Hear me when I’m well: A convergent parallel mixed methods study of Psychiatric Advance Directives in Virginia

Anne Metz  
James Madison University

Follow this and additional works at: https://commons.libjmu.edu/diss201019

Part of the Other Psychiatry and Psychology Commons

Recommended Citation


https://commons.libjmu.edu/diss201019/170

This Dissertation is brought to you for free and open access by the The Graduate School at JMU Scholarly Commons. It has been accepted for inclusion in Dissertations by an authorized administrator of JMU Scholarly Commons. For more information, please contact dc_admin@jmu.edu.
Hear me when I’m well: a convergent parallel mixed methods study of

Psychiatric Advance Directives in Virginia

Anne Loyer Metz

A dissertation submitted to the Graduate Faculty of

JAMES MADISON UNIVERSITY

In

Partial Fulfillment of the Requirements

for the degree of

Doctor of Philosophy

Department of Graduate Psychology

May 2018

FACULTY COMMITTEE:

Committee Chair: A. Renee Staton, PhD

Committee Members/ Readers:

Cara Meixner, PhD

Michele Kielty, PhD
Acknowledgements

I am fortunate to have had so many colleagues supporting me in the writing of this dissertation. First, I would like to sincerely thank my chair Dr. A. Renee Staton, who has patiently shepherded me through this entire process, and somehow managed to always be two steps ahead of things. Her wisdom, sharp instincts, and enthusiasm were invaluable, and I am grateful to have had her as a teacher and mentor.

Many thanks as well are due to my committee. To the superb methodologist Dr. Cara Meixner, who provided guidance on practically every detail of the study structure, and has fostered an interest in doing more research in the future. Thanks as well to Dr. Michele Kielty, who was so generous with her time and encouraging with her feedback. I am also grateful to Dr. Debbie Sturm and Dr. Lennie Echterling, who have been unwavering champions during my time at JMU. Thank you for seeing potential in me, and taking the time to foster it. I would also like to share my gratitude to Dr. Jennifer Cline and the soon-to-be Dr. Michael Horst whose company and conversation will be my best and most enduring memories of my doc program.

I would also like to thank Prof. Richard Bonnie of the University of Virginia, who generously offered me the opportunity to work on this project. This dissertation would not have been possible without the help of Dr. Heather Zelle, Dr. Cynthia Elledge, and Elena Diller of ILPPP, who provided practical support on through the Advance Directives Project here in Virginia. Many thanks as well to Jennifer Myers and Bob Tucker at Valley Community Services Board. They are without question, two of the most dedicated and hardest working people I have ever met.
I am especially grateful to my parents who have shown me so much love over the years, and have always trusted that I would — somehow — land on my feet. And finally, many thanks to Barton Biggs, who read, edited, and challenged every obvious conclusion. Your independent mind inspires me. I thank you for your love, support, and patience.
# Table of Contents

Acknowledgements............................................................................................................. ii
List of Tables ......................................................................................................................... vi
List of Figures ......................................................................................................................... vii
Abstract.................................................................................................................................. viii

Introduction............................................................................................................................... 1
  The Revolving Door .................................................................................................................. 1
  Psychiatric Advance Directives ............................................................................................... 3
  History of Psychiatric Advance Directives .............................................................................. 4
  PADs in practice ....................................................................................................................... 6
  PADs in Virginia ....................................................................................................................... 7
  Statement of the Problem ......................................................................................................... 11
  Purpose statement and Research Questions .......................................................................... 14
  Hypotheses .............................................................................................................................. 16
  Overview of chapters .............................................................................................................. 16

Literature Review...................................................................................................................... 18
  Introduction .............................................................................................................................. 18
  Empowerment ....................................................................................................................... 19
  Psychiatric Advance Directives .............................................................................................. 27
  PAD studies in Virginia .......................................................................................................... 47
  Limitations .............................................................................................................................. 53
  Conclusion ............................................................................................................................... 55

Methods.................................................................................................................................. 57
  Philosophical Foundation ....................................................................................................... 57
  Design ..................................................................................................................................... 58
  Quantitative strand ................................................................................................................. 60
  Qualitative strand ................................................................................................................... 65
  Mixed methods ....................................................................................................................... 69
  Trustworthiness ...................................................................................................................... 70
  Conclusion ............................................................................................................................... 73

Results.................................................................................................................................... 75
  Introduction .............................................................................................................................. 75
  Quantitative strand results..................................................................................................... 75
List of Tables

Table 1. Survey Respondent Demographics by Gender ........................................ 111
Table 2. Stakeholder Group Demographics by Race/Ethnicity ............................ 112
Table 3. Respondent Demographics by current profession and setting ............. 113
Table 4. Survey Respondent Demographics by education ................................. 114
Table 5. Survey Respondents by Familiarity with PADs .................................. 115
Table 6. PADs are discussed with consumers ................................................. 116
Table 7. PAD forms are provided to consumers .............................................. 117
Table 8. Consumers are assisted in completing PAD forms ............................... 118
Table 9. Written documentation of whether consumers have PADs ............... 119
Table 10. Descriptive Statistics for OPADQ Scores ......................................... 120
Table 11. Univariate Tests for OPADQ Total & subscale scores ...................... 121
Table 12. Post Hoc Comparisons of Stakeholder groups ................................. 122
Table 13. Correlations between RQ2 themes and UB subscores ..................... 123
Table 14. Correlations between RQ3 themes and OS subscores ....................... 124
Table 15. Joint Display Table of Themes and Quantitative Results – RQ2 ...... 125
Table 16. Joint Display Table of Themes and Quantitative Results – RQ3 ...... 126
Table 17. Tests of Between-Subjects Effects for Advocacy and UB Scores ..... 127
Table 18. Descriptive statistics for Clinicians and Clinician Advocates .......... 128
Table 19. T-test comparing Clinician & Clinician-Advocate OPADQ scores . 129
Table 20. Familiarity does seem to influence UB Scores .................................. 130
Table 21. Post Hoc Tests for Familiarity Effect on UB Scores ......................... 131
List of Figures

Figure 1. Methodology for Convergent Parallel Mixed Method Design .................132
Figure 2. Qualitative Themes by Research Questions ........................................133
Abstract

Psychiatric advance directives (PADs) are legal documents that allow individuals to express their wishes and desires regarding potential future psychiatric care. PADs have been theorized as a way to empower individuals through improved clinical outcomes, reduced coercion, and minimized involvement of individuals with mental illness in the criminal justice system. Since 2010, the Commonwealth of Virginia has had legislation in place to support the use of these advance planning documents. The purpose of this convergent parallel mixed methods study was to enhance our understanding of PADs in Virginia. Quantitative and qualitative data were collected concurrently via survey and follow-up interview procedures. Member checking, triangulation, and audit trail were used to ensure trustworthiness. These stands were analyzed separately and then mixed in the interpretation phase to provide a comprehensive understanding of PADs in Virginia and make recommendations for fostering their use in the state.

Keywords: psychiatry, law, mental health, incapacity
CHAPTER 1

Introduction

The Revolving Door

Individuals with serious mental illness (SMI) are a marginalized, stigmatized, and often voiceless population of mental health care consumers (Corrigan, 1999). In 2014, there were an estimated 9.8 million adults aged 18 or older in the United States with serious mental illnesses, such as bipolar disorder, schizophrenia, or major depressive disorder. This number represents 4.2% of all U.S. adults (Center for Behavioral Health Statistics and Quality, 2015). Individuals with SMI often experience periods of stability between episodic or acute crises. During these times of crisis, individuals may become incapacitated such that they are unable or unwilling to make healthcare decisions to protect themselves from undue harm, and in these cases they may be subject to involuntary treatment (Center for Behavioral Health Statistics and Quality, 2015).

Researchers have argued that involuntary or coercive treatment contributes to the “revolving door” phenomenon in mental health treatment (Davis, 1975). The revolving door describes a population of individuals experiencing chronic SMI frequently readmitted to psychiatric units due to noncompliance following discharge. Disempowered, discouraged, and stigmatized by the experience of forced hospitalization, coerced individuals may find themselves feeling mistrustful of the mental health care system. This, in turn, discourages people from following through on discharge plans. Features of certain disorders, such as impaired reasoning and judgment, poor insight, and decisional incapacity can also intensify the likelihood of poor follow-through (Zelle, Kemp, & Bonnie, 2015a). This cycle of coercion and system mistrust can lead to additional psychiatric crises and subsequent hospitalizations (Davis, 1975; Montgomery & Kirkpatrick, 2002).
The revolving door has a high cost to individuals, their families, and society (Insel, 2008; Knapp, 1997; Rossler, Salize, van Os, & Riecher-Rossler, 2005). Those involved in the revolving door phenomenon die an average of 25 years earlier than the general population due to treatable medical conditions (Parks, Svendsen, Singer, Foti, & Mauer, 2006) and are at an increased risk of suicide (Ward, Ishak, Proskorovsky, & Caro, 2006) and interpersonal violence (Alia-Klein, O'Rourke, Goldstein, & Malaspina, 2007). The difference between individuals with SMI and the general population is particularly pronounced among women. Research suggests that women with SMI had four-, ten- and four-fold increases in the odds of experiencing domestic, community, and sexual violence, respectively (Khalifeh et al., 2015). These negative outcomes are compounded among those with co-occurring substance disorders (Adams & Scott, 2000; Swanson, 2004). The revolving door is also financially costly. Estimates suggest that SMI costs the American economy $193.2 billion each year (Insel, 2008).

For the most part, the systemic response to the revolving door has been to expand coercive treatment through legal means (McGarvey, Leon-Verdin, Wanchek, & Bonnie, 2013; Swartz et al., 1999; Swanson et al., 2000). Virginia expanded its coercive treatment laws twice over the past decade, once in 2008 following the Virginia Tech Shooting, and then again in 2014 following the Creigh Deeds tragedy (Bonnie, Reinhard, Hamilton, & McGarvey, 2009; Vozzella, 2014). In addition to new civil commitment laws, coercive treatment practices have also expanded in more informal ways. For instance, Virginia requires evidence that an individual's condition poses a threat of “imminent danger” for the courts to override that individual’s objection to mental health intervention (McGarvey et al., 2013). Yet in practice, treatment objections by individuals with SMI are overridden even in instances where there is no imminent danger (Hashmi, Shad, Rhoades, & Parsaik, 2014; Stulz, Nevely, Hilpert, Bielinski, Spisla,
Maeck, & Hepp, 2015). Researchers argue that this gap between the law and its practical execution is not due to a clinical error (Turkheimer & Parry, 1992). This informal expansion of involuntary treatment is due to a lack of less restrictive alternatives to hospitalization, such as outpatient crisis stabilization centers (Turkheimer & Parry, 1992).

Unfortunately, studies suggest that the routine use of legal coercion to treat seriously ill individuals can have adverse consequences (Swartz, Swanson, & Hanson, 2003). Coercion may be experienced as traumatic, counter-therapeutic, and stigmatizing, and may further discourage those with mental illness from seeking the treatment needed to manage and recover from acute psychiatric episodes (Swanson et al., 2003; Swartz et al., 2003; Theodoridou et al., 2012). The deprivation of choice through coercion has also been associated with quality of life implications, including higher poverty rates, lower education levels, increased mortality rates, and increased unemployment (Colton & Manderscheid, 2006; Kosciulek, 1998; Priebé, Katsakou, Amos, Leese, M., Morriss, Rose, & Yeeles, 2009). In total, repeat experiences with treatment imposed over objection appear to thwart the healthy development and recovery of individuals with SMI.

Psychiatric Advance Directives

Studies demonstrating the negative impact of coercive treatment have fueled interest in psychiatric advance directives (PADs). PADs are legal documents that allow individuals to express their wishes and desires regarding potential future psychiatric care (Bonnie, 2012). PADs also allow individuals to legally authorize a proxy who can make healthcare decisions on their behalf when they are in crisis. The advanced instructions (AI) and proxy designations (also known as Health Care Power of Attorney or HCPA) within PADs are designed to help individuals with serious mental illness (SMI) manage future psychiatric crises. Advocates argue
PADs could reduce the need for coercion through client empowerment (Bonnie, 2012; Scheyett, Kim, Swanson, & Swartz, 2007; Swanson, Tepper, Backlar, & Swartz, 2000).

PADs also offer a promising approach to the revolving door syndrome by providing a platform for collaborative treatment planning (Srebnik, & La Fond, 1999). With a PAD, individuals can specify their treatment preferences when they are well and have full capacity for decision-making (Scheyett et al., 2007, Swanson et al., 2000). Then, in the event of a psychiatric emergency, consumers can expect that the health care system will acknowledge and honor their stated treatment preferences. By specifying these wishes in a legally binding document, PADs empower individuals with SMI to retain as much control as possible over their lives and their psychiatric care. It is speculated that PADs could also play a significant role in reducing coercion (Bonnie, 2012; Swanson et al., 2000) and improving long-term clinical outcomes for individuals with SMI through better treatment engagement and enhanced therapeutic alliance (Scheyett et al., 2007; Swanson et al., 2000).

**History of Psychiatric Advance Directives**

When a person is unable to indicate his or her preferences or give consent due to incapacity, treatment decisions are typically given over to family members, health care providers, or the legal system. Medical advance directives emerged as a way for individuals to retain control in situations of incapacity. Medical advance directives emerged in state and federal law following two high-profile legal cases, involving Karen Ann Quinlan (“In Re Quinlan,” 1976) and Nancy Cruzan (“Cruzan v. Missouri Department of Health,” 1990). Karen Ann Quinlan was a 21-year-old woman in a persistent vegetative state. After several months of deterioration, Quinlan’s family requested to discontinue the use of a ventilator so she could die naturally. Initially, the hospital refused this request. The New Jersey Supreme court asserted that
in the absence of any conclusive evidence of Quinlan’s wishes, her rights to privacy and choice could be “asserted on her behalf by her guardians” (In Re Quinlan, 1976, p. 34). Citing self-determination, best interests, and equality, the court recognized that patients have a constitutional right to refuse treatment even if they are unable or incompetent to make the decision.

The Quinlan decision influenced the outcome of the Cruzan case over a decade later. *Cruzan v. Director of Missouri Department of Health* (1990) involved Nancy Cruzan, a 25-year-old in a persistent vegetative state following a motor vehicle accident. After a period of deterioration without improvement, Cruzan's family requested that her feeding tube be removed. This request was based on a conversation between Ms. Cruzan and a friend, in which Cruzan stated that she would not want to be kept alive through artificial means without the hope of recovery. Initially, the Missouri Supreme Court denied the request based on the requirements of informed consent. The U.S. Supreme Court eventually upheld the state court's decision, ruling that the Due Process Clause allowed for treatment refusal by competent adults, but not by incompetent or incapacitated adults in the absence of "clear and convincing evidence" of the person's wishes (*Cruzan v. Director*, 1990).

Van Dorn et al. (2010) point out that the Cruzan decision did not mandate that patients' wishes be written, but did highlight the challenge of meeting the "clear and convincing" standard with only a verbal conversation. In response to these court decisions, Congress passed the Patient Self-Determination Act (PSDA) in 1991, which required hospitals and other health care organizations to inform patients of their rights to create medical advance directives (Van Dorn, et al., 2010). Although the Quinlan and Cruzan decisions focused on medical advance directives, these cases also provided a framework for the development of psychiatric advanced directives (Van Dorn, et al., 2010). In 1970, Paul Applebaum wrote of ADs in the *New England Journal of*
Medicine, stating, “The idea’s undoubted appeal in medical settings is exceeded only by its potential utility on the psychiatric ward... It would permit rational treatment based on a patient’s own rational wishes” (Appelbaum, 1979, p. 788).

**PADs in practice**

PADs exist in nearly 2/3 of the states, however, what can be included in them, as well as the practices guiding the creation and use of advance directives, varies depending on location. In general, however, psychiatric advance directives involve three basic forms of anticipatory planning: informed consent to future treatment, a forecast of personal values, and the designation of a proxy decision-maker (Henderson, Swanson, Szmukler, Thornicroft & Zinkler, 2008). The three features of PADs are described below:

*Informed consent to future treatment.* As mentioned earlier in this chapter, SMI is often a chronic condition. Many individuals who experience mental illness will also go through times when, due to their illness, they are not able or willing to consent to treatment. With an advance directive, an individual has the option of providing consent to treatment in advance that is legally-binding even if they later refuse. This aspect of PADs is also sometimes referred to as the Ulysses Clause or protestation provision, which is described in more detail in the following section on Virginia's PAD policy.

*A forecast of personal values.* PADs also provide individuals with an opportunity to specify personal preferences for future treatment. These instructions can include details about who the individual would like to involve in treatment as well as where and which methods he or she would prefer to receive. Many PADs name preferred hospitals, medications that have been helpful in the past, as well as other psychosocial interventions that might be helpful in a crisis, such as recreational therapy or journaling (Srebnick & La Fond, 1999). Individuals with PADs
can also specify what treatments they do not want in the event of a behavioral emergency. For instance, a consumer could specify that they do not want to be secluded or would prefer medication restraint rather than physical restraint. Some PADs also specify treatments to avoid such as electroconvulsive therapy (ECT) or specific classes or formularies of medications. Many who complete PADs also choose to outline "warning signs" that may precede a crisis, such as sleep disturbance or paranoia (Henderson, Swanson, Szmukler, Thornicrof, & Zinkler, 2008).

While many who specify treatment preferences in their PAD hope that their wishes will be followed, this section is not legally binding.

The entrusting of someone to act as a proxy decision maker. Also known as advanced designation, PADs also allow an individual to legally authorize a proxy who can make healthcare decisions on their behalf when they are in crisis. Many choose to name a trusted member as a proxy decision maker. However, in the event that no reliable family members are available to serve as a proxy decision maker, an individual can name their treating clinician as their health care power of attorney or proxy decision maker.

**PADs in Virginia**

While federal law distinguishes between medical advanced directives and psychiatric advance directives, Virginia makes no distinction between the two (Zelle et al., 2015). Since the passing of the Health Care Decisions Act in 2009 (HCDA), Virginians have been able to create a single, integrated document that specifies medical, psychiatric, and end-of-life directions. This approach was intended to convey the belief that mental health is a critical part of a person’s overall health. Virginia’s integrated AD\(^1\) also reinforced the notion that general medical health

---

\(^1\) Virginia’s integrated AD will be referred to as a PAD in this dissertation. This categorization references the psychiatric portion of the integrated AD, rather than the medical or end-of-life instructions.
and behavioral health should ideally be integrated. This integration is thought to have a two-fold purpose: to improve health outcomes and reduce the stigma of separate treatment (Zelle, Kemp, & Bonnie, 2015b). Virginia’s PAD can include instructions and/or designation of a health care proxy who can make medical decisions for the person during periods of incapacity (Bonnie, 2012). These advance care documents may also contain individualized, patient-centered plans to prevent, manage, and recover from acute symptomatic crises. While consumers can specify their treatment preferences, physicians in Virginia retain the power to override the PAD in situations where a person has specified contra-indicated interventions (for example, refusing all psychiatric treatment).

*Ulysses Clause.* Virginia’s HCDA also includes an enforceable “Ulysses Clause,” in which a patient gives advance consent to hospitalization over his or her own future objection. The so-called Ulysses Clause is taken from a famous scene in Homer’s Odyssey, in which Ulysses tied himself to the ship’s mast while instructing his men -- whose ears are filled with wax -- to ignore whatever he says as they sail by the maddening sirens. These instructions are analogous to the protestation or Ulysses Clause in PADs: when I have a crisis, I want you to follow the instructions I am writing now while I am capable of making informed decisions, and not follow my objections later when I am incapable of making informed decisions (Virginia Advance Directives, 2016). Unlike other aspects of the PAD, a physician or a clinical psychologist who can testify that the consumer was competent and understands the implications of their consent to future treatment must sign the Ulysses Clause.

