving mental health services through one of two county-based programs in North Carolina that agreed to collaborate with the study; and d) able to give informed consent to participate in the research project. This ability was determined through a two-step process. First, the consumer's treating provider used his/her clinical judgment to determine whether the individual should be referred to the study. Second, during the consent process the study research assistants were trained to stop and check with the consumer to ensure his/her understanding of the study. If the research assistant had concerns about the individual's capacity, a mini-mental status exam was administered. If this revealed a lack of capacity and thus ability to provide informed consent, the individual was not accepted into the study. Recruitment occurred from August 2004 through August 2005. The county mental health programs provided the study with a de-identified list of adult clients pre-screened for eligibility, and a random sample of individuals was drawn from this list. In addition, sequential admissions to the state psychiatric hospital from these counties who met study criteria also were identified by the study recruiters. In all cases treating clinicians were contacted to verify that the identified individual met study criteria, and they sought the person's permission to be contacted by a researcher. The total pool from which this sample was drawn was n= 12,615 (the total number of adult clients served by the two agencies from August 2004 to August 2005), the random sample was n=636. Approximately 20 percent of the sample was recruited from the hospital setting.

Fifty one individuals declined to participate and 167 were found ineligible for the study. Individuals willing to be contacted for the study were interviewed by a research team member who was blind to future study assignment of the participant. After providing informed consent, the participant received a baseline interview and was then randomized to the control or F-PAD arm of the study. At the baseline interview participants were asked to identify their mental health clinician, defined as the mental health provider who knew them the best. The research team then contacted and interviewed these clinicians at baseline and throughout the study, both to gather information on clinician characteristics and to corroborate information gathered from the study participants. Whether an individual had completed a PAD successfully was determined by facilitator report of PAD completion within two months of baseline for those in the F-PAD arm of the study. Study procedures were approved by the Institutional Review Boards of Duke University, the participating county mental health centers, and the psychiatric hospital (Swanson, Swartz, Elbogen et al., 2006). Further ethical review for this secondary analysis was not required by the Interdisciplinary Committee for Ethics in Human Research at Memorial University, whose policies indicate that "Research involving secondary use of data which is provided without any identifier or group of identifiers which would allow attribution of private information to an individual" is considered "Research that does not require ethics review." For the full Committee statement, refer to Appendix B.

3.2 Measures

All variables used in this dissertation are drawn from baseline data collected in the parent study described above, with the exception of the dependent variable PAD completion. As mentioned above, PAD completion was determined by facilitator report of successful PAD completion within two months of baseline for those in the F-PAD arm. Variables and measures are summarized in Appendix C, and established instruments are also listed in Appendix D, with references and documented psychometric properties. Exact wording used for each item can be found in Appendix E.

3.21 Outcome Variables

Two outcome variables from the original study are of interest in this project. The first is PAD completion, whether participants successfully completed a PAD document. In analyses of variables associated with PAD completion I chose to use only those participants in the F-PAD arm, even though three percent of the individuals in the control arm also completed a PAD. This was done because the process of completing a PAD with a facilitator, as in the F-PAD, may be very different than completing a PAD independently, and different characteristics may be associated with these processes. Therefore, in order to keep the analysis more clear and not confounded with two types of PAD processes, only the F-PAD arm was used. The second dependent variable is participants' valuing of PAD purpose as a proscriptive tool. This second variable was measured using a series of study-developed questions regarding participants' views of the importance of five possible purposes of a PAD. Participants were asked to rate how important each of the following statements regarding PADs was to them on a ten-point thermometer scale, with 1 representing least important and 10 most important:

1. Being free to change my mind about my treatment even when I am very ill.
2. Getting the treatment my doctor thinks is best for me.
3. Having family or friends make decisions about my treatment when I am very ill.
4. Avoiding treatment I don't want.
5. Getting whatever treatment works best for me.

The valuing PAD for proscriptive purpose variable was created by calculating the proportion of the total score accounted for by the response to #4 ("avoiding treatment I don't want) to measure participants valuing of PAD importance for proscriptive purposes (i.e. score for #4/total score for #1-5.) This variable was not normally distributed, even after log transformation efforts, and was therefore dichotomized at the median value of 0.1617.

All independent variables used to develop predictive models are described below. It should be noted that these varied slightly between the two dependent variables. To clarify, Appendix C identifies which independent variables were tested as predictors for each dependent variable. It should be noted that all continuous variables in the study were tested for normal distribution using the Shapiro Wilks test; those not normally distributed were dichotomized at the median to better capture possible non-linear relationships when appropriate. All ordinal variables (e.g. likert-type scaled questions) were also dichotomized; specific cut points for dichotomization are defined for each variable below.

3.22 Variables Measuring Individuals' Perceptions Regarding Coercion

Several variables were used in this research project to measure individuals' perceptions about the *risk* of experiencing coercive intervention. This was measured using individuals' baseline self-reported: a) number of lifetime coercive interventions; b) number of recent (past six months) coercive interventions; and c) overall level of perceived treatment coercion at baseline. Details of these measures are given below.

Number of lifetime coercive interventions were measured using participants' baseline self-reported:

- number of lifetime involuntary hospitalizations;
- number of types of involuntary intervention the individual had ever received as part of an inpatient process (handcuffed for transport to hospital, put in seclusion at hospital, put in restraints at hospital, forced medication);
- number of types of community-based treatment leverages the individual had experienced in the past (involuntary outpatient commitment, mandated to treatment by criminal justice, money from a representative payee contingent on treatment, housing contingent on treatment).

Number of recent coercive interventions were measured by the number of types of community-based treatment leverages the individual reported within six months of baseline (involuntary outpatient commitment, mandated to treatment by criminal justice, money from a representative payee contingent on treatment, housing contingent on treatment) and whether there had been an involuntary hospitalization in the past 6 months.

Overall current perceived coercion was measured using participant baseline responses to :

- The MacArthur Admission Experience Scale, perceived coercion subscale (Gardner et al., 1993), as adapted for assessing coercion in outpatient treatment (Swartz, Swanson, & Hannon, 2003). This has shown good internal reliability in other studies with individuals with SMI (alpha=0.85 for the sample studied by Swartz and colleagues) (Swartz, Swanson, & Hannon,

2003) and in this study sample (alpha=0.90 for both the F-PAD arm sample and the total sample). It assesses whether participants believed they were forced into treatment settings, were able to express their preferences and had these opinions considered, and were treated with procedural justice. Each of the fifteen items in the scale is rated from 1 to 5, with 1 representing "Strongly Agree" with the statement and 5 "Strongly Disagree." Response ranges are from 15-75; higher scores indicated higher levels of perceived coercion.

- The study-developed General Pressures survey, which asks individuals if in the past six months they perceived that if they did not take their medication or come for treatment someone would: a) make them go to the hospital; b) commit them to the hospital; c) notify criminal justice; d) not give them their spending money; or e) force them to leave where they live. Each item is rated either Yes=1 or No=0 for a response range of 0 to 5; higher scores indicated increased perceived pressure. Though no prior validity and reliability tests have been completed for this instrument, it showed good internal reliability with both of these study samples (alpha=0.87 for F-PAD arm and alpha=0.86 for total sample).

Seriousness of coercive intervention, i.e. how great a negative impact coercion has on the individual, was measured using individuals' baseline self reported distress regarding coercive interventions.. Details of these measures are given below.

<u>Distress regarding coercive interventions</u> was measured using individuals' responses to the questions:

- "How much did ________ bother you?", in reference to seclusion, restraint, and forced medication experiences in the past. Responses were on a 5 point scale (1= Not at all, 5=Very much), dichotomized with 1=Moderately/Quite a bit/Very much, 0=Not at all/A little bit;
- "How much did ________bother you?", in reference to community-based treatment leverages the individual experienced in the past, i.e. involuntary outpatient commitment, mandated to treatment by criminal justice, money from a representative payee contingent on treatment, housing contingent on treatment. Responses are on a 5 point scale (1= Not at all, 5=Very much), dichotomized with 1=Moderately/Quite a bit/Very much, 0=Not at all/A little bit.

3.23 Variables Measuring Individuals' View of Benefits of and Barriers to PADs and/or Mental Health Treatment

Several variables were used to measure individuals' view of the benefits and barriers to PADs and/or mental health treatment. These include measures of individuals': a) overall view of PAD utility and process; b) view of mental health treatment; and c) view of barriers to PAD completion and implementation; d) views of barriers to seeking mental health treatment.

The individuals' view of PAD utility and process was measured using baseline responses to a series of PAD attitudes questions; since currently no standardized instrument to measure PAD attitudes exists, study-developed questions were used. The series contains ten statements about PADs, each with a five point likert-type response

(1=Strongly Agree, 5=Strongly Disagree). This is a study-developed set of questions and not a scale or index with known psychometric properties. Therefore, rather than calculating a summative score, the mean value of responses across questions was calculated. In addition, responses to each question were analyzed independently.

Individuals' views of mental health treatment were measured using baseline responses to several instruments. These are:

- Insight and Treatment Attitudes Questionnaire (ITAQ) (McEvoy et al., 1989), a measure of awareness of mental health problems and need for treatment designed for individuals with SMI. Each of the eleven items in the scale is rated No=0, Possibly Yes=1, Yes=2, for a range of 0 to 22; higher scores indicated greater insight This measure has demonstrated reliability and validity in studies with individuals with SMI (alpha =0.82 for Swartz and colleagues, concurrent validity with psychiatrist rating of insight r=0.85 for McEvoy and colleagues) (McEvoy et al., 1989; Swartz, Swanson, & Hannon, 2003) and showed good internal reliability with the study samples (alpha=0.80 for both F-PAD and total sample).
- Drug Attitude Inventory (DAI), a measure to assess attitudes toward taking psychotropic medication with demonstrated good psychometric properties as shown in studies of individuals with schizophrenia by Hogan and colleagues (alpha =0.81, concurrent validity with Neuroleptic Dysphoria Scale r=0.76, predictive validity for compliance=96 percent and noncompliance=83 percent) (Hogan, Awad, & Eastwood, 1983). It showed acceptable internal reliability with the study samples (alpha=0.74 for both F-PAD and total sample). Each of the

seventeen questions can be answered True=1 or False=0; the inventory has a range of 0 to 17 and higher scores indicated more positive views of medication.

- Individuals' view of coercion in mental health treatment was measured by using baseline responses to two study-designed questions asking for level of agreement with the statements: "On the whole you are better off because of this pressure[community leverages] to *keep appointments* (1=Strongly Agree, 5=Strongly Disagree); and "On the whole you are better off because of this pressure[community leverages] to *take medications* (1=Strongly Agree, 5=Strongly Disagree), dichotomized with 1=Strongly Disagree/Disagree, 0=Neutral/Agree/Strongly Agree. Since these study-designed questions are analyzed as two independent questions rather than a scale or index, testing of psychometric properties has not been undertaken.
- Treatment Motivation Questionnaire (TMQ), a valid and reliable measure to assess internal motivation for treatment, motivation related to belief in the goals of treatment, confidence in treatment, and inclination to interpersonal help-seeking (Ryan, Plant, & O'Malley, 1995) Each of the 28 items can be answered from 1=Not At All True to 7=Very true. Higher scores indicated higher levels of motivation. A confirmatory factor analysis was done for the TMQ using the sample for this study. Five subscales were identified. The reliability of the subscales of "Intrinsic Motivating Factors" (alpha=.78), "Lack of Confidence in Treatment" (alpha= .82), "Relatedness in Treatment" (alpha=.87), and "Avoidance of Negative Introject" (alpha=.73) were acceptable, with the fifth

subscale, "External Motivating Factors" having minimal reliability (alpha= .51). (Ferron, Elbogen, Swanson, Swartz, & Wagner, under review). Concurrent validity of the scale has been demonstrated with the Beck Depression Inventory, Short Michigan Alcohol Screening Test, and Addiction Severity Index (average r=0.31) (Ryan et al., 1995)

- Treatment Satisfaction Scale, a thirteen item survey developed as part of the Mental Health Statistical Improvement Program Adult Consumer Survey. This is a measure used with consumers, with good psychometric properties (alpha= 0.73-0.81 (Jerrell, 2006) and demonstrated good internal reliability with this study sample (alpha=0.88 for F-PAD arm, 0.90 for total sample). Each item is answered on a 5 point scale (1=Strongly Agree, 5=Strongly Disagree); higher scores indicate greater dissatisfaction.

Individuals' views of barriers to PAD completion and implementation were measured by participants' baseline responses to a study-developed series of reasons why an individual may not want to create a PAD. There are 9 items (e.g. "You don't understand enough about psychiatric advance directives") each with a True=1 or False=0 response. Again, since these study-designed questions are analyzed as independent questions rather than a scale or index, testing of psychometric properties has not been undertaken.

Individuals' views of barriers/disadvantages to seeking mental health treatment were measured with a series of 16 study-developed questions asking why the individual might delay getting mental health treatment (e.g. concern about cost, concern about getting in trouble with law.) Each question is scored Yes=1 or No=0. Similar to other questions discussed, since these study-designed questions are analyzed as independent questions rather than a scale or index, testing of psychometric properties has not been undertaken.

3.24 Variables Measuring Relational Support, Clinician and Other

To examine consumers' relational supports as a context for PAD creation or valuing PADs more for proscriptive purposes I examined: a) clinician views of PADs and of coercion; b) clinician and consumer view of the working alliance in the therapeutic relationship at baseline; c) the concordance between clinician and consumer views on PADs, coercion, and their working alliance; d) how well the clinician reported knowing the individual; e) individuals' reports of having relationships with others outside of the clinician; e) individuals' report of having trusting relationships with clinician or others.

The <u>clinicians' view of PAD utility and process</u> was measured using baseline responses to the study-developed PAD Attitudes questionnaire, clinician version. This instrument contains ten statements about PADs, each with a five point Likert-type response (1=Strongly Agree, 5=Strongly Disagree). This is a study-developed set of questions and not a scale or index with known psychometric properties. Therefore, rather than calculating a summative score, the mean value of responses across questions was calculated. In addition, responses to each question were analyzed independently.

<u>Clinicians' view of coercion</u> in mental health treatment was measured by using their baseline responses to two study-designed questions asking for level of agreement

with the statements: "On the whole a patient who is often non-compliant with treatment would be better off with these type of reminders (that they might need to go to the hospital, be committed, get in trouble with the law, have their money withheld, or lose housing) to *keep appointments*."; "On the whole a patient who is often non-compliant with treatment would be better off with these type of reminders (that they might need to go to the hospital, be committed, get in trouble with the law, have their money withheld, or lose housing) to *take medications*." (1=Strongly Agree, 5=Strongly Disagree), dichotomized with 1=Strongly Disagree/Disagree, 0=Neutral/Agree/Strongly Agree.

Clinician and consumer view of the working alliance were measured using the Clinician Working Alliance Inventory (WAI) and the Client WAI. These instruments conceptualize the alliance as a collaboration and agreement between clinician and client on treatment goals and interventions, and a positive bond between the two people (Horvath & Greenberg, 1989). The WAI was adapted for individuals with SMI (Neale & Rosenheck, 1995) and has demonstrated good reliability and validity (alpha=0.89 in a study of individuals with SMI completed by Chinman and colleagues) (Chinman, Rosenheck, & Lam, 1999). Good internal reliability was shown in this study as well (for consumer WAI alpha=0.94 for both F-PAD and total sample, for clinician WAI alpha=0.92 for F-PAD and 0.91 for total sample).

Concordance in views between clinician and individual on coercion was measured by:

- A comparison of how consumers responded to the following statements regarding coercive interventions "On the whole you are better off because of this pressure (referring to the leverages of reminders that they might need to go to the hospital, be committed, get in trouble with the law, have their money withheld, or lose housing) to keep appointments." (1=Strongly Agree, 5=Strongly Disagree) and how their clinician responded to the question "On the whole a patient who is often non-compliant with treatment would be better off with these type of reminders (that they might need to go to the hospital, be committed, get in trouble with the law, have their money withheld, or lose housing) to keep appointments." (1=Strongly Agree, 5=Strongly Disagree.) Here each response was dichotomized as 1=Strongly Agree/Agree and 0= Neutral/Disagree/Strongly Disagree, and then responses were categorized as "Both clinician and consumer Strongly Agree/Agree", "Neither clinician nor consumer Strongly Agree/Agree", "Only clinician Strongly Agrees/Agrees" or "Only consumer Strongly Agrees/Agrees".

- A comparison of how individuals responded to the following question regarding coercive interventions "On the whole you are better off because of this pressure (referring to the leverages of reminders that they might need to go to the hospital, be committed, get in trouble with the law, have their money withheld, or lose housing) to take medications." (1=Strongly Agree, 5=Strongly Disagree) and how their clinician responded to the question "On the whole a patient who is often non-compliant with medications would be better off with these type of reminders (that they might need to go to the hospital, be committed, get in trouble with the law, have their money withheld, or lose housing) to take medications"

(1=Strongly Agree, 5=Strongly Disagree). Responses were dichotomized and categorized as above.

- A comparison of how individuals responded to the following question regarding PADs and coercion "People should have a PAD because otherwise they might be put in the hospital or get medicines they don't want." (1=Strongly Agree, 5=Strongly Disagree) and how their clinician responded to the same question. Responses were dichotomized and categorized as above.

Concordance in views between clinician and individual on PADs was measured by a comparison of clinician and individual responses to each question of the PAD Attitudes Questionnaire. Each response was dichotomized as 1=Strongly Agree/Agree and 0= Neutral/Disagree/Strongly Disagree, and then responses were categorized as "Both clinician and consumer Strongly Agree/Agree", "Neither clinician nor consumer Strongly Agree/Agree", "Only clinician Strongly Agrees/Agrees" or "Only consumer Strongly Agrees/Agrees";

Concordance in views between clinician and individual on working alliance was measured by a comparison of the Clinician Working Alliance Inventory (WAI) and the Client WAI. This instrument conceptualizes the alliance as a collaboration and agreement between clinician and client on treatment goals and interventions, and a positive bond between the two people (Horvath & Greenberg, 1989). The WAI was adapted for individuals with SMI (Neale & Rosenheck, 1995) and has demonstrated good reliability and validity (alpha=0.89 in a study of individuals with SMI completed by Chinman and colleagues) (Chinman et al., 1999). Good internal reliability was shown in this study as well (for consumer WAI alpha=0.94 for both F-PAD and total sample, for clinician WAI alpha=0.92 for F-PAD and 0.91 for total sample). Each score was dichotomized at the median, and then categorized as "Both clinician and consumer above median", "Both consumer and clinician below median", "Only clinician above median", "Only consumer above median."

How well the clinician knows the individual was measured by the number of months the clinician had provided services to the individual and by the clinician's self-reported knowledge of the individual (1=Only slightly, 5=Extremely well), dichotomized at 1=Very well/Extremely well, 0=Only slightly/Somewhat/Moderately well.

Individuals' relationships with others outside of the clinician was measured by the individual's response to four study-developed questions: a) Do you have any close friends who are not family members? (1=Yes, 0=No); b) Do you have someone who regularly helps you with your mental health treatment? (1=Yes, 0=No) ; c) In times of trouble can you count on someone at least most or some of the time? (1=Yes, 0=No); and d) have you been victimized in the past 6 months (1=Yes, 0=No). This last question was asked to see if consumers had relationships that were protective and resulted in their safety or if they were at risk of victimization. In addition, relationship was measured using a version of the Duke Social Support Scale, a standardized instrument with adequate psychometric properties and an internal reliability of between 0.58 and 0.80 (Powers, Goodger, & Byles, 2004); in this study the instrument demonstrated adequate reliability as well (alpha=0.72 for F-PAD arm and 0.75 for the total sample.)

Individuals' views of trusting relationships and mental health care was measured by response to the following study-developed items:

- You don't have someone to trust to make decisions for you (1=Yes, 0=No)
- You don't have a doctor you trust (1=Yes, 0=No)
- People with serious mental health problems should talk to their doctor or therapist about what to write down in a PAD (1=Strongly Agree, 5=Strongly Disagree), dichotomized with 1=Strongly Agree/Agree, 0=Neutral/Disagree/Strongly Disagree.
- People with a serious mental illness should choose a family member or someone they trust and give them the right to make decisions about their treatment in the future if they become very ill (1=Strongly Agree, 5=Strongly Disagree), dichotomized with 1=Strongly Agree/Agree, 0=Neutral/Disagree/Strongly Disagree.

3.25 Other Co-variates for the Study

Additional co-variates were chosen based on prior studies or the conceptual model proposed. For individuals with SMI, clinical co-variates included the Brief Psychiatric Rating Scale (BPRS) to measure symptomatology (Moerner, Mannuzza, & Kane, 1988), the Global Assessment of Functioning (GAF) to measure functional impairment (Endicott, Spitzer, Fleiss, & Cohen, 1976), identification of substance abuse by at least one positive response on the CAGE regarding alcohol or drugs (Ewing, 1984), and the Decisional Competence Assessment Tool for Psychiatric Advance Directives

(DCAT-PAD) to evaluate understanding and reasoning regarding PADs and regarding hospitalization (Elbogen et al., 2006). Demographic variables considered in analyses include race, gender, and age. For clinicians, additional variables included race, gender, age, educational level, years of mental health experience, and caseload size.

3.3 Data Analysis Plan

A variety of statistical analyses were conducted in order to test the study hypotheses. Analysis began with appropriate univariate statistics to describe the sample, including means, standard deviations, and frequencies, followed by analyses specific to each hypothesis as outlined below.

Hypothesis 1a. Individuals are more likely to complete a PAD if clinician support for PADs is high.

Hypothesis 1b. The impact of clinician support on PAD completion will be moderated by how well the clinician knows the individual; clinician knowledge of the individual will be based on self-report.

To test these hypotheses, data from participants offered the F-PAD intervention were examined. Given the multi-level nature of the data (participants nested within clinicians), multi-level logistic regression analysis was used to determine if level-two variables (i.e. clinician characteristics) were significant predictor variables of PAD completion (Bryk & Raudenbush, 1992). Analyses were completed using the statistical package HLM 6.02 for Windows (Raudenbush, Bryk, & Congdon, 2005). First the Intraclass Correlation (ICC) was calculated to determine the proportion of variation in the dependent variable explained by level two independent variables, using only the empty model, where the dependent variable is expressed as the sum of the general mean, a random effect at the clinician level (level-two), and a random effect at the consumer level (level-one). The formula used for the ICC was $\rho_I = \tau_0^2 / (\tau_0^2 + \pi/3)$ (Snijders & Bosker, 1999). As discussed in Results, the ICC was quite low, and much below the 0.15 recommended as a minimum for multi-level analysis (Bryk & Raudenbush, 1992). An analysis using clinician level variables (not considering any level-one consumer variables), including PAD attitudes, coercion attitudes, case size, and years in practice was completed to ensure no significant level-two variables existed. The moderating effect of clinician knowledge of individual was not examined given the lack of evidence for a significant level-two effect..

Hypothesis 2.1. PAD completion is significantly associated with concordance in the working alliance between clinician and individual.

Hypothesis 2.2. PAD completion is significantly associated with clinician/individual concordance in views on coercion in mental health treatment.