*Creating a PAD in Virginia.* The state of Virginia requires little for an advance directive to be considered legally binding. While there are pre-made forms available online to help consumers make decisions in organized ways, they are not required to make the document legal.
The only requirement is that the person signs the documents with two adults present to witness the signature. Consumers do not need an attorney to complete an AD, nor do they need a treating provider’s consent unless they add a protestation provision (i.e. Ulysses Clause). After completing a PAD, consumers are encouraged to provide copies of this document to their health care providers. It is recommended that consumers upload these documents onto the Virginia Department of Health (VDH) Advance Health Care Directive Registry and the US Living Will Registry. Storing the document in these registries ensures that if someone has a mental health crisis away from their home hospital or provider, the treating facility will have access to their PAD.

**PAD trends in Virginia.** In 2010, The Institute for Law, Psychiatry, and Public Policy conducted a study examining the utilization of PADs in Virginia (Wilder et al., 2013). Using survey procedures drawn from prior studies (Elbogen et al., 2006; Swanson, Swartz, Ferron, Elbogen, & Van Dorn, 2006b; Swartz et al., 2005), the researchers collected quantitative baseline data that identified knowledge, attitudes, use, and key barriers affecting the use of these legal innovations among five stakeholder groups (consumers, clinicians, administrators, advocates, and family members) in Virginia. This study indicated that there was high demand for PADs among all five groups as well as significant barriers to implementation. Similar studies conducted nationwide and in North Carolina pointed to a gap between the level of demand for PADs and their actual utilization, as well as significant barriers to implementation (Kim et al., 2008; Swanson, Swartz, Ferron, Elbogen, & Van Dorn, 2006a; Van Dorn et al., 2006). These findings were consistent with the Wilder et al. (2013) study in Virginia. In response to the gap between utilization and demand, Swanson et al. (2006) conducted a randomized controlled trial of a facilitated advance directive intervention in North Carolina. The researchers discovered that
providing one-to-one facilitation increased PAD completion (84% for those who received facilitation versus 3% who did not receive facilitation), and improved satisfaction with treatment and treatment providers.

Utilizing a model based on Swanson et al.’s (2006) facilitation study, PAD advocates in Virginia worked to increase implementation of these legal tools through efforts to embed these documents into routine mental health care practices (Kemp, Zelle, & Bonnie, 2014). Initially, these efforts targeted Virginia's Community Services Boards (CSB), the state public mental health system (Zelle et al., 2015). Of the 40 CSBs in Virginia, five were identified as “vanguard sites” for piloting the one-on-one consumer case manager facilitation modeled after the Swanson et al. (2006) study. However, this approach was eventually abandoned due to high caseloads within the CSBs as well as the time-intensive nature of the one-on-one facilitation.

This initial effort to embed PAD completion into routine mental health services was quickly replaced by a more flexible approach to facilitation (Zelle et al., 2015). This more flexible approach enabled each CSB to deliver PAD facilitation services in ways that addressed consumer preferences or resource constraints. Zelle et al. (2015) identified three types of PAD facilitation that have continued across the state over the past four years. The first approach is one-on-one facilitation by staff, including case managers or designated PAD clinical facilitators (LPCs, LCSWs, MFTs, and LCPs). A second approach is a one-on-one education and facilitation by peer support specialists. Peer Support Specialists are people living in recovery with mental illness and / or substance use disorder and who provide support to others whom can benefit from their lived experiences. In this model, consumers are either self-referred or referred by a case manager. The third model is group education and facilitation in which consumers are provided with basic information about advance directives during the already-implemented CSB WRAP
(Wellness Recovery Action Plan) groups. Interested participants are then provided with opportunities for group facilitation. Since adopting this more flexible approach in how PADs are incorporated into routine mental health care, advocates have hoped that PAD utilization has increased across the state.

**Statement of the Problem**

Advance care planning has been a part of the U.S. healthcare system since 1990 when Congress enacted the Patient Self-Determination Act (PSDA). The PSDA was designed to allow for legally binding advance care planning in instances of incapacity. This federal legislation was followed by state-level statutes designed to promote greater use of advance directives. In 1992, Virginia enacted the Health Care Decisions Act (HCDA), which enabled Virginians to craft legally binding instructions for end-of-life care.

While HCDA was an important step in allowing individuals to document their values and wishes in the event of incapacity, this legislation was limited in scope. Unless a person had a terminal illness or was in a persistent vegetative state, there was no mechanism for individuals to record legally-binding instructions in other instances of incapacity, such as during a psychiatric crisis.

When it came to psychiatric incapacity, either due to treatment refusal or inability to give consent, individuals with mental illness were subject to involuntary or coercive treatment. Between 40-50% of these individuals with serious mental illness experience repeat hospitalization for psychiatric crisis due to noncompliance with treatment (Montgomery & Kirkpatrick, 2002). For this subset of the population, coercive or involuntary treatment is routine. However, research suggests that coercive treatment negatively impacts client recovery and often leads to repeat hospitalization (Swanson et al., 2003; Theodoridou et al., 2012). This revolving
door of hospitalization is also financially burdensome. Estimates suggest the revolving door phenomenon costs $193.2 billion each year to the American economy.

In the mid-2000s, advocacy groups in Virginia had grown concerned about the increasing reliance on involuntary and coercive methods to address treatment issues for individuals with serious mental illness. Influenced by the rise of the consumer empowerment movement, the state General Assembly authorized the Virginia Commission for Mental Health Reform. The Commission was tasked with the goal of identifying mental health reforms that could foster recovery while reducing reliance on coercive treatment.

Following three years of consensus-building among stakeholder groups, the Commission issued specific recommendations for mental health law reform. One key recommendation expands the scope of the HCDA to all forms of incapacity, not just end-of-life treatment. While innovative from a legal perspective, this extension of advance directives to psychiatric incapacity was not a new idea. Since the 1980s, the psychiatric and legal literature had proposed the idea of the psychiatric will, or the psychiatric advance directive (PAD). PADs had been theorized as a way to empower individuals, improve clinical outcomes, and reduce coercion. Though the research was limited at that time, preliminary studies on PADs suggested that PAD benefits were not merely theoretical, but were empirically supported (Scheyett, Kim, Swanson, & Swartz, 2007; Swanson, Tepper, Backlar, & Swartz, 2000).

The Commission recommended that Virginia adopt what was dubbed an “integrated advance directive.” These integrated (ADs²) allowed individuals to execute legally binding instructions for end-of-life care, general medical instructions, and psychiatric treatment. The

---

² Virginia’s integrated AD will be referred to as a PAD in this dissertation. This categorization references the psychiatric portion of the integrated AD, rather than the medical or end-of-life instructions
amended HCDA allowed people to designate a proxy decision maker in the event of incapacity, as well as protestation provision that enabled voluntary consent to treatment even over future objection. The hope was that these reforms might play a role in shifting practices around caring for serious mental illness in the state from coercion to one of empowerment and self-determination.

The Commission recognized that a new law was not enough to create meaningful social change. Since the passage of the amended HCDA in 2009/2010, PAD advocates have embarked upon unprecedented efforts to encourage advance planning throughout the state. For the implementation of HCDA to be successful, it was necessary to develop a clearer picture of how PADs were being used in Virginia.

In 2013, Wilder et al. published a quantitative study examining the knowledge, experience, and attitudes regarding the use of PADs among five stakeholder groups (clinicians, consumers, advocates, family members, and administrators). This baseline data suggested that there was strong support for PADs in Virginia, but that there were significant practical barriers to widespread use. The barriers included low PAD completion rates among consumers, a lack of clinician knowledge, limited facilitation resources, and cross-system communication issues. The barriers identified in this study have been addressed through bottom-up and top-down efforts throughout the state to foster the use of PADs by mental health consumers, and to provide practical assistance in completing and executing these legal documents.

These efforts have included additional legislative reforms, including the establishment of an online advance directive registry, increasing educational opportunities for clinicians, facilitation training, pilot studies within the Community Services Boards, and formal guidelines
from the Department of Behavioral Health and Developmental Services (Zelle, Kemp & Bonnie, 2015; Kemp, Zelle & Bonnie, 2015).

At the outset of this research study, it was unclear whether these efforts have had an impact on how PADs are perceived and used across the state. In this sense, our understanding of how implementation initiatives have influenced attitudes and utilization of PADs in Virginia remains incomplete. This knowledge gap indicates a need for additional research utilizing both qualitative and quantitative data in order to obtain a more robust picture of PADs in Virginia.

Whether or not the potential benefits of advance directives will ever be fully realized depends greatly on the stakeholders who utilize them. A greater understanding of how stakeholders perceive, use, and understand PADs in light of the implementation efforts over the past seven years could have significant implications for future clinical, education, and public policy initiatives.

**Purpose statement and Research Questions**

The purpose of this convergent parallel mixed methods design (Creswell & Plano-Clark, 2011) was to understand stakeholder perceptions, knowledge, utilization, and perceived barriers to psychiatric advance directives. This research was designed as a convergent parallel mixed methods study in order to provide a more complete, valid, and clinically useful understanding of PAD utilization in Virginia. Quantitative and qualitative data were gathered concurrently to determine how PAD utilization has converges and diverges among key stakeholder groups. Concurrent data was analyzed separately and then merged for integration.

In this study, quantitative and qualitative data were collected concurrently through a mixed method online stakeholder survey administered to participants from all five stakeholder groups. The quantitative survey data were collected to determine whether significant differences
exist between stakeholder groups on measures of PAD knowledge, attitudes, utilization and barriers.

The quantitative strand in phase one of this study was guided by the following research question:

- *Is there a statistically significant difference on measures of knowledge, attitudes, experience, and barriers regarding PADs between five stakeholder groups (clinicians, consumers, administrators, advocates, and family members) in Virginia?*

Qualitative data were also collected from two sources: via open-ended questions nested in the online stakeholder survey and topical semi-structured follow-up interviews. Both sources of qualitative data were collected to enhance understanding of what has continued to promote or thwart the use of PADs in Virginia, and to generate recommendations from participants regarding methods for increasing PAD utilization. The qualitative strand was guided by the following research questions:

- *What has encouraged the use of psychiatric advance directives in Virginia?*
- *What has discouraged the use of PADs in Virginia?*
- *What can be done to increase their utilization?*

Data collected from these strands were analyzed separately, and then merged to determine how qualitative data converged or diverged from the quantitative data.

This mixed methods study provided a richer understanding of the attitudes, knowledge, experiences and barriers regarding PADs in Virginia. This study is unique in that it will be the first mixed methods study of PADs in Virginia, and will likely yield valuable insights into what challenges remain in process of fully adopting these legal innovations within the mental health system.
Hypotheses

With regard to the quantitative research question (RQ1), I hypothesized that there would be a difference in all four domains of this study (attitudes, knowledge, experience, and barriers) between each of the stakeholder groups (clinicians, administrators, consumers, advocates, and family members). I predicted that there would be significant differences in the attitudes, knowledge, and experience towards PADs among stakeholders. Based on prior research, I hypothesized that the perception of PAD barriers would be most pronounced among clinicians and least pronounced among administrators.

In keeping with the constructivist paradigm of qualitative research, I did not generate a hypothesis for the qualitative research questions of this study (RQ2, RQ3, and RQ4). Rather I drew from the literature to identify several sensitizing concepts that might emerge in the qualitative parts of the survey and the follow up interviews with clinicians and advocates. These sensitizing concepts included the idea of power tensions between clinicians and consumers, and systematic barriers such as communication difficulties and time-concerns with regard to PAD completion. These idea helped frame the themes that emerged in the qualitative analysis of this study against the backdrop of prior research on PADs.

Overview of chapters

This dissertation consists of five chapters. Chapter one includes an introduction to the topic as well as the study’s research question, purpose statement, and hypotheses. Chapter two contains a review of the literature, which explores empowerment theory from a historical perspective. Included in chapter two is a critique of related prior research on PADs, as well as a rationale for this study based on the limitations of previous inquiries. Chapter three addresses methodology. In this chapter, I define the research paradigm, outline the theoretical lens of
inquiry, and describe the design, instrument, sample, data collection process, analysis procedures, study limitations, and ethical considerations. Chapter four presents the results of the separate strands as well as the mixed methods analysis. Chapter five summarizes the key findings of the study and applies these findings to the field of counseling.
CHAPTER 2

Literature Review

Introduction

Psychiatric advance directives (PADs) have been theorized as mechanisms of empowerment that can improve clinical outcomes, reduce reliance on coercion, and minimize the involvement of individuals with mental illness in the criminal justice system (Scheyett, Kim, Swanson, & Swartz, 2007; Swanson, Tepper, Backlar, & Swartz, 2000). Despite their hypothesized benefits, studies suggest that PADs remain underutilized due to multiple clinical and practical barriers (Swanson, Swartz, Ferron, Elbogen, & Van Dorn, 2006; Wilder et al., 2013). This chapter examines two areas of literature that are pertinent to the topic of this dissertation: empowerment theory and psychiatric advance directives research. Empowerment theory provides a rationale for using PADs in mental health care, while PAD studies provide a contextualized understanding of how the documents are used in practice. Taken together, these two bodies of literature provide both a theoretical and empirical framework for this proposed dissertation research.

The first section on empowerment theory provides a synopsis of this concept within a historical framework. This section draws from secondary and historical works written by clinicians, theorists, and scholars, and provides an ethical rationale for the use of PADs within the mental health care system. After examining empowerment, this chapter turns to a review of prior research on psychiatric advance directives to provide an understanding of how these legal tools have been used in clinical practice. This section begins with an exploration of early theoretical works written by prominent psychiatric and legal scholars, and then transitions to an analysis of empirical research. Covered in this review are prior stakeholder studies,
implementation studies, and finally, an examination of extant research on PADs in Virginia. The inclusion and exclusion criteria for this systematic review of PAD research are covered in the introduction to this section. Throughout this chapter, I identify both the contributions and the limitations of prior research on PADs. In doing so, I attempt to reveal both the knowledge and methodological gaps in our understanding of PADs here in Virginia, thereby providing a clear rationale for the mixed methods study of this dissertation.

**Empowerment**

*What is empowerment?*

PADs are said to empower people with mental illness. Although the term *empowerment* is a familiar one, it is not so easily defined. Empowerment can apply to a broad range of contexts from social reform to education to advertising. In the helping professions, such as counseling, social work, and psychology, empowerment has been incorporated into Codes of Ethics and the professional practices of these disciplines (McWhirter, 1997; Schwiebert & Giordano, 1994). Because empowerment is thought to be a potential benefit of PADs, it is worthwhile to provide a definition of this term as it pertains to this dissertation.

Linhorst (2006) argues that empowerment for individuals with mental illness involves eight related concepts. These eight related concepts include:

*Power, control, and influence*

Deegan (1992) suggests that the empowerment of persons with mental illness should involve the sharing of power. Deegan (1992) also argues that power is not a fixed entity, but can be generated between and among people. Others have suggested that this aspect of empowerment implies partnership, negotiation, and shared decision-making, with consumers having authority to make meaningful decisions about their lives (Linhorst, 2006).
**Resources and empowerment**

Hasenfeld (1987) emphasizes the importance of resources to empowerment. He suggests that it is "a process through which clients obtain resources -- personal, organizational and community -- that enable them to gain greater control over their environment and to attain their aspirations" (p. 478-479).

**Empowerment as a process**

Some theorists have suggested that one of the elements of empowerment is a process (Ratts, DeKruyf, & Chen-Hayes, 2007; Ratts, 2009). Zimmerman (2000) points out that any process can be empowering if it prepares people to participate more meaningfully in a way that increases power, control, or influence.

**Empowerment as an outcome**

Some theorists have suggested that another element of empowerment is ensuring empowerment as an outcome (M. Ratts, DeKruyf, & Chen-Hayes, 2007; M. J. Ratts, 2009; Zimmerman, 2000), meaning that empowerment can be the result of empowerment processes (Zimmerman, 2000). Linhorst (2006) argues that these outcomes can be subjective or objective, and might include "increased confidence, improved social skills, greater knowledge of resources, stabilization of psychiatric symptoms, having decision-making power" (p. 6).

**Empowerment as ideology**

The third element of empowerment is often described as the ideology of empowerment. Empowerment can be a way of viewing the world. An empowerment ideology might emphasize strengths and efficacy over pathology, "wellness over illness, and competence over deficiency" (Linhorst, 2006, p. 7). Helping professionals who adopt an empowerment ideology see themselves not as experts, but as collaborators, resources, and advocates (Zimmerman, 2000).
**Interconnected relationship between individuals and their environment**

Empowerment suggests an ecological perspective that links people with their surroundings. Individuals are empowered when they can influence or control aspects of the world around them (Zimmerman, 2000).

**Empowerment is situational**

Empowerment theorists have suggested that these processes and outcomes are not fixed, but are contextually specific (Linhorst, 2006; Zimmerman, 2000). Handler (1996) argues that empowerment is sometimes precarious, and relies heavily on the stability of relationships, availability of resources, and the demands of people in power. Empowerment, in other words, can be gained and lost.

**One cannot empower another**

Although helping professionals can facilitate and support the advancement of people with mental illness, they cannot directly empower them. Simon (1990) suggests that empowerment can only be "initiated and sustained... [by the] subject who seeks power or self-determination" (p. 32). In essence, individuals with mental illness can only empower themselves (Linhorst, 2006).

Linhorst combines these eight aspects of empowerment and defines the term as the "meaningful participation of people with severe mental illness in decision making and activities that give them increased power, control, or influence over important areas of their lives" (2006, p. 9).

This emphasis on empowerment for individuals with mental illness has emerged in the literature for both practical and philosophical reasons (Croft & Beresford, 1992). Possible reasons for this emergence in the literature include the fact that empowerment benefits both individuals and the organizations that serve them (Linhorst, 2006). For instance, the involvement
of persons with mental disorders in treatment planning has been demonstrated to increase follow-through and satisfaction (Roth & Crane-Ross, 2002). Philosophically speaking, empowerment also matters because the participation it fosters has come to be seen as a right rather than a privilege (Katan & Prager, 1986). This right to participation, unfortunately, has not always been granted for individuals with mental illness.

A history of powerlessness

Throughout Western civilization, people with mental illness have been subjected to oppression, coercion, and maltreatment, all of which are, by definition, disempowering (Foucault, Lagrange, & Burchell, 2008). Indeed, Linhorst suggests that individuals with mental illness have a unique "history of powerlessness" (2006, p. 12). This powerlessness has been exhibited in a variety of ways, from inhumane treatments and stigma (Hogan, 2003) to social control (Avriam, 1990). This history of powerlessness extends back to the Middle Ages, when communities often expelled the "mad," sometimes onto boats known as Ships of Fools which reportedly sailed around Europe, docking in seaports for only as long as passengers were tolerated by the locals (Foucault, 1965). Later during the Enlightenment Period, coercive and forced treatment ushered those with mental illness into "privatized madhouses" (Kemshall, 2001, p. 90). In later eras, these madhouses gave way to state asylums. During this so-called asylum period of the late 19th and early 20th centuries, a person could be committed permanently at the request of family members and the consent of a doctor (Levenson, 1986). These mental asylums were later converted into state psychiatric hospitals, which dominated the landscape of psychiatric treatment until the 1950s. Between the 1950s and 1970s, involuntary treatment continued to be initiated and managed medically rather than judicially (Linhorst, 2006), which led to "broader grounds for commitment and the loosening of the procedural restrictions."
During this time, a person committed to a state asylum had no rights or recourse and could be held indefinitely based on a two-physician certificate indicating a need for treatment.

However, in the 1970s, psychiatric treatment began to change following the publication of Goffman's groundbreaking ethnographic book *Asylum* (1961), which examined the lives of psychiatric patients at a facility in Washington, DC. Goffman argued that in a psychiatric hospital, patients "underwent a mortification of self, through physical and social abuse, which then lead to the loss of their usual identity" (Goffman, as cited in Chow & Priebe, 2013, p. 1). This process involved stripping individuals of past roles and leaving them with a purely institutional identity. Like prisons, concentration camps, and monasteries, Goffman argued that patients were subjected to stigma and severe restrictions on their liberties (1961). The publication of *Asylum* has been credited with raising public awareness and increasing public concern for the rights of citizens, particularly those with mental illness (Levenson, 1986). Motivated by public outcry, states enacted more clearly defined involuntary commitment laws (Linhorst, 2006). Simply being diagnosed with a mental illness was no longer legitimate grounds for hospitalization. New laws narrowed the criteria for involuntary commitment by requiring that patients be judged dangerous (Zhang, Mellsop, Brink, & Wang, 2015). This dangerous criterion could include danger to the self or others, or alternatively, potential danger brought about by an inability to care for self (Linhorst, 2006). During this period, patients were also granted legal due process including the right to an attorney, hearing, and appeals to the commitment decision (Zhang et al., 2015). These legal changes were intended to protect the rights of psychiatric patients that had been ignored for centuries.
At the same time as the initial codification of the civil commitment laws, psychiatric care entered the deinstitutionalization phase in which long-term facilities were replaced by community care (Linhorst, 2006). This movement towards community care was initially motivated by an increasing respect for the autonomy and rights of individuals with psychiatric conditions (Linhorst, 2006). However, some activists have argued that the transition from institutions to community settings has done little to improve the quality and effectiveness of care for persons with mental illness (Kemshall, 2001).

Although there are many ways in which deinstitutionalization has fallen short of its goal of improving the lives and treatment of individuals with psychiatric illness, one specific critique aimed at community-based care is that it has not afforded opportunities for self-determination for people with mental illness (Kemshall, 2001). Indeed, advocates have viewed this lack of consumer autonomy in community-based care as a form of oppression called mentalism (Deegan, 1992). Like sexism, ableism, and racism, which devalue and stereotype groups of people, mentalism suggests that those with psychiatric conditions are dangerous, unpredictable, and must rely on others to help them decide what is in their own best interests (Linhorst, 2006). Deegan (1992) argues that mentalism is not just an interpersonal phenomenon, but that it is also institutionalized in systems, policies, and laws. The consequence of mentalism is that even during periods of mental stability, individuals with psychiatric conditions are denied meaningful ways to become more involved in their treatment (Deegan, 1992). Unlike people without psychiatric conditions that are allowed to make mistakes and learn from them, those with mental illness are denied what Deegan calls the dignity of risk (1992).
Social justice and empowerment through treatment planning

In the previous section, the literature review indicated that institutions for treating mental illness are and have been structured in ways that systematically deprive persons with mental illness of autonomy and self-determination. Denying individuals with mental illness the freedom of choice privileges the power of clinicians at the expense of the client's right to self-determination (Chamberlin, 1978; Charlton, 1998). Adams, Bell, and Griffin (2007) argue that oppression is present whenever social relations are structured in ways that privilege some groups at the expense of others. These oppressive systems, Adams and her colleagues argue, sustain injustice and thwart healthy human development. To address this history of powerlessness requires a "reconfiguration of society in accordance with equity, recognition, and inclusion" (Adams et al., 2007, p. 4). Adams and her colleagues' social justice framework align with the consumer empowerment movement in community mental health (Charlton, 1998). Shafer, Staples, and George (2016) point out that there has been a greater emphasis over the past decade on the rights of clients to make choices — not only about their lives but also about their care, their providers, and their treatment methods.

Although this emphasis on consumer rights is philosophical, some have applied these values in practical ways to clinical work and suggested that one way to empower individuals with mental illness is to engage them in treatment planning (O'Connell & Stein, 2005). Empowerment through treatment planning can take place in the present through person-centered treatment plans, but also in the future through planning tools such as PADs (Linhorst, 2006). Advocates argue that PADs can be used to target this history of powerlessness by creating meaningful opportunities for client self-determination (Bonnie, 2012; Scheyett et al., 2007; Swanson, Tepper, Backlar, & Swartz, 2000).
PADs and social justice advocacy

Van Dorn, Scheyett, Swanson, and Swartz (2010) have drawn a direct connection between social justice advocacy and the need to empower consumers through collaborative treatment planning. In particular, Van Dorn et al. (2010) argue that psychiatric advance directives are consistent with social justice principles. Citing prior research on the benefits of PADs, Van Dorn et al. (2010) suggest that these legal documents support client empowerment through increased individual autonomy, improved clinical outcomes, and a reduction in the use of coercive practices. Referencing social work specifically, the authors suggest that social workers have an imperative to address oppression as outlined in their Code of Ethics, and as such, social workers should promote the use of psychiatric advance directives as tools for remediating the persecution of individuals with mental illness.

Although no one has made this argument in the field of counseling, Van Dorn et al.'s (2010) point could certainly apply to counselors. Indeed, the ACA Code of Ethics (American Counseling Association, 2014) and the ACA Advocacy Competencies (Lewis, Arnold, House, & Toporek, 2003) provide an ethical framework for counselors considering the use of psychiatric advance directives. In section A.2.d., the ACA Code of Ethics specifies that when working with incapacitated adults, counselors must "seek the assent of clients to services and include them in decision-making as appropriate (ACA, 2014, p. 4)." In this sense, advance directives are highly consistent with the ethics of the counseling profession.

Similarly, ACA Advocacy Competencies encourage counselors to engage in forms of social justice advocacy across individual, systems, and societal domains (Toporek et al., 2010). These competencies expand the role of the counselor to include empowerment and advocacy practices aimed at addressing roadblocks that inhibit healthy human development. Toporek et al.
(2010) describe empowerment as a way of assisting clients in a) identifying the external forces that may influence their development, b) collaborating on a plan of action to reduce these barriers, and c) assisting clients in developing self-advocacy skills. Advocacy, on the other hand, takes place when counselors assist clients in accessing resources in situations where the clinician has greater access than clients (Toporek et al., 2010). As mental health professionals who work with individuals with mental illness, PADs represent a critical topic for counselors and counselor educators to consider in their work.

**Psychiatric Advance Directives**

*Introduction*

Although there is no research on psychiatric advance directives within the counseling field, there has been keen interest in the topic in other disciplines such as law and psychiatry. The abundance of research on psychiatric advance directives in other disciplines perhaps suggests that this subject warrants further study in the field of counseling. For the purpose of establishing a rationale for this dissertation, I drew from previous PADs studies conducted in other helping professions as well as related disciplines such as law and health policy administration. This analysis and critique of the literature on PADs begins with a broad overview of the early theoretical works on PADs. These early works establish a set of research considerations that shape subsequent PAD studies. The focus of this review then narrows to consider empirical studies on PAD, starting with the stakeholder studies. After examining prior stakeholder studies conducted in other states, this literature review then transitions to research on the implementation of PADs into a mental health care system. At that point, the emphasis shifts to the setting of this dissertation, namely, the Commonwealth of Virginia, which has undertaken an unprecedented implementation effort since the passage of the amended HDCA in
Several prior studies have examined PADs in Virginia. These studies were analyzed in depth to identify knowledge gaps and methodological considerations that provide a rationale for this proposed dissertation research.

Inclusion criteria for this review include PAD stakeholder and implementation studies conducted in the United States and published in peer-reviewed psychiatric and health administration journals over the past 20 years. It is important to point out that there is an equally large body of studies examining the impact of PADs. This impact research examines PAD outcomes such as the reduction of coercion, improved clinical outcomes, and strengthened the therapeutic alliance (Bonnie, 2012; Campbell & Kisely, 2009; Houben, Spruit, Groenen, Wouters, & Janssen, 2014). However, a review of these outcome studies is beyond the scope of this literature review, as they do not directly pertain to the research question of this dissertation, which concerns embedding PADs into the routine delivery of mental health care in Virginia.

**Early theory on psychiatric advance directives**

The first person to propose the psychiatric advance directive was the psychiatrist Thomas Szasz. Szasz was one of the leading figures in the anti-psychiatry movement. Concerned with the excesses and the power of psychiatry, Szasz (1982) examines the literature on living wills and last wills to find justification for his idea. He turns to the work of Robert Bryn who asserted that "every competent adult is free to reject life-saving medical treatment. This freedom is grounded, depending upon the patient's claim, either on the right to determine what shall be done with one's body or the right of free religious exercise-both fundamental rights" (Bryn, as cited in Szasz, 1982, p. 766). He argued that the psychiatric will "rests on the same principle and seeks to extend it to 'mental treatment'" (p. 766). Despite his optimism for the potential of PADs, Szasz was more realistic when it comes to psychiatry's willingness to embrace this innovation. Szasz
concluded that it will not be easy to introduce the psychiatric will into the field of mental health. He was quick to acknowledge that even good ideas that are in people's best interest are often not readily adopted until laws and social policies are crafted to support them. While Szasz (1982) pointed to the benefits of the psychiatric will, as well as their precedence in American medical care, he does not make specific recommendations or place a call for legal change.

Paul Sherman (1995) was another early proponent ofPADs. Sherman argued that although these documents were promising, they would face significant barriers to widespread acceptance and use within the field of mental health. In his speech at the National Symposium on Involuntary Intervention (1995), Sherman identified what he foresaw as potential barriers to the widespread use ofPADs, including educational concerns, logistical issues, legal hurdles, consumer behavioral barriers, and enforcement problems. At the time of his talk, no research studies had been conducted to verify whether or not these barriers existed (Elbogen et al., 2006; Shields, Pathare, Van Der Ham, & Bunders, 2014). Although Sherman's work is influential for future research examining PAD utilization, his claims remain theoretical rather than actual.

Both Sherman and Szasz before him acknowledged that for PADs to go mainstream, there would need to be legal changes to promote adoption by the broader mental health community as well as mechanisms for accountability when it came to following the specified instructions (i.e. liability). In other words, for PADs to be successful, lawyers would need to enter the conversation (Sherman, 1995; Szasz, 1982). As Alexander Brooks argued it: "Lawyers have taught mental health professionals, particularly psychiatrists, what many of them had long ignored and should have known, that their patients have a moral as well as a legal right to participate in their own treatment" (Brooks, as cited in Miller, 1998). To that end, BJ Winick wrote an often-cited legal perspective on PADs. Winick (1996) lists what he envisioned as
positive potentials for PADs, including the reduction in stigma, effective planning, encouraging preparation, more equality between psychiatrists and patients, reduced stress, improved self-esteem, and better follow-through. Winick was also one of the first legal thinkers to argue that the court decisions governing Quinlan and Cruzan should be extended to psychiatric treatment, although he recognized that law reform would be necessary for PADs to take hold in the United States.

**Legal reform**

As mentioned in the introduction chapter, in 1990, following the Quinlan (*In re Quinlan*, 1976) and Cruzan (*Cruzan v. Director, Mo. Dept. of Health*, 1990) decisions, the federal government passed the Patient Self-Determination Act (PSDA). This law enabled individuals to craft legally binding advance instructions for end-of-life care. Throughout the 1990s, prominent psychiatrists and legal scholars argued that the PSDA should be extended to include psychiatric care. In 1993, the Oregon Legislature enacted Senate Bill 859, which created state provisions for advance declarations of mental health treatment (Backlar, 1995). Oregon was one of the first states to take Szasz's idea and make it a legal tool (Backlar, 1997).

Consequently, many of the articles from the mid-late 1990s focused on PADs in Oregon. One of the key publications from this period was a 1997 article published in the *Community Mental Health Journal* by its editor, Patricia Backlar. While the medical advance directive promotes a "good death," Backlar (1997) argues that a psychiatric advance directive encourages "a good life." Despite the differences, Backlar predicts that PADs will face many of the same challenges faced by medical advance directives in the adoption by the broader health care community. Backlar suggests that there may be legitimate reasons that community mental health providers will be slow to adopt and encourage the use of PADs. These barriers were later
confirmed by empirical PAD barrier studies and included: organizational and administrative
issues within community mental health, the time-consuming nature of PAD completion, and a
general resistance to legal encroachment within clinical practice. In closing, she points out that
even with enforceable laws, education and training for clinicians, and procedures to encourage
their use, the adoption of PADs may be modest. She points out that "Just as many people do not
get vaccines or stop smoking, many people will not engage in such [advance] planning despite
our best efforts" (Backlar, 1997, p. 266).

**Stakeholder studies**

O'Connell and Stein (2005) argue that whether or not the benefits of PADs will ever be
fully realized depends greatly on the stakeholders who utilize them. If this is true, then O'Connell
and Stein's assertion provides several framing questions for this literature review. *How do
stakeholders perceive PADs, and how are these attitudes different for clinicians than for
consumers? Have stakeholders received adequate information on PADs to make use of them? If
they have not, how does a lack of information impact utilization? How do barriers within the
system thwart the use PADs, and what strategies can be applied to address these obstacles?* This
proposed research study examines some of these questions for stakeholders in the state of
Virginia to determine whether or not the implementation efforts since Virginia passed the
amended HDCA have yielded to greater system utilization of this powerful legal tool. To provide
a rationale for this study, the remainder of this chapter reviews extant utilization literature. This
exploration begins with a discussion of prior research on PAD demand and utilizations and
concludes with a discussion of the barriers and enabling factors that influence PAD
implementation. The review then focuses on contextually relevant prior research on PAD studies
in Virginia. This section concludes with the discussion of the limitations of prior research, which identifies the knowledge and methodological gaps motivating this proposed dissertation research.

**PAD prevalence and demand**

In addition to the federal Patient Self Determination Act (PSDA), PAD legislation currently exists in nearly every state. Despite the legal provisions enabling the creation of PADs by consumers of mental health services, research suggests that very few individuals have done so (Srebnik, Russo, Sage, Peto & Zick, 2003; Swanson, Swartz, Ferron, Elbogen, & Van Dorn, 2006; Swanson, Swartz, Hannon, Elbogen, Wagner, McCauley, & Butterfield, 2003).

**Latent demand**

Several prior studies have attempted to quantify PAD prevalence and demand here in the United States. These studies indicated that there while there is high demand for PADs among mental health consumers, completion rates remain low (Srebnik et al., 2003; Swanson, Swartz, Ferron, et al., 2006; Swanson, Swartz, Hannon, et al. 2003). In a sample of 303 participants with SMI diagnoses, no PAD, and a history of crisis services, Srebnik et al. (2003) found that 53% of these individuals were interested in completing a PAD. This finding echoed results found in a similar-sized study of 104 individuals with SMI in North Carolina (Swanson, Swartz, Hannon, et al., 2003). Swanson, Swartz, Hannon et al. (2003) found that only 7 people with schizophrenia had a PAD, but that most (64.7%, n=62) were interested in completing a PAD if they had support doing so. In this same study, only 10 clinicians (n=85) reported working with a client who had a PAD, although 95.8% of clinicians would recommend patients complete a PAD (Swanson, Swartz, Hannon, et al., 2003). These data suggest a latent demand for PADs among both clinicians and consumers (Swanson, Swartz, Hannon, et al., 2003). Similarly low completion rates were also found in a large-scale study of PAD prevalence, demand, and
correlates in five American cities (Swanson, Swartz, Ferron, et al., 2006). Swanson, Swartz, Ferron, et al. (2006) surveyed a convenience sample of 1,011 persons with SMI receiving services at community mental health centers in five urban US cities. Of this sample, only 4-14% of the participants reported having a completed a PAD. Of the individuals in this sample who did not have a PAD, 66-77% of participants stated they would like to complete a PAD if offered the necessary assistance (Swanson, Swartz, Ferron, et al., 2006).

**Correlates with demand and completion**

Prior research has also explored what might account for PAD completion and demand. In their large-scale study (N=1,011) of PADs in five American cities, Swanson, Swartz, Ferron, et al. (2006) identified statistically significant correlates associated with PAD demand and completion. Correlates with PAD demand included: prior coercive, unwanted and inadequate intervention in the past, as well as experiences of disempowerment in the decision-making process (Swanson, Swartz, Ferron, et al., 2006). Correlates with PAD completion include high insight scores, previous police involvement in hospitalization, and high social resources.

Strikingly, participants with the strongest demand for a PAD — women of color with a history of self-harm — were the least likely to have completed a PAD (Swanson, Swartz, Ferron, et al., 2006). These findings, however, were somewhat inconsistent with the findings of Srebnik et al. (2003). In a mixed methods study of PAD interest among 303 consumers in Washington state, Srebnik et al. (2003) found that demographics and functional impairment were nonsignificant factors in influencing PAD demand. Through consumer interviews and quantitative analysis of PAD interest, Srebnik et al. (2003) identified numerous reasons for consumer PAD demand, including case manager's suggestion (27%), a general belief that PADs would be helpful (27%), to avoid repeating negative experiences (17%), curiosity (11%), to have input in future treatment
(10%), and to develop a plan for future incapacity (8%). Although in analysis, Srebnik et al. (2003) concluded that the only statistically significant variables influencing PAD interest were an absence of outpatient commitment orders and having a case manager with favorable opinions of PADs.

**PAD attitudes and knowledge**

**Attitudes**

Although most studies suggest that all stakeholder groups hold positive opinions of PADs, research points to variations in attitudes across stakeholder groups (Swanson, Swartz, Hannon, et al., 2003; Van Dorn et al., 2006; Wilder, et al., 2013). In their stakeholder study on understanding, attitudes, and experience with PADs (N=272), Swanson, Swartz, Hannon, et al. 2003 found that of all stakeholder groups, consumers of mental health services tended to have the most positive attitudes regarding PADs. In the analysis of study interviews and self-report questionnaires, Swanson, Swartz, Hannon, et al. (2003) found that although the majority of consumers (n=104) and family members (n=83) felt that PADs would help people stay well, while clinicians (n=85) were less likely to agree with this statement. The authors also concluded that mental health providers were more skeptical than other stakeholder groups regarding the purposes and the utility of PADs. Swanson, Swartz, Hannon, et al. (2003) also found that while there were no significant differences between the groups in their endorsement of PADs, there were between-group differences on reasons for favoring these legal documents. Clinicians were much less likely than patients to agree that avoiding unwanted treatment was a good reason for crafting a PAD. Clinicians were also more likely to support the idea that the only reason for crafting a PAD was to make consumers feel more empowered, not to avoid unwanted treatment or obtain needed treatment (Swanson, Swartz, Hannon, et al., 2003). Other group differences
included divergent beliefs regarding the penalties for failing to follow through on PAD instructions. Consumers were more likely than family members and much more likely than clinicians to agree that there should be financial penalties for ignoring a PAD (Swanson, Swartz, Hannon, et al., 2003).

In a study on the impact of clinician attitudes on decision-making with patients and clients who had PADs, Elbogen et al. surveyed 597 psychiatrists, social workers, and psychologists. Of this sample, 280 (47%) clinicians reported that they approved of North Carolina's laws on advance directives. However, 46% of the respondents said that the benefits of PADs could be negated by treatment refusals (e.g. consumers using PADs to refuse ALL treatments during a crisis). In a treatment refusal scenario, 61% of clinicians reported that they would follow the instructions, but that their reasons for doing so varied across professional groups. Based on the data collected for this study, Elbogen et al. (2003) concluded that professional identity (e.g. psychiatry, social work, psychology) was not a statistically significant influence on PAD attitudes, but that clinicians who were well-informed were more likely to have positive attitudes towards PADs.