To test these hypotheses, data from participants offered the F-PAD intervention were examined. Bivariate logistic regression analyses were completed for all variables of interest. (See Appendix C) Next, variables were grouped into conceptual domains and multivariate logistic regression analyses completed for purposes of variable reduction. To develop a final model all significant variables from domain analyses were entered into a multivariate logistic regression analysis, with stepwise inclusion and exclusion at *p*=0.10, to capture possible trends towards significance. All regression analyses were completed using the statistical package SAS 9.1 (SAS Institute, 2002).

Hypothesis 3a. Individuals are more likely to value PADs as a proscriptive tool if clinician support for coercion in mental health treatment is high.

Hypothesis 3b. The impact of clinician support for coercion in mental health treatment on the individual's likelihood of valuing PADs as a proscriptive tool will be moderated by how well the clinician knows the individual; clinician knowledge of the individual will be based on self-report.

To test these hypotheses, data from all participants in the sample were examined. Given the multi-level nature of the data (participants nested within clinicians), multi-level logistic regression analysis was used to determine if level-two variables (i.e. clinician characteristics) were significant predictor variables of PAD completion (Bryk & Raudenbush, 1992). Analyses were completed using the statistical package HLM 6.02 for Windows (Raudenbush, Bryk et al., 2005). First the Intraclass Correlation (ICC) was calculated to determine the proportion of variation in the dependent variable explained by level-two independent variables, using only the empty model, where the dependent variable is expressed as the sum of the general mean, a random effect at the clinician level (level-two), and a random effect at the consumer level (level-one). The formula used for the ICC was $\rho_I = \tau_0^2 / (\tau_0^2 + \pi/3)$ (Snijders & Bosker, 1999). As discussed in Results, the ICC was quite low, and much below the 0.15 recommended as a minimum for multi-level analysis (Bryk & Raudenbush, 1992). An analysis using clinician level variables (not considering any level-one consumer variables), including PAD attitudes, coercion attitudes, case size, and years in practice was completed to ensure no significant level two variables existed. The moderating effect of clinician knowledge of individual was not examined given the lack of evidence for a significant level-two effect.

Hypothesis 4.1. Individuals are less likely to value PADs as a proscriptive tool if there is concordance in the working alliance between clinician and individual and both rate the working alliance as positive.

Hypothesis 4.2. Individuals' valuing of PAD as a proscriptive tool are significantly associated with clinician/individual concordance in views on coercion in mental health treatment.

To test these hypotheses, data from all participants in the sample were examined. Bivariate logistic regression analyses were completed for all variables of interest. (See Appendix C.) Next, variables were grouped into conceptual domains and multivariate logistic regression analyses completed for purposes of variable reduction. To develop a final model, all significant variables from domain analyses were entered into a multivariate logistic regression analysis, with stepwise inclusion and exclusion at p=0.10, to capture possible trends towards significance. All regression analyses were completed using the statistical package SAS 9.1 (SAS Institute, 2002).

3.31 Sample Size and Statistical Power

Four hundred sixty nine individuals consented to participate in the study and provided baseline information. Of these, 239 were randomized to the F-PAD group, and 146 (61 percent) of these completed PADs. Seventy eight clinicians were interviewed for the study, of these 57 provided services to the 239 participants in the F-PAD arm. Testing of hypotheses 1 and 2 (outcome variable: PAD completion) used multilevel modeling (Raudenbush, Spybook, Liu, & Congdon, 2005) and logistic regression and was based on analysis of the n=239 F-PAD group, with number of clinician clusters j=57 and average number of individuals per clinician n=4. Testing of hypotheses 3 and 4 (outcome variable: valuing PAD for proscriptive purpose) used multilevel modeling (Raudenbush, Spybook et al., 2005) and logistic regression and was based on analysis of the entire sample (N=469), with number of clinician clusters j=78 and average number of individuals per clinician n=6. In all cases, power estimates assumed a bidirectional alpha level of *p*=.05.

For hypotheses 1 and 2, the probability of completing a PAD when the participant has a PAD-supportive clinician was assumed to be 0.7 and when the participant has a non-supportive clinician to be 0.5 (NOTE: Overall completion for the entire sample=.61). With j=57 clusters and n=4 participants per cluster on average the sample achieved a power of 80 percent to detect a moderate effect size of 0.4 (See Figure 2).

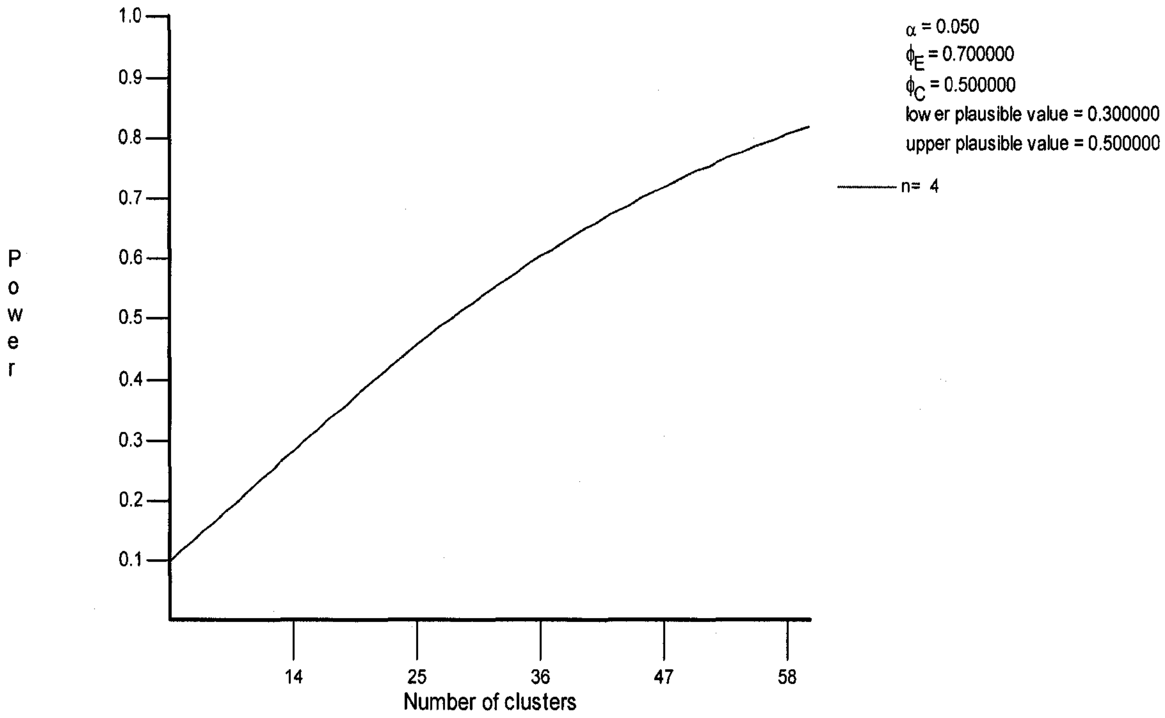

Figure 2 Power vs. Number of Clusters for Binary Outcome PAD Completion

For hypotheses 3 and 4, the probability of placing higher value on a PAD for proscriptive purposes when the participant had a coercion-supportive clinician was assumed to be 0.6 and when the participant has a non-coercion-supportive clinician to be 0.4. With j=78 clusters and n=6 participants per cluster on average the sample achieved a power of over 90 percent to detect a small effect size of 0.2 (See Figure 3). All estimates have been obtained using Optimal Design software (Raudenbush, Spybook et al., 2005).

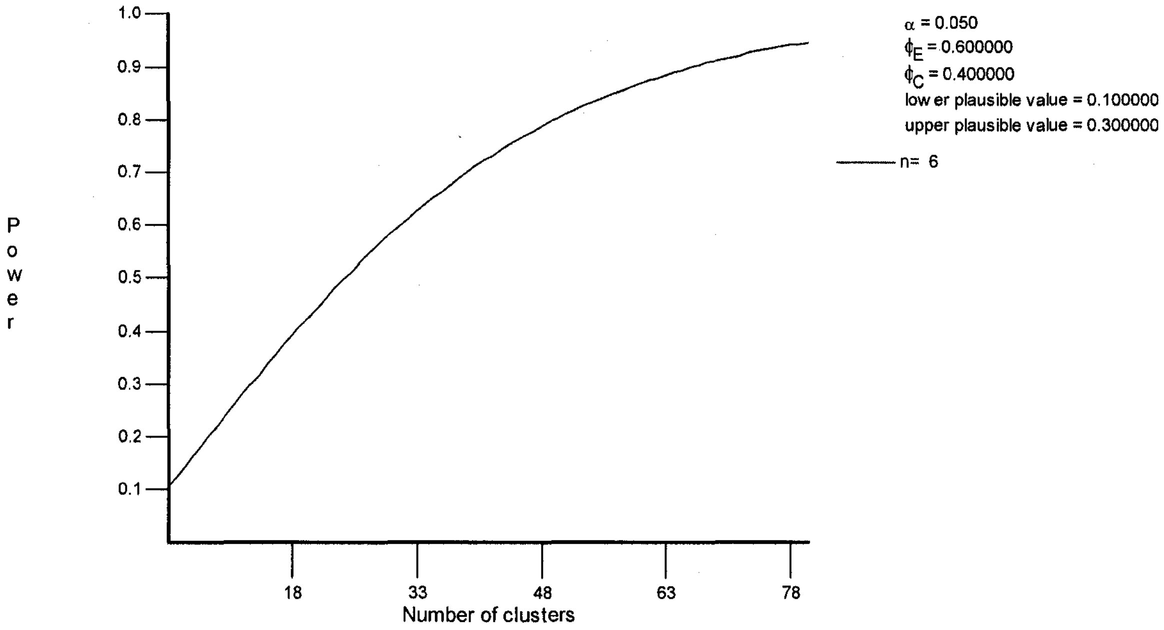

Figure 3 Power vs. Number of Clusters for Binary Variable PAD Purpose

Chapter 4 Results

4.1 Sample Characteristics

4.11 Consumer Characteristics

Characteristics of consumers for both the entire sample and for those participating in the F-PAD study arm are summarized in Table 1. On average, consumers were in their early 40s (42.2 and 41.9 years, S.D. 10.79 and 10.65, respectively), about 40 percent male (40.3 percent and 41.4 percent), and slightly over half were Black/African American (57.8 percent and 56.5 percent). Few consumers were married at the time of the study (10.7 percent and 11.3 percent). About a quarter of the sample reported working in the month prior to the study (23.4 percent and 24.4 percent) and slightly over half reported living independently (56.9 percent and 57.3 percent).

Consumers in the sample most commonly had a chart diagnosis of schizophrenia (58.6 percent and 60.5 percent), with bipolar disorder (26.9 percent and 24.0 percent) and major depression (13.9 percent and 15.6 percent) also present in the sample. Nearly a tenth of the sample (7.9 percent and 8.4 percent) had a concurrent diagnosis of substance abuse. Mean scores on the Brief Psychiatric Rating Scale were 33.6 and 34.0, (S.D. 9.24 and 9.46) indicating moderate symptom severity, not unexpected for consumers living in the community. The average Global Assessment of Functioning score for both groups was 40 (S.D. 10.31 and 10.32), indicating a moderate level of impairment in functioning. About a quarter of consumers reported being victimized in the six months prior to the study (24.2 percent and 25.6 percent). The majority of consumers reported some level of social support, with over three quarters reporting that they had at least one close friend (77.7 percent and 75.2 percent).

Most consumers had some experience with involuntary or leveraged treatment. Nearly two thirds reported at least one involuntary hospitalization experience (65.5 percent and 61.1 percent); a little over a tenth had experienced this in the past six months (13.2 percent and 13.4 percent). In addition, nearly a third reported experiencing some form of community treatment leverage (either outpatient commitment, treatment mandated by the criminal justice system, receiving money from a representative payee contingent on treatment, or housing contingent on treatment) in the prior six months (31.1 percent and 33.9 percent).

Table 1

Characteristics of Consumer Sample

	Total Sample (N=469)	**F-PAD Group (N=239)**
Demographics		
Age (Mean, S.D.)	42.2 (10.79)	41.9 (10.65)
Male	189 (40.3%)	99 (41.4%)
Race: White	183 (39.0%)	95 (39.8%)
Race: Black	271 (57.8%)	135 (56.5%)
Race: Other	15 (3.2%)	9 (3.7%)
Married	50 (10.7%)	27 (11.3%)
Years of education (Mean, S.D.)	12.3 (2.46)	12.2 (2.47)
Lives independently	267 (56.9%)	137 (57.3%)
Consumer worked in past month	105 (23.4%)	55 (24.4%)
Functioning and Mental Health		
GAF (Mean, S.D.)	40.0 (10.31)	40.0 (10.32)
Brief Psychiatric Rating Scale (Mean, S.D.)	33.6 (9.24)	34.0 (9.46)
Diagnoses:		
Schizophrenia	275 (58.6%)	144 (60.5%)
Bipolar	126 (26.9%)	57 (24.0%)
Major Depression	65 (13.9%)	37 (15.6%)
Substance Abuse	37 (7.9%)	17 (8.4%)
Consumer victimized in past 6 months	113 (24.2%)	61 (25.6%)
Consumer reports a close friend	356 (77.7%)	176 (75.2%)
Treatment Experiences		
Consumer ever involuntarily hospitalized	307 (65.5%)	146 (61.1%)
Consumer involuntarily hospitalized in past 6 months	62 (13.2%)	32 (13.4%)
Consumer experienced community leverage in past 6 months	146 (31.1%)	81 (33.9%)

4.12 Clinician Characteristics

Characteristics of the clinicians providing services to consumers in both the entire sample and in the F-PAD study arm are summarized in Table 2. Clinicians were on average slightly over 40 years old (41.3 and 40.4 years, S.D. 13.74 and 14.65, respectively), and slightly over a quarter of the clinicians were male (26.9 percent and 29.8 percent). Nearly half the clinicians were White (46.2 percent and 49.1 percent), with the majority of the remainder Black/African American (44.9 percent and 43.9 percent). Less than half of the samples had a bachelor's degree or less (42.3 percent and 42.1 percent). Clinicians were on average quite experienced, reporting over 11 years of mental health services experience (12.0 and 11.5, S.D. 8.78 and 8.85). Their reported caseload size was large, with an average of 73.7 (S.D. 94.66) for the total sample and 92.6 (S.D. 111.25) for the F-PAD group. It should be noted, however, that the range of caseload size varied dramatically, from a low of 7 to a high of 450.

Table 2

Characteristics of Clinician Sample

	Total Sample (N=78)	F-PAD Group (N=57)
Age (Mean, S.D.)	41.3 (13.74)	40.4 (14.65)
Male	21 (26.9%)	17 (29.8%)
Race: White	36 (46.2%)	28 (49.1%)
Race: Black	35 (44.9%)	25 (43.9%)
Race: Other/Unknown	7 (8.9%)	4 (7.0%)
Bachelor's Degree or less	33 (42.3%)	24 (42.1%)
Years of MH Experience (Mean,S.D.)	12.0 (8.78)	11.5 (8.85)
Caseload size (Mean, S.D.)	73.7 (94.66)	92.6 (111.25)

4.2 Research Question 1: Clinician Support for PADs and PAD Completion.

The first research question addressed in this dissertation examined whether clinician support for PADs is a significant variable in a predictive model of PAD completion for individuals with SMI. Specific hypotheses were:

Hypothesis 1a. Individuals are more likely to complete a PAD if clinician support for PADs is high.

Hypothesis 1b. The impact of clinician support on PAD completion will be moderated by how well the clinician knows the individual; clinician knowledge of the individual will be based on self-report.

Clinician support for PADs is a level-2 variable, with multiple consumers nested within one clinician. Therefore, multilevel logistic regression analysis was used to test whether clinician support for PADs is a significant predictor variable for PAD completion. Results using only the empty model, where the dependent variable is expressed as the sum of the general mean, a random effect at the clinician level, and a random effect at the consumer level, are shown in Table 3.

Based on this level two variance, the Intra Class Correlation (ICC) is calculated by $\rho_I = \tau_0^2 / \tau_0^2 + 3.29 = 0.18198/0.18198+3.29 = \underline{0.0524}$ (Snijders & Bosker, 1999). Thus only 5 percent of the variation in the dependent variable PAD completion is explained by clinician level variables. Though small, and much less than the ICC of 0.15 suggested as a cutoff by the literature (Bryk & Raudenbush, 1992), a second multi-level analysis was completed to see specifically if clinician support for PADs was a significant level two predictor, and was found to be non-significant. The hypothesis that clinician support for PADs is a significant predictor of PAD completion was not supported and therefore analysis of clinician knowledge of consumer as a moderating variable was not examined.

Table 3. *Empty Model for PAD Completion*

Fixed Effect	Coefficient	S.E.
γ_{00}=Intercept	0.448097	0.174759

Random Effect	Variance Component	S.D.
τ_0^2=var(U_{0j})	0.18198	0.42660

4.3 Research Questions 2.1 through 2.3: Clinician/Individual Concordance and PAD Completion

The second set of research questions in this dissertation examined whether clinician/individual concordance in the working alliance, in PAD attitudes, or in views on coercion are significant variables in a predictive model of PAD completion. Specific hypotheses were:

Hypothesis 2.1. PAD completion is significantly associated with concordance in the working alliance between clinician and individual, and with whether both rate the alliance as positive.

Hypothesis 2.2. PAD completion is significantly associated with concordance in PAD attitudes between clinician and individual.

Hypothesis 2.3. PAD completion is significantly associated with clinician/individual concordance in views on coercion in mental health treatment, and with whether both have high or low endorsement of coercion in treatment.

A predictive model of PAD completion was developed using the conceptual model outlined previously, testing independent variables for risk of coercion, seriousness of coercion, benefits of PAD completion and treatment, barriers to PAD, and relational context, including concordance between clinician and consumer on working alliance, PAD attitudes, and views on coercion. Bivariate logistic regression analyses were completed, followed by multivariate logistic regression analyses with variables grouped by conceptual domains (completed for purposes of variable reduction.) Variables found to be significant at the $p<0.05$ level were included in a final multivariate logistic regression model. (See Appendix C for a complete listing of all variables and domains tested.)

In bivariate analyses, the following variables were significantly (*p<0.05*) associated with an increased likelihood of PAD completion:

1) Age (dichotomized at median 42), with older age more likely to complete;

2) Higher GAF score;

3) Higher PAD Reasoning score of DCATPAD;

4) Higher Hospital Reasoning score of DCATPAD;

5) Higher Treatment Motivation Questionnaire (TMQ) total score;

6) Higher TMQ intrinsic motivation subscale;

7) Higher TMQ relatedness subscale;

8) Higher Consumer Working Alliance Inventory (WAI) score;

9) Only consumer agrees that people with SMI should:

    a) when well, write down their treatment preferences;

    b) have a PAD because otherwise they might be put in the hospital or get medication they don't want;

    c) have a PAD because otherwise they might go without treatment they need;

10) Clinician reports knowing consumer very well or well;

11) Consumer reports having at least one close friend.

Bivariate analyses revealed a significantly (*p<0.05*) decreased likelihood of PAD completion for the following variables:

1) Potential alcohol abuse;

2) Ever arrested;

3) Having an involuntary hospitalization in the past 6 months;

4) MacArthur Admission Experience score above the median of 30;

5) Consumer above median in mean score on PAD attitude questions;

6) Consumer reports not having a doctor to trust;

7) Consumer but not clinician has above the median mean score on PAD attitude questions;

8) Clinician but not consumer agrees that:

  a) having a PAD will help a consumer stay well;

  b) people with SMI should, when well, write down their treatment preferences;

  c) providers should pay a legal penalty if they fail to follow a PAD;

  d) people with SMI should have a PAD because otherwise they might be put in the hospital or get medication they don't want;

9) Both consumer and clinician agree that:

  a) people with SMI should have a PAD because otherwise they might be put in the hospital or get medication they don't want;

  b) people with SMI should have a PAD because otherwise they might go without the treatment they need.

10) Consumer history of victimization in the past six months

In domain analyses the following additional variables were associated with a significantly (*$p<0.05$*) increased likelihood of PAD completion:

1) Consumer reports delaying treatment because going to treatment might get them in trouble with family or friends;

2) Consumer and Clinician WAI within 4 points;

3) An interaction of consumer and clinician WAI within four points and clinician reports knowing consumer very well/well.

Additional variables associated with a significantly ($p<0.05$) decreased likelihood of PAD completion included:

1) Consumer reported distress at experiencing involuntary outpatient commitment;

2) Drug Attitude Inventory (DAI) above the median score of 14;

3) Both consumer and clinician have mean PAD attitude question scores below the median.

Table 4 summarizes the significant associations seen in bivariate analyses and domain analyses [Note: if all variables for a domain were not significant at bivariate or domain level they were not included in this table.] The final model is shown in Table 5 and was found to explain nearly 27 percent (pseudo R^2= 0.269) of the variation in the dependent variable ($p<0.0001$). In this model, PAD completion was significantly more likely if the consumer was older than the sample median of 42 (OR=3.399), had a higher PAD Reasoning score on the DCATPAD (OR=1.422), had a higher score on the Treatment Motivation Questionnaire relatedness subscale (OR=1.072), and if the consumer reported having at least one close friend (OR=3.969). PAD completion was significantly less likely if the consumer scored above the sample median of 14 for the

Drug Attitude Inventory (OR=0.273), the consumer reported any victimizations in the prior six months (OR=0.360), and if the consumer and clinician were discordant on PAD attitudes, specifically if only the clinician agreed that providers should pay a legal penalty if they fail to follow a PAD (OR=0.137). Concordance in working alliance or in views on coercion were not significantly associated with PAD completion.