Knowledge

Prior studies suggest that PAD knowledge remains low among all stakeholder groups (Elbogen et al., 2003; O’Connell & Stein, 2005). In a study on the impact of clinician attitudes on decision-making with patients and clients who had PADs, Elbogen et al. (2003) found that among a sample of 591 clinicians, only 220 participants were able to correctly answer thePAD knowledge question regarding treatment refusals that are inconsistent with community practice (Elbogen et al., 2003). These data suggested that many clinicians who believed they had accurate knowledge of PADs, in fact, did not. Consistent with Elbogen et al. (2003), O’Connell and Stein
(2005) found that among a sample of 272 participants from six stakeholder groups, only a minority of the respondents reported they had ever heard of PADs before the survey (45%), and only 11.4% considered themselves very familiar with the legal tools. This study also found that respondents who had higher levels of contact with individuals with mental illness were more likely to be familiar with PADs than those with less contact with this population (O’Connell & Stein, 2005). In a meta-analysis of six studies on PADs, Shields, Pathare, van der Ham, and Bunders (2014) concluded that between 29 and 54% of clinicians who had participated in research had any prior knowledge of PADs. Shields et al. (2014) also suggested that inpatient and outpatient clinicians tend to receive less training than administrators (30% and 100%, respectively). Henderson et al. (2010) found that limited knowledge of PADs by emergency care and inpatient providers were rated as highly significant barriers to PAD implementation.

*Connecting knowledge and attitudes*

Several studies have indicated that there is a relationship between PAD knowledge and PAD attitudes. Across the research, there is consistency in the conclusion that higher levels of PAD knowledge were associated with more positive opinions regarding PADs (Elbogen et al., 2003; O’Connell & Stein, 2005; Swanson et al., 2003). Studies have shown that clinicians who were well informed and aware of state laws were significantly more likely to endorse positive attitudes towards PADs (Elbogen et al., 2003; O’Connell & Stein, 2005; Swanson et al., 2003).

*Barriers*

PAD researchers have sought explanations for the low prevalence rates found in previous stakeholder studies. A review of prior research points to numerous number of operational, clinical, and consumer-related barriers that appear to have derailed widespread PAD implementation (Van Dorn et al., 2011).
**Operational barriers**

Operational barriers are defined as barriers that stem from the work environment and include communication difficulties and problems with accessing the PAD document (Van Dorn et al., 2011).

**Communication**

Several studies identified communication issues as barriers for PAD utilization (Kim, Appelbaum et al., 2007; Srebnik & Brodoff, 2003; Van Dorn et al., 2006). In one survey of 591 US mental health professionals, 66% of providers cited communication difficulties between hospital staff (ED and inpatient units) as an obstacle (Van Dorn et al. 2006). In another survey of stakeholders within the US Veterans administration (N=55), communication difficulties between inpatient staff and outpatient staff were considered a highly significant barrier by both consumers and providers in a Delphi Method analysis (Henderson et al., 2010).

**Resource issues**

Another systemic issue that emerges in the literature on PADs is resource limitations. Resource limitations can include issues related to time, money, personnel, and agency process limitations (Van Dorn et al., 2010). Prior studies indicated concerns among mental health providers regarding how PADs would be accessed in crisis situations; in particular, clinicians reported questions regarding how hospital staff would know someone had a PAD, and how these treating providers could find a copy of the document (Kim, Appelbaum et al., 2007; Van Dorn et al. 2006). In the O’Connell and Stein (2005) self-report survey of stakeholders in Ohio (N=272), 25% of respondents also reported resource barriers, including issues such as locating a PAD in a crisis, and adding PADs into agency documentation. Backlar et al., (2001) drew similar conclusions. Among a sample of 40 consumer and provider participants, 80% of respondents
reported low confidence in the ability of organizations such as hospitals, EDs, and community clinics to enable PAD access (Backlar et al., 2001). This perception by consumers and clinicians is partially substantiated by research. Srebnik and Russo (2008) found that completed PADs were accessed only 20% of the time in a two-year study of crisis PAD utilization.

**Clinician barriers**

In a study on clinician perceptions of PADs (N=591), Van Dorn et al. (2006) suggested that clinicians tend to perceive more operational barriers (i.e. barriers related to the work environment) than clinical barriers (i.e. barriers that relate to treatment). Van Dorn et al. (2006) also found that higher status mental health professionals (i.e. psychiatrists) perceived more barriers than the lower status professionals (i.e. social workers). This research suggests that professional affiliation might account for significant variation in the perception of barriers.

**Treatment barriers**

Treatment barriers refer to the features of clinical practice that might produce obstacles for PAD completion or utilization. Often these treatment barriers relate to concerns on the part of clinicians regarding the instructions written in a PAD. For example, in a study of 591 mental health providers (psychiatrists, n=167; psychologists, n=237; social workers, n=193), Van Dorn et al. (2006) concluded that treatment refusals or inappropriate instructions were perceived as significant barriers to PAD utilization among practicing clinicians. Van Dorn et al. (2006) also found that 46% of the respondents reported that they believed that the benefits of PADs could be negated by treatment refusals (i.e. consumers using PADs to refuse ALL treatments during a crisis). Psychiatrists were also significantly more likely than the other two groups to identify a lack of quality information in a PAD as a barrier, while social workers were more likely than the other groups to identify not having enough time to review a document as being a barrier (Van
Dorn et al., 2006). In the analysis of correlates, Van Dorn et al. (2006) suggested that psychiatrists working in the public sector perceived higher barriers than those working in the private sector. Likewise, those who believed that the benefits of PADs could be outweighed by treatment refusals endorsed barriers at higher rates than those who did not (Van Dorn et al., 2006). The researchers also identified a significant and positive relationship between legal defensiveness and perceived barriers (Van Dorn et al., 2006).

Other treatment-related barriers that emerge in the literature include concerns about consumer competency to complete a PAD (Shields et al., 2014; Winnick, 1999). Competency is defined as the capacity to make and write PAD instructions (Shields et al., 2014). Although one study of 106 consumers with SMI indicated that nearly all individuals were able to complete a PAD (Peto et al., 2004), clinicians continue to view competency as a barrier to PAD completion (Shields et al., 2014; Winnick, 1999). In a study of stakeholder attitudes in Virginia, Wilder et al. found that 90% of clinicians (n=268) reported they would be more likely to follow PAD instructions if a clinician had attested to competence at the time of completion. Clinician attestation of competence is not necessary for a PAD to be considered valid in Virginia, so these data indicated a perceived difference among clinicians between advance instructions written in the past and the current preferences of a competent person (Van Dorn et al., 2011).

**Knowledge barriers**

Many studies have identified a lack of knowledge as a barrier to PAD completion and utilization (Elbogen et al., 2006; O’Connell & Stein 2005). In a metaanalysis of six studies examining PAD barriers, Shields et al. (2014) found that between 29 and 54% of clinicians reported any knowledge of PADs prior to participating in research on the topic. Shields et al. (2014) went on to conclude that inpatient and outpatient clinicians tend to receive less training
than administrators, and that emergency care providers receive even less training. While a number of studies point to discrepant opinions between stakeholder groups regarding PAD barriers, Henderson et al. (2010) found that the primary point of consensus for all groups of experts was that poor knowledge of PADs was a barrier to PAD use, particularly in ER and inpatient settings. This finding is consistent with prior stakeholder studies identifying a lack of PAD knowledge as a significant barrier to implementation (Elbogen et al., 2006; O'Connell & Stein, 2005; Shields et al., 2014).

**Attitudinal barriers to completion**

A review of the literature suggests that the influence of clinician attitudes on PAD completion is mixed. Some studies have found that clinician involvement is not a statistically significant factor in PAD completion (Peto, Srebnik, Zick & Russo 2004; Srebnik & La Fond, 1999). While others, such as Srebnik et al., 2003, have reported evidence of a positive correlation between clinician attitudes and consumers interest in completing a PAD. Though not a statistically significant factor, Peto et al. (2004) argued that clinician support had practical significance for PAD completion due to the fact that most consumers required assistance in completing the documents.

**Attitudinal barriers to accessing PADs**

Clinician attitudes have also been identified as a barrier to utilization of PADs in crisis situations. In a study examining clinical decision making and views about advance directives, Elbogen et al. (2003) concluded that clinicians (N=597) who held more negative views of PADs were less likely to follow a consumers advance instructions during crisis situations. This finding was consistent with Swanson, McCrary, Swartz, Van Dorn, and Elbogen’s (2007) survey of 164 psychiatrists in North Carolina, which found that 47% of participants reported that they would
override a valid PAD that refused medication and hospitalization. Of this sample (N=164), a willingness to override a PAD was most likely among psychiatrists who worked in emergency departments, were concerned about risk of violence and lack of insight, and rated high on a measure of legal defensiveness (Swanson et al., 2007). On the other hand, PAD override was found less likely among respondents who believed that in a high-quality mental health system, involuntary treatment was largely unnecessary (Swanson et al., 2007).

Disputing attitudinal barriers

Interestingly, not all stakeholders are in agreement that clinician attitudes represent a significant barrier to PAD utilization. In Henderson et al.’s (2010) study on best practices for implementation, the researchers concluded that there was no consensus regarding attitudinal barriers among the consumer and non-consumer groups. Consumers believed that clinician attitudes were barriers to PAD completions, while non-consumer groups did not. This disparity in the perception of attitudinal barriers was consistent with other studies examining the impact of clinician attitudes on PAD implementation, which found that clinicians tend to minimize the impact of their attitudes, while consumers seem them as highly problematic (Backlar et al., 2001; O’Connell & Stein, 2005; Swanson et al., 2003).

Consumer barriers

Comprehension issues

PADs are legal documents, and as such, can prove difficult to understand and complete correctly. Comprehension issues emerge in the literature as a perceived barrier to PAD completion among service users (Shields et al., 2014). Swartz, Swanson, Van Dorn, Elbogen, and Shumway (2006) found that 56% of a 469-person sample indicated difficulty with understanding the purpose of a PAD. Van Dorn et al. (2008) found similar comprehension issues
among a sample of 85 consumers, 50% of whom reported that they struggled to understand the legal language of the PAD. Researchers have also identified the challenging of knowing what to include in a PAD (Swanson et al., 2003; Van Dorn et al. 2008). In one study of 85 service users, 79% of participants reported that completing a PAD was too much of a burden (Van Dorn et al. 2008). Some studies have also pointed to reluctance among mental health consumers to sign legal documents, even though signatures were necessary to complete a legally binding PAD (Swanson et al., 2003; Van Dorn et al. 2008).

*Trust*

Another theme that emerges in the literature on consumer perceptions of PAD barrier is the issue of trust (Backlar et al., 2001; Swanson, Swartz, Ferron, et al., 2003; Swartz et al., 2006; Van Dorn et al., 2008). Trust-related barriers are multi-faceted and can emerge in response to consumer experience with family members, clinicians, or the mental health system. Researchers have concluded that consumer participants often did not have someone they trusted to serve as a proxy decision maker. Van Dorn et al. (2008) found that among 389 consumer participants, 43% did not feel they had someone in their life they could trust to serve as a proxy. Other studies have identified clinician mistrust as a PAD barrier (Swanson, Swartz, Ferron, et al., 2003; Swartz et al., 2006). Backlar et al. (2001) reported that many consumers expressed concerns regarding whether or not a PAD could be accessed and honored in times of crisis. Other studies have found that a majority of consumers doubt that completing a PAD will have any impact on future treatment (Swartz et al., 2006; Van Dorn et al., 2008).

*Fear of negative attitudes*
PAD barrier studies have also identified concerns among consumers regarding the willingness of care providers to use and access their PADs. For example, in a follow-up study to an intervention of facilitated PADs (Swanson, Swartz, Elbogen, et al., 2006), Swanson, Swartz, Elbogen, Van Dorn, and Wagner (2008) found that among 147 participants who had completed a PAD and experienced a period of decisional incapacity, only 35% of consumers reported an awareness that their providers had read their PAD instructions. Other related studies have found that consumers were often reluctant or afraid to tell their providers that they have a PAD (Elbogen et al., 2007; Kim, Appelbaum et al., 2007). The primary reasons cited for this apprehension was a fear of negative response from clinicians or involuntary treatment (e.g. medication over objection) during future hospitalizations (Kim, Appelbaum et al., 2007).

Henderson et al. (2010) found that among clinicians and consumers, negative provider attitudes were rated as a significant barrier. On a scale of 1-9 with 1 being highly significant and 9 being insignificant, the mean score for this barrier was found to be a 3.4 (SD=1.4) (Henderson et al., 2010). This same study went on to report that many consumers were afraid to tell hospital staff that they had a PAD out of fear of being ignored or punished for objecting to medications or restraints (Henderson et al., 2010). These concerns were also identified in Kim, Appelbaum, et al. (2007), which found that a fear of clinician intimidation during a crisis, such as threatening to involuntarily hospitalize, deterred consumers from informing hospital staff that they had a PAD.

**Legal issues**

Although PADs are considered legally-binding documents, a review of the literature points to skepticism on the part of consumers regarding whether or not these documents will be honored in times of crisis (Shields et al., 2014). In a study of 69 consumers who had completed a
PAD and experienced a subsequent psychiatric episode in which a PAD could be accessed, Srebnik and Russo (2008) found that 74% of respondents reported that they were concerned about the enforceability of a PAD. Similar numbers of participants reported concerns over whether or not the document would be regarded as legally-binding even if providers override certain provisions in the course of treatment (Srebnik & Russo, 2008).

These consumer concerns regarding the legality of PADs are likely warranted. Unlike medical advance directives, many states allow providers to override or ignore instructions in PADs (Shields et al., 2014). Atkinson, Garner, Stuart, and Patrick (2003) point out that medical advance directives allow a person to refuse life-saving treatment based on personal or religious beliefs, while individuals with mental illness are not afforded treatment refusals even when instructions are written during periods of competency. Shields et al. (2014) characterized these divergent medical practices as “discriminatory towards individuals with mental illness” (p. 762).

**Enabling factors**

Previous studies have demonstrated a high demand for PADs among stakeholders coupled with strikingly low completion and utilization rates (Peto et al., 2004; Swanson, Swartz, Ferron, et al., 2006; Swanson, Swartz, Hannon, et al., 2003). Researchers have suggested that these low prevalence rates were likely due to perceived systemic, clinician, and consumer barriers. Only a few studies have been explored ways to address these barriers in the mental health system. Though small in number, these studies identified several enabling factors that appeared to foster higher PAD completion and utilization rates.

**Positive attitudes**

In their study on PADs among high-users of crisis and hospital consumers, Srebnik et al. (2003) conducted a multiphase intervention study with 303 adults who had had at least two
psychiatric ED visits or hospitalizations in the past two years. The study found that several bivariate factors were positively related to interest in PADs. These statistically significant factors influencing PAD interest included the case manager's support for the directives, having major depression but not schizophrenia, and having no hospitalizations or commitment orders over the past two years. Nonsignificant factors included demographics and functional impairment. The logistic regression suggested that the only variables found to be positively associated with PAD interest were an absence of outpatient commitment orders and having a case manager with favorable opinions of PADs. Srebnik et al. (2003) yielded the insight that positive clinician attitudes were related to consumer interest in executing a PAD.

**Involvement of a surrogate decision maker**

In a study of PAD utilization during psychiatric crisis events, Srebnik et al. (2008) followed 106 frequent users of emergency and hospital services with PADs over two years. Of this sample, 69 participants had at least one psychiatric crisis during the course of the study for a total of 450 crisis events. Of these 540 incidents, PADs were accessed in 90 events, suggesting that there was a 20% rate of accessing directives. Interestingly, the researchers found that when a surrogate decision maker was involved in the crisis, the PAD was ten times more likely to be accessed than if a surrogate decision maker was not involved.

**Access to facilitation**

In 2006, Swanson, Swartz, Elbogen, et al. conducted a randomized trial of a structured, manualized facilitation intervention for psychiatric advance directives to determine whether or not facilitation could overcome completion barriers. In this study, the researchers compared the outcomes of the randomly assigned treatment group provided with PAD facilitation to those of the control. In the treatment group, 61% of the participants completed a PAD compared to 3% in
the control group. Data analysis suggested that PAD completion was determined by several factors such as motivation, cognitive ability, help-seeking motivation, and duration of illness. When the researchers analyzed the content in the treatment group's PADs, the instructions from the treatment group were far more consistent with community practice standards (as rated by two psychiatrists) when compared to the control group. According to this study, facilitation increased completion rates and allowed for advance instructions that were consistent with standard care (Swanson, Swartz, Elbogen, et al., 2006).

*Increasing knowledge and training*

Shields et al. (2010) argued that another way to address PAD barriers would be to introduce a practice-based training program targeting stakeholders on the utility and implementation of these documents. Although no studies have been conducted to demonstrate the efficacy of such a curriculum, Srebnik and Russo (2008) provided some insights into the benefits of structured training for PAD utilization. As part of the study protocol, Srebnik and Russo’s (2008) research team provided training and process support for hospital and crisis center staff. Although these efforts were not related to the study’s research questions, procedures such as staff trainings, implementing system prompts (i.e. crisis cards and PAD dog tags), as well as the inclusion of PADs in the outpatient medical record appeared to increase access rates over time. This change in PAD access rate led Srebnik and Russo (2008) to conclude that with additional training, prompts, and organizational reminders, the mental health system grew more familiar with the documents. Time and exposure also appeared to increase client and clinician awareness of PADs. The individuals in this sample who had repeat crises were five times more likely to have their PAD accessed than those who did not (Srebnik & Russo, 2008). Although
modest, Srebnik & Russo’s (2008) study provides some evidence that training can influence PAD utilization.

**PAD studies in Virginia**

Over the past seven years, Virginia has undertaken efforts to implement the amended Health Care Decisions Act (HCDA) by promoting the use of psychiatric advance directives among mental health consumers. The purpose of this dissertation was to understand how PADs were being used in Virginia, and how practices, attitudes, barriers, and knowledge have changed since 2010. Although this study has implications for PADs in other localities, this study was highly contextualized and focused on state-specific laws and practices. For this reason, it was necessary to review prior literature on PADs in Virginia. To date, there were only three prior studies on this topic. Although these prior studies drew meaningful inferences on PAD utilization and implementation in Virginia, they were completed early in the implementation process (pre-2015). The following section will review prior studies on PADs in Virginia and identify both the knowledge and methodological gaps that remain in our understanding of this issue.

**Stakeholder studies**

In 2013, Wilder et al. published a quantitative study examining the knowledge, experience, and attitudes regarding the use of PADs among five stakeholder groups (clinicians, consumers, advocates, family members, and administrators). This study collected baseline data from five stakeholder groups on knowledge, attitudes, and experiences of PADs in the mental health context. This study utilized cross-sectional quantitative procedures with five stakeholder groups via an online survey that contained a core set of questions regarding knowledge, attitudes, and experiences. The core questions allowed for comparison across stakeholder groups. The survey also included group-specific questions that elaborated on issues about each class of
stakeholders. Using purposive sampling, survey participants (N=460) included clinicians (n=268), administrators (n=67), advocates (n=25), consumers (n=40), and family members (n=60) recruited through professional and advocacy organization mailing lists. The researchers analyzed data through descriptive statistics, multivariable regression, and t-test of statistical significance.

Latent demand

Wilder et al. (2013) concluded that based on the survey results, all stakeholder groups held favorable opinions of PADs. Additionally, all respondent stakeholder groups reported that they were generally supportive of HDCA’s expansion to include all types of incapacity, including psychiatric emergencies. Less than a fifth of all respondents endorsed any negative attitudes about PADs. The survey also indicated that PAD demand is greater than PAD completion rates. Interestingly, Wilder et al. (2013) found that 29% of consumer respondents in Virginia had completed a PAD. This figure was striking, given that prior studies on PAD completion rates were somewhere around 3.9-12.9% (Swanson et al., 2006). Nonetheless, Wilder et al. (2013) concluded that significant barriers have derailed the implementation process in Virginia.

Stakeholder divergence

Attitudes

Wilder et al. (2013) found common ground among stakeholders (e.g. broad support for PADs under the HDCA) but also identified key group differences. In particular, the study revealed that baseline knowledge, use, and perception of barriers varied across stakeholder groups (Wilder et al., 2013). Based on quantitative analysis, clinicians and administrator groups appeared to underestimate consumer interest in PADs. Likewise, these groups also expressed more concern regarding consumer comprehension and capacity to complete a PAD. Other
attitudinal differences included a perception among family members and consumers that clinicians will not respect PADs. The authors argue that the misperception of consumer interest by clinicians coupled with the assumption that clinicians will ignore PADs “logically results in very few [PADs] being completed” (Wilder et al., 2013, p. 237).

Knowledge

Wilder et al. (2013) concluded that a lack of PAD knowledge was a significant issue for implementation in the state. Survey respondents reported widely different experiences with training in the legal and clinical aspects of PADs. Of this sample, administrators tended to be more knowledgeable about PADs than clinicians, while inpatient providers tended be better informed than their outpatient counterparts. Wilder et al. (2013) also suggested that there was an inverse relationship between perceived barriers and knowledge about PADs.

Barriers

Perceptions of barriers also appeared to vary among the respondent groups. Clinician and administrator groups identified the time needed to complete a PAD as the most problematic resource barrier to PAD completion. Wilder et al. (2013) also noted that 71% of administrators and 52% of clinicians believed that providers did not have enough time in the workday to help consumers understand and complete PADs. Clinicians were also more concerned about the ability of consumers to complete PADs than the consumer stakeholder group. Consumers, on the other hand, were far more concerned that clinicians would not honor their treatment preferences than the clinician stakeholder group (Wilder et al., 2013). These findings indicate some misunderstanding if not mistrust of other stakeholder groups with regard to PAD implementation.
In response to the low prevalence rates reported in Wilder et al. (2013), the Commission on Mental Health Law Reform recommended that Virginia replicate the Swanson, Swartz, Elbogen, et al. (2006) facilitation study within its public mental health system. This effort was an attempt to capitalize on the success of this original study in the hopes that the facilitation model could increase PAD completion rates across the state (Zelle et al., 2015). The results of this replication attempt were described by Zelle, Kemp, and Bonnie (2015) in a policy paper published in the peer-reviewed journal World Psychiatry.

Piloting the facilitator model.

In keeping with the Swanson, Swartz, Elbogen et al. (2006) model, case managers at five CSB vanguard sites were identified as potential facilitators. These case managers were provided with a one-day training on PAD facilitation and were then asked to provide one-on-one PAD facilitation with consumers receiving services through the CSB system. Zelle et al. (2015) did not report any specific quantitative or qualitative data, but instead described the replication project's failure as it "quickly became evident that case managers' typical caseloads were too demanding to allow time for thorough facilitation of services" (Zelle et al., 2015, p. 8).

Adapting the facilitator model.

Recognizing the shortcomings of the one-size-fits-all approach to facilitation, Zelle et al. (2015) suggested three adaptations to the Swanson, Swartz, Elbogen, et al. (2006) model. The first recommendation mostly follows the standard one-on-one facilitation and education model used in the Swanson, Swartz, Elbogen, et al. (2006) RCT. However, the researchers point out that some CSBs found more success in PAD completion when the agencies identified specific staff, such as a coordinator of clinical services, to provide facilitation rather than placing this
expectation on all case managers. In the second model, peer-support specialists provided education and facilitation. Peer support specialists are trained individuals who also have mental or psychiatric issues. In the third model, consumers of CSB services are provided with general information on PADs in group settings. Often these concepts are incorporated into the CSB's Wellness Recovery Action Plan (WRAP) groups. The researchers point out that embedding PAD content into WRAP groups capitalized on the overlap between these legal documents and crisis planning, which is a major topic of these psychoeducational groups. Individuals who were interested in finding out more about PADs are provided with one-on-one facilitation resources or additional information to help them complete their PAD. Zelle et al. (2015) concluded that each of the models could be used in other states.

**Barriers to implementation**

The same research team published a follow-up article on PAD barriers to implementation later in 2015. Kemp, Zelle, and Bonnie (2015) used qualitative inquiry to identify thematic challenges that have emerged during the early phases of Virginia's implementation process. The researchers collected data from feedback on early training attempts, staff experiences at pilot sites, and the experiences of the work group tasked with implementation.

**Systemic barriers.** The authors identify several system-level barriers. As mentioned previously, the public mental health system operates through 40 independently run Community Service Boards (CSBs) that are funded and run locally. For this reason, the state has limited the influence within individual CSBs, as there is no governing body to "prescribe intervention-specific cross-site policies" (Kemp et al., 2015, p. 12). In other words, if a CSB happens to be motivated and interested in PADs, then they can receive help in achieving this goal. But if a CSB is reluctant or even hostile to PADs, there is little the state can do to impact this organization's
culture. Other system implementation barriers include challenges with cross-system communication, limited treatment for clients in crisis (i.e. bed shortages when consumers specific facility preferences), and difficulty with electronic medical records, which could have eased the difficulty of accessing a client’s PAD in times of crisis (Kemp et al., 2015).

*Lack of access to facilitation.* Although PADs do not require facilitation to be valid, for many people, the legal language included in an PAD, as well as the nature of the decisions made in this document, can be so daunting that facilitation becomes a practical necessity (Kemp et al., 2015). Kemp et al. (2015) suggested that low rates of PAD prevalence were due to a lack of access to facilitation services. The authors identified several factors contributing to the lack of access to facilitation services in the state. For instance, PAD facilitation is not a billable service. Kemp et al. (2015) argued that this issue was particularly problematic for healthcare providers working with community agencies that had been hit hard by Virginia's state budget cuts. Although other stakeholders groups could potentially serve as PAD facilitators (e.g. peer support specialists or advocates), the Virginia state bar has ruled that any attempt to help another person complete a legal document is considered an unauthorized practice of law (UPL), and can lead to liability or criminal charges. Concerns about UPL have prevented advocates and peer-support specialists from involvement in PAD facilitation. Kemp et al. (2015) concluded there was limited access to facilitation services in the state.

*Addressing barriers*

To address these barriers, Kemp et al. (2015) introduced several recommendations to increase PAD utilization across the state. One innovation described was the development of standardized training and orientation materials for both clinicians and facilitators (Kemp et al., 2015). This recommendation was consistent with prior literature that arguing that knowledge and
training were enabling factors for increasing PAD utilization (Shields et al., 2010; Srebnik & Russo, 2008). This strategy also addressed the facilitator shortage in the state. To address the decentralized CSB system barriers, Kemp et al. (2015) recommended the appointment of an implementation coordinator who could proactively work with CSBs to provide support and education on PADs. It was suggested that this point person could develop agency procedures and champion the inclusion of PAD facilitation in routine agency procedures. A third recommended measure was the creation of a state registry for PADs to circumvent the challenges of cross-system communication difficulties (Kemp et al., 2015). The idea of a centralized PAD registry has long been present in the literature as a way to address a major operational barrier that discouraged PAD implementation (Sherman, 1994; Srebnik & Russo, 2008; Winnick, 1996).

Kemp et al. (20105) reported that by publication, each of these three initiatives had begun across the state. However, Kemp et al. (20105) point out that further research would be needed to determine whether these efforts have had any meaningful impact on how PADs are used in the state.

**Limitations**

Despite the promising benefits of PADs, there appear to be some limitations in prior research on the topic. One of the significant gaps in our knowledge is that there has been little research on the long-term impact of PAD laws and implementation efforts over time. Most utilization and implementation studies analyze samples taken over one-to-two year periods. To fully understand the phenomenon, studies are needed over multiple year periods (Van Dorn et al., 2003). Another limitation is that much of PADs research emphasizes the clinician stakeholder group. In prior studies with consumers, the sample size for the group is usually much smaller than other stakeholders. For this reason, the clinician perspective heavily biases findings
from previous stakeholder research. As Van Dorn et al. (2013) points out, it is "ironic that, though PADs are tools for consumer empowerment and autonomy, consumers have had little involvement in PAD research" (p. 13). In addition to these temporal and sampling concerns, there is also a lack of methodological diversity in PAD studies, which exacerbates the sense that consumers have been disempowered within this area of research. Most PAD studies tend to be quantitative. Although quantitative data are valuable, these studies fail to capture the unique voice of the consumer. Another significant limitation of prior research concerns the localization of PAD studies. Because state-specific law heavily influences PADs, a well-executed, robust study in one state cannot be easily generalized to other areas of the country.

To date, Wilder et al. (2013) is the only study on stakeholder knowledge, experience, opinions, and obstacles in Virginia; as such, it offers substantive insight into our research topic: the implementation of psychiatric advance directives in Virginia. But despite the research value of Wilder et al. (2013) for our understanding of PAD utilization post-HDCA, this study has several limitations. One concern with this study was the participant recruitment procedures. Respondents to the survey were self-selected among individuals involved in professional and advocacy organizations. In other words, respondents were engaged stakeholders, and may not have been representative of the general population of Virginia. The consumer, family, and advocate response rates were exceptionally low, which raises the possibility of bias in the data. The high incidence of PAD completion (49%), when compared with prior studies on PAD prevalence (3-14% in Swanson, Swartz, Ferron, et al., 2006) also strengthens these bias concerns. Likewise, there were measurement concerns with some of the items in the original survey.
Although there have been several studies on PADs in Virginia, no research has been conducted as a follow-up to Wilder et al. (2013) to determine how PAD utilization has changed over time in response to the state's concerted implementation efforts (Kemp et al., 2015; Zelle et al., 2015). This lack of existing research on PADs following these studies points to a knowledge gap in our understanding of how these legal tools are used in Virginia. Likewise, there have been no prior mixed methods studies of PADs in Virginia, as all of the empirical studies have been quantitative or loosely qualitative. A mixed methods study would capitalize on the strengths of each tradition while offsetting associated limitations of monomethod design (Creswell & Plano Clark, 2011). What research has been conducted on Virginia PADs has also failed to capture the qualitative voice of stakeholders, particularly, mental health consumers. The research of this dissertation addressed both content and methodological gaps to enhance our understanding of PADs in Virginia.

Conclusion

This literature review began by establishing a rationale for studying PADs by drawing on the empowerment movement that has emerged in the literature over the past three decades. By tracing the history of powerlessness, persons with mental illness have faced oppression within the mental health care system as they have been denied opportunities for choice and self-determination. Advocates and scholars have argued that legally-binding PADs can be tools of empowerment to remediate the legacy of this oppression. Drawing from the ACA Code of Ethics (2014) and the ACA Advocacy Competencies, counselors have a vested interested in knowing about PADs and promoting their use with clients. After establishing an ethical argument for PADs, the chapter shifted to a systematic review of the extant literature. Beginning with early theoretical works, and moving on to stakeholder, barrier, and implementation studies, this
chapter identified significant milestones in our understanding as well as many unanswered questions regarding these legal tools. I then shifted to a review of prior research on PADs in Virginia. This examination revealed several limitations in our understanding of PADs in Virginia. In this sense, our knowledge of this issue remained incomplete from both a content and methodological perspective. In the following chapter, I propose a research methodology to address these gaps in our understanding.
CHAPTER 3

Methods

Philosophical Foundation

Research in the social sciences often begins with a discussion of philosophical paradigms. Creswell and Plano Clark (2011) suggest there are four major paradigms within social science research, including post positivism, constructionism, participatory, and pragmatism. For my study, I adopted an overarching pragmatic worldview with a pluralistic lens. Onwuegbuzie and Johnson (2006) argue that mixed methods researchers can achieve this pluralistic lens by making "Gestalt switches from qualitative to a quantitative, going back and forth, again and again" (p. 59). In this sense, mixed methods research can "transcend the forced dichotomy" (Feilzer, 2010, p. 4) by creating a third viewpoint that "is informed by, is separate from, and goes beyond what is provided by either a pure qualitative viewpoint or a pure quantitative viewpoint" (Onwuegbuzie & Johnson, 2006, p. 59). Researchers adopt mixed methods approaches because they can provide more complete answers than could be obtained through monomethod designs (Creswell & Plano Clark, 2011). Greene, Caracelli, and Graham (1989) elaborated on this point by suggesting that mixed methods enables the triangulation, complementarity, initiation, development, and expansion of research findings.

Johnson and Onwuegbuzie (2004) argue that mixed methods research always begins with the problem statement. The problem statement generates a series of investigative questions, which in turn, inform methodological decisions (Creswell & Plano Clark, 2011). As mentioned in my problem statement, the goal of this research study was to address methodological and knowledge gaps in our understanding of PADs in Virginia. After reviewing the literature, it was clear that prior research had generated an incomplete picture of PADs in Virginia. Previous
research on PADs in Virginia had failed to consider the subjective layer of the phenomenon. However, an exclusively qualitative study would also fail to capture the more objective aspects of the topic such as whether or not statewide PAD implementation efforts had been effective in improving utilization. I chose a mixed methods design to answer my research question because it would enable triangulation through convergence and corroboration of data, complementarity through an elaboration of strand results in mixed analysis and interpretation, and expansion through a breadth of methods (Greene, Caracelli, & Graham, 1989). I was also interested in discovering what works and how (Creswell & Plano Clark, 2011) with the hope that the results of this study could be used to inform effective practice (Johnson & Onwuegbuzie, 2004). A mixed methods paradigm with a pluralistic lens afforded the tools necessary for accomplishing these research goals.

**Design**

A hybrid convergent parallel mixed method design was used with an equal emphasis on the qualitative and quantitative strands ([QUAN + qual] + QUAL = more complete understanding). Quantitative and qualitative data were collected to obtain different but "complementary data on the same topic" (Morse, as cited in Creswell & Plano Clark, 2011, p. 77). These databases were analyzed separately, and results were compared for converge and divergence. The advantage of the convergent parallel mixed method design was that it capitalized on the strengths while minimizing the weaknesses of monomethod approaches (Creswell & Plano Clark, 2011). The quantitative strand enabled generalization, while the qualitative strand captured the respondents' categories and understanding (i.e. the emic viewpoint) and identified contextual factors that related to the phenomenon (Johnson & Onwuegbuzie, 2004). The weaknesses of each strand were offset by the strengths of the other.
Collecting qualitative data from two sources, the survey and in-depth interviews, enhanced the study by providing detailed insight into the research questions. The in-depth interviews also enhanced the clinical significance of the study by capturing the unique experiences of clinician stakeholders. Through Gestalt switches between quantitative and qualitative lenses across the two phases, the study generated a more complete, valid, and clinically useful picture of PADs in Virginia (Johnson & Onwuegbuzie, 2004).

Although the convergent parallel design was selected for its comprehensiveness and applicability to practice (Creswell & Plano Clark, 2011), the design was not without complications. Creswell and Plano Clark (2011) suggest that convergent parallel designs generate methodological and practical hurdles that must be addressed at the outset of this study. The first challenge was that this method required a significant amount of effort since the data were collected concurrently from multiple sources. A second challenge was the issue of disparate samples, sample sizes, and types of data that problematizes data merging. To address these concerns, I paid attention to the timing, weighting, and mixing of the two approaches. Regarding timing, both strands of data were collected concurrently. To manage the time demands of concurrently collection, I staggered the start data of the phases by a period of six weeks. Regarding weighting, qualitative and quantitative data were given equal emphasis in the study. To support this choice, I ensured that both strands addressed the same concepts through parallel qualitative and quantitative questions (weighting). And finally, the data were mixed at the level of interpretation, as is depicted in Figure 1. I included the same participants (e.g. samples and sample sizes) in both strands to facilitate the comparison of the data sets (mixing).

I refer to the quantitative strand of this research as the stakeholder survey, which was used to answer research question one. The stakeholder survey adapted a questionnaire developed
by O’Connell and Stein (2002) to measure stakeholder PAD attitudes, knowledge, utilization, and barriers. The second strand of the study is referred to as the experience study, and aimed to answer research questions 2, 3, and 4. The experience study collected qualitative data through two sources: topical semi structured follow-up interviews with clinicians and open-ended questions nested in the stakeholder survey.

The participants, recruitment, study procedures, data collection, analyses, and legitimization considerations for each of these strands are discussed in the following section. In keeping with the mixed methods tradition, I also outline the procedures used for mixing the data alongside a description of the analysis used as well as my mixed method legitimization strategies.

**Quantitative strand**

The stakeholder survey addressed research question one (RQ1) of this dissertation: *Is there a statistically significant difference on measures of knowledge, attitudes, experience, and barriers regarding PADs among five stakeholder groups (clinicians, consumers, administrators, advocates, and family members) in Virginia?*

To answer research one, I administered an online stakeholder survey designed to measure four themes: PAD knowledge, attitudes, experience, and barriers. The cross-sectional survey contained a core set of questions that were relevant to all stakeholder groups, as well as additional items targeting more specific issues that applied to each stakeholder category. These core questions enabled comparison of responses across groups while the group-specific questions provided further elaboration of each group's interest, knowledge, and needs.
Participants and recruitment

This study was approved by the James Madison University IRB as well as the University of Virginia's Health Sciences IRB. Nonrandom purposive sampling was used to identify study participants. To qualify for participation in the stakeholder survey, individuals had to report employment as a facility administrator or clinician (e.g., psychiatrist, psychologist, social worker, or counselor) at a Virginia CSB, psychiatric hospital, or residential mental health treatment facility. Other inclusion criterion was self-identification as a mental health service recipient, family member, or mental health advocate residing in Virginia.

I submitted survey information and URL links to professional and advocacy organizations that had stakeholder members, including the Department of Behavioral Health and Developmental Services (DBHDS). These organizations emailed the link to members, posted the link to their website, or included the link within their newsletter. Wilder et al. (2013) had a low response number for mental health consumers, family members, and advocates (n=40, n=60, and n=25, respectively), which raised the possibility of selection bias. To increase responses and reduce the likelihood of selection bias, I employed also snowball sampling procedures for these three stakeholder groups. Snowball or chain sampling involves locating a few participants who meet criteria for participation, and then ask them to refer you to other respondents (Merriam & Tisdell, 2015). Snowball sampling has been identified as a way to increase the participation of traditionally marginalized or hard-to-reach subgroups (Sadler, Lee, Lim, & Fullerton, 2010). To employ this sampling procedure, I contacted case managers at several Virginia CSBs who were willing to forward the survey on to their clients and family members. To increase advocate responses, I contacted an area mental health advocate to ask for her assistance with the research study.
Study procedures

To answer RQ1, recruited participants who were willing to complete the stakeholder survey were provided with an online consent letter providing information about the study. All data gathered from the stakeholder survey were anonymous and confidential. Study participants completed the questionnaire online through Qualtrics. Participants took between 15-25 minutes to complete the survey.

The online survey was divided into four sections that measured respondent demographics, familiarity with PADs, experience with PADs, and PAD attitudes and perceived barriers. The survey also contained three open-ended items that were used for qualitative analysis. The demographic section asked participants questions on age, gender, ethnicity, profession, working setting, years of experience, and highest education completed. The familiarity with PADs asked participants, “Prior to this survey, how familiar would you say you were with psychiatric advance directives?” Respondents answered on a five point Likert scale that ranged from no knowledge to very knowledgeable. Experience with PAD was measured by four questions regarding organizational practices around PADs, including “PADs are discussed with consumers,” “PAD forms are provided to consumers,” “Consumers are assisted in completing PADs,” and “There is written documentation of whether someone has a PAD.” Respondents were asked to select an answer that best described practice at his or her current organization on a five-point Likert Scale with items ranging from No Consumers to All consumers. Consumers, family members, and advocates were asked questions regarding whether or not they have a PAD or would have an interest in completing one if given guidance. Stakeholder attitudes towards PADs were then assessed through the Opinions on Psychiatric Advance Directives Questionnaire (OPADQ) (O’Connell, 2002). The OPADQ contains three
subscales: Obstacles to Success, Utility and Benefits, and Decision-Making Capacity.

Respondent scores were calculated and treated as dependent variables while stakeholder groups were treated as categorical independent variables.