Table 4

Analyses for PAD Completion (N=239)

	BIVARIATE MODEL			DOMAIN MODEL		
Variable	**Odds Ratio**	**95% CI**	***p value***	**Odds Ratio**	**95% CI**	***p value***
Demographics						
Age (dichotomized at median 42)	1.961	1.157-3.393	*0.0128*	1.758	1.013-3.053	*0.0450*
Gender (male=1)			*ns*			*ns*
Race (white=1)			*ns*			*ns*
GAF	1.030	1.001-1.60	*0.0412*			*ns*
BPRS			*ns*			*ns*
1 or more YES in CAGE for alcohol	0.424	0.228-0.788	*0.0067*	0.467	0.247-0.883	*0.0190*
1 or more YES in CAGE for drugs			*ns*			*ns*
DCATPAD						
PAD Understanding			*ns*			*ns*
Hospital Understanding			*ns*			*ns*
PAD Reasoning	1.280	1.106-1.480	*0.0009*	1.280	1.106-1.480	*0.0009*
Hospital Reasoning	1.212	1.034-1.420	*0.0173*			*ns*
Risk: Community Leverages, Lifetime						
Number of types of community leverages			*ns*			*ns*
IOC			*ns*			*ns*
Threat of criminal justice			*ns*			*ns*
Threat by rep payee			*ns*			*ns*
Threat of housing loss			*ns*			*ns*
Ever arrested	0.532	0.310-0.913	*0.0221*	0.494	0.286-0.855	*0.0118*
Risk: Coercion Experiences, in Past 6 months						
Involuntary hospitalizaton	0.373	0.174-0.798	*0.0110*	0.373	0.174-0.798	*0.0110*
Number of types of community leverage			*ns*			*ns*
Any leverages			*ns*			*ns*
Arrest			*ns*			*ns*
IOC			*ns*			*ns*
Threat of criminal justice			*ns*			*ns*
Threat by rep payee			*ns*			*ns*
Threat of housing loss			*ns*			*ns*
Risk: Overall Coercion Perception						
MacArthur Admission Experience Scale (dichotomized at median 30)	0.560	0.328-0.957	*0.0340*	0.571	0.334-0.977	*0.0410*
General Pressures Survey			*ns*			*ns*
Distress at Community Leverage						
Distress at IOC (1=SA/A)			*ns*	0.355	0.150-0.839	*0.0184*
Distress at crimnal justice (1=SA/A)			*ns*			*ns*
Distress at rep payee (1=SA/A)			*ns*			*ns*
Distress at housing (1=SA/A)			*ns*			*ns*
Any leverage distressing			*ns*			*ns*

Table 4

Analyses for PAD Completion (continued)

	BIVARIATE MODEL			DOMAIN MODEL		
Variable	Odds Ratio	95% CI	*p value*	Odds Ratio	95% CI	*p value*
PAD and MH Treatment Barriers						
PAD Barriers, sum			*ns*			*ns*
Items:						
Don't understand enough about PAD			*ns*			*ns*
Takes a lot of time and trouble			*ns*			*ns*
Hard to get help			*ns*			*ns*
No one will pay attention to my wishes			*ns*			*ns*
A PAD won't make a difference			*ns*			*ns*
Don't know what to say in PAD			*ns*			*ns*
Don't have anyone to trust to make decisions for me			*ns*			*ns*
Don't have a MD to trust	0.534	0.291-0.979	*0.0426*			*ns*
Don't like to sign legal documents			*ns*			*ns*
MH TX Barriers						
Number of Barriers to MH treatment, sum			*ns*			*ns*
Reports any barriers to MH tx			*ns*			*ns*
Consumer may delay treatment because:			*ns*			*ns*
Problem may get better by itself			*ns*			*ns*
Concern about cost			*ns*			*ns*
Unsure where to go			*ns*			*ns*
Treatment probably won't do any good			*ns*			*ns*
Transportation or distance			*ns*			*ns*
Concern about what others may think			*ns*			*ns*
Want to solve problem on your own			*ns*			*ns*
Might get you in trouble with the law			*ns*			*ns*
Might get you in trouble with family or friends			*ns*	3.669	1.002-13.428	*0.0496*
Might be forced to take unwanted medicine or treatment			*ns*			*ns*
Might be placed on IOC			*ns*			*ns*
Might be involuntarily hospitalized			*ns*			*ns*
Afraid may be put in seclusion			*ns*			*ns*
Afraid may be put in restraints			*ns*			*ns*
Afraid may be forced to take medications if hospitalized			*ns*			*ns*
Afraid may be given an unwanted injection			*ns*			*ns*

Table 4

Analyses for PAD Completion (continued)

	BIVARIATE MODEL			DOMAIN MODEL		
Variable	Odds Ratio	95% CI	*p value*	Odds Ratio	95% CI	*p value*
Benefits of PADs and Treatment						
PAD Attitude questionnaire, MEAN	0.392	0.206-0.746	*0.0043*	0.346	0.173-0.694	*0.0028*
ITAQ (dichotomized at median 20)			*ns*			*ns*
DAI17 (dichotomized at median 14)			*ns*	0.516	0.292-0.913	*0.0231*
Pressure Scale			*ns*			*ns*
Consumer sees coercion beneficial to keep appointments (SD/D)			*ns*			*ns*
Consumer sees coercion beneficial to take medications (SD/D)			*ns*			*ns*
Treatment Motivation						
TMQ total	1.017	1.001-1.034	*0.0354*			*ns*
TMQ external factor, sum			*ns*			*ns*
TMQ intrinsic factor, sum	1.036	0.999-1.075	*0.0494*			*ns*
TMQ lack confidence in treatment factor, sum			*ns*			*ns*
TMQ introject factor, sum			*ns*			*ns*
TMQ relatedness factor, sum	1.050	1.021-1.081	*0.0005*	1.053	1.022-1.084	*0.0007*
Treatment Satisfaction Scale			*ns*			*ns*
Relational Supports: WAI						
Consumer WAI total score	1.043	1.002-1.086	*0.0417*			*ns*
Clinician WAI total score			*ns*			*ns*
Both clinician and consumer rate WAI high			*ns*			*ns*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Both rate WAI low			*ns*			*ns*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Clinician high consumer low WAI			*ns*			*ns*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Clinician low consumer high WAI			*ns*			*ns*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Consumer and clinician WAI within 4 points			*ns*	2.236	1.068-4.678	*0.0327*
interaction with clinician knows consumer very well/well			*ns*	2.364	1.167-4.787	*0.0169*

Table 4

Analyses for PAD Completion (continued)

	BIVARIATE MODEL			DOMAIN MODEL		
Variable	Odds Ratio	95% CI	*p value*	Odds Ratio	95% CI	*p value*
Concordance, PAD Attitude						
Clinician and consumer have PAD attitude mean score above median			*ns*			*ns*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Only clinician has PAD attitude mean score above median			*ns*			*ns*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Only consumer has PAD attitude mean score above median	0.333	0.181-0.612	*0.0004*	0.343	0.159-0.740	*0.0063*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Clinician and consumer have PAD attitude mean score below median			*ns*	0.362	0.167-0.784	*0.0100*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Concordance with individual PAD Attitude questions						
A PAD will help people with MI stay well (consumer response)			*ns*			*ns*
Both SA/A			*ns*			*ns*
Neither SA/A			*ns*			*ns*
Clinician only SA/A	0.173	0.044-0.679	*0.0118*	0.155	0.026-0.903	*0.0381*
Consumer only SA/A			*ns*			*ns*
People with MI should, when well, write down treatment preferences (consumer response)			*ns*			*ns*
Both SA/A			*ns*			*ns*
Neither SA/A			*ns*			*ns*
Clinician only SA/A	0.156	0.041-0.587	*0.0067*			*ns*
Consumer only SA/A	3.491	1.627-7.489	*0.0013*			*ns*
People with MI should choose someone they trust and given them right to make decisions (consumer response)			*ns*			*ns*
Both SA/A			*ns*			*ns*
Neither SA/A			*ns*			*ns*
Clinician only SA/A			*ns*			*ns*
Consumer only SA/A			*ns*			*ns*

Table 4

Analyses for PAD Completion (continued)

	BIVARIATE MODEL			DOMAIN MODEL		
Variable	Odds Ratio	95% CI	*p value*	Odds Ratio	95% CI	*p value*
Concordance with individual PAD Attitude questions (continued)						
Providers should pay a legal penalty if they fail to follow a PAD (consumer response)			*ns*			*ns*
Both SA/A			*ns*			*ns*
Neither SA/A			*ns*			*ns*
Clinician only SA/A	0.233	0.067-0.807	*0.0216*	0.256	0.070-0.934	*0.0391*
Consumer only SA/A			*ns*			
People should have a PAD because otherwise they might be put in hospital or get medications they don't want (consumer			*ns*			*ns*
Both SA/A	0.488	0.258-0.921	*0.0269*			*ns*
Neither SA/A			*ns*			*ns*
Clinician only SA/A	0.296	0.100-0.875	*0.0278*			*ns*
Consumer only SA/A	2.175	1.139-4.153	*0.0186*			*ns*
People should have a PAD because otherwise they might go without treatment they need (consumer response)			*ns*			*ns*
Both SA/A	0.414	0.211-0.810	*0.0101*	0.413	0.180-0.951	*0.0377*
Neither SA/A			*ns*			
Clinician only SA/A			*ns*			
Consumer only SA/A	2.504	1.120-5.600	*0.0254*			
Clinician						*ns*
Months worked with consumer			*ns*			*ns*
Knowledge of consumer (very, extremely well)	1.981	1.069-3.669	*0.0298*	2.064	1.102-3.865	*0.0236*
Other Relational						
Have any close friends	2.336	1.277-4.274	*0.0059*	2.304	1.248-4.254	*0.0076*
Someone regularly helps you with MH			*ns*			*ns*
Can you count on at least someone (most or some of the time)			*ns*			*ns*
Duke Social Support scale			*ns*			*ns*
Any victimization in past 6 months	0.543	0.301-0.980	*0.0427*	0.449	0.202-0.999	*0.0497*

Table 5

PAD Completion Final Model (N=239)

		FINAL MODEL	
Variable	Odds Ratio	95% CI	*p value*
Age dichotomized at median	3.399	01.468-7.868	*0.0043*
DAI dichotomized at median	0.273	0.114-0.654	*0.0036*
DCATPAD Pad Reasoning score	1.422	1.138-1.776	*0.0019*
Treatment Motivation Questionnaire relatedness factor	1.072	1.023-1.124	*0.0036*
Only Clinician strongly agrees/agrees that providers should pay a legal penalty if they fail to follow a PAD	0.137	0.028-0.666	*0.0138*
Do you have any close friends (1=yes)	3.969	1.658-9.499	*0.002*
Consumer has had any victimization in past 6 months	0.360	0.145-0.894	*0.0276*

Pseudo R-Square=0.2685
Somer's D=0.669

Liklihood ratio Chi-Square=52.5186, $p<.0001$

4.4 Research Question 3: Clinician Support for Coercion and Valuing PADs as a Proscriptive Tool.

The third research question in this dissertation examined whether clinician support for coercion in mental health treatment is a significant variable in a predictive model of the individual's valuing of PADs as a proscriptive tool. Specific hypotheses were:

Hypothesis 3a. Individuals are more likely to value PADs as a proscriptive tool if clinician support for coercion in mental health treatment is high.

Hypothesis 3b. The impact of clinician support for coercion in mental health treatment on the individual's likelihood of valuing PADs as a proscriptive tool will be moderated by how well the clinician knows the individual; clinician knowledge of the individual will be based on self-report.

Clinician support for coercion in mental health treatment is a level-2 variable, with multiple consumers nested within one clinician. Therefore, multilevel logistic regression analysis was used to test whether clinician support for coercion in mental health treatment is a significant predictor variable for valuing PADs as a proscriptive tool. Results using only the empty model, where the dependent variable is expressed as the sum of the general mean, a random effect at the clinician level, and a random effect at the consumer level, are shown in Table 6.

Based on this level two variance, the Intra Class Correlation (ICC) is calculated by $\rho_I = \tau_0^2 / \tau_0^2 + 3.29 = 0.03707/0.03707 + 3.29 = \underline{0.0111}$ (Snijders & Bosker, 1999). Thus only 1 percent of the variation in the dependent variable valuing PADs as a proscriptive tool is explained by clinician level variables. Though small, and much less than the ICC of 0.15 suggested as a cutoff by the literature (Bryk & Raudenbush, 1992), a second multi-level analysis was completed to see specifically if clinician support for coercion in mental health treatment was a significant level two predictor and was found to be non-significant. The hypothesis that clinician support for coercion in mental health treatment is a significant predictor of valuing PADs as a proscriptive tool was not supported and therefore analysis of clinician knowledge of consumer as a moderating variable was not examined.

Table 6

Empty Model for Valuing PADs as a Proscriptive Tool

Fixed Effect	Coefficient	S.E.
γ_{00}=Intercept	-0.019408	0.115046

Random Effect	Variance Component	S.D.
τ_0^2=var(U_{0j})	0.03707	0.19253

4.5 Research Questions 4.1 and 4.2: Clinician/Individual Concordance and Valuing PADs as a Proscriptive Tool

The final set of research questions in this dissertation explored whether clinician/individual concordance in the working alliance or in views of coercion in mental health treatment are significant variables in a predictive model of the individual's valuing of PADs as a proscriptive tool. Specific hypotheses were:

Hypothesis 4.1. Individuals are less likely to value PADs as a proscriptive tool if there is concordance in the working alliance between clinician and individual and both rate the working alliance as positive.

Hypothesis 4.2. Individuals' valuing of PADs as a proscriptive tool are significantly associated with clinician/individual concordance in views on coercion in mental health treatment, and with whether both have high or low endorsement of coercion in treatment.

A predictive model of valuing PADs as a proscriptive tool was developed using the conceptual model outlined previously, testing independent variables for risk of coercion, seriousness of coercion, benefits and barriers to proscribing certain treatments, and relational context, including concordance between clinician and consumer on working alliance and views on coercion. Bivariate logistic regression analyses were completed, followed by multivariate logistic regression analyses with variables grouped by conceptual domains (completed for purposes of variable reduction.) Variables found to be significant at the $p<0.05$ level were included in a final multivariate logistic regression model. (See Appendix C for a complete listing of all variables and domains tested.)

In bivariate analyses, the following variables were significantly ($p<0.05$) associated with an increased likelihood of valuing PADs as proscriptive tools:

1) Race, white
2) Higher PAD Understanding score of DCATPAD
3) Higher Hospital Understanding score of DCATPAD
4) Higher PAD Reasoning score of DCATPAD
5) Consumer was ever involuntarily hospitalized
6) Consumer experienced any involuntary intervention (e.g. seclusion, forced medication) while hospitalized
7) Consumer reports delaying treatment because might be forced to take unwanted medicine or treatment
8) Higher Pressure Scale score
9) Higher TMQ, lack of confidence in treatment subscale score

10) Higher Treatment Satisfaction score (where higher score represents increased ***dis***satisfaction)
11) Clinician but not consumer agrees that people with mental illness should talk with providers about what to write in a PAD
12) Consumer reports not having anyone to trust to make a decision for them

In bivariate analyses the following variables were significantly ($p<0.05$) associated with a decreased likelihood of valuing PADs as proscriptive tools:

1) Consumer reports doesn't understand enough about PADs
2) Higher consumer WAI score
3) Higher clinician WAI score
4) Neither clinician nor consumer agree that people with mental illness should have a PAD because otherwise they might be put in the hospital or get medications they don't want
5) Consumer reports has someone to count on at least some of the time
6) Consumer agrees that people with mental illness should talk with a provider about what to write in a PAD
7) Consumer agrees that people with mental illness should choose someone they trust and give them the right to make decisions

In analysis by domains, the additional variable "consumer reports delaying treatment because of fear of being put in seclusion" was significantly ($p<0.05$) associated with lower likelihood of valuing PADs as a proscriptive tool, and the variable "both clinician and consumer rate WAI low" was associated with a higher likelihood of valuing PADs as a proscriptive tool.

Table 7 summarizes the significant associations seen in bivariate analyses and domain analyses [Note: if all variables for a domain were not significant at bivariate or domain level they were not included in this table.] The final model is shown in Table 8 and was found to explain nearly 22 percent (Pseudo $R^2 = 0.217$) of the variation in the dependent variable ($p<0.0001$).

In this model, being above the sample median in valuing PADs as a proscriptive tool was significantly more likely if the consumer was white (OR=2.008), had ever experienced an involuntary hospitalization (OR=1.963), reported more dissatisfaction with treatment (OR=1.059), and if the consumer reported they could not make a PAD because they had no one to trust to make decisions for them (OR=2.677). In addition, there was a trend ($p<.10$) towards being more likely to value PADs as a proscriptive tool if consumers stated they had delayed treatment for fear of being forced to take medication or receive treatment they did not want (OR=1.951). Being above the median in valuing PADs as a proscriptive tool was significantly less likely if the consumer reported not knowing enough about PADs to make one (OR=0.405), reported delaying treatment for fear of being placed in seclusion (OR=0.388), agreed that people with a serious mental illness should talk with their provider about what to write down in a PAD (OR=0.283), and if neither the consumer nor clinician agreed that people should have a PAD because otherwise they might be put in the hospital or get medication they don't want (OR=0.347). Concordance in working alliance or views of coercion were not significantly associated with being above the sample median in valuing PADs as a proscriptive tool.

Table 7

Analyses for Valuing PADs as a Proscriptive Tool (N=469)

	BIVARIATE MODEL			DOMAIN MODEL		
	Odds Ratio	95% CI	*p value*	Odds Ratio	95% CI	*p value*
Demographics						
Age (dichotomized at median 42)			*ns*			*ns*
Gender (male=1)			*ns*			*ns*
Race (white=1)	1.732	1.187-2.527	*0.0044*	1.669	1.141-2.440	*0.0082*
GAF			*ns*			*ns*
BPRS			*ns*			*ns*
1 or more YES in CAGE for alcohol			*ns*			*ns*
1 or more YES in CAGE for drugs			*ns*			*ns*
PAD Understanding						
PAD Understanding	1.054	1.028-1.081	*<0.0001*	1.041	1.013-1.070	*0.0036*
Hospital Understanding	1.076	1.034-1.120	*0.0003*			*ns*
PAD Reasoning	1.135	1.031-1.250	*0.01*			*ns*
Hospital Reasoning			*ns*			*ns*
Consumer reports doesn't understand enough about PAD	0.34	0.228-0.507	*<0.0001*	0.389	0.258-0.585	*<0.0001*
Risk: Inpatient Coercion Lifetime						
Ever involuntarily hospitalized	1.755	1.189-2.589	*0.0046*	1.755	1.189-2.589	*0.0046*
Lifetime types of inpatient coercion			*ns*			*ns*
Seclusion			*ns*			*ns*
Restraints			*ns*			*ns*
Forced medications			*ns*			*ns*
Handcuffed			*ns*			*ns*
Any involuntary intervention while in hospital	1.492	1.006-2.213	*0.0464*			*ns*
Treatment motivation and satisfaction						
TMQ total			*ns*			*ns*
TMQ external factor, sum			*ns*			*ns*
TMQ intrinsic factor, Sum			*ns*			*ns*
TMQ lack confidence in treatment factor, sum	1.035	1.009-1.061	*0.0081*			*ns*
TMQ introject factor, sum			*ns*			*ns*
TMQ relatedness factor, sum			*ns*			*ns*
Treatment Satisfaction	1.063	1.036-1.090	*<0.0001*	1.059	1.032-1.088	*<0.0001*

Table 7

Analyses for Valuing PADs as a Proscriptive Tool (continued)

	BIVARIATE MODEL			DOMAIN MODEL		
	Odds Ratio	95% CI	*p value*	Odds Ratio	95% CI	*p value*
Benefits/barriers to MH treatment						
Number of fear of coercion barriers to MH treatment , sum			*ns*			*ns*
Consumer may delay treatment because:						
Problem may get better by itself			*ns*			*ns*
Concern about cost			*ns*			*ns*
Unsure where to go			*ns*			*ns*
Treatment probably won't do any good			*ns*			*ns*
Transportation or distance			*ns*			*ns*
Concern about what others may think			*ns*			*ns*
Want to solve problem on your own			*ns*			*ns*
Might get you in trouble with the law			*ns*			*ns*
Might get you in trouble with family or friends			*ns*			*ns*
Might be forced to take unwanted medicine or treatment	1.692	1.086-2.636	*0.0201*	2.333	1.380-3.946	*0.0016*
Might be placed on IOC			*ns*			*ns*
Might be involuntarily hospitalized			*ns*			*ns*
Afraid may be put in seclusion			*ns*	0.601	0.374-0.966	*0.0355*
Afraid may be put in restraints			*ns*			*ns*
Afraid may be forced to take medications if hospitalized			*ns*			*ns*
Afraid may be given an unwanted injection			*ns*			*ns*
ITAQ			*ns*			*ns*
DAI17 (dichotomized at median 14)			*ns*			*ns*
Pressure Scale	1.064	1.025-1.104	*0.0009*	1.066	1.027-1.108	*0.0009*
Relational Supports: WAI						
Consumer WAI total score	0.954	0.926-0.963	*0.002*	0.957	0.924-0.992	*0.0172*
Clinician WAI total score	0.963	0.931-0.995	*0.0299*			*ns*
Both consumer and clinician rate WAI high			*ns*			*ns*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Both rate WAI low			*ns*	1.860	1.181-2.930	*0.0074*
interaction with clinician knows consumer very well/well			*ns*			*ns*

Table 7

Analyses for Valuing PADs as a Proscriptive Tool (continued)

	BIVARIATE MODEL			DOMAIN MODEL		
	Odds Ratio	95% CI	*p value*	Odds Ratio	95% CI	*p value*
Relational Supports: WAI (continued)						
Clinician high consumer low WAI			*ns*			*ns*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Clinician low consumer high WAI			*ns*			*ns*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Consumer and clinician WAI within 4 points			*ns*			*ns*
interaction with clinician knows consumer very well/well			*ns*			*ns*
Concordance some PAD Attitude questions						
People with MI should choose someone they trust and give them right to make decisions						
Both SA/A			*ns*			*ns*
Neither SA/A			*ns*			*ns*
Clinician only SA/A			*ns*			*ns*
Consumer only SA/A			*ns*			*ns*
People with MI should talk with provider about what to write down						
Both SA/A			*ns*			*ns*
Neither SA/A			*ns*			*ns*
Clinician only SA/A	2.362	1.227-4.546	*0.0101*	2.465	1.212-5.015	*0.0128*
Consumer only SA/A			*ns*			*ns*
People should have a PAD because otherwise they might be put in hospital or get medications they don't want						
Both SA/A			*ns*			*ns*
Neither SA/A	0.49	0.247-0.973	*0.0415*	0.359	0.168-0.768	*0.0083*
Clinician only SA/A			*ns*			*ns*
Consumer only SA/A			*ns*			*ns*

Table 7

Analyses for Valuing PADs as a Proscriptive Tool (continued)

	BIVARIATE MODEL			DOMAIN MODEL		
	Odds Ratio	95% CI	*p value*	Odds Ratio	95% CI	*p value*
Other Relational						
Have any close friends			*ns*			*n*
Someone regularly helps you with MH			*ns*			*n*
Can you count on at least someone (most or some of the time)	0.479	0.281-0.817	*0.0069*			*ns*
Duke Social Support scale			*ns*			*ns*
Any victimization in past 6 months			*ns*			*ns*
Trust reasons for not making PAD						
Don't have anyone to trust to make decisions for me	2.049	1.311-3.203	*0.0016*	1.890	1.115-3.092	*0.0113*
Don't have a MD to trust			*ns*			*ns*
People with MI should talk with provider about what to write down (consumer response)	0.509	0.299-0.865	*0.0128*	0.421	0.235-0.753	*0.0036*
People with MI should choose someone they trust and given them right to make decisions (consumer response)	0.583	0.353-0.962	*0.0347*			*ns*

Table 8

Final Model for Valuing PADs as a Proscriptive Tool (N=469)

	Odds Ratio	95% CI	*p value*
Race (white=1)	2.008	1.119-3.606	*0.0195*
Consumer reports doesn't understand enough about PAD	0.405	0.224-0.733	*0.0029*
Ever involuntarily hospitalized	1.963	1.065-3.616	*0.0306*
Consumer may delay treatment because might be forced to take unwanted medicine or treatment	1.951	0.960-3.965	*0.0646*
Consumer may delay treatment because might be put in seclusion	0.388	0.198-0.759	*0.0057*
Treatment Satisfaction Scale	1.059	1.019-1.101	*0.0036*
Neither clinician nor consumer agree that people should have a PAD because otherwise they might be put in hospital or get medications they don't want	0.347	0.128-0.941	*0.0376*
Consumer reports can't make a PAD because doesn't have anyone to trust to make decisions	2.677	1.373-5.216	*0.0038*
People with MI should talk with provider about what to write down (consumer response)	0.283	0.118-0.678	*0.0046*

Pseudo R square=0.2168
Somer's D=0.533

Likelihood ratio Chi Square=64.7722, $p<0.0001$

Chapter 5 Discussion

Psychiatric Advance Directives (PADs) hold promise as a way to help consumers, when well, express their wishes for care during times of crisis and thus avoid unwanted and coercive intervention. For PADs to be maximally useful, both proscriptive and prescriptive wishes may need to be stated by the consumer, i.e. what treatment *does* the consumer want and what treatment is *not* wanted. These decisions regarding PAD creation and content may be influenced by a number of factors, including the attitudes of consumers' clinicians and the relationship between consumers and clinicians. This research therefore examined several possible associations: 1) the association between clinician attitudes towards PADs and the decisions individuals with SMI make regarding PAD creation; 2) the association between clinician attitudes towards coercive intervention in mental health care and how much value consumers place on PADs as proscriptive tools; 3) the association between characteristics of the relationship between the clinician and individual with SMI and individuals' decisions regarding PAD creation; and 4) the association between characteristics of the relationship between the clinician and individual with SMI and individuals' valuing PAD more for proscriptive purposes.