**Instrumentation**

The stakeholder survey contained forced choice and Likert-scale questions measuring four themes: PAD knowledge, attitudes, experience, and barriers. Experience items were based on the Wilder et al. (2013) stakeholder survey, while PAD familiarity and attitudes were measured by the Opinions on Psychiatric Advance Directives Questionnaire (OPADQ) (O’Connell, 2002). The OPADQ contains 60 items concerning the perceived barriers and benefits of PADs. Following procedures from O’Connell (2002), participants were then asked to rate how strongly they agreed with each statement on a five-point Likert Scale ranging from strongly disagree to strong agree. These 60 items are grouped into three subscales: Obstacles to Success (OS), Utility and Benefits (UB), and Decision-Making Capacity (DM). The OS subscale included 26 items that identify concerns regarding the use of PADs, from their implementation, to access issues, to whether or not the instructions will be followed. The UB subscale was comprised of 20 items that regarding beliefs about the benefits of PADs, such as improved clinical outcomes and professional communication. The DM subscale contained 14 items that suggest consumers have the capacity to make decisions regarding their mental health care treatment. The OPADQ was selected for its strong psychometric properties. O’Connell (2002) reports Cronbach's alpha for each of the three subscales: Obstacles to Success $\alpha=.90$, Utility and Benefits, $\alpha=.88$, Decision-making capacity, $\alpha=.81$.

The Wilder et al. (2013) survey was developed from pre-existing questionnaires had that been used in prior studies conducted in North Carolina (Elbogen et al., 2006). Items from the
Elbogen et al. (2006) survey were adapted to reflect the specifics of Virginia PAD law. The study’s Coordinating Committee of content experts then reviewed the instrument. Changes were made based on the committee's recommendations. The survey was then piloted with a group of 10 individuals, including consumers, clinicians, and administrator volunteers. Final changes were made to the survey based on feedback from the pilot study respondents. The stakeholder survey (Wilder et al., 2013) demonstrates content validity based on the formal validation processes used in its development (Neukreg & Fawcett, 2015). Wilder et al. (2013) did not report formal psychometric properties for external validity or reliability. This issue is discussed further in the section on trustworthiness.

For use in this study, changes to the Wilder et al. (2013) survey language were made to reflect current understanding and practices surrounding PAD utilization. Specifically, the phrase “the new Health Care Decisions Act (HDCA)” was replaced with the phrase “advance directives for mental health.” These changes were made to increase the clarity of items and reduce confusion on the part of study participants, who are likely not aware of the HDCA. Likewise, double barrel and leading questions were removed and new items were constructed to replace the problematic items. Members of the researcher team as well as content experts reviewed these changes to ensure validity.

Data analysis

Data were collected in the quantitative strand to test the hypotheses associated with RQ1. During this phase of analysis, I used a quantitative lens to apply appropriate deductive techniques. Quantitative data were cleaned and entered into the Statistical Package of Social Sciences (SPSS Version 24.0, 2017). These data were then analyzed for frequency distribution, and descriptive statistics. Between group differences on measures of OPADQ total scores and
subscales were calculated using multiple one-way ANOVAs. Statistical significance was determined at a $p$-value of $\leq 0.05$. Tukey's Honestly Significant Difference post hoc tests were conducted where differences occurred. Post hoc power analyses were carried out for nonsignificant findings.

**Qualitative strand**

The *experience study* addressed three research questions in this dissertation:

RQ2: “What encourages the use of PADs in Virginia?”

RQ3: “What discourages the use of PADs in Virginia?”

RQ4: “What can be done to increase PAD utilization?”

To answer these questions, I collected qualitative data from two sources. The first source of qualitative data came from responses to open-ended questions nested in the quantitative stakeholder survey. The second source of qualitative data was collected through one-on-one telephone interviews with clinicians. These data were collected concurrently with the QUAN strand to enhance understanding of what has continued to promote or thwart the use of PADs in Virginia.

**Sources of qualitative data**

*Open-ended questions*

Qualitative data were collected through open-ended questions nested in the online stakeholder survey. All survey participants were provided with an online informed consent letter before completing the questionnaire. Anonymous surveys required between 5-20 minutes for completion. Three open-ended questions were nested into the quantitative stakeholder survey to gather perspectives from these respondents. These three questions asked about use, encouragers, and discouragers of PADs in Virginia. Members of the research team reviewed the open-ended
questions. Reviewers were instructed to respond to questions as if they were a participant and then comment on the content, grammar, and understandability of each prompt. To ensure that the categories of the researchers did not influence qualitative responses, the open-ended questions were asked at the beginning of the survey.

*Follow-up interview script*

A semi-structured interview guide was developed to elaborate on recommendations for increasing PAD utilization. The semi-structured interview was designed such that all participants were asked a core set of questions developed to elicit information regarding critical experiences with PADs. Participants were first asked a *grand tour question* to build rapport and provide context regarding the interviewee’s clinical experience (Merriam & Tisdale, 2015). Participants were then asked about experience, behavior, opinions and values regarding PADs in Virginia (Patton, 1990). In a closing question, participants were asked if they had any specific recommendations for increasing PAD utilization. Although the questions were used flexibly, optional probes were included to evoke specific information based on the participant’s emerging worldview (Merriam & Tisdale, 2015).

After developing the interview guide, members of the research team reviewed the questions. Reviewers were instructed to respond to prompts as if they were a participant and then comment on the content, grammar, and understandability of each item. After some revisions, the script was piloted with a mental health clinician. Minor changes were made to the script following the pilot interview.

Participants were scheduled at a mutually-convenient time for a telephone interview, which was designed to take less than 30 minutes to complete. On the date of the interview, verbal informed consent and audio recording permission were obtained over the phone and
recorded in the study's audit trail. For consistency, I conducted all of the clinician follow-up interviews. All recordings were transcribed verbatim using Dragon for Mac transcription software. Participants who consented to audio recording were provided with copies of interview transcripts to ensure accuracy. After confirming transcript accuracy through member checking, these data were then entered into NVivo software for coding and analysis.

**Ethics**

Unlike the open-ended responses, which collected only anonymous data from respondents, the one-on-one interviews necessarily involved the collection of identifiable data through interview procedures. The collection of identifiable data increases the risk of harm to study participants due to the potential for confidentiality breaches. Because this study involved vulnerable populations, I decided, in consultation with my research team, to only include the clinician stakeholder group in this portion of the study. In addition to concerns regarding harm through breach of confidentiality, there were additional harm concerns related to the sensitive nature of the questions. The interview protocol was designed to elicit critical participant experiences with PADs. For the advocate, family, and consumer stakeholder groups, these critical experiences might well involve prior traumatic or unwanted hospitalizations. Without a prolonged engagement with me as a researcher, I had concerns that sharing these stories could be traumatizing or upsetting to interview subjects. Although I am a trained mental health clinician who regularly works with advocates, consumers, and family members, in my capacity as a researcher, I felt that the benefits of interviewing all five stakeholder groups did not outweigh the risk of harm. Out of concern for the well-being of participants, I elected to collect only anonymous qualitative data from these vulnerable stakeholder groups.

**Participants and recruitment**
To qualify for participation in the follow-up interviews, individuals had to report employment as a clinician (e.g., psychiatrist, psychologist, social worker, or counselor) at a Virginia CSB, psychiatric hospital, or residential mental health treatment facility or self-identify as a mental health advocate. Participants for interviews (N=8) were recruited through the clinician stakeholder survey through an additional question that asked if the participant would be willing to complete a follow-up interview on PADs. If interested (as indicated by a yes to this question), this item directed the participant to a separate website or survey that was not connected to the main instrument to preserve anonymity. The respondent was then led to an informed consent agreement before submitting contact information. Interested participants were then contacted via email within two weeks of the closure of the stakeholder survey. Participants selected for follow-up interviews were chosen using maximum variation sampling to enhance the trustworthiness of these data. Maximum variation sampling identifies and seeks out patterns from participants who represent the widest possible range of characteristics (Merriam & Tisdell, 2015).

Data analysis

All QUAL data were entered verbatim into NVivo for coding and analysis. Qualitative responses were later analyzed using inductive content analysis. Inductive content analysis is a coding and categorization approach that examines textual information to “describe who says what, to whom, and with what effect” (Vaismoradi, Turunen, & Bondas, 2013, p. 400). The goal of inductive content analysis is to “attain a condensed and broad description of a phenomenon … [through] categories” (Elo & Kyngas, 2008, p. 8). Inductive content analysis is considered ideal for qualitative research on topics, such as psychiatric advance directives, where there is an absence of prior studies examining a phenomenon (Vaismoradi et al., 2013). Inductive content
analysis also lends itself well to mixed methodology since it enables the quantification of qualitative data through the measurement of frequencies of categories and themes (Gbrich, 2012). This quantification of qualitative data can support comparisons of QUAL and QUAN findings (Vaismoradi et al., 2013).

During open coding, segments of texts were labeled with codes or headings that described a text’s content or meaning (Creswell & Plano Clark, 2011). These headings were then collected onto coding sheets to generate broad categories that could capture the codes. These categories were then grouped into higher order headings (Elo & Kyngas, 2008). Using comparison procedures in which codes were interpreted not only for similarities, but also for whether they belonged together, a process called horizontalization (Mousakas, 1994), this grouping strategy reduced the overall number of categories. In the next step, the categories were abstracted into “content-characteristic words” (Elo & Kyngas, 2008, p. 111) that offered a general description of the phenomenon. These categories were then organized and reported in a conceptual map. An audit trail and memoing were used to guide decisions throughout the QUAL analysis.

**Mixed methods**

Quantitative and qualitative data were mixed in this convergent parallel study at the level of interpretation. The goal of mixing was to seek convergence, complementarity, and enhancement to develop a more complete, valid, and clinically useful understanding of PADs in Virginia (Creswell & Plano Clark, 2011).

**Procedures**

In keeping with the tradition of convergent parallel mixed method research, qualitative and quantitative data were collected both concurrently, analyzed separately, and were then
integrated for a mixed analysis. This mixed method analysis was guided by two sensitizing questions: to what extent do the qualitative and quantitative results converge, and in what ways do they diverge. Combined database results were analyzed and later reported through a joint display of themes and quantitative results across each of these phases. After completing the mixed methods analysis, the findings were interpreted through a pragmatic lens to draw meta-inferences (Teddlie & Tashakkori, 2009).

Analysis

The merged data analysis strategy used in this study was based on the seven-step model of Teddlie and Tashakkori (2009). Teddlie and Tashakkori’s (2009) process-oriented model involves seven stages of data analysis including 1) data reduction, 2) data display, 3) data transformation, 4) data correlation, 5) data consolidation, 6) data comparison, and 7) data integration. Steps one and two (data reduction and data display) of this process were completed through the concurrent data collection and analysis. In steps three and four (data transformation and data correlation), qualitative data were converted into numerical codes and correlated with the quantitative data. In step five (data consolidation), quantitized qualitative data and quantitative data were combined to create a new data set. In step six (data comparison), data sets were compared through both a qualitative and quantitative lenses. In step seven (data integration), the merged results were reported both through the correlations and in a joint table displaying themes and quantitative results.

Trustworthiness

Quantitative legitimization

Merriam and Tisdell (2015) argue that for research to be considered trustworthy, studies must be "rigorously conducted" (p. 238). In quantitative research, trustworthiness is evaluated by
the study’s validity (Onwuegbuzie & Johnson, 2006). In one of the seminal texts on quantitative research, Shadish, Cook, and Campbell (2002) identified four key types of validity: statistical conclusion validity, internal validity, construct validity, and external validity. Steps were taken to ensure the validity of the QUAN strand. Statistical conclusion validity refers the extent to which conclusions are correct or reasonable based on the data. To demonstrate statistical conclusion validity (Shadish et al., 2002), I conducted power analyses to ensure that statistical tests had a power of greater than 0.8 in value and sought consistency in implementation procedures from the 2010 administration (Wilder et al., 2013). Content validity refers to the degree to which a test measures what it claims to be measuring (Shadish et al., 2002).

To demonstrate content validity, I administered the Wilder et al. (2013) stakeholder survey, a content valid measure of PAD knowledge, attitudes, barriers, and experience. Although the stakeholder survey appeared to demonstrate content validity based on the formal validation processes described in Wilder et al. (2013), the developers did not report any specific psychometric properties (e.g. validity or reliability). The failure to report validity or reliability measures was likely because the instrument was developed without exploratory or confirmatory factor analysis. The absence of psychometric data on the stakeholder survey presents a limitation for the trustworthiness of the quantitative findings of this dissertation. However, in keeping with a pragmatist philosophical orientation, I used the Wilder et al. (2013) survey for data collection with the expectation that clinically useful results would nonetheless emerge.

**Qualitative legitimization**

Firestone (1987) argues that rigorous qualitative research "provides the reader with a depiction in enough detail to show that the author's conclusions ‘make sense'" (p. 19). To make
sense to a reader, qualitative research must be credible, transferable, dependable, and confirmable (Lincoln & Guba, 1985).

Methodological rigor was ensured through credibility, transferability, dependability, and confirmability. Credibility suggests that the data are believable from the perspective of the participants and that there is congruence between the findings and reality (Merriam & Tisdell, 2015). Creswell and Plano Clark (2011) point out one possible threat to credibility generated by the study’s design. These authors suggest that qualitative questions nested in a quantitative survey do not generate “rich content and detailed information” (Creswell & Plano Clark, 2011, p. 276). To address this threat to credibility, I collected multiple sources of QUAL data to enable triangulation (Merriam & Tisdell, 2015) between the two QUAL databases. Credibility was also ensured through member checking with interview participants (Merriam & Tisdell, 2015).

Transferability suggests that the findings of a study allow for application by the reader to other contexts (Merriam & Tisdell, 2015). To increase transferability, I utilized maximum variation sampling in the follow-up interviews. Additionally, I attempted to provide an emic account in my reporting, which would facilitate the application of findings to other contexts. Dependability is the sense of consistency between the data collected and the results (Merriam & Tisdell, 2015). To increase dependability, I kept an audit trail to ensure that others could trace the logic of decisions and conclusions. Finally, confirmability refers to the process of verifying the data collection and analysis by others (Merriam & Tisdell, 2015). To increase confirmability, I utilized peer review of interview protocols, transcripts, coding, analysis, and interpretation. These deliberate methodological decisions were intended to increase the rigor and trustworthiness of the qualitative strand of this study.
Mixed methods legitimization

Attention was paid to issues of rigor and trustworthiness in this mixed methods analysis. Onwuegbuzie & Johnson (2006) suggest a typology of legitimization for mixed methods research. Several elements of their typology were incorporated in this study: sample integration, weakness minimization, and paradigmatic mixing. Sample integration as a rigor strategy implies that the same sample is used for both strands. Because both the QUAN and QUAL strand used the same individuals, it was possible to combine strand inferences and construct meta-inferences. Weakness minimization refers to the extent to which the weakness of one strand is compensated by the strengths of the other (Onwuegbuzie & Johnson, 2006). Weaknesses were minimized in this study by collecting data qualitatively and quantitatively to accurately capture both the emic and the etic perspective within the study. Qualitative data were also collected from two sources, which minimized the weakness of the open-ended nested questions (Creswell & Plano-Clark, 2011). Onwuegbuzie & Johnson (2006) also suggest that paradigmatic mixing can enhance trustworthiness. Although I sought to develop an overarching pragmatic worldview for this research, paradigm shifts between post positivism and constructivism occurred when I moved between the QUAN and QUAL strands. In conducting this study, I adopted the epistemological, ontological, axiological, methodological, and rhetorical practices of each strand through "Gestalt switches from a quantitative to a qualitative lens" (Onwuegbuzie & Johnson, 2006, p. 57). These choices were made with the goal of increasing the trustworthiness of the mixed methods findings.

Conclusion

This chapter began with a discussion of philosophical foundations. After discussing the philosophical underpinnings of this inquiry, I introduced mixed methods research, and explained
how my research questions motivated design choices. I then outlined the strengths and
weaknesses of the multiphase mixed methods design before transitioning to the procedures used
in the convergent parallel design. Attention was paid in these sections to issues of sampling and
analysis. The chapter concluded with a discussion of the mixed methods analysis as well as steps
that were taken to enhance trustworthiness of the study.

In the following chapter, the results of quantitative, qualitative, and mixed method
analysis are reported. In chapter five of this dissertation, the mixed methods results are
interpreted with an eye towards whether or not there was convergence among the findings, and
what meaning can be derived from these connections (Creswell & Plano Clark, 2011).
CHAPTER 4

Results

Introduction

In keeping with the convergent parallel mixed methods design outlined in the previous chapter, quantitative and qualitative data were collected concurrently through two sources, the online stakeholder study and follow-up interviews. Data were analyzed separately using appropriate deductive and inductive techniques to answer the corresponding research questions. The quantitative strand sought to define how PADs were currently being used in the state (RQ1); the qualitative strand sought to clarify the enabling factors and obstacles that influence PAD utilization in the state (RQ2 & RQ3), and identify strategies for increasing the use of PADs in the future (RQ4). Results from both strands were then mixed at the level of interpretation to evaluate the extent to which the quantitative and qualitative results converged or diverged (RQ 5). In this chapter, I report study results organized by strand and conclude with a discussion of the integrated analysis results. I also discuss study limitations and suggestions for future research on the topic.

Quantitative strand results

Data were collected in the quantitative strand to test the hypotheses associated with RQ1. Participants completed the Opinions on Psychiatric Advance Directives Questionnaire (OPADQ) online (see Appendix A). Quantitative data were cleaned and entered into the Statistical Package of Social Sciences (SPSS Version 24.0, 2017). These data were then analyzed using descriptive and inferential statistical procedures. During this phase of analysis, I used a quantitative lens to apply appropriate deductive techniques.
Sample Characteristics

Completed surveys were received from 150 respondents. Due to recruitment procedures, it was not possible to calculate response rate for this study. Seventy-two percent of respondents identified as female (n=110), while 16.4% (n=25) identified as male [see Table 1]. Over three-quarters of the sample identified as White (n=120), while 7% identified as Black (n=10) [see Table 2]. Professionally, 47% (n=71) of respondents identified as clinicians, 13% (n=20) as consumers, 20% (n=31) as administrators, 3% (n=5) as family members, and 7% (n=11) as advocates [see Table 2]. Of the respondents who identified as clinicians, 30% (n=46) identified as Mental Health Counselors (LPC) while 18% (n=28) identified as social workers [Table 3]. The next largest professional group was of case managers, who comprised 6% (n=9) of the clinician group. Only one psychiatrist and one psychologist completed this survey. More than half of survey respondents (n=88) reported working for a public agency or organization, while 18% (n=27) reported working at a private not-for-profit organization. Respondents working in outpatient settings comprised 71% of the sample (n=108), while 6% (n=9) worked in an inpatient setting. Respondents had an average age of 45 years old (SD=10.80). Participants had worked an average of 14.41 (SD=10.36) years in their current profession. Sixty percent of respondents (n=89) reported a professional degree as their highest level of education (see Table 4).

Opinions on Psychiatric Advance Directives Questionnaire (OPADQ)

The first theme of the study considered stakeholder attitudes towards PADs. To measure stakeholder attitudes towards PADs, study participants were asked to complete the 60-item Opinions on Psychiatric Advance Directives Questionnaire (OPADQ). The OPADQ contains three subscales Obstacles to Success (OS), Utility and Benefits (UB), and Decision-Making Capacity (DM). Item responses to the Likert Scale questions of the OPADQ [Appendix A] were
entered as ordinal variables. Total OPADQ scores and subscale scores (OS, UB, DM) were calculated for each participant as continuous variables [see Table 10]. The mean total score for OPADQ was calculated to be 183.84 (SD= 11.52). The mean OS Score was 63.95 (SD= 11.46). The mean UB Score was 68.28 (SD= 8.95), and the mean DM Score was 51.60 (SD= 3.86). A series of one-way ANOVAs were planned to compare mean scores on the three factors of the OPADQ. Before conducting these tests, the dataset was analyzed to ensure conformity to the pertinent statistical assumptions of ANOVA. The Levene’s test of homogeneity yielded nonsignificant results for each of the four dependent variables (Total, \( p = 0.85 \); OS, \( p = 0.08 \); UB, \( p = 0.19 \); DM, \( p = 0.30 \)) suggesting that the assumption of equality of variance had not been violated. The skew and kurtosis were also calculated for the dataset suggesting the assumption of normality was also not violated. Likewise, there was no clustering outside of the independent variable of stakeholder group, indicating that the assumption of independence of samples had not been violated.

After determining that the dataset conformed to the assumptions noted above, a one-way ANOVA was conducted to evaluate the differences between stakeholder group and Total score on the OPADQ. The independent variable, Simple Group, contained five levels: administrators, clinicians, advocates, consumers, and family members. The dependent variable was Total Score on the OPADQ instrument. Statistical significance was determined at a \( p \)-value of \( \leq 0.05 \). The omnibus ANOVA was nonsignificant, \( F(4, 138) = 2.32, p =.06 \). The effect size of the difference between stakeholder group and Total Score on the OPADQ was very small, as evidenced by partial eta-squared, with stakeholder group accounting for 6.5% of the variance in Total Score. Due to the nonsignificant result, a post-hoc power analysis was conducted for the previous omnibus ANOVA. The observed power for this one-way omnibus ANOVA was determined to
be 0.66, suggesting that if there were truly an effect of stakeholder group on Total OPADQ scores, this result would be found 66.1% of the time.

Similar one-way ANOVAs were conducted to evaluate the difference between stakeholder groups on the three subscales of the OPADQ. The independent variable in these tests contained five levels: administrators, clinicians, advocates, consumers, and family members. The dependent variable was the total score for each of the OPADQ’s three subscales, Utility and Benefits, Obstacles to Success, and Decision-Making Capacity. The ANOVA for the Utility and Benefits subscore, $F(4, 138) = 2.21, p = 0.07$, indicated there was no statistically significant difference in mean UB scores among stakeholder groups [see Table 11]. Likewise, analysis of variance on the Decision-Making Capacity subscale yielded no statistically significant differences between stakeholder groups, $F(4, 138) = 0.21, p = 0.93$.

However, the omnibus ANOVA for the Obstacles to Success subscale was found to be statistically significant, $F(4, 138) = 2.93, p = 0.02$. The strength of this relationship as evidenced by partial eta-squared was found to be small with stakeholder group accounting for 8.1% of the variance in Obstacles to Success scores. Follow-up tests were conducted to evaluate pairwise differences among the means [see Table 12]. There was a statistically significant difference in the means of OS scores between participants who were administrators and clinicians (mean difference = 6.76, SE = 2.4) with clinicians having higher OS scores than administrators. There were no statistically significant differences found between the family member, advocate, or consumer stakeholder groups.

*Interpretation.* I hypothesized that there would be a statistically significant difference in OPADQ scores between stakeholder groups. However, the results suggest no statistically significant differences between the five groups on Total OPADQ scores, but there was an effect
of stakeholder group on the Obstacles to Success subscale. Specifically, there was a statistically significant difference between clinicians and administrators on measures of Obstacles to Success, with clinicians identifying more obstacles than administrators.

**Familiarity with Psychiatric Advance Directives (PADs)**

To measure Familiarity with Psychiatric Advance Directives, respondents were asked to rate how familiar they were with PADs prior to completing this survey. The familiarity item was designed to measure both PAD awareness (e.g. Have you heard of PADs before?) and PAD knowledge (e.g. Do you know how PADs are used in the community?). Respondents rated themselves on a Likert Scale ranging from “I have never heard of PADs” to “I would consider myself very knowledgeable on PADs and how they work in my community.” Overall, more than half of respondents (59%) rated themselves as having some awareness but limited knowledge on PADs work in the community. Fourteen percent (n=21) of respondents reported that they had never heard of PADs before taking the survey, 16% (n=25) reported having heard of the term but knowing little about them, 15% (n=23) reported knowing that PADs had something to do with treatment planning, but would be unable to describe how they were used, and 13% (n=19) reported being able to describe PADs to someone else, but being unsure of how they apply in the community. However, 41% of respondents (n=61) rated themselves as “Knowledgeable on PADs and how they work in the community.”

Familiarity with PADs was then entered as a continuous, dependent variable in multiple ANOVAs with demographic information as the independent variables. No significant differences were found in familiarity with PADs as a function of stakeholder group, profession, professional setting, gender, education level, or race.
Interpretation. I hypothesized that PAD familiarity would be low for all stakeholder groups. The results of the survey suggest that more than half of respondents rated themselves have being less than very familiar with PADs, which confirmed my hypothesis. I also hypothesized that there would be a statistically significant difference in PAD familiarity between stakeholder groups; however, no effects were found.

Experience with PADs

The second theme, Experience with PADs, asked respondents five questions regarding how PADs were used in their current agency. The first question asked what percentage of consumers in your agency had PADs. The second question asked whether PADs were discussed with consumers. The third question asked if PAD forms were provided to consumers. The fourth question asked if consumers were provided assistance in completing PAD forms, and the fifth question asked whether there was written documentation of whether consumers have PADs.

Responses to question one were entered as a continuous ratio variable, while data for questions 2-5 were entered as ordinal data. Histograms of responses suggest that data were not normally distributed. The mean response (n=20) for the item “What percentage of consumers in your setting have completed a PAD?” was 14.6 with SD of 15.97. The median response to this item was 10%, suggesting that only a small number of consumers had completed a PAD.

Twenty-nine percent of respondents (n=44) reported that they did not know if PADs were discussed with consumers in their agencies while only 16% reported (n=24) that PADs were discussed with most consumers, and only 15% of respondents (n=22) indicated that PADs were discussed with all consumers [see Table 6]. For the remaining three items regarding PAD experience, the most common response was “Don’t know” (38% for “PADs are provided to consumers”) [see Table 7]; 36% for “Consumers are assisted in completing PAD forms” [see
Table 8]; and 31% for “There is written documentation of whether consumers have PADs” [see Table 9]). Only 2.6% (n=4) respondents reported that PAD forms were provided to all consumers, while only 4.6% of respondents (n=7) reported that all consumers were provided assistance in completing PADs. Notably, “All consumers” was the second most frequent response on the item of whether there was written documentation of PADs [see Table 9].

Interpretation. I hypothesized that Experience with PADs would be low for all stakeholder groups. The results of the survey that a small percentage of consumers appear to have completed PADs. Likewise, results indicated that PAD practices within agencies very greatly. Some agencies consistently documented the presence of a PAD, while others appear to provide minimal support for consumers wanting to complete a PAD. My hypothesis regarding the lack of Experience with PADs was confirmed.

Qualitative strand results

The experience study is the secondary focus of this dissertation and addressed three research questions:

RQ2: “What encourages the use of PADs in Virginia?”

RQ3: “What discourages the use of PADs in Virginia?”

RQ4: “What can be done to increase PAD utilization?”

During this phase of analysis, I used a qualitative lens to apply appropriate inductive techniques.

Participant characteristics

Data for the qualitative strand of this dissertation were drawn from two sources: nested open-ended questions in the stakeholder survey and one-on-one telephone interviews with clinicians who agreed to a follow-up through a recruitment request in the stakeholder survey. Interviews were semi-structured in nature, but followed a general interview script [See Appendix
B) to answer each of the qualitative research questions. The average time of the follow-up interview was 22 minutes in length.

Demographic characteristics for respondents to the qualitative portion of the stakeholder survey (N=150) were described in the previous section [see Tables 1-4]. Eight clinicians agreed to participate in follow-up interviews; however, only 7 individuals met the inclusion criteria of having heard of PADs prior to study recruitment. Five of these 7 participants worked in outpatient settings, while two participants reported working in inpatient settings such as private or state hospitals. Two interview participants were licensed as professional counselors (LPCs), three identified as social workers (LCSW), one identified as a case manager, and one participant was a psychiatrist (MD). Interview participants reported having careers in the mental health field for 5-34 years, with the mean of 21 years of experience. Three participants were male, and four were female. Six identified as White, and one participant identified as Asian.

**Interview summary**

*PAD knowledge*

All seven interviewees rated themselves as extremely familiar with PADs. Four of the seven clinicians interviewed during this strand had been certified as Advance Directives Facilitators through the Department of Behavioral Health and Disability services. This certification requires 18 hours of class time, as well as the successful demonstration of facilitation skills and PAD knowledge.

*PAD Attitudes*

Overall, interview participants expressed optimism for the potential value of PADs within the mental health system. Six of seven interview participants expressed aspirational hopes that every consumer of mental health services would eventually have a PAD. Two of the interview
participants indicated their belief that PADs would be beneficial for everyone, including those who did not currently have a psychiatric diagnosis. In these instances, the participants noted the possibility of unexpected psychiatric incapacity due to unexpected medical issues or dementia later in life. One participant said that she had completed her own PAD, and that the process had facilitated a meaningful conversation with her family members about her desire for future treatment. In this sense, she indicated that the process generated its own benefits even if she never needed to make use of her PAD.

However, one participant indicated that he did not think PADs would be useful for all consumers. This participant suggested that PADs would not be helpful for individuals who had substance use issues or a dual-diagnosis. In these instances, this participant suggested that they “wouldn’t be very useful and might be a way to avoid treatment.” When asked to elaborate, this participant suggested that PADs would likely inhibit clinical decision-making, and force treatment providers to seek out judicial authorization over objections.

**PAD utilization**

Each participant was asked how and when they had encountered PADs in their clinical work. Only three of the clinicians reported encountering a PAD in the course of their work outside of offering facilitation services. Of these three participants, no one reported encountering a PAD at the time of a behavioral emergency. One clinician reported encountering a PAD prior to a civil commitment special hearing, and another mentioned accessing a consumer’s PAD during the course of an involuntary hospitalization. No participants had encountered a PAD at the time of hospitalization to avoid involuntary treatment through the activation of the Ulysses Clause. Interviews indicated that PADs are infrequently used in Virginia.
**Analysis Stages**

Using NVivo 11 for Mac (2017), I employed the following methodology to answer the qualitative research questions. First, the research team open-coded interview transcripts and qualitative survey responses to find initial codes. During this initial phase, coders attended to the text closely and considered to what extent the content provided an answer to the research question. Interview transcripts were weighted more heavily; open-ended survey responses were used to enrich the interview data and to provide multiple stakeholder perspectives.

Following this initial open coding stage, codes were reorganized based on similar content. The research team paid particular attention to ensuring that each code emerged more than once in the data. This prevented a single perspective, including those of the more heavily weighted interviews, from dominating the common experiences across stakeholder perspectives. In the next stage, horizontalization (Moustakas, 1994) was applied through which all codes within a research questions were considered without regard to the frequency of references. In this stage, the research team considered how each code uniquely contributed to the research question. This yielded a set of categories, which were then organized into content related themes. In the next step, the categories were abstracted into “content-characteristic words” (Elo & Kyngas, 2008, p. 111) that offered a general description of the phenomenon. These themes were then organized and reported in a conceptual map.

**Analysis details.** As outlined in the previous section, the research team began by open-coding the open-ended responses and the interview transcripts. This phase of open coding generated 190 initial codes. Following the initial codes, the research team reorganized the data into 146 codes. In the next phase of axial coding, the 146 codes were organized into 20 categories. During the horizontalization phase, these categories were considered, regardless of
the number of times they appeared in the data, based on how well they reflected the research questions. Members of the research team were consulted to ensure trustworthiness. Four themes emerged for RQ2; four themes emerged for RQ3, and two themes emerged for RQ4. Figure 2 depicts these themes in a conceptual map.

**RQ2 Results**

Related to the second research question (i.e., “What encourages the use of PADs in Virginia?”), four themes were discovered: **Encouraged by person-related benefits, Encouraged by clinical-related benefits, Encouraged by PAD champions, and Awareness.** Each theme is described below.

*Encouraged by person-related benefits.* Participants indicated that there were two types of benefits that encourage the use of PADs. The first type were the benefits to the person, namely the consumer. These person-centered benefits included features such as personal-empowerment, fostering autonomy, and giving voice to a person. One interview respondent pointed out that, “[Consumers] feel good about the fact that they have an avenue to express their desires and their preferences.” Another survey respondent stated, when it comes to a PAD, “you're your own expert of yourself.” A third respondent suggested, “I think it's useful for everybody. I filled one out, and I liked the conversation that it sparked with my family.”

*Encouraged by clinical-related benefits.* Participants identified a second type of encouragement related to PAD benefits, namely clinical benefits. Both survey and interview participants suggested that PADs should be encouraged because they could improve clinical outcomes by informing clinicians of what works well in crisis situations. Another interviewee suggested that PADs could also help with cultural understanding in clinical settings. She stated, “When it comes to cultural issues—you know, different people have different ways of dealing
with mental health and it’s not always through the same lens as a psychiatrist.” Other participants identified the fact that PADs might even be preventative in that they help people to identify the signs of crisis, or expedite the treatment process. One survey respondent stated that PADs could “connect people with treatment, especially in times of crisis, and take out many middle steps, and ensuring the client is getting care that they want, whether or not they can articulate it at that time.”

*Encouraged by PAD champions.* Participants suggested that PADs were encouraged by the presence of PAD champions. PAD champions could be clinicians, administrators, consumers, or advocates. These PAD champions function within organizations to encourage the incorporation of PADs into clinical practice. Champions also encouraged consumers to complete their own PADs. Several interview respondents stated that they were champions in their organization. One interviewee referred to herself as the “the golden child of Advanced Directives” after becoming certified as a facilitator. Interestingly, several participants commented that they were interested in finding a consumer champion who could speak to the value of having a PAD. As one survey respondent suggested, “one of our peer support specialists has been very instrumental,” and many other respondents in both sets of qualitative data expressed a desire to identify just such a consumer champion.

*Awareness.* Awareness also emerged as an important encourager for PADs. Awareness included the idea of knowing what a PAD was, how to complete one, and how they operate in crisis situations. Both survey and interview participants suggested that awareness of PADs was a critical enabling factor. To support this theme, a number of interview participants stated that receiving training on PADs or facilitation made them more likely to discuss the tools with clients and colleagues. One interview participant stated, “I was trained as a facilitator and was involved
in the committee to try to bring the Advanced Directives more into client awareness and staff awareness.” Another survey respondent suggested that with “ongoing exposure to the idea… People get more familiar with [PADs].”

**RQ3 Results**

Four themes -- *Not knowing, Lack of capacity, Client-related obstacles, and Power struggles* -- emerged that were related to the research question: “What discourages the use of *PADs in Virginia*?” Each theme is described below.

*Not knowing.* Many participants endorsed the idea that not knowing about PADs was a significant discourager. One respondent stated that PADs were discouraged by “Ignorance/unfamiliarity, especially on the part of providers.” Another interview respondent who worked in an inpatient setting stated, “I don’t think people are aware of psychiatric advanced directives to be quite honest.” Another survey respondent pointed out that, “I think people do not know what PADs are or how to explain their purpose, and how or when to discuss this with services users. A lot of the time it’s our own limitations on knowledge that hold us back.” In fact, many participants stated that they themselves did not know enough to describe how PADs should be used in their community.

*Lack of resources.* Many participants identified a lack of resources as a significant barrier to PAD utilization. These scarce resources included time, trained personnel, facilitation services, and reimbursement for PAD completion. One participant commented, “There are so many other higher prioritizations coming across our desk between… meeting [a person’s] needs first and foremost, but then the various regulatory bodies wanting their form of paperwork their way.” Another identified resource issue was the inability to access a PAD in a crisis situation if the person or the agent did not have a copy of the PAD on hand. Several respondents noted that the
PAD registry was not terribly useful in practice because, “it is not helpful to ensure [the PAD] is enforced.”

*Client-related obstacles.* Some participants had concerns about the ability of consumers to understand and complete the complicated 10-page PAD form. Several survey respondents stated that the legal language in the document was difficult for clients to comprehend. Other survey and interview respondents cited a lack of demand from consumers. As one survey respondent wrote, “Clients don’t want them.” Related to a lack of demand from consumers, both survey and interview participants cited comprehension difficulties that stemmed from the clinical features of the behavioral health disorders. As one interview participant stated, “We are talking about groups of people [who] may have some very significant impairments and disabilities.” Other clinicians suggested that consumers would not have enough social support to identify an appropriate agent. Another interviewee stated, “It’s been hard for quite a few of our clients to identify an agent that they really trust or that even have access to.”

*Power struggles.* Participants suggested that issues of control and power also thwart the utilization of PADs. At the heart of these power struggles were skeptical attitudes towards the intentions and behaviors of other stakeholder groups. A number of consumer respondents suggested that they believed that clinicians would simply ignore their instructions while one clinical respondent mentioned, “when a patient has more control over what they choose… the doctor may feel like their hands are tied.” The idea that a PAD would tie a clinician’s hands also came up during several interviews. An interviewee pointed out that in the one clinical case where he had seen with a PAD, the document’s instructions were contraindicated by standard medical advice. The respondent summarized these concerns by stating: “[The PAD] wasn’t very well written and it didn’t make great sense and the treatment team had major problems with it.” This
interviewee went on to suggest that PADs could even lead to treatment delays because doctors would be forced to seek judicial authorization to override contraindicated treatment instructions, which can take several days to obtain.

**RQ4 Results**

Two themes -- *Need for education and training* and *Technological solutions* – emerged that were related to the research question: “*What can be done to increase their utilization?*” Each theme is described below.

*Need for education and training.* Given that a lack of knowledge was identified as a discourager and the possession of knowledge was identified as an encourager, the theme of needing more education and training emerged in the data as a strategy for increasing their use. Three interviewees suggested that it would be particularly helpful to have a peer educator who could speak to other clients about the benefits of PADs. As one interview participant suggested, “[We want to find] someone whose actually had a successful usage of their PAD that, you know, that kind of played out the way they wanted it and they had identified on their PAD and how that was beneficial and helpful.” Likewise, other participants indicated a need to train and educate mental health and medical staff in hospitals and organizations. Several participants stated that education was particularly needed in hospitals among the emergency room staff. As one interview participant (1) pointed out, “At least in the hospitals, we all are educated on advanced directives and went to a training for it, so, you know, why not have that same type of training like in hospitals and like in the community services board or behavioral health systems?”

*Technological solutions.* Several participants proposed technological solutions to some of the system barriers that present access issues. One interview participant suggested distributing bracelets containing digitized medical records that could be accessed in crisis situations. This
participant stated that these USB drives could contain a copy of the PAD. This participant stated that consumers could “have a USB drive on that you could plug in and read the information they wanted a clinician to know if they showed up somewhere in an emergency.” Another interviewee pointed to the need to share data across systems. This interviewee participant suggested that PADs might be more readily utilized if it was possible for a crisis clinician to “pick up the phone, enter in their ID, and their entire medical record flows into the provider’s computer, in which could include the PAD.”

**Mixed methods results**

In keeping with the convergent parallel mixed methods design, data were analyzed separately and merged at the level of interpretation to answer a mixed method research question (RQ5). This mixed method analysis was guided by two sensitizing questions: (1) *to what extent do the qualitative and quantitative results converge*, and (2) *in what ways do they diverge*. In order to perform the most robust analysis possible, I shifted between quantitative and qualitative lenses.