The conceptual framework used in this study was a modification of the Health Beliefs Model, positing that individuals with SMI engage in health behaviors based on: a) their perceptions of seriousness of the condition the behavior seeks to address ; b) their perception of the risk or threat of the condition; c) their perceived benefits of and barriers to the behavior. Thus it is hypothesized that consumers will choose to complete a PAD or value PADs for proscriptive purposes based on: 1) how serious or harmful they perceive coerced treatment to be; 2) how much at risk of coerced treatment they perceive themselves to be; and 3) how much benefit they see in completing a PAD and/or getting mental health care, versus how many barriers they see to completing PADs and/or getting mental health care. To augment this model, the study added an additional construct, the relational context. Grounded in the concept of relational autonomy, this construct was added to the Health Beliefs model by positing that consumers engage in health behaviors when they have relational support for their actions. Thus it is proposed in this conceptual framework that an important element of consumers' decisions regarding PADs is the relationships supporting these decisions; one of the most important of these relationships was hypothesized to be the relationship with their clinician.

5.1 Support for Hypotheses

The hypotheses for this study were that consumers are more likely to complete a PAD if clinician support for PADs is high, and are more likely to complete a PAD if there is a positive and concordant view of the working alliance between clinician and consumer. Consumer are also more likely to complete a PAD if there is concordance in PAD attitudes and in views on coercion in mental health care between the clinician and the individual. In addition, consumers are more likely to value PADs for proscriptive purposes if clinician support for coercion in mental health treatment is high. Consumer valuing of PADs for proscriptive purposes is also more likely with concordance in the working alliance between clinician and consumer and with concordance in views on coercion in mental health treatment.

The results of this study support these hypotheses only in part (see Tables 5 and 8). Neither clinician views on PADs or coercive treatment, nor the working alliance between clinician and consumer, were predictive of PAD completion or valuing PAD for proscriptive purposes. One variable regarding clinician and consumer concordance in views was predictive of PAD completion. If consumer and clinician were discordant in their views that providers should pay a legal penalty if they fail to follow a PAD, with only the clinician endorsing that statement, then consumers were significantly less likely to complete a PAD. Consumer and clinician concordance, where neither agreed that people should make a PAD because otherwise they might be put in the hospital or get medication they don't want, was predictive of consumers being significantly less likely to value PADs for proscriptive purposes.

Interestingly, while hypotheses regarding clinician impact on consumer decisions regarding PADs were not strongly supported, the inclusion of a relational context component in the study model was supported overall. Valuing relationship with others as motivation for treatment and having a close friend were both significantly and positively associated with PAD completion. Consumers who reported having no one to trust to help them make a PAD were more likely to value PADs for proscriptive purposes, and those who trusted clinicians enough to agree that people should consult with their provider regarding PAD content were less likely to value PADs for proscriptive purposes.

Other components of the model, derived from the Health Beliefs model, were inconsistently supported. Consumer perception of seriousness of coercive intervention was not shown to be significant for either dependent variable. This finding is somewhat different than would be suggested by some of the literature, wherein the consumer's subjective experience of coercion (i.e. how serious the coercion was from the consumer's point of view) was associated with outcomes such as quality of life and treatment engagement (Kaltiala-Heino et al., 1997; Swanson, Elbogen et al., 2003). Risk of coercive intervention, based in the experience of a prior involuntary hospitalization, was associated with increased likelihood of valuing PADs for proscriptive purposes. The benefits (or lack thereof) and barriers to getting treatment were significantly associated with the outcomes of interest. A higher score on the Drug Attitude Inventory, indicating more endorsement of the benefits of medication and therefore possibly less need to avoid medication, was negatively associated with PAD completion. Lower overall satisfaction with mental health treatment increased the likelihood that one would value PADs for proscriptive purposes, as did reporting that one might delay treatment because of concerns regarding forced medication or treatment. Reporting that one might delay treatment because of concerns regarding seclusion, decreased the likelihood that one valued PADs for proscriptive purposes. Thus the findings support the hypotheses in part, and indicate that relationships with others beyond the clinician play an important role in PAD creation by consumers.

5.2 Final Models

5.21 PAD Completion

The hypothesis that PAD completion was associated with clinician characteristics was not supported by the model, nor was the hypothesis that PAD completion was associated with the working alliance between clinician and consumer. This result could have a number of explanations. First, it could be that clinicians simply are not that influential in consumers' decisions regarding PAD creation. Alternately, clinician turnover in public systems is often high and it may be that this disrupts the relationships between clinicians and consumers that otherwise could impact decisions such as PAD creation. Though the number of months a clinician worked with the consumer was not a significant variable in the final model (suggesting that turnover resulting in a brief length of time working with the current clinician did not impact PAD completion) we have no data on the total number of clinicians a consumer had over his/her mental health "career." It may be that cumulative clinician loss decreases consumer willingness or ability to be influenced by clinician views. Additional research examining the impact of clinician turnover is needed.

The final predictive model, as shown in Table 5, did reveal some interesting findings. Older consumers (those above the median age of 42) were over three times more likely to complete a PAD; this may be due to greater maturity and understanding of how the mental health system works (or does not work), which could make having a PAD more desirable. It also could be a result of more cumulative coercive experiences, both formal (i.e. leverages and commitment), and informal (e.g. pressure to be medication adherent from family and clinicians), so that a consumer would feel a greater need for the protection of a PAD. Finally, younger consumers are sometimes more difficult to engage in treatment. Similarly, younger consumers might be more difficult to engage in the PAD preparation process than older individuals.

Consumers with higher scores on the Drug Attitude Inventory, signifying a more positive view of psychotropic medication, were significantly less likely to complete a PAD. One could suppose that consumers who felt no need to avoid particular medications during a crisis and who felt positively about this form of treatment would have less incentive to complete a PAD. Consumers with positive views of medications might believe that mental health providers had accurately met their needs in the past, and assume that it would be similar during times of crises, therefore no specific crisis instructions would be necessary.

The ability to understand and think clearly about PADs, as indicated by the DCATPAD PAD reasoning score, was associated with a greater likelihood of PAD completion. Seeing this result, one could posit that consumers who can clearly see the benefits of a PAD would be more likely to complete such a document. Similarly, consumers who could reason through and engage in the PAD preparation process would be more likely to be able to complete a PAD.

Several variables regarding relational context were associated with PAD completion, supporting the overall proposed study model wherein relational context was added as a construct to the Health Beliefs Model. Only one of these involved an aspect of the consumer/clinician relationship, specifically lack of consumer/clinician concordance in opinion. If the clinician but not the consumer supported the statement that providers who fail to follow a PAD should pay a legal penalty, then the consumer was significantly less likely to complete a PAD. This result could indicate that consumers whose clinicians are even more rights-focused than they are do not feel the need for the protection of a PAD. Alternately, it could indicate that consumers who do not believe that the legal system will support their rights and are more jaded than their clinicians are less likely to believe that PADs will be attended to, and are thus not worth completing.

Several variables not involving clinicians but rather other relationships were found to be significantly associated with PAD completion. The Relatedness subscale of the Treatment Motivation Questionnaire, which measures consumers' motivation to participate in treatment because of a desire to relate to others (e.g. "I want to share some of my concerns and feelings with others.", "I look forward to relating with others who have similar problems.") was positively associated with PAD completion. In addition, consumers who reported having at least one close friend were nearly four times more likely to complete a PAD. These results suggest that consumers who value and are able to engage in connection are more likely to complete a PAD. One might argue that this also could mean that consumers whose level of functioning is high enough to engage in relationship also have a level of functioning high enough to create a PAD. However the Global Assessment of Functioning Scale was not a significant variable in the model, suggesting that these results are not simply the result of overall functioning. Rather, it may be that PADs are seen as a form of connection and relating to others among consumers who value relationships, and these individuals are thus more likely to complete a PAD.

Finally, consumers who reported any victimization in the prior six months were significantly less likely to complete a PAD. This could indicate that individuals who do not have supportive and protective relationships and are at higher risk for victimization are less likely to complete PADs. Victimization could also be a proxy for an overall chaotic and stressful life; individuals in such circumstances may have been unable to keep track of and attend the appointment for the PAD completion process. Alternately, this result may also indicate lowered self-efficacy or lowered trust among consumers who have been victimized; those who have been recent victims may believe there is no point in creating a PAD because they have no power to impact their life situation or because they do not trust anyone to listen to them and honor a PAD.

5.22 Valuing PADs More Highly for Proscriptive Purposes

As with the dependent variable PAD completion, the hypotheses that valuing PADs more highly for proscriptive purposes was associated with clinician characteristics and with the working alliance between clinician and consumer were not supported by the model. Possible explanations for this are the same as for the prior dependent variable, and could include that clinicians have less influence over consumers than anticipated or that clinician turnover may be responsible for this result.

The final predictive model for valuing PADs for proscriptive purposes is shown in Table 8. In this model, consumers were twice as likely to value PADs for proscriptive purposes if they were white. This is a somewhat interesting result given that in a study by Swanson and colleagues it was found that non-white consumers were more likely to wish to create a PAD overall (Swanson, Swartz, Ferron et al., 2006), and one might expect individuals with more experiences of oppression, such as racial minorities, to value the protection of a proscriptive PAD more highly. However, it may be that racial minorities experience disparity in access to treatment, and therefore using PADs as a prescriptive tool to ensure receiving treatment, rather than as a proscriptive tool, is a valued use of the document.

Consumers who report that they might have difficulty completing a PAD because they do not understand enough about PADs were significantly less likely to value PADs for proscriptive purposes. Without fully understanding what a PAD is and how it functions it may be that consumers cannot fully grasp its potential as a proscriptive tool. Without this, consumers are unable to value PADs for that function.

One variable related to consumers' conceptualization of the risk of coercive treatment was shown to be significant in the final model. Consumers who had ever experienced an involuntary hospitalization (and thus fully understood the risk of such coercive treatment) were nearly twice as likely to value PADs more highly for proscriptive purposes. Interestingly, no other prior coercive experience such as community leverage or arrest was shown to be significantly associated with this dependent variable. These results may indicate that involuntary hospitalization is a much more invasive and upsetting intervention than outpatient leverages. This is supported by the work of Swartz and colleagues (2003), who found that involuntary hospitalization, but not community leverages, resulted in fear of returning to treatment because of concerns about coercive intervention.

Several variables regarding the benefits of or barriers to mental health treatment were associated with valuing PADs more highly for proscriptive purposes. There was a trend towards significance for consumers who reported they might delay treatment because they might be forced to take unwanted medicine or treatment. These individuals were nearly twice as likely to value PADs more highly for proscriptive purposes. Though not statistically significant, this finding may be clinically significant and inform clinicians' discussions with consumers regarding PAD content.

Consumers who were less satisfied with their overall mental health treatment were statistically significantly more likely to value PADs for proscriptive purposes. It seems that consumers who are afraid of receiving unwanted treatment or who do not believe treatment they receive is helpful or of high quality would be concerned about and wish to control the treatment they might receive during a crisis, and thus value PADs more highly for proscriptive purposes.

Less understandable is the finding that consumers who reported they might delay treatment because they might be placed in seclusion were *less* likely to value PADs more highly for proscriptive purposes. It seems counterintuitive that consumers avoiding going for treatment because they feared seclusion would then not value PADs highly for proscriptive purposes, as a way to prevent seclusion in the future. It may be that individuals who are most concerned about experiencing seclusion do not believe the proscriptive function of PADs is a way to avoid seclusion, and thus do not value PADs as highly for their proscriptive purposes. Alternately, this may be a spurious finding, a result of the number of independent variables examined for this study (see Study Limitations for further discussion.)

Similar to the findings for PAD completion, several variables addressing relational context were found to be significant in this final model. When there was concordance between clinician and consumer, where neither agreed that people should have a PAD or they might be put in the hospital or get medicines they do not want, consumers had a significantly lower likelihood of valuing PADs for proscriptive purposes. It may be that the cumulative effect of a relationship where neither clinician nor consumer sees coerced hospitalization or medication as a reality or alternately, as a negative event, results in a lowered sense of need for proscriptive PAD. Additionally, if neither sees PADs as effective in preventing unwanted treatment, then consumers may not value the proscriptive function of PADs.

A second variable related to clinicians also was associated with lower likelihood of valuing PADs more highly for proscriptive purposes. Consumers who endorsed the statement that individuals with SMI should talk with their provider about what to write down in a PAD were significantly less likely to value PADs for proscriptive purposes. Implicit in this statement is the idea that consumers see providers as trustworthy people with whom they can talk about their needs and who will have useful ideas. Individuals with such views may not see a great need for protection from providers' decisions during crises via a proscriptive PAD and thus value them less highly.

A final significant variable regarding relational context did not address the clinician/consumer relationship, but rather relationships more broadly. Consumers who stated they might not be able to make a PAD because they have no one to trust to make decisions for them were over two and a half times more likely to value PADs for proscriptive purposes. One could imagine that without a supportive relational context consumers might be more reluctant to receive treatment and see PADs as more useful for avoiding treatment. In addition, with no one to trust, using PADs as a way to appoint a health care proxy via the Health Care Power of Attorney function of a PAD is impossible, increasing the weight of the value placed on proscriptive PAD functions by the consumer. Alternately, consumers who have difficulty trusting others might also have difficulty trusting treatment and providers and value the protection of a more proscriptive PAD.

5.3 Alternate Model

The conceptual model originally proposed in this study was only in part supported by the findings. Upon careful examination of these results, a somewhat different model is suggested, which I would like to propose as the subject of further research. In this study's modified health beliefs model, the constructs are: 1) the *seriousness* of the condition as perceived by the consumer; here the seriousness of, or how disturbed the consumer is by, coercive mental health intervention; 2) the *risk* of the condition; here the likelihood of coercive intervention, based in prior experience; 3) the *benefits of or barriers to* the behavior; here the benefits of or barriers to PADs and/or mental health treatment; and 4) the *relational context* in which treatment and PAD decisions occur. In neither original analysis was the seriousness construct supported, and risk was supported only for the second dependent variable. Benefits of or barriers to treatment emerged as a set of significant variables, and relational context variables, both with clinician and with others, was also significant. However, other variables that did not fit the model were found significant in the models, specifically age, race, DCATPAD score, and consumer report of lack of PAD understanding.

An alternate model (see Figure 4 below for a reiteration of the original model in contrast with the alternate model depicted in Figure 5), which would include all the variables found significant in this study's analyses, could consist of the following constructs:

1) Consumers' *experiences* with mental health treatment, broadly defined. This could include both involuntary treatment and experiences that are the result of demographic characteristics such as age (cumulative experiences with the mental health system over years) or race (experiences with discrimination, disparity, differential access.)
2) Consumers' *perceptions of the benefits or dangers* of mental health treatment. This could include perceptions of the utility of treatment, satisfaction with treatment, possible unwanted results of treatment.
3) Consumers' *understanding* of the intervention (i.e. PADs). This could include both objective and self-reported ability to understand the intervention.
4) Consumers' *relational context*, including relationships with clinicians, others in treatment, others outside of treatment.

Given that this study utilized secondary data, variables that could more specifically examine this model are not consistently available. Additional primary data collection is necessary to evaluate this model.

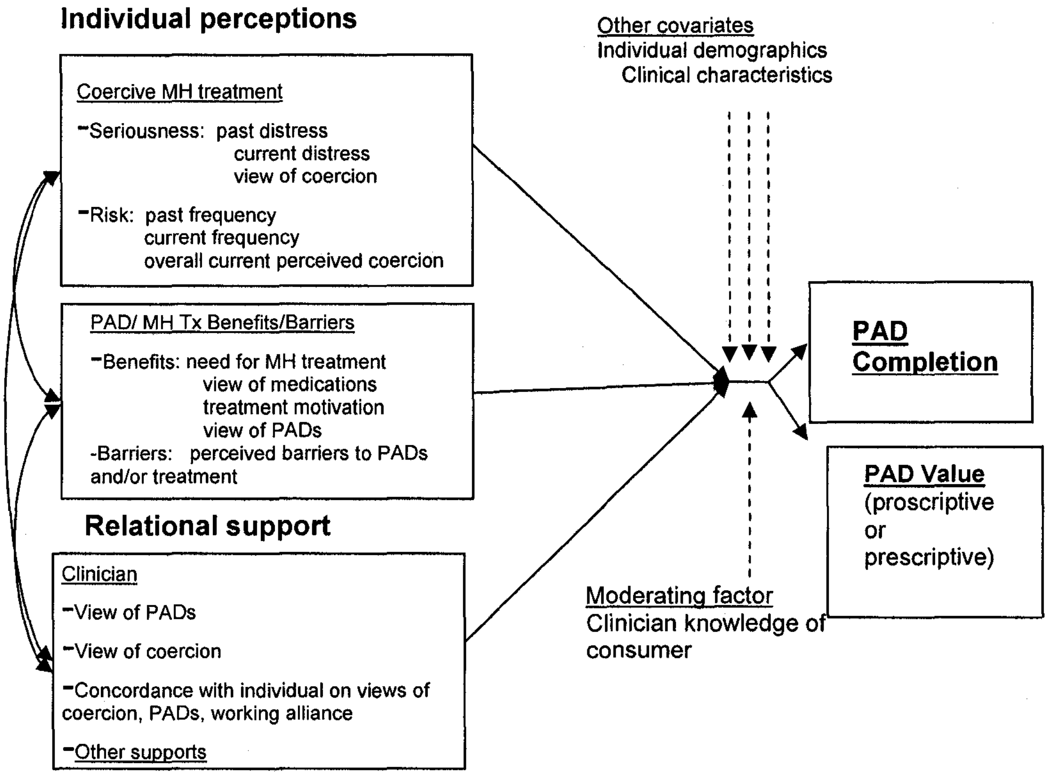

Figure 4 Original Model

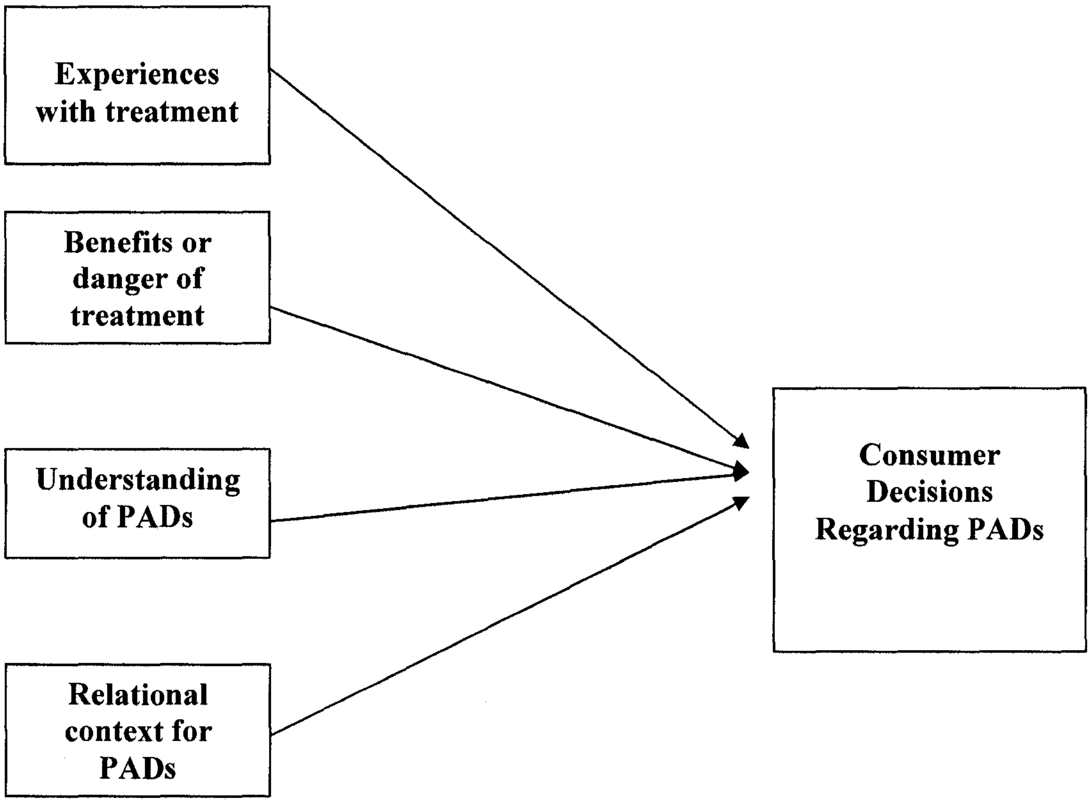

Figure 5 Alternate Model

5.4 Study Limitations

As with all studies, particularly secondary analyses of existing data sets, there were a number of limitations to this study. First were limitations resulting from the secondary nature of the analysis. Variables identified for this study were useful, but not ideal nor what I would have gathered had I engaged in data collection myself. The data set contained a number of study-developed questions with untested psychometric properties. Had I the opportunity to design and implement an ideal study the questions used would have been ones with tested validity and reliability with this population. Additionally, there are variables not contained in the data set that I would have included, had I designed the study specifically to answer my research questions An example of this is clinician turnover. Anecdotally I have heard of high turnover among the clinicians in the agencies participating in this study. However, the median number of months clinicians reported working with consumers was 12, and the number of months clinicians worked with consumers was not a significant variable. In addition, data were not collected on the number of clinicians a consumer had worked with over their mental health "careers." Therefore, clinician turnover may have had an effect on the results (e.g. multiple turnovers may make the consumer more reluctant to truly engage with the clinician) but cannot be measured because of the limitations of the data set. Due to these limitations in the existing data set, the alternate model proposed above cannot be adequately tested, and must await additional research with more tailored interview questions and data collection.

Additional study limitations resulted from the study design. Since the study was limited to subjects in two counties in North Carolina, results may not be generalizable to other populations, particularly in other jurisdictions with different mental health systems. In addition, since the study limited participants to individuals with capacity to give consent, results cannot be generalized to less functional individuals.

The study may not be generalizable for reasons other than convenience sampling as well. Participants in the F-PAD study arm made their decisions regarding PAD completion under circumstances somewhat dissimilar from those in regular clinical situations. They were provided with extensive information regarding PADs as well as support in completing, witnessing, and notarizing the document from an individual who is not their clinician. Predictors of PAD completion in these circumstances may not be the same as those in standard clinical settings where such levels of support may not be available and where clinicians may also serve as the consumers' PAD facilitators. The impact of clinician characteristics on consumer decisions regarding PADs may be greater if the clinician plays both a practitioner and PAD facilitator role. Additionally, this study examined participants' statements about the purposes for which they value PADs (proscriptive versus prescriptive) rather than the actual content of their PADs. It has not yet been determined that consumers' statement about how they wish to use a PAD and their actual PAD content are the same. This is an important avenue for future study. Given all of these limitations, study findings should be generalized with caution.

Since this was an exploratory study, a large number of independent variables were examined. This raises the issue of possible spurious findings because of the number of independent variables tested. Had this been a study utilizing more focused and targeted questions designed specifically to answer the research questions, rather than an exploratory secondary analysis of an existing data set, it would have been appropriate to control for possible spurious findings using a Bonferroni correction. This corrects the alpha level when n statistical comparisons are done simultaneously by taking each independent variable's alpha value and setting it to $0.05/n$. The disadvantage of this method is that while decreasing the chances of a Type 1 error, it increases the risk of a

Type 2 error. Since in an exploratory study one is attempting to identify significant variables but anticipates additional study to further confirm and understand the findings, I would argue that avoiding a Type 2 error is more important at this point than minimizing the risk of a Type 1 error. Thus for this study a Bonferroni correction is premature but should be done on subsequent, more targeted studies with fewer and more focused independent variables (Kutner, Nachtsheim, Neter, & Li, 2005).

The study is also limited because of a possible lack of adequate power to detect effects of interest. For the PAD completion dependent variable, the study was powered to detect a medium effect size (0.35-0.40)—thus any small effects would be missed. Power was adequate for the valuing PADs for proscriptive purposes dependent variables, even for a small effect size. However, when considering moderating variables higher power is needed, thus for both dependent variables the study may have been underpowered to detect moderating variables with small effects.

A final study limitation raises the philosophical and ethical question of whether the research processes have supported and been syntonic with the values and principles underlying PADs. PADs are ultimately about consumer voice, allowing the individual to speak for his/herself and express desires and preferences as much as possible. This study was grounded in individual self-report and interview, so data are based on individuals speaking for themselves rather than being spoken for by clinicians. However, the quantitative nature of the analyses preclude "hearing" the actual voices of the individuals. A much fuller research process would include qualitative interviews to allow both consumer and clinician participants to expand on and explain quantitative findings. An ongoing research agenda should include such mixed method approaches and is recommended in "Next Steps for Research" below.

5.5 Study Implications

5.51 For Practice

The results of this study have a number of implications for practice with consumers of mental health services. Findings suggest that clinicians can engage in several activities to increase the chances that consumers will complete a balanced and maximally useful PAD. First, clinicians can work to educate consumers regarding PADs, ensuring that they understand what these documents are and can logically apply PAD concepts to their own situation. Education for consumers' families or other supportive individuals may also be of importance, given the findings that the consumer's relational context is significantly associated with PAD decisions. In addition, consumers who feel positively about their mental health treatment, particularly their medications, may not see the utility of creating a PAD or of proscriptive PAD content. Clinicians can examine these assumptions with consumers, helping consumers understand the range of functions PADs can serve and how they may be helpful during times of crisis.

Similarly, engaging with the consumer in an assessment process of his/her prior experiences with coercive or pressured mental health treatment, and possible resultant concerns regarding future coercive care, may be a beneficial intervention by clinicians. Through a reflective and exploratory process the consumer can share past difficult experiences, which may help the consumer process these events. The clinician can gain greater understanding of the consumer, can offer support and validation for past difficult coercive experiences, and can provide information and support to address incorrect assumptions and possible cognitive distortions regarding the risk of future coercion. This process and understanding can be used to inform PAD creation and content.

Finally, it may be of benefit for clinicians to consider carefully the relational context when offering consumers the opportunity to create a PAD. Though the importance of human relationship is a fundamental principle in the Code of Ethics of the National Association of Social Work (NASW, 2000), the importance of relationships, particularly relationship beyond the therapeutic alliance, is sometimes forgotten. Clinicians should be sure to have an humble and expanded view of relational context, realizing that consumers' relationships and lives are only in small part about mental health treatment. For consumers who value relating with others, PADs may be appealing as a tool for connection and relationship. Clinicians may wish, for these individuals, to frame PADs as vehicles for communication and connection with others about treatment even during times when consumers themselves are unable to engage in connection because of illness. Clinicians may also, with consumer permission, wish to engage consumers' relevant others in the PAD creation process, so that friends and important others can provide support and encouragement to the consumer regarding PAD completion and utilization when needed. Clinicians should be aware not only of the support available in a relational context, but of its potential as a barrier to PAD creation as well. Lack of a trusting relationship may be associated with inability to complete a PAD or with a heavier emphasis on proscriptiveness in the PAD. A context barren of positive relationships or filled with chaos and lacking safety can be a serious barrier to many things, including PAD creation. Interventions to create and build on natural supportive relationships in the community, as is highlighted in the social work strengths model (Rapp, 1998), may increase the likelihood of consumers completing a useful and comprehensive PAD.

5.52 For Education

If social workers and other clinicians are to help consumers fully understand PADs and their uses, it is essential that they themselves have a comprehensive understanding of PADs and their functioning. Research has indicated that few social workers know a great deal about PADs; a survey of social workers in North Carolina found that less than 16 percent reported being very familiar with PADs (Scheyett et al., in press-b). PAD content is therefore needed in both university curricula as well as continuing education offerings. In addition, training in effective ways to educate consumers about PADs is needed; utilization of a psychoeducational model may be of benefit.

Prior experiences with mental health treatment and views of the benefits of treatment may play important roles in consumer decisions regarding PADs and other interventions. However, traditional clinician education in assessment does not typically include training on ways to engage in dialogue with consumers regarding their prior experiences with and views of treatment. Helping trainees learn to be comfortable having these important but difficult discussions is necessary if clinicians are to understand the experiential context from which consumers make decisions. Thus expanded assessment skills that include these content areas are important aspects of clinician education.

Education for social workers and other clinicians usually includes content on the importance of relationship, often in the form of content on the therapeutic alliance, on social support as a protective factor, and on use of natural supports as a strategy for resource acquisition. This study suggests that relationship should be discussed more broadly in the curriculum, seen as a context in which consumers make decisions about their treatment (and their lives). Learning to assess consumer relational context beyond the therapeutic alliance, to identify consumers who lack trusting and supportive relationships, and to help consumers build more positive relational contexts may be protective for consumers, help them obtain more needed resources, *and* help them make positive decisions regarding treatment—such as the creation of maximally useful PADs.

5.6 Next Steps in a Research Agenda

5.61 Quantitative Research

The results of this study raise a number of questions for subsequent research. Perhaps the two most pressing of these are: 1) confirmation that consumers' statement of how much they value the different potential functions of PADs (proscriptive, prescriptive, etc.) are consistent with what they would actually write in a PAD; and 2) testing of the proposed alternate conceptual model for understanding PAD decision-making.

In the current study, all consumers were asked to rate the importance of various functions of a PAD, irrespective of study arm assignment. Since what people say they value and what they support through actions can be quite different, this rating by consumers is informative, but not necessarily the same as the actual content they might write in a PAD. If what is wanted is an understanding of the variables associated with the creation of a more proscriptive PAD, then more than self-report is needed. A necessary next step is to examine the rating of PAD functions by consumers who subsequently completed PADs in the study, comparing actual PAD content with self-reported rating and determining the correlation between the two. If the two are highly correlated, then it may more safely be assumed that self-reported ranking of PAD purposes is indicative of the PAD content individuals would specify, and the model developed in this study could be seen as more truly predictive of PAD content.

Research to test the alternate conceptual model proposed in this paper will require additional studies. It could be of benefit to modify the current study design by having consumers' clinicians serve as PAD facilitators. This would serve two purposes. First, it would approximate more closely what may actually occur in "real world" settings where separate PAD facilitators do not exist. Second, if the relationship between clinician and consumer is influential regarding PAD decisions, the closer proximity of the clinician to PAD decision-making through the facilitation process may bring this dynamic to the surface for more ready observation.

In addition to modified study design, careful selection of independent variables specifically focused on the testing of the model are needed. Testing of this model, which contains the latent variables experience with treatment, understanding of PADs, views of benefits or dangers of treatment, and relational context, would be done most effectively with structural equation modeling (SEM) (Kline, 2005). This requires multiple observed variables per latent variable. Selection of these observed variables should be tailored specifically to the research question, with the use of standardized scales that have been shown valid and reliable with this population whenever possible. By careful selection of observed variables, use of a sufficiently large sample size (at least 200 subjects), and analysis using SEM, one should be able to test the proposed model for consumer decisions regarding PAD creation and valuing of PAD purposes.

One particularly interesting aspect of the alternate conceptual model is the importance of the relational context to PAD decision-making. More in-depth exploration of a number of questions in this domain are needed. Specifically, it may be of interest to understand why individuals with a close relationship are more likely to complete PADs. Are their friends directly providing support so that consumers can complete PADs? Is this result part of a larger underlying phenomenon wherein consumers who value connection both value completing PADs and having close relationships? In addition, research examining PAD benefits may wish to explore PADs as an intervention to help consumers communicate with and feel more connected to others beyond their clinicians, such as fellow consumers or family members.

5.62 Qualitative Research

One of the limitations of this study, as discussed above, is the lack of direct consumer voice. This research identifies variables statistically associated with PAD creation and valuing PADs for proscriptive purposes, but does not drill down to the consumers' meaning and reasoning behind these decisions. In a study of a tool to increase consumer choice and voice, this lack of direct consumer voice is somewhat self-contradictory. A necessary next step is qualitative research exploring the lived experience and personal meaning fueling consumer decisions regarding PADs.

Qualitative study could include discussion of consumers' conceptualization and understanding of PADs and the meanings they ascribe to PADs, followed by an exploration of the reasons consumers have for choosing to complete a PAD or not. For those who complete a PAD, an exploration of what they hope to gain from a PAD, as well as a finely-grained analysis of the PAD content, asking consumers the reasons behind each entry, would be informative. Finally, exploratory questions regarding the relationships that may have influenced or shaped consumers' decisions regarding PADs could occur, providing insight into the importance and dynamics of the relational context during PAD decision-making.

Though qualitative study of consumers and PADs has been done in the past (see, for example, the work of Amering, et al., 2005), little has been done to examine the relational context and consumer PAD decisions. This could be a fruitful area of research, expanding our understanding of the processes by which consumers decide to create PADs. In addition, to date there has been no mixed method study of consumer decisions regarding PAD creation and purposes. Triangulation of data from qualitative research such as described above with quantitative research such as that completed for this study could provide meaningful insight into consumers' reasoning and motivations regarding the creation of and valued purposes for their PADs.

5.7 Summary Conclusion

Psychiatric Advance Directives are potentially empowering tools, giving consumers voice and choice at a time when they are most vulnerable, helping to resolve or avoid crises, and promoting recovery. The results of this study suggest that for consumers to utilize fully these tools they may require more than a facilitator who helps them in PAD preparation. Consumers require careful and in-depth education in order to develop a full understanding of PADs. In addition, clinicians should work with consumers in a reflective process to develop understanding of the consumers' views of and prior experiences with mental health treatment and how these inform PAD content and their view of PAD utility. Finally, consumers need a supportive and safe relational context within which to make decisions regarding PADs. Though much additional research is needed to understand fully consumers' decisions regarding PAD creation and purpose, clinicians who can partner with consumers to educate them regarding PADs, reflect on their experiences, and build stronger relationships in and out of treatment may well maximize the chances that consumers will create useful and effective PADs.

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Appendix A

Summary of quantitative studies examining working alliance and consumer outcomes

Authors	Sample	Setting	Instrument	Results
Allen et al., 1985	Axis I and II disorders N=37	Long term inpatient until	Author-developed alliance rating scale	Better alliance associated with better functioning at discharge
Beauford et al., 1997	SMI N=328	Inpatient unit	Therapeutic alliance scale based on hospital chart notes	Poor alliance associated with displaying violent behavior during hospitalization
Calsyn et al., 2002	SMI, homeless or at risk N=165	Broker or ACTT case management	Subscale of the Client Expectancies scale	Improved alliance associated with increased consumer satisfaction
Chinman et al., 2000	SMI, homeless N=2,798	ACCESS program for homeless	Working Alliance Inventory	Higher alliance associated with fewer days homeless and higher life satisfaction
Clarkin et al., 1987	SMI and personality disorder N=96	Inpatient	Therapeutic alliance scale based on hospital chart notes	Better working alliance at admission associated with higher functioning at discharge
Coffey, 2003	SMI N=55	Intensive Case Management	Structural Analysis of Social Behavior instrument	Higher case manager alliance associated with treatment participation and satisfaction
Donnell et al., 2004	SMI N=305	Vocational Rehabilitation	Study-developed Working Alliance Survey	Working alliance was higher for those employed, and among those employed, for those with job satisfaction

Appendix A (continued)

Authors	Sample	Setting	Instrument	Results
Frank & Gunderson, 1990	Schizophrenia N=143	Inpatient, followed outpatient by same provider, either insight-oriented or reality adaptive supportive therapy	Psychotherapy Status Report scale	Association between working alliance and total length of time in treatment; medication compliance, improved symptomatology, increased functioning, increased social relationships and activities over 2 years; fewer number of hospitalizations
Gehrs & Goering, 1994	Schizophrenia or schizoaffective disorder, in treatment for 2-7 months N=22	Community-based rehabilitation program	Working Alliance Inventory	Provider and consumer working alliance score correlated with consumer goal attainment, with provider working alliance more strongly correlated with goal attainment scores than consumer's
Goering et al., 1997	Homeless, primarily schizophrenia N=55	Case management linked with housing program	Working Alliance Inventory	All consumers improved in level of functioning and symptomatology, but consumer with higher working alliance scores improved more quickly

Appendix A (continued)

Authors	Sample	Setting	Instrument	Results
Hansson & Berglund, 1992	SMI N=106	Inpatient	Study-developed questions	Better alliance associated with better outcome at hospital discharge
Klinkenberg et al., 1998	SMI, homeless or at risk N=105	ACTT program	Helping Alliance Measure scale	Working alliance associated with consumer satisfaction with treatment, Global Severity Index of symptoms, and level of hostility
Loneck et al.,2002	Mentally ill with co-morbid substance abuse in crisis N=39	Crisis intervention clinic attached to a psychiatric emergency room	Vanderbilt Psychotherapeutic Process scale and Working Alliance Inventory	Residual working alliance score beyond what would be expected for a given level of therapist warmth resulted in more successful connecting of consumer with treatment
McCabe et al., 1999	Schizophrenia N=90 first admission and N=176 long term in and outpatients	Inpatient and followed in outpatient clinic	Helping Alliance Scale	Working alliance associated with quality of life in long term but not first-admitted consumers

Appendix A (continued)

Authors	Sample	Setting	Instrument	Results
Neale & Rosenheck, 1995	Veterans with SMI N=143	Veterans Administration ACTT program	Working Alliance Inventory	Consumer perceived outcomes significantly accounted for by consumer alliance, and case manager perceived outcomes by case manager alliance. Case manager alliance significantly contributed to total variance in living skills, level of functioning, symptom severity
Priebe & Gruyters, 1993	SMI N=72	Community care system for long term treatment	Five study-developed questions	Lower alliance associated with increased hospitalization and partial hospitalization; alliance correlated with employment
Solomon et al., 1995	SMI and significant treatment history N=90	Consumer ACT team or professional ACT team	Working Alliance Inventory	Working alliance associated with quality of life, attitude towards medication compliance, satisfaction with treatment.
Weiss et al., 2002	SMI N=162	Community hospital outpatient center, schizophrenia disorders program	California Psychotherapy Alliance Scale	Working alliance significant predictor of adherence to treatment

Appendix B

Statement of the Interdisciplinary Committee for Ethics in Human Research at Memorial University (Interdisciplinary Committee for Ethics in Human Research, 2003)

4.3 Research not Requiring Ethics Review

The following kinds of studies do not require ethics review. However, if the investigator is in doubt, the relevant REB office should be contacted.

- Research about an individual(s) in the public arena using only publicly available or accessible records without contact with the individual(s).

- Research involving naturalistic observation in public venues.

- Research resulting in a case study of one patient with the expectation that written informed consent has been obtained from the relevant patient.

- Quality assurance studies, program evaluations, performance reviews, testing within normal educational requirements if there is no research question involved and if there is no intention to present or publish the results of the studies to persons outside the relevant program.

- Research based on review of the published/publicly report literature.

- Research involving secondary use of data which is provided without any identifier or group of identifiers which would allow attribution of private information to an individual.

- Consulting unless carried out under the auspices of the University.

Appendix C

Summary of independent variables, domains, and measures used for dependent variable models

Domain	Variables and how measured	PAD at 2 months	Valuing PAD for proscriptive
Risk & Seriousness of Coercive Intervention			
Domain: Risk of inpatient coercion, lifetime	Consumer self-report of number of lifetime coercive interventions, including: o Lifetime involuntary hospitalizations o Involuntary interventions while in hospital (seclusion, restraint, handcuffed, forced medication)	++	++
Domain: Risk of community coercion/leverage, lifetime	Consumer self-report of number of lifetime community coercive interventions/leverages, including: o Involuntary outpatient commitment, o Criminal justice mandated treatment, o Representative payee controls money contingent on treatment, o Housing contingent on treatment)	++	++
Domain: Risk of coercion, past 6 months	Consumer self-report of number of coercive interventions in past 6 months, including: o Involuntary hospitalizations o Community-based leverages (involuntary outpatient commitment, criminal justice mandated treatment, representative payee controls money contingent on treatment, housing contingent on treatment)	++	++

++ variable used in analysis -- variable not used in analysis

Appendix C (continued)

Domain	Variables and how measured	PAD at 2 months	Valuing PAD for proscriptive
Domain: Risk of coercion, overall perceived coercion	o MacArthur Admission Experience Scale (Gardner et al., 1993) as modified for SMI (Swartz, Swanson, & Hannon, 2003). Fifteen items, for each 1=Strongly Agree 5=Strongly Disagree, higher scores indicate higher levels of perceived coercion	++	++
	o General Pressures Survey, study developed, five questions asking if the individual was treatment nonadherent did they fear someone would: hospitalize them; involuntarily commit them; involve criminal justice; withhold their money; force them to leave their housing. 1=Yes, 0=No, higher score indicates higher perceived pressure	++	++
Domain: Distress at inpatient coercive interventions	o Study developed questions on level of distress experienced in past during: seclusion; restraint; forced medication. For each, 1=Not at all, 5=Very much	++	++
Domain: Distress at community coercive intervention/leverage	o Study developed questions on level of distress experienced in past during: outpatient commitment; mandate to treatment from criminal justice, money contingent on treatment, housing contingent on treatment. For each, 1=Not at all, 5=Very much	++	++
Benefits/Barriers to PADs and/or Mental Health Treatment			
Domain: Benefits of PADs and/or of getting treatment	o Study developed PAD attitude questions, Ten statements, for each 1=Strongly Agree, 5=Strongly Disagree, higher score= less PAD endorsement	++	--

Appendix C (continued)

Domain	Variables and how measured	PAD at 2 months	Valuing PAD for proscriptive
Domain: Benefits of PADs and/or getting mental health treatment	o Insight and Treatment Attitudes Questionnaire (McEvoy, et al, 1989) as modified for SMI (Swartz, Swanson, & Hannon, 2003). Measures consumer's ability to discern own mental illness and see a need for treatment. Eleven items, for each Yes=2, Possibly Yes=1, 0=No. Higher score indicates greater insight into disorder	++	++
	o Drug Attitude Inventory (Hogan et al., 1983). Measures consumers perceptions of psychotropic medication purpose, effectiveness, and side-effects. Seventeen items, Yes=1, 0=No. Higher score indicates more positive attitude towards psychotropic medications	++	++
	o Pressure Scale, study developed questions asking if consumer views leverages as positive	++	++
	o Study developed questions asking if consumer sees leverage as helpful in keeping appointments and taking medication	++	++

Appendix C (continued)

Domain	**Variables and how measured**	**PAD at 2 months**	**Valuing PAD for proscriptive**
Domain: Treatment motivation and satisfaction	o Treatment Motivation Questionnaire (Ryan et al., 1995), modified for this study (Ferron et al., under review), a measure of motivation for treatment. Twenty eight items, 1=Not At All True 7= Very True, higher score indicates greater motivation. Five subscales: Intrinsic motivation; Extrinsic motivation; Lack of confidence in treatment; Relating to others in treatment; Introject or wanting to avoid guilt and shame.	++	++
	o Treatment Satisfaction Scale, 13item survey developed as part of the Mental Health Statistical Improvement Program Adult Consumer Survey (Ganju, 1999). Each item is answered on a 5 point scale (1=Strongly Agree, 5=Strongly Disagree); higher scores indicate greater dissatisfaction.	++	++
Domain: Barriers to PADs	o Study developed list of reasons why an individual might not get a PAD. Nine items, 1=True 0=False, higher scores indicate more perceived barriers to PAD completion. Used as a sum and each individual item: Don't understand enough about PADs; PADs take a lot of time and trouble; It's hard to get help to make a PAD; No one will pay attention to my wishes; A PAD won't make a difference; I don't know what to say in a PAD; I don't have anyone I trust to make decisions for me; I don't have a doctor I trust; I don't like to sign legal documents	++	--

Appendix C (continued)

Domain	Variables and how measured	PAD at 2 months	Valuing PAD for proscriptive
Domain: Barriers to mental health treatment	o Study developed list of reasons consumer might delay treatment, 16 items, 1=Yes, 0=No. Used as a sum and each individual item: Problem may get better by itself; Cost concerns; Unsure where to go; Won't do any good; Transportation; Concern what others might think; Want to solve on own; Might get in trouble with law; Might get in trouble with family or friends; Might be forced to take unwanted medication or treatment; Might be placed on outpatient commitment; Might be involuntarily hospitalized; Fear being put in seclusion; Fear being put in restraints; Fear being forced to take medication in hospital; Fear being given unwanted injection.	++	++
	o Study-developed question "People should have an Advance Instruction because otherwise they might be put in the hospital or get medicine they don't want" 1=Strongly Agree, 5=Strongly Disagree	--	++
Relational Supports			
Domain: WAI, consumer and clinician	o Working Alliance Inventory (Horvath, 1994) as modified for SMI (Neale & Rosenheck, 1995). Seven items in scale, for each 1=Strongly Agree 5=Strongly Disagree, with higher score indicating higher alliance. Given to both consumer and clinician.	++	++

Appendix C (continued)

Domain	Variables and how measured	PAD at 2 months	Valuing PAD for proscriptive
Domain: WAI concordance	o Concordance between clinician and consumer WAI. Specifically are both above median, below median, only consumer above median, only clinician above median. For each, also examined interaction with variable "how well does clinician know consumer=very well/well"	++	++
	o Clinician and consumer WAI scores within 4 points	++	++
Domain: Concordance in attitudes towards coercion	o Concordance between clinician and consumer in response to benefits of community-based coercion because it helps people with MI keep their appointments, and because it helps them take their medications. 1=Not at all, 5=Very much. Concordance defined as in WAI above	++	++
Domain: Concordance in attitudes towards PADs	o Concordance between clinician and consumer in response to study developed PAD attitude questions (see above). Concordance defined as in WAI above, examined for mean response score and each individual item.	++	++
Domain : Relational supports, clinician knowledge of consumer	o Number of months clinician reports knowing consumers	++	++
	o Clinician report of knowing consumer, 1=Not at all, 5=Very well	++	++

Appendix C (continued)

Domain	Variables and how measured	PAD at 2 months	Valuing PAD for proscriptive
Domain: Relational supports, non-clinician	o Study developed questions: Do you have any close friends? Do you have someone who regularly helps you with mental health care? Can you count on someone at least some of the time?	++	++
	o Duke Social Support Scale (Powers et al., 2004)	++	++
	o Consumer report of any violent victimization in the past 6 months	++	++
Domain: Consumer views of trusting relationships and mental health care	o Response to study-developed questions: You don't have someone you trust to make decisions for you; You don't have a doctor you trust (1=Yes, 0=No)	--	++
	o Response to study-developed questions: People with SMI should talk to their doctor or therapist about what to write down in a PAD; People with SMI should choose a family member or someone they trust and give them the right to make decisions about their treatment (1=Strongly Agree, 5=Strongly Disagree)	--	++
Consumer Characteristics Domain: PAD understanding	o Decisional Competence Assessment Tool for Psychiatric Advance Directives (DCAT-PAD) to evaluate understanding and reasoning regarding hospitalization and regarding PADs (Elbogen, Swanson et al., in press)	++	++

Appendix C (continued)

Domain	Variables and how measured	PAD at 2 months	Valuing PAD for proscriptive
Domain: Demographics and functioning	Age	++	++
	Race	++	++
	Gender	++	++
	Brief Psychiatric Rating Scale (Moerner et al., 1988)	++	++
	Global Assessment of Functioning (Endicott et al., 1976)	++	++
	Alcohol use and drug use : at least one positive response on the CAGE regarding alcohol or drugs (Ewing, 1984).	++	++
Clinician Characteristics			
Domain: PAD and coercion attitudes (for multi-level modeling only)	Study developed PAD attitude questions, Ten statements, for each 1=Strongly Agree, 5=Strongly Disagree, higher score= less PAD endorsement	++	--
	Study developed attitudes toward coercion, asking benefits of community-based coercion because it helps people with SMI keep their appointments, and because it helps them take their medications. 1=Not at all, 5=Very much.	++	++
Domain: Demographics and professional characteristics	Age	++	++
	Race	++	++
	Gender	++	++
	Years of mental health experience	++	++
	Level of education	++	++
	Caseload size	++	++

Appendix D

Psychometric information for validated instruments used in study

Instrument	Source	Findings
MacArthur Admission Experience Scale	Gardner et al., 1993	Constructed the scale for patients' perception of hospital admission coercion and compared with a more extensive patient interview. Used correspondence analysis to demonstrate internal reliability and loading on one latent variable (eigenvalue .65)
	Swartz, Swanson, & Hannon, 2003	Used scale modified for outpatient settings, had good internal reliability (α=0.85)
Insight and Treatment Attitudes Questionnaire	McEvoy et al, 1989	Developed scale and tested concurrent validity by comparison with psychiatrists' rating of insight (r=0.85),
	McEvoy, Freter, Everett, et al, 1993	Demonstrated test-retest reliability at one year follow up (r=0.70)
	Swartz, Swanson, & Hannon, 2003	Demonstrated good internal reliability (α=0.82)
Drug Attitude Inventory	Hogan et al, 1983	Developed scale and demonstrated good internal reliability (α=0.81) and test-retest reliability (α==0.82) Concurrent validity demonstrated between DAI and Neuroleptic Dysphoria scale (r=0.76). Predictive validity demonstrated by ability to predict both compliance (96% accuracy) and noncompliance (83% accuracy)
Treatment Motivation Questionnaire	Ryan, Plant, & O'Malley, 1995	Developed scale for motivation in alcohol treatment. Principle component analysis demonstrated internal reliability with four factors (α=0.70-0.98). Concurrent validity with Beck Depression Index, Short Michigan Alcohol Screening Test and Addiction Severity Index (average r=0.31)

Appendix D (continued)

Instrument	Source	Finding
	Ferron, et al., under review	Modified scale for SMI population and tested on PAD study subjects. Confirmatory factor analysis revealed five factors. The reliability of the four primary subscales of "Intrinsic Motivation" (α=.78), "Lack of Confidence in Treatment" (α= .82), "Relatedness in Treatment" (α=.87), and "Avoidance of Negative Introject" (α=.73) had respectable to good Cronbach's alpha scores whereas, the fifth subscale, "External Motivation" has weaker reliability (α= .51)
Treatment Satisfaction Scale	Jerrell, 2006	Part of the Mental Health Statistical Improvement Program Adult Consumer Survey. Found good internal reliability (α=0.73-0.81) and convergent validity with the Consumer to Consumer Evaluation Team survey (r=0.42-0.79 for subscales).
Working Alliance Inventory	Horvath & Greenberg, 1989	Developed scale to measure the alliance between client and therapist. Found good internal reliability (α=0.82-0.85). Concurrent validity shown with treatment satisfaction (r=0.50) and perceived change (r=0.33) subscales of the Client Post-therapy Questionnaire
	Neale & Rosenheck, 1995	Modified scale for work with SMI, found good internal reliability (α=0.89)
Duke Social Support Index	Powers et al, 2004	Measure of social support used in a wide range of settings. Internal reliability adequate (α=0.58-0.80)

Appendix E

Questions and instruments used in analysis

Questions and instruments are shown here in the same order as they are listed in Appendix C

Risk of inpatient coercion, lifetime

- Have you ever, at any time in your adult life, been involuntarily committed to a hospital for mental health, alcohol or drug problems?

Yes (1)___
No (0)___

- Were you handcuffed (when brought to the hospital or ER by the police or sheriff)?

Yes (1)___
No (0)___

- When you were hospitalized: Were you ever put in a seclusion room, that is, a locked room?

Yes (1)___
No (0)___

- When you were hospitalized, were you ever placed in physical restraints, that is, straps or a harness that prevented you from moving (not including handcuffs used while transported to the hospital)?

Yes (1)___
No (0)___

- When you were hospitalized: Were you ever forced to take medication against your will?

Yes (1)___
No (0)___

Risk of community coercion/leverage, lifetime

- Sometimes people with mental health, alcohol or drug problems are put on "outpatient commitment" by a judge at a legal hearing. If you are on outpatient commitment, the judge orders you to accept treatment in the community, whether you want it or not. Are you now on outpatient commitment , or have you ever been on it?

Yes (1)___
No (0)___

Appendix E (continued)

- Sometimes a police officer or judge tells you or your lawyer that you can avoid having charges filed, or going to jail or prison if you get treatment for your mental health, alcohol or drug problems in the community. Did anyone ever tell you this (did this ever happen to you)?

Yes (1)___
No (0)___

- Did the representative payee ever require that you stay in treatment for a mental health, alcohol, or drug problem (or take your medication) in order to get your spending money?

Yes (1)___
No (0)___

- Sometimes you are told that you can't live in a certain house or apartment unless you stay in mental health treatment and stay away from illegal drugs and alcohol. Did you ever live some place where you were required to stay in mental health treatment or stay away from illegal drugs and alcohol?

Yes (1)___
No (0)___

Risk of coercion, past 6 months

- Have you been involuntarily committed in the past 6 months?

Yes (1)___
No (0)___

- Are you currently on outpatient commitment? [If not currently on OPC] Were you on outpatient commitment in the past six months?

Yes (1)___
No (0)___

- Did this [avoiding charges filed or going to jail if you get treatment for your mental health, alcohol, or drug problem] happen in the last six months?

Yes (1)___
No (0)___

- Did this [representative payee required that you sat in treatment for a mental health, alcohol, or drug problem (or take your medications) in order to get your spending money] happen in the last six months?

Yes (1)___
No (0)___

Appendix E (continued)

- Did someone tell you this [you can't live in a certain house or apartment unless you stay in mental health treatment and stay away from illegal drugs and alcohol] about where you currently live? Did someone tell you this in the past six months?

Yes (1)___
No (0)___

Risk of coercion, overall perceived coercion
MacArthur Admission Experience Scale

Now lets get back to you and your experiences of treatment. Think back over your experience of going to the mental health center [or other outpatient mental health services] over the past six months. Think about all of the things people might have done to keep you going to the mental health center or taking medications as prescribed. Then tell me how you feel about the following statements.

- I felt free to do what I wanted about going to the (mental health center).
- People tried to force me to go to the (mental health center).
- I had enough of a chance to say whether I wanted to go to the (mental health center).
- I chose to go to the (mental health center).
- I got to say what I wanted about going to the (mental health center).
- Someone threatened me to get me to go to the (mental health center).
- It was my idea to go to the (mental health center).
- Someone physically tried to make me go to the (mental health center).
- No one seemed to want to know whether I wanted to go to the (mental health center).
- I was threatened with commitment.
- They said they would make me go to the (mental health center).
- No one tried to force me to go to the (mental health center).
- My opinion about going to the (mental health center) didn't matter.
- I had a lot of control over whether I went to the (mental health center).
- I had more influence than anyone else on whether I went to the (mental health center).

For each:

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

General Pressures Survey

In the past 6 months, did you feel that if you did not keep your appointments at the Mental Health Center or clinic, or if you did not take your prescribed medications for mental health, alcohol or drug problems:

- Someone would make you go to the hospital? Yes (1)___ No (0)___
- Someone would commit you to the hospital? Yes (1)___ No (0)___

Appendix E (continued)

- Someone would notify the sheriff/judge/police? Yes (1)___ No (0)___
- Someone would not give you your spending money? Yes (1)___ No (0)___
- Someone would force you to leave where you live? Yes (1)___ No (0)___

Distress at inpatient coercive intervention

- How much did that [seclusion] bother you?
  - Not at all (1) ___
  - A little bit (2) ___
  - Moderately(3) ___
  - Quite a bit (4) ___
  - Very much (5)___
- How much did that [restraints] bother you?
  - Not at all (1) ___
  - A little bit (2) ___
  - Moderately(3) ___
  - Quite a bit (4) ___
  - Very much (5)___
- How much did that [forced medication] bother you?
  - Not at all (1) ___
  - A little bit (2) ___
  - Moderately(3) ___
  - Quite a bit (4) ___
  - Very much (5)___

Distress at community coercive intervention/leverage

- Here's a statement. "Being placed on OPC bothered me." Please tell me how you feel about this statement.
  - Strongly Agree (1) ___
  - Agree (2) ___
  - Neutral (3) ___
  - Disagree (4) ___
  - Strongly Disagree (5) ___
- Here's a statement. "Being told to get treatment by a police officer or judge bothered me." Please tell me how you feel about this statement.
  - Strongly Agree (1) ___
  - Agree (2) ___
  - Neutral (3) ___
  - Disagree (4) ___
  - Strongly Disagree (5) ___

Appendix E (continued)

- Here's a statement. "Being told that I had to go to treatment to get my money bothered me." Do you

Strongly Agree (1) ___
Agree (2) ___
Neutral (3) ___
Disagree (4) ___
Strongly Disagree (5) ___

- Here's a statement. "Being told to get treatment in order to keep my housing bothered me." Do you

Strongly Agree (1) ___
Agree (2) ___
Neutral (3) ___
Disagree (4) ___
Strongly Disagree (5) ___

Benefits of PADs and/or of getting treatment

Insight and Treatment Attitudes Questionnaire

- Have you at any time had mental ("nerve," "worry") problems that were different from most other people's?
- Have you at any time needed treatment (hospitalization or outpatient care) for mental ("nerve," "worry") problems?
- Do you now have mental ("nerve," "worry") problems?
- Do you now need treatment (hospitalization or outpatient care) for mental ("nerve," "worry") problems?
- Is it possible that in the future you may have mental ("nerve," worry") problems?
- Will you in the future need continued treatment (outpatient care or, possibly, hospitalization) for mental ("nerve," "worry") problems?
- Have you at any time needed to take medications for mental problems ("nerves" or "worries")?
- Do you now need to take medications for mental problems ("nerves" or "worry")?
- Will you in the future need to take medications for mental problems ("nerves" or "worries")?
- Will you take the medications?
- Do the medications do you any good?

For each:

No	Possibly Yes	Yes
0	1	2

Appendix E (continued)

Drug Attitudes Inventory

- For me, the good things about medication outweigh the bad
  True (1)___ False (0)___
- I feel weird, like a "zombie", on medication.
  True (1)___ False (0)___
- I take medications of my own free choice.
  True (1)___ False (0)___
- Medications make me feel more relaxed.
  True (1)___ False (0)___
- Medications make me feel tired and sluggish.
  True (1)___ False (0)___
- I take medications only when I am sick.
  True (1)___ False (0)___
- I feel more normal on medication.
  True (1)___ False (0)___
- It is unnatural for my mind and body to be controlled by medications.
  True (1)___ False (0)___
- My thoughts are clearer on medication.
  True (1)___ False (0)___
- By staying on medications, I can prevent getting sick.
  True (1)___ False (0)___
- The medications make me less depressed.
  True (1)___ False (0)___
- The medications help me sleep.
  True (1)___ False (0)___
- The medications help me control my moods.
  True (1)___ False (0)___
- Medications help me stay out of the hospital.
  True (1)___ False (0)___
- The medications make me feel restless, like I can't sit still.
  True (1)___ False (0)___
- The medications interfere with my sexual functioning (my sex life).
  True (1)___ False (0)___
- The medications make my hands shake or make my muscles twitch or spasm.
  True (1)___ False (0)___

Appendix E (continued)

Pressure Scale

Overall, the pressures or things people have done to try to get me to get treatment or stay in treatment…

- Made me more likely to keep appointments and take my medications.
- Were done by people who tried to be fair to me.
- Were for my own good.
- Were not done out of real concern for me.
- Helped me get [well] and stay well.
- Helped me gain more control over my own life.
- Did not make me feel respected as a person.
- Should be done again in the future if needed.
- Made me angry.

For each:

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

PAD Attitude Questionnaire (for consumer and clinician)

Thinking about a psychiatric advance directive, tell me how you feel about the following statements.

- An advance instruction will help people with serious mental health problems stay well
- People with serious mental health problems should, at some time when they are feeling well, write down what kind of medicine or other treatment they want in the future if they become very ill.
- People with serious mental health problems should choose a family member or someone they trust, and give that other person the right to make decisions about their treatment in the future if they become very ill.
- Writing down advance instructions for mental health treatment will probably not do any good.
- People with serious mental health problems should talk to their doctor or therapist about what to write down in an advance instruction for mental health treatment.
- Even if someone has written advance instructions for mental health treatment, they should always be allowed to change their mind -- even when they are ill -- about whether to go in the hospital and whether to take medicine.
- Doctors and hospitals should pay a legal penalty if they fail to follow a patient's legal advance instruction for mental health treatment.

Appendix E (continued)

People with serious mental health problems should write down advance instructions for their treatment in a crisis, because:

- otherwise they might be put in a hospital against their will or be given medicine that they do not want.
- otherwise they might go without treatment that they need in order to get well.
- An advance instruction will give them more control over their own lives and what happens to them in the future.

For each:

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Treatment motivation and satisfaction

Treatment Motivation Questionnaire

I came for treatment at the clinic because:

- My family/friend said I should get some help (EM)
- I really want to make some changes in my life (IM)
- My doctor/therapist told me that I should be in treatment (EM)
- I won't feel good about myself if I don't get some help (I)
- I feel so guilty about my problem that I have to do something about it (I)

If I remain in treatment, it will probably be because:

- I'll get in trouble if I don't (EM and I)
- I'll feel very bad about myself if I don't (I)
- Others will be angry with me if I don't (EM)
- I'll feel like a failure if I don't (I)
- I feel like it's the best way to help myself (IM)
- I don't really feel like I have a choice about staying in treatment. (EM)

Rate each of the following in terms of how true each statement is for you.

- I came to treatment because I was under pressure to come. (EM)
- I am not sure this treatment will work for me. (LC)
- I am looking forward to getting some personal support (R)
- I am confident this treatment will work for me (LC)
- I wouldn't be here if I really had a choice about it (EM)

- I decided to come to treatment because I was interested in getting help (IM)
- I'm not convinced that this treatment will help much with my concerns or difficulties (LC)
- I wanted to openly relate with others in treatment (R)
- I want to share some of my concerns and feelings with others (R)
- It will be important for me to work closely with others in solving my problem (R)
- I am responsible for this choice of treatment (IM)
- I doubt that this treatment will solve my problems (IM)
- I look forward to relating to others who have similar problems (R)
- I chose this treatment because I think it is an opportunity for change (IM)
- I am NOT very confident that I will get results from treatment this time (LC)
- It will be a relief for me to share my concerns with others in treatment (R)
- I accept the fact that I need some help and support from others to beat my problem. (IM and RE)

For each:

Not at all true						Very true
1	2	3	4	5	6	7

EM=External Motivation subscale
IM=Intrinsic Motivation subscale
LC=Lack of Confidence in Treatment subscale
IN=Introject
RE=Relatedness

<u>Treatment Satisfaction Scale</u>

Now, let's talk about the treatment you have received in the past for mental health, drug and alcohol problems. Please tell me how you feel about the following statements:

- I like the services (treatment) that I have received in the past.
- If I had other choices, I would still get services from the places I have gotten them (in the past).
- Staff where I received services were willing to see me as often as I felt it was necessary.
- I was able to get all the services I thought I needed.
- Staff where I received services believe that I can grow, change and recover.
- I felt free to complain.
- Staff where I received services encouraged me to take responsibility for how I live my life.
- Staff where I received services respected my wishes about who is and who is not to be given information about my treatment.

Appendix E (continued)

- I deal more effectively with daily problems.
- I am better able to control my life.
- I am getting along better with my family.
- I do better in school and/or work.
- My symptoms are not bothering me as much.

For each:

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Barriers to PADs

PAD Barriers

You might have difficulty when trying to complete a psychiatric advance directive (or advance instruction) because:

- You don't understand enough about psychiatric advance directives (advance instructions).
  True (1)___ False (0)___
- It will take a lot of time and trouble.
  True (1)___ False (0)___
- It will be hard to find someone or somewhere to get help to complete the psychiatric advance directive (advance instruction).
  True (1)___ False (0)___
- You don't think anyone will pay attention to your wishes.
  True (1)___ False (0)___
- You don't think a psychiatric advance directive (advance instruction) will make any difference in your treatment.
  True (1)___ False (0)___
- You don't know what to say or write in the psychiatric advance directive (advance instruction).
  True (1)___ False (0)___
- You don't have anyone you trust enough to make decisions for you.
  True (1)___ False (0)___
- You don't have a doctor you trust.
  True (1)___ False (0)___
- You don't like to sign legal documents (or you don't trust legal documents)?
  True (1)___ False (0)___

Appendix E (continued)

Barriers to mental health treatment

Barriers
If you think about getting help for mental health, alcohol or drug problems, do you delay getting help because...

- You think that your problem might get better by itself?
  Yes (1)___ No (0)___
- Are you concerned about the cost?
  Yes (1)___ No (0)___
- Are you unsure about where to go for help?
  Yes (1)___ No (0)___
- Do you think that going for help probably wouldn't do any good?
  Yes (1)___ No (0)___
- Is it too difficult to get care because of distance or transportation problems?
  Yes (1)___ No (0)___
- Are you concerned about what others might think if you went for help?
  Yes (1)___ No (0)___
- Do you want to solve the problem on your own?
  Yes (1)___ No (0)___
- Do you think that going for treatment might get you in trouble with the law?
  Yes (1)___ No (0)___
- Do you think that going for treatment might get you in trouble with friends or family?
  Yes (1)___ No (0)___
- Do you think that if you went for treatment that you might be forced to take medicine or treatment that you don't want?
  Yes (1)___ No (0)___
- Do you think you might be placed on outpatient commitment?
  Yes (1)___ No (0)___
- Do you think that going for treatment might lead to an involuntary hospitalization?
  Yes (1)___ No (0)___
- Do you fear being put in seclusion if you are hospitalized?
  Yes (1)___ No (0)___
- Do you fear being placed in restraints if you are hospitalized?
  Yes (1)___ No (0)___
- Do you fear being forced to take medication if you are hospitalized?
  Yes (1)___ No (0)___
- Do you fear being given an injection you don't want if you are hospitalized?
  Yes (1)___ No (0)___

Appendix E (continued)

People should have an Advance Instruction because otherwise they might be put in the hospital or get medicine they don't want.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Working Alliance Inventory (WAI)

WAI, Consumer

Next are some statements about how people might think or feel about their clinician. Please think about your experiences with (identified clinician) over the past six months.

- ___________ (identified clinician) perceives accurately what my goals are.
- The goals of my work with _____________ are important to me.
- ______________ and I have established a good understanding of the kinds of changes that would be good for me.
- ________________ and I are working toward mutually agreed upon goals.
- I am confident in ______________'s ability to help me.
- My relationship with _____________ is very important to me.
- _______________ and I trust one another.
- Overall, I can count on _____________ for help when I need it.

For each:

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

WAI, Clinician

Please answer the following questions about your current relationship with this client.

- This client and I have a common perception of his/her goals.
- The current goals of our work are not important to this client.
- We have established a good understanding of the kinds of changes that would be good for him/her.
- We are working toward mutually agreed upon goals.

Appendix E (continued)

- I do not feel confident in my ability to help this client.
- This relationship is important to this client.
- This client trusts me.

- This client and I have established a strong working alliance and rapport

For each:

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Attitudes towards coercion, used independently and for concordance between clinician and consumer

Consumer attitude toward coercion

- On the whole you are better off because of this pressure [leverages] to keep appointments.
- On the whole you are better off because of this pressure [leverages] to take medication.

For each:

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Clinician attitude toward coercion

- Please indicate how you feel about this statement: "On the whole a patient who is often noncompliant with treatment would be better off with these types of verbal warnings or reminders to keep appointments."

- Please indicate how you feel about this statement: "On the whole a patient who is often noncompliant with treatment would be better off with these types of verbal warnings or reminders to take medications."

For each:

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Appendix E (continued)

Relational supports from clinician

Clinician Knowledge of Consumer

- Obviously, case managers and clinicians cannot know everything about all their many clients. How well do you think you know (CLIENT'S NAME)?

Only slightly (1)	___
Some knowledge, but not as well as average client (2)	___
Moderately well (average client) (3)	___
Very well, Better than average client (4)	___
Extremely well, Much better than average client (5)	___

Number of months clinician knows consumer

- For how many months have you provided case management or other clinical services for (CLIENT'S NAME) ?

Relational supports, non-clinician

- Now I'd like to know about other people in your life. Do you have any close friends who are not family members?
  Yes (1)___ No (0)___

- Thinking over the last month, is there a family member, friend, or someone else who regularly helps you with your mental health treatment?
  Yes (1)___ No (0)___

- In time of trouble, can you count on at least some of your family and friends most of the time, some of the time, or hardly ever?

Most of the time (2)	___
Some of the time (1)	___
Hardly ever (0)	___

Duke Social Support Scale

Now I want to ask you about some of the ways your family and friends help you out. Do your family or friends ever help you in any of the following ways:

- Shop or run errands for you?
  Yes (1)___ No (0)___

Appendix E (continued)

- Help you out with money?
  Yes (1)___ No (0)___
- Keep house for you or do household chores?
  Yes (1)___ No (0)___
- Provide companionship to you?
  Yes (1)___ No (0)___
- Give you advice on dealing with life's problems?
  Yes (1)___ No (0)___
- Provide transportation for you?
  Yes (1)___ No (0)___
- Prepare or provide meals for you?
  Yes (1)___ No (0)___

<u>Violent victimization</u>

In the past six months,

- Has anyone thrown something at you?
  Yes (1)___ No (0)___
- Has anyone pushed, grabbed, or shoved you?
  Yes (1)___ No (0)___
- Has anyone slapped you?
  Yes (1)___ No (0)___
- Has anyone kicked, bitten, or choked you?
  Yes (1)___ No (0)___
- Has anyone hit you with a fist or object, or beaten you up?
  Yes (1)___ No (0)___
- Has anyone tried to force you to have sex against your will?
  Yes (1)___ No (0)___
- Has anyone threatened you with a gun or knife or other lethal weapon in their hand?
  Yes (1)___ No (0)___
- Has anyone used a knife or fired a gun at you?
  Yes (1)___ No (0)___

Appendix E (continued)

Consumer views of trusting relationships and mental health care

You might have difficulty when trying to complete a psychiatric advance directive (or advance instruction) because:

- You don't have anyone you trust enough to make decisions for you.
  Yes (1)___ No (0)___
- You don't have a doctor you trust.
  Yes (1)___ No (0)___
- People with serious mental health problems should choose a family member or someone they trust, and give that other person the right to make decisions about their treatment in the future if they become very ill.
- People with serious mental health problems should talk to their doctor or therapist about what to write down in an advance instruction for mental health treatment.

For each:

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Appendix E (continued)

DCAT-PAD

INTRODUCTION

I am going to read some information and then I'll ask you some questions about what I've said. If you miss any part of the information, I'll repeat it for you once. We'll keep going with information and then questions until the end of the interview. Not all of the things I say will apply to you personally, but they often apply to people with the same condition that you have and who are receiving the same type of treatment. Any questions before we begin?

UNDERSTANDING SCORING GUIDELINES: (The following guidelines are used to score each item in the Understanding sections of the MacCAT procedure (the Disorder, Treatment, and Benefits/Risks sections).

3 point rating scale	SCORING GUIDELINES
2	Subject recalls the content of the item and offers a fairly clear version of it. A verbatim repetition of the interviewer's description is not required; in fact, if the patient only repeats verbatim, probe further to see if patient really understands (paraphrase in the subject's own words is preferred).
1	Subject shows some recollection of the item content, but describes it in a way that renders understanding uncertain, even after the clinician has made efforts to obtain clarification from the subject. Examples include responses that could possibly indicate understanding but are too broad or vague for one to be sure (e.g., for pain of surgery, "It might make me feel uncomfortable"), or responses that contain some specific and correct piece of information but lack some other part of the critical content (e.g., for hallucinations, "I might hear things).
0	Subject (a) does not recall the content of the item; or (b) describes it in a way that is clearly inaccurate; or (c) describes it in a way that seriously distorts its meaning, even after the clinician has made efforts to obtain clarification from the patient; or offers a response that is unrelated to the question or unintelligible.

Appendix E (continued)

CP1a. UNDERSTANDING-DISORDER

Interviewer:	*Give Understanding-Disorder show card (card 1) to subject and say,* "Here is a card that you can read along as I read the information to you."
Interviewer Disclosure:	*Read all 5 elements of the disclosure below then preface patient response with:* "Now please explain in your own words what I've said.
Probe (if necessary):	*Re-Disclose and Re-Inquire (if necessary).*

Disclosure	**Subject Response**
# 1 Diagnosis You are being seen in this clinic because you have been diagnosed as having a mental disorder.	Rating ☐
# 2 Feature of Disorder Mental disorders affect a person's thinking and understanding of what's going on around them.	Rating ☐
# 3 Feature of Disorder Mental disorders can include schizophrenia, depression, or bipolar disorder.	Rating ☐
# 4 Feature of Disorder People with mental disorders can re-experience increased symptoms in the future, which is called a 'relapse.'	Rating ☐
#5 Feature of Disorder When they have a relapse, people with mental disorders sometimes have trouble making decisions about their treatment and medications.	Rating ☐

Appendix E (continued)

APPRECIATION-DISORDER SCORING GUIDELINES:

3 point rating scale	SCORING GUIDELINES
2	Subject acknowledges that he or she manifests the disclosed disorder, and all or most of the disclosed symptoms. OR Subject does not agree with the proceeding, but offers reasons that are not delusional and have some reasonable explanation (e.g., "Another doctor told me something different. In my culture this is not considered unusual or a 'sickness.'").
1	Subject acknowledges manifesting the disorder and some of the disclosed symptoms but does not acknowledge other symptoms that are critical to understanding the disorder and/or its treatment. OR Subject disagrees or is ambivalent about the existence of the disorder or the symptoms, but for reasons that are vague or not clearly expressed.
0	Subject clearly does not agree that he or she has the disclosed disorder, with reasoning based on a delusional premise or some other belief that seriously distorts reality and does not have a reasonable basis in the patient's culture or religious background. OR Subject believes that the symptoms are related to circumstance other than a medical/psychiatric disorder (e.g., psychiatric symptoms seen simply as consequences of work-related stress). OR Subject clearly disagrees with symptoms of disorder, but with no comprehensive explanation offered.

CP1b. APPRECIATION-DISORDER

Inquire: A mental disorder is the kind of problem that your doctor thinks you have been having. If you have any reason to doubt that, I'd like you to tell me so. What do you think?

☐ Agrees ☐ Disagrees ☐ Ambivalent

What is it that makes you agree/disagree?

Probe (if necessary): If patient disagrees or is ambivalent, description of disagreement and patient's explanation.

Explanation	
Appreciation-Disorder	☐

Appendix E (continued)

CP2a. UNDERSTANDING-TREATMENT [PSYCHIATRIC ADVANCE DIRECTIVES]

Interviewer:	*Give Understanding-Treatment show card (card 2) to subject and say,* "Here is a card that you can read along as I read the information to you.
Interviewer Disclosure:	*Read all 4 elements of the disclosure below then preface patient response with:* "Now please explain in your own words what I've said about this treatment."
Probe (if necessary):	*Re-Disclose and Re-Inquire (if necessary).*

Disclosure	**Subject Response**
#1 Name of Treatment Under new laws in North Carolina, people can complete a form called a psychiatric advance directive.	Rating ☐
# 2 Feature Treatment On this form, people can describe the kind of mental health treatment they want to receive if they can't make decisions for themselves in the future.	Rating ☐
# 3 Feature of Treatment This can include a person's wishes about medications, ECT, or admission to a hospital.	Rating ☐
# 4 Feature Treatment It is important to realize that someone can change these forms at any time if they wish.	Rating ☐

Appendix E (continued)

CP2b. UNDERSTANDING-BENEFITS [PSYCHIATRIC ADVANCE DIRECTIVES]

Interviewer: *Give Understanding Benefits show card (card 3) to subject and say,* "Here is a card that you can read along as I read the information to you."

Interviewer Disclosure: *Read all 4 disclosures below then preface patient response with:* "Now please explain in your own words what I've said about benefits and risks about psychiatric advance directives."

Probe (if necessary): *Re-Disclose and Re-Inquire (if necessary).*

Disclosure	**Subject Response**
# 1 Benefit One benefit is that people can document what medications they would want or not want in a crisis.	Rating ☐
# 2 Benefit Another benefit is that people can say what hospital they would want or not want to be admitted to in a crisis.	Rating ☐
# 3 Benefit Psychiatric advance directives can tell clinical staff how people would want to be treated while in the hospital (like being treated with respect).	Rating ☐
# 4 Benefit Finally, people can choose someone they trust (like a family member) to make treatment decisions for them if they can't do it themselves.	Rating ☐

Appendix E (continued)

CP2c. UNDERSTANDING- RISKS [PSYCHIATRIC ADVANCE DIRECTIVES]

Interviewer: *Give Understanding Risks show card (card 4) to subject and say,* "Here is a card that you can read along as I read the information to you."

Interviewer Disclosure: *Read all 4 disclosures below then preface patient response with:* "Now please explain in your own words what I've said about benefits and risks about psychiatric advance directives."

Probe (if necessary): *Re-Disclose and Re-Inquire (if necessary).*

Disclosure	**Subject Response**
# 1 Risk One risk is that when these forms are used, people may have changed their mind about the treatment they want.	Rating ☐
# 2 Risk Also, their chosen person may not do exactly what they say on the forms they would want them to do.	Rating ☐
# 3 Risk It is important to realize that the hospitals people wish to be admitted to may not have beds at the time of a crisis.	Rating ☐
# 4 Risk Finally, doctors can still use commitment and don't have to provide treatment they believe is inappropriate.	Rating ☐

Appendix E (continued)

APPRECIATION-TREATMENT SCORING GUIDELINES:

3 point rating scale	SCORING GUIDELINES
2	Subject acknowledges at least some potential for the treatment to produce some benefit, and the reason is not based on a delusional premise or a serious distortion of reality. OR Subject does not believe the treatment has the potential to produce some benefit, but offers reasons that are not delusional and have some reasonable explanation (e.g., explanations that are consistent with the subject's religious beliefs or cultural background; explanations based on past experience with the treatment in question).
1	Subject does or does not believe that the treatment has the potential to produce some benefit but the reason is vague or does not allow the examiner to determine whether the reason represents delusional thinking or serious distortion of reality. OR Subject is ambivalent concerning whether the treatment has potential to produce some benefit.
0	Subject acknowledges at least some potential for the treatment to produce some benefit, but for reasons that seem to be based on a delusional premise or a serious distortion of reality. OR Subject does not believe that the treatment has the potential to produce any benefit, and offers reasons that appear to be delusional or as serious distortion of reality or strongly influenced by extremes in affective symptoms (e.g., severe mania, severe depression).

CP2d. APPRECIATION-PSYCHIATRIC ADVANCE DIRECTIVES

Inquire: Do you think it's possible that filling out a psychiatric advance directive might be of some benefit to you? Why or why not?

☐ Agrees ☐ Disagrees ☐ Ambivalent

What is it that makes you agree/disagree?

Probe (if necessary): So you feel that it is/isn't possible for that PADs to be of some help for your condition. Can you explain that to me? What makes it seem that the treatment would/wouldn't be of possible benefit to you?

Explanation

Appreciation-Treatment ☐

Appendix E (continued)

CONSEQUENTIAL REASONING SCORING GUIDELINES:

3 point rating scale	SCORING GUIDELINES
2	Subject mentions at least two specific consequences when explaining the choice. The consequences may be related to only one or more than one treatment option. The consequences need not be for treatments or alternatives that were in the disclosure. The consequences must be more specific than "_______will help me" or "______will make me feel better." For example: "With medication, the voices I hear will go away."
1	Subject mentions only one specific consequence when explaining the choice.
0	Subject mentions no specific consequences when explaining the choice, even after being asked directly whether there were "any more specific reasons why that choice seems best."

COMPARATIVE REASONING SCORING GUIDELINES:

3 point rating scale	SCORING GUIDELINES
2	Subject offers at least one statement that is a comparison of the two options. The statement should include at least one specific difference between taking the medication and not taking it.
1	Subject makes comparison statement, but does not include a statement of a specific consequence. For example, stating that one choice is "better" than the other without stating why.
0	Subject makes no comparative statements.

CP2e. FIRST CHOICE AND REASONING [PSYCHIATRIC ADVANCE DIRECTIVES]

Choice: If you were given the choice between writing a psychiatric advance directive and not, wh
of these do you think that you would choose?
Choice____

Inquire: Tell me what it is that makes that choice better than the other one.
Probe: Discuss explanation to explore reasoning process.

Explanation

1. Consequential ☐
2. Comparative ☐

Appendix E (continued)

GENERATING CONSEQUENCES SCORING GUIDELINES:

3 point rating scale	SCORING GUIDELINES
2	Subject must give at least two reasonable consequences, including at least one for each of the two inquiry questions. Note: These consequences must go beyond those in the disclosure, and must refer to practical activities or social relationships. For example, if drowsiness is a side-effect of medication, "I would be sleepy" is not sufficient; "I might have trouble awakening and be late for work all the time" is sufficient.
1	Subject gives one or more reasonable consequences for one of the inquiry questions, but none for the other.
0	Subject gives no reasonable consequences, even with adequate encouragement.

CP2f. GENERATING CONSEQUENCES [PSYCHIATRIC ADVANCE DIRECTIVES]

Inquire- 1: We mentioned some benefits of psychiatric advance directives, including documenting what medications and hospitals people want and choosing a trusted person to make treatment decisions if people can't do it themselves. On the other hand, hospitals and medications are not guaranteed because beds might not be available or doctors think the treatment is medically inappropriate. A trusted person may not act exactly as wanted, too. How might choosing psychiatric advance directives affect your life?

Consequences-1

Consequences-1 ☐

Inquire-2: What are some ways that not writing a psychiatric advance directive might affect your life?

Consequences-2

Consequences-2 ☐

Appendix E
(continued)

Final Choice Scoring Guidelines:

3 point rating scale	SCORING GUIDELINES
2	Subject's states a choice, or subject indicates desire for professional or other responsible person (e.g., relatives) to make the choice.
1	Subject states two or three choices, seems ambivalent.
0	Subject states no choice.

CP2g. FINAL CHOICE [PSYCHIATRIC ADVANCE DIRECTIVES]

Inquire: When I asked you a few minutes ago whether you would choose to write a psychiatric advance directive or not, you said that you (would/would not). What do you think now that we've discussed everything? Which would you want to do?

Choice

Choice ☐

Logical Consistency Guidelines:

3 point rating scale	SCORING GUIDELINES
2	Subject's final choice (in Expressing a Choice) follows logically from the subject's own reasoning, as explained by the subject in response to the three previous subparts.
1	It is not clear whether the choice follows logically from the subject's own reasoning.
0	Subject's choice clearly does not follow logically from subject's own reasoning.

CP2h. LOGICAL CONSISTENCY OF CHOICE [PSYCHIATRIC ADV. DIRECTIVES]

(Rate based on previous responses)

Examiner's Explanation

Logical Consistency ☐

Appendix E (continued)

CP3a. UNDERSTANDING-TREATMENT [HOSPITALIZATION]

Interviewer:	*Give Understanding-Treatment show card (card 5) to subject and say* "Here is a card that you can read along as I read the information to yo
Interviewer Disclosure:	*Read all 4 elements of the disclosure below then preface patient resp* *with:* "Now please explain in your own words what I've said about thi treatment."
Probe (if necessary):	*Re-Disclose and Re-Inquire (if necessary).*

Disclosure	**Subject Response**
#1 Name of Treatment In a psychiatric advance directive, you have an option to choose whether you want to come into the hospital or get help somewhere else during a time of crisis.	Rating ☐
# 2 Feature Treatment Psychiatric hospitalization is sometimes needed if a person with a mental disorder becomes very ill.	Rating ☐
# 3 Feature of Treatment A psychiatric hospital stay is at least overnight and usually lasts until a person is well enough to go home.	Rating ☐
# 4 Feature Treatment In a psychiatric hospital, nurses and doctors are around to take care of and treat people.	Rating ☐

Appendix E (continued)

CP3b. UNDERSTANDING-BENEFITS/RISKS [HOSPITALIZATION]

Interviewer:	*Give Understanding Benefits / Risks show card (card 6) to subject and say,* "Here is a card that you can read along as I read the information to you."
Interviewer Disclosure:	*Read all 4 disclosures below then preface patient response with:* "Now please explain in your own words what I've said about benefits and risks of this treatment."
Probe (if necessary):	*Re-Disclose and Re-Inquire (if necessary).*

Disclosure	**Subject Response**
# 1 Benefit One benefit is that psychiatric hospitals provide a safe environment where people can't hurt themselves or others.	Rating ☐
# 2 Benefit Another benefit is that medications can be adjusted more quickly.	Rating ☐
# 3 Risk However, psychiatric hospitals do limit some freedoms, such as smoking cigarettes and drinking alcohol.	Rating ☐
# 4 Risk Hospitals may also not provide treatments you like.	Rating ☐

Appendix E (continued)

APPRECIATION-TREATMENT SCORING GUIDELINES:

3 point rating scale	SCORING GUIDELINES
2	Subject acknowledges at least some potential for the treatment to produce some benefit, and the reason is not based on a delusional premise or a serious distortion of reality. OR Subject does not believe the treatment has the potential to produce some benefit, but offers reasons that are not delusional and have some reasonable explanation (e.g., explanations that are consistent with the subject's religious beliefs or cultural background; explanations based on past experience with the treatment in question).
1	Subject does or does not believe that the treatment has the potential to produce some benefit but the reason is vague or does not allow the examiner to determine whether the reason represents delusional thinking or serious distortion of reality. OR Subject is ambivalent concerning whether the treatment has potential to produce some benefit.
0	Subject acknowledges at least some potential for the treatment to produce some benefit, but for reasons that seem to be based on a delusional premise or a serious distortion of reality. OR Subject does not believe that the treatment has the potential to produce any benefit, and offers reasons that appear to be delusional or as serious distortion of reality or strongly influenced by extremes in affective symptoms (e.g., severe mania, severe depression).

CP3c. APPRECIATION- HOSPITALIZATION

Inquire: Do you think that if you became very ill that psychiatric hospitalization might be of some benefit to you? Why or why not?

☐ Agrees ☐ Disagrees ☐ Ambivalent

Probe (if necessary): So you feel that it is/isn't possible for that treatment to be of some help for your condition. Can you explain that to me? What makes it seem that the treatment would/wouldn't be of possible benefit to you?

Explanation	
Appreciation-Treatment	☐

Appendix E (continued)

CONSEQUENTIAL REASONING SCORING GUIDELINES:

3 point rating scale	SCORING GUIDELINES
2	Subject mentions at least two specific consequences when explaining the choice. The consequences may be related to only one or more than one treatment option. The consequences need not be for treatments or alternatives that were in the disclosure. The consequences must be more specific than "_______ will help me" or "_______ will make me feel better." For example: "With medication, the voices I hear will go away."
1	Subject mentions only one specific consequence when explaining the choice.
0	Subject mentions no specific consequences when explaining the choice, even after being asked directly whether there were "any more specific reasons why that choice seems best."

COMPARATIVE REASONING SCORING GUIDELINES:

3 point rating scale	SCORING GUIDELINES
2	Subject offers at least one statement that is a comparison of the two options. The statement should include at least one specific difference between taking the medication and not taking it.
1	Subject makes comparison statement, but does not include a statement of a specific consequence. For example, stating that one choice is "better" than the other without stating why.
0	Subject makes no comparative statements.

CP3d. FIRST CHOICE AND REASONING [HOSPITALIZATION]

Choice: If you became very ill and were given the choice between going to a psychiatric hospital or not, which of these do you think that you would choose?

Choice____

Inquire: Tell me what it is that makes that choice better than the other one.

Probe: Discuss explanation to explore reasoning process.

Explanation

1. Consequential ☐

2. Comparative ☐

Appendix E (continued)

GENERATING CONSEQUENCES SCORING GUIDELINES:

3 point rating scale	SCORING GUIDELINES
2 1	Subject must give at least two reasonable consequences, including at least one for each of the two inquiry questions. Note: These consequences must go beyond those in the disclosure, and must refer to practical activities or social relationships. For example, if drowsiness is a side-effect of medication, "I would be sleepy" is not sufficient; "I might have trouble awakening and be late for work all the time" is sufficient.
	Subject gives one or more reasonable consequences for one of the inquiry questions, but none for the other.
0	Subject gives no reasonable consequences, even with adequate encouragement.

CP3e. GENERATING CONSEQUENCES [HOSPITALIZATION]

Inquire- 1: I told you about some of the possible benefits from going to the hospital if someone with mental disorder became very ill. If you were very ill, how would going to the psychiatric hospital affect your life?

Consequences-1

Consequences-1 ☐

Inquire-2: What would happen to you if you were very ill and you didn't go to a psychiatric hospital?

Consequences-2

Consequences-2 ☐

Appendix E (continued)

Final Choice Scoring Guidelines:

3 point rating scale	SCORING GUIDELINES
2	Subject's states a choice, or subject indicates desire for professional or other responsible person (e.g., relatives) to make the choice.
1	Subject states two or three choices, seems ambivalent.
0	Subject states no choice.

CP3f. FINAL CHOICE [HOSPITALIZATION]

Inquire: When I asked you a few minutes ago whether you would choose to go to the psychiatric hospital or not if you became very ill, you said that you (would/would not). What do you think now that we've discussed everything? Which would you want to do?

Choice	
	Choice ☐

Logical Consistency Scoring Guidelines:

3 point rating scale	SCORING GUIDELINES
2	Subject's final choice (in Expressing a Choice) follows logically from the subject's own reasoning, as explained by the subject in response to the three previous subparts.
1	It is not clear whether the choice follows logically from the subject's own reasoning.
0	Subject's choice clearly does not follow logically from subject's own reasoning.

CP3g. LOGICAL CONSISTENCY OF CHOICE [HOSPITALIZATION]

(Rate based on previous responses)

Examiner's Explanation	
	Logical Consistency ☐

Appendix E (continued)

Consumer Demographics and Functioning

- What is your birth date?
- Which of the following best describes your racial background:
    White ___
    Black ___
    American Indian ___
    Asian ___
    Pacific Islander ___
    Alaskan Native ___
    Other (specify below) ___

- Are you Spanish/Hispanic/Latino(a)? Yes(1) ___ No (0) ___

- RECORD GENDER AS OBSERVED Female___ Male___

Brief Psychiatric Rating Scale

Somatic

Somatic Concern Questions

- Have you been concerned about your physical health?
- Have you had any problems with your health lately?
- Have you had any physical illness or seen a medical doctor?
  [Follow-up to determine the extent of the subject's concern about these problems E.g., how much do these headaches worry you?]

X1. SOMATIC CONCERN: Degree of concern over present bodily health. Rate the degree to which physical health is perceived as a problem by the patient, whether the complaints have a realistic basis or not. Do not rate mere reporting of somatic symptoms. Rate only concerns for (or worrying about) physical problems (real or imagined).

1 Not Reported.

2 Very Mild; Occasionally is somewhat concerned about body, symptoms, or physical illness.

3 Mild; Occasionally is moderately concerned, or often is somewhat.

4 Moderate Severe; Occasionally is very concerned or often is moderately concerned.

5 Moderately Severe; Often is very concerned.

6 Severe; Is very concerned most of the time.

7 Very Severe; Is very concerned nearly all of the time.

Appendix E (continued)

Anxiety

Anxiety Questions

- Have you felt worried or anxious?
- Do unpleasant thoughts constantly go round and round in your head?
- Are there (other) things that you are worried about?
- Did your heart beat fast (or sweating, trembling, choking)?
- Has it interfered with your ability to perform your usual activities/work?
  [Follow-up to determine the extent of the subject's anxiety about these things. Do they make it hard for you to fall asleep? How much do your money problems worry you?]

X2. Anxiety: Worry, fear, or over concern for present or future. Rate solely on the basis of verbal report of patient's own subjective experiences. Do not infer anxiety from physical signs or from neurotic defense mechanisms. Do not rate if restricted to somatic concern.

1 Not reported.

2 Very mild; Occasionally feels somewhat anxious.

3 Mild; Occasionally feels moderately anxious, or often feels somewhat anxious.

4 Moderate; Occasionally feels very anxious, or often feels moderately anxious.

5 Moderately Severe; Often feels very anxious.

6 Severe; Feels very anxious most of the time.

7 Very Severe; Feels very anxious nearly all of the time.

Appendix E (continued)

Emotional Withdrawl

X3. Emotional Withdrawal: Deficiency in relating to the interviewer and to the interview situation. Overt manifestations of this deficiency include poor/absence of eye contact, failure to orient oneself physically toward the interviewer, and a general lack of involvement or engagement in the interview. Distinguish from BLUNTED AFFECT, in which deficits in facial expression, body gesture, and voice pattern are scored. Rate on the basis of observations made during the interview.

1 Not Observed.

2 Very Mild; e.g., Occasionally exhibits poor eye contact.

3 Mild; e.g., As above, but more frequent.

4 Moderate; e.g., Exhibits little eye contact, but still seems engaged in the interview and is appropriately responding to all questions.

5 Moderately Severe; e.g., Stares at floor or orients self away from interviewer, but still seems moderately engaged.

6 Severe; e.g., As above, but more persistent or pervasive.

7 Very Severe; e.g., Appears "spacey" or "out of it" (total absence of emotional relatedness) and is disproportionately uninvolved or unengaged in the interview. (DO NOT SCORE IF EXPLAINED BY DISORIENTATION.)

Conceptual Disorganization

X4. Conceptual Disorganization: Degree of speech incomprehensibility. Include any type of formal thought disorder (e.g., loose associations, incoherence, flight of ideas, neologisms). DO NOT include mere circumstantiality or pressured speech, even if marked. DO NOT rate on the patient's subjective impressions (e.g., "My thoughts are racing. I can't hold a thought." "My thinking gets all mixed up.") Rate ONLY on the basis of observations made during the interview.

1 Not Observed.

2 Very Mild; e.g., Somewhat vague, but of doubtful clinical significance.

3 Mild; e.g., Frequently vague, but the interview is able to progress smoothly; occasional loosening of associations.

4 Moderate; e.g., Occasional irrelevant statements, infrequent use of neologisms, or moderate loosening of associations.

5 Moderately Severe; As above, but more frequent.

6 Severe; Formal thought disorder is present for most of the interview, and the interview is severely strained.

7 Very Severe; Very little coherent information can be obtained.

Appendix E (continued)

Guilt Feelings

Guilt Feelings Questions

Have you been thinking about past problems?
Do you tend to blame yourself for things that have happened?
Have you done anything you're still ashamed of?
Are there things that you have done in the past that you feel guilty about?
[Follow-up to determine the extent of the subject's guilt. E.g. how badly do you feel when you think about having broken off your engagement?]

X5. Guilt Feelings: Overconcern or remorse for past behavior. Rate on the patient's subjective experiences of guilt as evidence by verbal report. Do not infer guilt feelings from depression, anxiety or neurotic defenses.

1 Not Reported.

2 Very Mild; Occasionally feels somewhat guilty.

3 Mild, Occasionally feels moderately guilty or often feels somewhat guilty.

4 Moderate; Occasionally feels very guilty or often feels moderately guilty.

5 Moderately Severe; Often feels very guilty.

6 Severe; Feels very guilty most of the time or encapsulated delusion of guilt.

7 Very Severe; Agonizing constant feeling of guilt or pervasive delusion(s) of guilt.

Tension

X6. Tension: Rate motor restlessness (agitation) observed during the interview. DO NOT rate on the basis of subjective experiences reported by the patient. Disregard suspected pathogenesis (e.g., tardive dyskinesia).

1 Not Observed.

2 Very Mild; e.g., Occasionally fidgets.

3 Mild; e.g., Frequently fidgets.

4 Moderate; e.g., Constantly fidgets or frequently fidgets, wrings hands and pulls clothing.

5 Moderately Severe; e.g., Constantly fidgets, wrings hands and pulls clothing.

6 Severe; e.g., Cannot remain seated (i.e., must pace).

7 Very Severe; e.g., Paces in a frantic manner.

Mannerisms and Posturing

X7. Mannerisms and Posturing: Unusual and unnatural motor behavior. Rate only abnormality of movements. Do not rate simple heightened motor activity here. Consider frequency, duration and degree of bizarreness. Disregard suspected pathogenesis.

1 Not Observed.

2 Very Mild; e.g., Odd behavior but of doubtful clinical significance, e.g., occasional unprompted smiling, infrequent lip movements.

3 Mild; e.g., Strange behavior but not obviously bizarre, e.g., infrequent head-tilting (side to side) in a rhythmic fashion, intermittent abnormal finger movements.

4 Moderate; e.g., Assumes unnatural position for a brief period of time, infrequent tongue protrusions, rocking, facial grimacing.

5 Moderately Severe; e.g., Assumes and maintains unnatural position throughout interview, unusual movements in several body areas.

6 Severe; As above, but more frequent, intense, or pervasive.

7 Very Severe; e.g., Bizarre posturing throughout most of the interview, continuous abnormal movements in several body areas.

Appendix E (continued)

Grandiosity

Grandiosity Questions

- Is there a special purpose or mission to your life?
- Have you thought that you might be somebody rich or famous?
- Do you have powers or abilities that most people don't have?
  [IF YES:] Could you tell me about them?
  [Follow-up to determine the extent of the subject's belief in the uniqueness of his/her powers. E.g., how many people do you think can play the guitar as well as you do?]

X8. Grandiosity: Inflated self-esteem (self-confidence) or inflated appraisal of one's talents, powers, abilities, accomplishments, knowledge, importance, or identity. Do not score mere grandiose quality of claims (e.g., "I'm the worst sinner in the world," "The entire country is trying to kills me") unless the guilt/persecution is related to some special exaggerated attribute of the individual. Also, <u>the patient must claim exaggerated attributes</u>; e.g., If patient denies talents, powers, etc., even if he/she states that others indicate that he/she has these attributes, this item should not be scored.

1 Not reported.

2 Very mild; e.g., Is more confident than most people, but of only possible clinical significance.

3 Mild; e.g., Definitely inflated self-esteem or exaggerates talents somewhat out of proportion to the circumstances.

4 Moderate; e.g., Inflated self esteem clearly out of proportion to the circumstances, or suspected grandiose delusion(s).

5 Moderately severe; e.g., A single (definite) encapsulated grandiose delusion, or multiple (definite) fragmentary grandiose delusions.

6 Severe; e.g., A single (definite) grandiose delusion/delusional system, or multiple (definite) grandiose delusions that the patient seems preoccupied with.

7 Very Severe; e.g., As above, but nearly all conversation is directed toward the patient's grandiose delusion(s).

Appendix E (continued)

Depressive Mood

Depressive Mood Questions

- Have you felt unhappy or depressed?
- Have you been feeling sad lately?
  [Follow-up to determine the extent of the subject's sadness (duration, frequency)]
- How much of the time?
- Are you able to switch your attention to more pleasant topics when you want to?
- Have your interests in work, hobbies, social or recreational activities changed?
- Has it interfered with your ability to perform your usual activities/work?

X9. Depressive Mood: Subjective report of feeling depressed, blue, "down in the dumps, etc. Rate only the degree of reported depression. Do not rate on the basis of inferences concerning depression based upon general retardation and somatic complaints.

1 Not Reported.

2 Very Mild; Occasionally feels somewhat depressed.

3 Mild; Occasionally feels moderately depressed or often feels somewhat depressed.

4 Moderate; Occasionally feels very depressed or often feels moderately depressed.

5 Moderately Severe; Often feels very depressed.

6 Severe; Feels very depressed most of the time.

7 Very Severe; Feels very depressed nearly all of the time.

Appendix E (continued)

Hostility

Hostility Questions

- How have you been getting along with people (family, board and-care residents, co-workers)?
- Have you been irritable or grumpy lately?
- Have you been involved in any arguments or fights?
- Are there people at whom you are angry?
  [IF YES:] what is it about them that annoys you?
  [Follow-up to determine extent of anger. E.g., how much do you find yourself thinking about your neighbor? Do you ever yell at him? Throw things at him? Get into physical fights with him?]

X10. Hostility: Animosity, contempt, belligerence, disdain for other people outside the interview situation. Rate solely on the basis of the verbal report of feelings and actions of the patients toward others. Do not infer hostility from neurotic defenses, anxiety, or somatic complaints.

1 Not reported.

2 Very mild; Occasionally feels somewhat angry.

3 Mild: Often feels somewhat angry or occasionally feels moderately angry.

4 Moderate; Occasionally feels very angry or often feels moderately angry.

5 Moderately Severe; Often feels very angry.

6 Severe; Has acted on his anger by becoming verbally or physically abusive on one or two occasions.

7 Very Severe; Has acted on his anger on several occasions.

Appendix E (continued)

Suspiciousness

Suspiciousness Questions

- Do you ever feel uncomfortable as if people are watching you?
- Is anyone trying to harm or interfere with you in any way?
- Are you concerned about anybody's intentions toward you?
- Have you felt that any people are out to get you?
  [IF YES:] Could you tell me what they tried [are trying] to do to you?
  [Follow-up to determine extent of suspiciousness. E.g., do you have any doubt that your professor gave you an "F" to get even with you for disagreeing with him in class?]

X11. Suspiciousness: Belief (delusional or otherwise) that others have now, or have had in the past, malicious or discriminatory intent toward the patient. On the basis of verbal report, rate only those suspicions which are currently held, whether they concern past or present circumstances.

1 Not reported.

2 Very Mild; Rare instances of distrustfulness which may or may not be warranted t the situation.

3 Mild; Occasional instances of suspiciousness.

4 Moderate; More frequent suspiciousness.

5 Moderately Severe; Pervasive suspiciousness.

6 Severe; Definite delusion(s) of reference or persecution that is/are not wholly pervasive (e.g., an encapsulated delusion).

7 Very Severe; As above, but more widespread, frequent, or intense.

Appendix E (continued)

Hallucinatory Behavior

Hallucinatory Behavior Questions

- In the last week, have you heard any sounds or people talking to you or about you when there has been nobody around?
- Have you seen things that other people couldn't see?
- Have you seen any visions or smelled any smells others don't seem to notice?
- Have these experiences interfered with your ability to perform your usual activities/work?

[IF YES:] Could you tell me what you heard [saw?]
[IF AUDITORY:] Were the voices coming from outside of your head?
[Follow-up to determine the extent of hallucinatory perceptions. E.g., how often do you hear the voices? Do they ever leave you alone?]

X12. Hallucinatory Behavior: Perceptions (in any sense modality) in the absence of an identifiab external stimulus. Rate only those experiences that have occurred during the last week. DO NOT rate "voices in my head" or "visions in my mind" unless the patient can differentiate between thes experiences and thoughts.

1 Not Reported.

2 Very Mild; Suspected hallucinations only.

3 Mild; Definite hallucinations, but insignificant, infrequent, or transient (e.g., occasional formless visual hallucinations, a voice calling the patient's name).

4 Moderate; As above, but more frequent or extensive (e.g., frequently sees the devil's face, two voices carry on a lengthy conversation).

5 Moderately Severe; Hallucinations are experienced nearly every day or are a source of extreme distress.

6 Severe; As above and has had a moderate impact on the patient's behavior (e.g., concentration difficulties leading to impaired work functioning).

7 Very Severe; As above and has had a severe impact (e.g., attempts suicide in response to command hallucinations).

Appendix E (continued)

Motor Retardation

X13. Motor Retardation: Reduction in energy level evidenced in slowed movements. Rate on the basis of observed behavior of the patient only. Do not rate on the basis of the patient's subjective impression of this or her own energy level.

1 Not Observed.

2 Very Mild; Of doubtful clinical significance.

3 Mild; e.g., Conversation is somewhat retarded, movements somewhat slowed.

4 Moderate; e.g., Conversation is notably retarded but not strained.

5 Moderately Severe; e.g., Conversation is strained, moves very slowly.

6 Severe; e.g., Conversation is difficult to maintain, hardly moves at all.

7 Very Severe; e.g., Conversation is almost impossible, does not move at all throughout the interview.

Uncooperativeness

X14. Uncooperativeness: Evidence of resistance, unfriendliness, resentment, and lack of readiness to cooperate with the interviewer. Rate solely on the basis of the patient's attitude and responses to the interviewer and the interview situation. Do not rate on the basis of reported resentment or uncooperativeness outside the interview situation.

1 Not Observed.

2 Very Mild; e.g., Does not seem motivated.

3 Mild; e.g., Seems evasive in certain areas.

4 Moderate; e.g., Monosyllabic, fails to elaborate spontaneously, somewhat unfriendly.

5 Moderately Severe; e.g., Expresses resentment and is unfriendly throughout the interview.

6 Severe; e.g., Refuses to answer a number of questions.

7 Very Severe; e.g., Refuses to answer most questions.

Appendix E (continued)

Unusual Thought Content

Unusual Thought Content Questions

- Do you sometimes have ideas that other people might consider unusual?
- Did you see any references to yourself on TV or in the newspaper?
- Do you have a special relationship with God?
- How do you explain the things that have been happening (specify?)
- Have you felt that you were under the control of another person or force?
  [IF YES] Could you tell me about them?
  [Follow-up to determine the oddness of the thoughts]

X15. Unusual Thought Content: Severity of delusions of any type - consider conviction and effect on actions. Assume full convictions if patient has acted on his of her beliefs.

1 Not Reported.

2 Very mild; Delusion(s) suspected or likely.

3 Mild; At times, patient questions his or her belief(s) (partial delusion).

4 Moderate: Full delusional conviction, but delusion(s) has little or not influence on behavior.

5 Moderately Severe; Full delusional conviction, but delusion(s) has only occasional impact on behavior.

6 Severe; Delusion(s) has significant effect, e.g., neglects responsibilities because of preoccupations with belief that he/she is God.

7 Very Severe; Delusion(s) has major impact, e.g., stops eating because believes food is poisoned.

Appendix E (continued)

Blunted Affect

X16. Blunted Affect: Diminished affective responsivity, as characterized by deficits in facial expression, body gesture, and voice pattern. Distinguish from Emotional Withdrawal, in which the focus is on interpersonal impairment rather than affect. Consider degree and consistency of impairment. Rate based on observations made during interview.

1. Not Observed.
2. Very mild; e.g., Occasionally seems indifferent to material that is usually accompanied by some show of emotion.
3. Mild; e.g., Somewhat diminished facial expression or somewhat monotonous voice or somewhat restricted gestures.
4. Moderate; e.g., As above, but more intense, prolonged, or frequent.
5. Moderately Severe; e.g., Flattening of affect, including at least two of the three features: severe lack of facial expression, monotonous voice, or restricted body gestures.
6. Severe; e.g., Profound flattening of affect.
7. Very Severe; e.g., Totally monotonous voice and total lack of expressive gestures throughout the evaluation.

Excitement

X17. Excitement: Heightened emotional tone, including irritability and expansiveness (hypomanic affect). Do not infer affect from statements or grandiose delusions. Rate based on observations made during the interview.

1. Not Observed.
2. Very Mild and of doubtful clinical significance.
3. Mild; e.g., Irritable or expansive at times.
4. Moderate; e.g., Frequently irritable or expansive.
5. Moderately Severe; e.g., Constantly irritable or expansive or at times enraged or euphoric.
6. Severe; e.g., Enraged or euphoric throughout most of the interview.
7. Very Severe; e.g., As above, but to such a degree that the interview must be terminated prematurely.

Disorientation

X18. Disorientation: Confusion or lack of proper association for person place or time. Rate based on observations made during the interview (and information from Section L [cognitive functioning]).

1 Not Observed.

2 Very mild; e.g., Seems somewhat confused.

3 Mild; e.g., Indicates 1991 when in fact it is 1992.

4 Moderate; e.g., Indicates 1978.

5 Moderately Severe; e.g., Is unsure where he/she is.

6 Severe; e.g., Has no idea where he/she is.

7 Very Severe; e.g., Does not know who he/she is.

Appendix E (continued)

Global Assessment of Functioning

GLOBAL ASSESSMENT OF FUNCTIONING SCALE

Y1. Consider psychological, social, and occupational functioning on a hypothetical continuum of mental health-illness. Do not include impairment in functioning due to physical (or environmental) limitations.

Code (Note: Use intermediate codes when appropriate, e.g., 45, 68, 72.)

☐☐☐

100 91	**Superior functioning in a wide range of activities, life's problems never seem to get out of hand, is sought out by others because of his or her many positive qualities.** No symptoms
90 81	**Absent or minimal symptoms** (e.g., mild anxiety before an exam), **good functioning in all areas, interested and involved in a wide range of activities, socially effective, generally satisfied with life, no more than everyday problems or concerns** (e.g., an occasional argument with family members).
80 71	**If symptoms are present, they are transient and expectable reactions to psychosocial stressors** (e.g., difficulty concentrating after family argument); **no more than slight impairment in social, occupational, or school functioning** (e.g., temporarily falling behind in school work).
70 61	**Some mild symptoms** (e.g., depressed mood and mild insomnia) **OR some difficulty in social occupational, or school functioning** (e.g., occasional truancy, or theft within the household), **but generally functioning pretty well, has some meaningful interpersonal relationships.**
60 51	**Moderate symptoms** (e.g., flat affect and circumstantial speech, occasional panic attacks) **OR moderate difficulty in social, occupational, or school functioning** (e.g., few friends, conflicts with peers or co-workers).
50 41	**Serious symptoms** (e.g., suicidal ideation, severe obsessional rituals, frequent shoplifting) **OR any serious impairment in social, occupational, or school functioning** (e.g., no friends, unable to keep a job).
40 31	**Some impairment in reality testing or communication** (e.g., speech is at times illogical, obscure, or irrelevant) **OR major impairment in several areas, such as work or school, family relations, judgment, thinking, or mood** (e.g., depressed man avoids friends, neglects family, and is unable to work; child frequently beats up younger children, is defiant at home, and is failing at school).
30 21	**Behavior is considerably influenced by delusions or hallucinations OR serious impairment in communication or judgment** (e.g., sometimes incoherent, acts grossly inappropriately, suicidal preoccupation) **OR inability to function in almost all areas** (e.g., stays in bed all day; no job, home, or friends).
20 11	**Some danger of hurting self or others** (e.g., suicide attempts without clear expectation of death; frequently violent; manic excitement) **OR occasionally fails to maintain minimal personal hygiene** (e.g., smears feces) **OR gross impairment in communication** (e.g., largely incoherent or mute).
10 1	**Persistent danger of severely hurting self or others** (e.g., recurrent violence) **OR persistent inability to maintain minimal personal hygiene OR serious suicidal act with clear expectation of death.**

Appendix E (continued)

Alcohol and drug use

- In the last 30 days ...

Have you felt you ought to cut down on your drinking?
Yes(1) ___ No (0) ___
Have people annoyed you by criticizing your drinking?
Yes(1) ___ No (0) ___
Have you felt bad or guilty about your drinking?
Yes(1) ___ No (0) ___
Have you had a drink first thing in the morning to steady your nerves or get rid of a hangover (eye-opener)?
Yes(1) ___ No (0) ___

- In the last 30 days …

Have you felt you ought to cut down on your drug use?
Yes(1) ___ No (0) ___
Have people annoyed you by criticizing your drug use?
Yes(1) ___ No (0) ___
Have you felt bad or guilty about your drug use?
Yes(1) ___ No (0) ___
Have you taken drugs to steady your nerves or to stop symptoms of withdrawal?
Yes(1) ___ No (0) ___

Clinician demographics and professional characteristics

- What is your birth date?

- Which of the following best describes your racial background:
  White ___
  Black ___
  American Indian ___
  Asian ___
  Pacific Islander ___
  Alaskan Native ___
  Other (specify below) ___

- RECORD GENDER AS OBSERVED Male___ Female___

Appendix E (continued)

- o How many years of mental health experience have you had (excluding time spent in training)?

- o What is your highest degree? (Check one)

High school	___
Some college	___
BA/BS	___
MSW	___
M.A./M.S./M.Ed./Other Master's	___
RN	___
M.D	___
Ph.D.	___
Other (Specify Below)	___

- o For how many clients do you currently act as the primary case manager, clinician or care coordinator?

PAD Purposes

P1. When you think about making a psychiatric advance directives there are several things that may be more or less important to you. Please look at these 5 cards that have several things that may be important to you. Please put these 5 cards in order to show how important these things are to you. Start with the one that is most important to you and work your way down to the one that is least important. [Show Blue Cards and read choices]

[Interviewer: Record answers so that:
The LEAST important = 1
And the MOST important = 5]

☐ a. Being free to change my mind about my treatment even when I am very ill

☐ b. Getting the treatment that my doctor thinks is best for me.

☐ c. Having a family or friend make decisions about my treatment when I am very ill.

☐ d. Avoiding treatment I don't want.

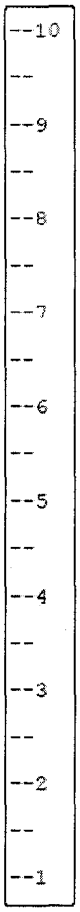
☐ e. Getting whatever treatment that works best for me.

Appendix E (continued)

You said that [most important--card =5] was most important to you [confirm]. [Next card= 5] is somewhat less important than [card = 5]. Can you put these card on this scale so it shows how important it is to you on a scale of 1 to 10?

So on a scale of 1 to 10 how important is [card = 5] to you?

[Repeat for card = 4 to card = 1.]



[SHOW THERMOMETER CARD, Card #7.]

[Interviewer: Record thermometer ratings here.]

☐☐.☐☐ a. Being free to change my mind about my treatment even when I am very ill.

☐☐.☐☐ b. Getting the treatment that my doctor thinks is best for me.

☐☐.☐☐ c. Having a family or friend make decisions about my treatment when I am very ill.

☐☐.☐☐ d. Avoiding treatment I don't want.

☐☐.☐☐ e. Getting whatever treatment that works best for me.