**Quantitative lens on mixed data**

Following Teddlie and Tashakkori’s (2009) mixing procedures outlined in the previous chapter, I initially quantitized my qualitative data and then compared it to the quantitative data set. To do this, 7 new dichotomous variables were created for each of the qualitative themes addressing the encouragers and discouragers. The final two themes of ways of increasing PAD utilization were not present as items in the QUAN strand, and thus did not have a basis for mixing at the level of interpretation. Among the remaining seven qualitative themes, if a theme was presented in a respondent’s case, that person was given a ‘1’; if the theme was not present, the person assigned a ‘0’. This created a new data set of variables. These quantitized qualitative
data were correlated with the respective subscale scores on the OPADQ. The encouragers themes (RQ2) were correlated with the Utility and Benefits (UB) subscale scores, and the discouragers (RQ3) were correlated with the Obstacles to Success (OS) to subscale scores.

No statistically significant relationships were found between the quantitized qualitative variables and the UB and OS subscale scores (see Tables 13 &14), suggesting that the study strand results diverged when viewed quantitatively.

**Qualitative lens on the mixed data**

In the next phase, the quantitative and qualitative strands were mixed through a qualitative lens. Although the attitudinal items in the OPADQ did not entirely align with the qualitative research questions, several themes in the qualitative data also emerged in the quantitative data, suggesting convergence between the strand results. For RQ2 (“What encourages PADs in Virginia?”) all four themes (Awareness of PADs, PAD Champions, Client-related Benefits, and Clinical Benefits) converged with items found in the quantitative results that had lower standard deviations across respondents. These points of intersection as viewed through the qualitative lens were displayed in joint table (see Table 15). Similarly, convergent data was also identified across the strands for RQ3 (“What discourages PADs in Virginia?”) Each of the four themes identified for RQ3 (Lack of awareness, Lack of Bandwidth, Power Struggles, and Client-related Obstacles) were present among items in the quantitative results. These intersections were identified by having lower standard deviations in mean scores. These convergent QUAN and QUAL results were depicted in a joint display table of stakeholder survey variables and the qualitative themes (see Table 16).
Metainferences of mixed data

As suggested by Teddlie and Tashakkori (2009), *gestalt-shifting* between the qualitative and quantitative lenses enabled the drawing of meaningful metainferences across the strands. By iteratively comparing the results, additional insights were generated from the original data sets.

**Metainference 1. Clinician advocates as PAD champions.** During the interview portion of the QUAL strand, several participants shared that they were certified as PAD facilitators. Certification as a facilitator appeared to be a specific way in which individuals served as PAD champions within their organizations — a theme that emerged in the QUAL strand. While I did not ask survey participants if they were facilitators, participants were permitted to indicate a secondary stakeholder group in the demographic section of the online survey. Seventy-three participants (48%) selected “Advocate” as a secondary stakeholder choice. Although being a PAD champion and identifying as an Advocate may differ in meaningful ways, for instance, a person could champions PADs for liability reasons rather than for the empowerment of consumers, this secondary identity could be a useful proxy for drawing metainferences.

To explore the dimension of PAD champions in the survey results, I compared mean scores for individuals who identified as Advocates and those who did not. Statistically significant differences (*t* = -2.00, *p* = .047) were found between the advocates (M = 69.7; SD = 9.15) and the Non-advocates (M = 66.68; SD = 8.51) on the UB subscore (See Table 17). Post hoc Tukey tests of pairwise differences suggested that these variations were especially pronounced among clinicians. Non-Advocate clinicians (n=38; M = 63.87; SD = 8.68) scored significantly lower on the UB score (*t* = -2.091, *p* = .04) in comparison to Clinician Advocates (n=14; M = 69.43; SD = 7.98) [see Table 18 &19].
Interpretation. In general, respondents who identified as Advocates tended to have higher scores on the UB subscale. Based on these data, it appears that when people see themselves as advocates within the mental health system, they view PADs more favorably than those who do not see their role as that of an advocate. This difference is particularly pronounced among clinicians who strongly endorsed empowerment as a reason for using PADs in the community.

Metainference 2. PAD Awareness is associated with higher Utility and Benefit subscores. Another relevant area of intersection between the QUAN and QUAL results involved the concept of PAD Awareness. PAD Awareness emerged twice in the QUAL strand, first as a theme in RQ2 (“What encourages PADs in Virginia?”) and then again as a theme in RQ3 (“What discourages PADs in Virginia?”). PAD Awareness also emerged in the quantitative strand through the ordinal variable of PAD Familiarity (“Never heard of PADs” to “Knowledgeable on PADs and how they work in my community”). The variable of PAD Familiarity was constructed to measure both knowledge and awareness. For instance, a person could endorse “I’ve heard of the term, but knew little about them” (e.g. awareness, but not knowledge) or “I would be able to describe PADs to someone else, but am not sure how they apply in my community” (e.g. awareness and some knowledge).

To evaluate the dimensions of PAD Familiarity and PAD Awareness, I compared the OPADQ scores of survey respondents based on their self-reported familiarity [see Table 20]. Statistically significant differences based on familiarity were found among UB scores ($F(133, 4) = 3.48, p = .10$). Post hoc tests indicated significant differences between respondents with Awareness/Some knowledge (e.g. “I knew PADs had something to do with treatment planning, but would not be able to describe how they were used” {n=20; M = 63.15; SD = 9.81}) and those who reported being Very Aware/Knowledgeable (n=60; M = 70.9; SD = 8.51) and between those
with Awareness with Minimal Knowledge ("I’ve heard of the term but knew little about them" \(n=24; M = 66.5; SD = 6.19\)) and Very Aware/Knowledgeable Respondents \(n=60; M = 70.9; SD = 8.51\).

**Interpretation.** In general, respondents with more knowledge scored higher on the UB subscale, indicating that knowing more about PADs appeared to increase a participant’s belief that these tools had greater utility and benefits. In other words, the QUAN and QUAL strands appear to converge around the notion that knowledge was a mediating factor in a respondent’s positive perceptions of PADs.

**Limitations**

Although this study was the first of its kind in Virginia, there were limitations to the generalizability of this research. One limitation is the relatively small sample \(n=150\), which yielded low power in several inferential tests. Other limitations include high rates of attrition during the administration of the stakeholder survey. While the OPADQ reports strong psychometrics, over 125 participants did not complete the full battery of questions. These incomplete scores were not included in the final data set. It is possible that the conclusions drawn from these data were based on either very interested or highly motivated study participants rather than the general stakeholder population. Another possible limitation is the fact that many of the survey participants indicated that they had either no or minimal knowledge of PADs prior to the survey. Although a lack of knowledge of the study topic among respondents has meaningful implications for evaluating the success of the implementation process over the past seven years, it does raise concerns regarding the reliability of these data.

Another potential limitation to this study was a lack of alignment between the quantitative and qualitative strands. The quantitative strand involved an attitudinal instrument,
while the qualitative strand considered more process-oriented aspects of the research. As such, the mixed analysis – particularly the quantizing of the qualitative data – did not generate any statistical correlations. It is possible that the quantizing of the qualitative data would have yielded more statistically significant convergence if the quantitative instrument and the qualitative questions were better aligned.

Likewise, the interviews were limited in number and only provided rich descriptions of the phenomenon from the perspective of one stakeholder group. Indeed, in the QUAL analysis, the stakeholder survey responses, which came from all five stakeholder groups, were weighted less heavily than the clinician interviews. Although this methodological choice was made based on the assumption that open-ended survey questions generated less useful pieces of data for qualitative analysis (Creswell & Plano-Clark, 2011), it does raise the prospect that the qualitative themes were biased towards the clinician perspective.

Because this research was designed as a mixed methods study, these concerns were largely neutralized through the triangulation of data. For instance, although the interviews were few in number and conducted only with clinicians — the QUAN strand coupled with the nested qualitative questions (N=150) made it possible to gather representative perspectives from all of the stakeholder groups. The study’s key findings, which are discussed in Chapter 5, emerged across the strands and through multiple data sources. In this sense, the mixed methods approach offsets the weaknesses generated by the stands in isolation (Creswell & Plano-Clark, 2011).

Overall, the legitimization strategy of triangulation generated a more complete understanding of PADs in Virginia.

The mixed methods approach also enabled the generation of metainferences across the stands. Examined in isolation, the lack of knowledge among respondents might pose a threat to
the study’s validity. Because there was a qualitative strand, I was also able to identify that lack of awareness was a theme that emerged in the RQ4 as a discourager. In other words, the lack of familiarity and low rates of consumers with PADs (M=14.6, SD=15.7) in the quantitative strand provided data triangulation for the qualitative theme. The issue of PAD knowledge among respondents once again highlights how the mixed method approach enabled a more complete, valid picture to emerge.

**Future directions**

Although this study provided a more complete, valid and clinically useful understanding of PADs in Virginia, there remains abundant opportunity for future research in this area. As mentioned in the mixed methods results section, the attitudinal instrument of the OPADQ did not entirely align with the experience-oriented qualitative questions nested in the stakeholder survey and posed to interview participants. Building a better instrument to measure not only stakeholder attitudes, but also some of the process obstacles, would likely improve future research on PADs in Virginia.

Future studies might also disentangle why it is that consumers of mental health services are not interested in PADs. At present, all implementation efforts have started from the assumption that PADs were useful, and therefore would be desired by consumers. However, this study identified the surprising fact that consumers may not be interested in completing a PAD, even if they have access to facilitation. To fully understand the low PAD utilization rates around the state, it would be beneficial to explore this factor in more depth through further mixed methods research.

Another area of future research would be to explore the clinician-advocate group in further depth. This hybrid identity emerged unexpectedly, and would be worth studying in the
future. Additional insights into this stakeholder group could provide actionable strategies for PAD utilization, and more broadly, a meaningful contribution to the literature of the helping professions, such as counseling, which have formally adopted advocacy as a component of training programs (Toporek et al., 2010). Addressing the limitation of the current study, crafting more effective instruments, and building stronger studies could yield relevant implications for policy makers and stakeholders around the state.

**Conclusion**

This study found evidence that PADs remain limited in their use in Virginia. The study also suggested that there was not widespread disagreement among stakeholder attitudes. However, there do appear to be significant barriers that remain to completion and utilization across the state. These results are discussed in depth in the following chapter with an eye towards how this study is positioned within the context of previous research on the topic.
CHAPTER 5

Discussion

Introduction

Since the 1980s, psychiatric and legal literature have proposed the idea of the psychiatric will, or the psychiatric advance directive (PAD). PADs were theorized as a way to empower individuals, improve clinical outcomes, and reduce coercion (Scheyett et al., 2007; Swanson, Swartz, Ferron et al., 2000). In the 1990s, the federal government passed legislation to support the use of PADs among mental health consumers. In 2007, Virginia’s General Assembly enacted the Healthcare Decisions Act (HDCA), which enabled individuals to craft legally-binding advance care planning documents. Since that time, Virginia’s Commission for Mental Health Reform has promoted PADs as part of a series of reforms to the mental health care system that advocates say make the system more consumer-oriented. As part of this initiative, the Commission has funded the Virginia Advance Directives, which offers education and training on PADs to healthcare professionals and oversees outreach to consumers, community services boards, and advocacy groups throughout the state.

The convergent parallel mixed methods study discussed in this dissertation had four primary goals. The first goal was to understand how PADs were currently being used in the state (RQ1), the second goal was to clarify the enabling factors and obstacles that influence PAD utilization in the state (RQ2 & RQ3), and the third goal was to identify strategies for increasing the use of PADs in the future (RQ4). Finally, the fourth goal was to understand to what extent the quantitative and qualitative strands converged and diverged (RQ5). Overall, this research study achieved these ends. Bolstered by the mixed methods design that guided the process of data collection, analysis, and interpretation, this dissertation provided a valid, more complete
understanding of PADs in Virginia. In this conclusion chapter, I discuss key findings and connect them to the broad body of prior research on PADs. I also discuss the methodological implications of this study, and conclude with a discussion of what these findings mean for the field of counselor education.

**Key Finding 1. Stakeholders agree in their attitudes towards PADs.** At the outset of this study, I hypothesized that there would be statistically significant differences between stakeholder groups on each of the subscales of the OPADQ. This hypothesis was based on prior research, which had found statistically significant differences between stakeholder groups when asked about their attitudes and perceptions of barriers (Swanson, Swartz, Ferron et al., 2006; Wilder et al., 2013). In previous literature, clinicians held less positive attitudes towards PADs and perceived more barriers to use compared to other groups, particularly compared to consumers (Srebnik et al., 2003; Swanson, Swart, Ferron et al., 2006). The results of this study contrast with previous literature in that PAD Attitudes, as measured by the OPADQ, were consistent across stakeholder groups.

The only statistically significant difference among the stakeholder groups identified in this study was in the area of Obstacles to Success. This finding suggests that, on aggregate, this study is consistent with previous literature on PADs in Virginia (Wilder et al., 2013). Post hoc results indicated that this difference was between clinicians and administrators. This finding was also consistent with the previous literature, which had identified key differences between clinicians and administrators on perceptions of PAD barriers (Wilder et al., 2013). Wilder et al. (2013) had previously hypothesized that this difference was due to the fact that administrator attitudes often reflect organizational values rather than actual practice. A clinician, on the other hand, may be less aware of the organizational values, but more aware of the practical barriers. To
support this explanation of key differences, numerous clinician respondents cited the burden of large caseloads and a lack of time in their responses to the qualitative questions on PAD barriers. It is likely that this difference in perspective between administrators and clinicians (e.g. aspirational versus practical, respectively) could explain the statistically significant difference found in the survey results.

Surprisingly, no statistically significant differences were found between the clinician and the consumer stakeholder groups as hypothesized in the planning stages of this study. This hypothesis was based on previous studies that found significant differences between clinicians and consumers (Swanson, Swartz, Ferron et al., 2006; Wilder et al., 2013). However, consumer participation was low in this study, which meant that the study’s inferential tests were underpowered for identifying statistically significant difference between these groups. Given that the Wilder et al. (2013) study suffered similar limitations, one could conclude that consumers of mental health services in Virginia remain a challenging group to recruit for research.

Another possible explanation for the lack of attitudinal differences between clinicians and consumers could be due to the distinctive feature of this study’s sample. In general, most of the previously conducted studies on PADs have involved higher proportions of psychologists and psychiatrists in comparison to this study (Elbogen et al., 2003; Swanson, Swartz, Ferron et al., 2006). Prior research has highlighted significant differences in PAD attitudes between high-status (psychiatrists) and low-status (counselors and social workers) mental health professionals (Van Dorn et al., 2006). This study’s clinician sample was primarily comprised of licensed professional counselors and social workers, which could account for why this study’s results were inconsistent with previous research on PAD attitudes.
A third possible explanation for the lack of statistically significant differences between stakeholder groups could also be attributed to variations in mean scores over time. Although Wilder et al. (2013) is the only other study on PADs in Virginia, it would be difficult to compare mean scores with this study due to differences in study instrumentation. However, comparisons can be made to other studies that have made use of the OPADQ. For instance, comparing the mean item responses for each subscale found by O’Connell and Stein (2005) (Obstacles to Success=2.78, SD=.48; Utility and Benefits=3.56, SD=.42; Self-Determination=3.20, SD=.50), this study’s clinician sample had comparatively lower mean item responses. Having a lower mean item responses (Obstacles to Success=2.55, SD=.40; Utility and Benefits=3.31, SD=.45; Self-Determination=2.57, SD=.21) might account for the lack of statistically significant differences between stakeholder groups in this study, which sets the results apart from previous literature on the topic.

**Key Finding 2. PAD utilization remains low.** Overall, this study indicated that utilization of PADs remains low in Virginia. During the study’s seven interviews, only 3 of the participants reported encountering a PAD in the course of their work as clinicians. The remaining 4 interviewees, although familiar with the tools, reported no clinical experience with PADs. Similar results emerged in the QUAN strand, with the stakeholder study indicating that PADs were uncommon among consumers. Respondents reported a mean of 14.6% (SD = 15.88; median=10) of consumers having PADs within their agencies. These findings were consistent with previous research, which has found low PAD utilization rates in other states (Srebnik et al., 2003; Swanson, Swartz, Ferron et al., 2006; Swanson, Swartz, Hannon et al. 2003).

However, this study’s results were inconsistent with the Wilder et al. (2013) study in Virginia, which had found that that 29% of consumers in the state had completed a PAD. A
direct comparison of reported utilization rates between Wilder et al. (2013) and this study raises the alarming prospect that there were currently fewer PADs in use than there were in 2013. To untangle this unexpected finding, quantitative and qualitative data were triangulated. As mentioned previously, only 3 interview participants reported having encountered PADs during the course of their clinical work. The remaining 4 clinicians, who had an average career length of 21 years, had never encountered a PAD in their work – a result that could indicate that the Wilder et al. (2013) finding of a 29% utilization rate is misleading. Without a reliable baseline measurement, it would be impossible to conclude whether utilization has decreased or not.

Key Finding 3. PAD awareness remains low. Overall, this study indicated that lack of PAD awareness was common among stakeholders around the state. As reported in Chapter 4, 58.7% of respondents reported “Never heard of PADs” or “I have heard of PADs but know little about them” of PADs. Lack of awareness of PADs also emerged in the qualitative data source. Surprisingly, when compared in aggregate to the results of Wilder et al. (2013), this study’s results indicated a decline in PAD awareness over the past several years. Specifically, more study respondents indicated low awareness (“Never heard of PADs” or “I have heard of PADs but know little about them”) than in Wilder et al. (2013), in which a strong majority of respondents reported that they were familiar with PADs. Again, evidence of a decline in PAD knowledge was unexpected given that the state has invested in a formal implementation process over the past several years (Zelle et al., 2015). Once again, these results must prompt questions about the reliability of the baseline measure from the Wilder et al. (2013) study given that, typically, more training means more awareness.

If the awareness decline were taken at face value, however, one contributing factor could be that implementation has not kept pace with employee turnover within the CSB system. It is
plausible to have trained a majority of staff members only to have those employees leave the organization and, in so doing, take with them the organization’s institutional PAD awareness. Again, triangulating the quantitative results of a decline in knowledge with the qualitative interviews, the interview transcripts supported the idea of high staff turnover as an explanation for the decline in awareness over time.

**Key Finding 4. PAD attitudes and awareness are related.** Determining whether low utilization was due to lack of awareness or another factor is beyond the scope of this dissertation. However, it is clear from the mixed methods design of this study that awareness played some role in mediating the PAD attitudes. During the mixed methods analysis portion of this study, a metainference suggested that higher familiarity with PADs was associated with more positive attitudes. In general, this finding was consistent with the bulk of previous studies examining the relationship between knowledge and attitudes (Elbogen et al., 2003; O’Connell & Stein, 2005; Swanson et al., 2003). Given disparities in awareness, continued training of all stakeholder groups appeared critical to future implementation efforts.

**Key Finding 5. We may need PAD nudges.** Three of the interview respondents made mention that even when their organizations offered free facilitation services, few or no consumers appeared interested in completing a PAD. Several survey respondents also commented simply that consumers “don’t want PADs.” This apparent lack of consumer interest in PADs set this study in sharp contrast to previous research on PADs (Swanson, Swartz, Elbogen, et al., 2006; Zelle et al., 2015a). Nearly all prior studies have pointed to high latent demand among consumers; moreover, researchers have suggested that when provided with facilitation services, consumers were much more likely to complete the documents. In a randomized controlled trial of facilitation in North Carolina, 61% of consumers elected to
complete a PAD when provided with facilitation as compared to 5% who were not offered this service (Swanson, Swartz, Elbogen, et al., 2006).

Based on both the qualitative themes and low utilization results from the QUAN strand, it would be easy to conclude that perhaps consumers were not as interested in PADs as prior researchers had suggested (Srebnik et al., 2003; Swanson, Swartz, Hannon, et al., 2003). However, a more nuanced interpretation of this study’s results might suggest that, given the many challenges facing mental health consumers, completing a PAD was a low priority. Although the current integrated form used in Virginia was crafted at a fourth-grade reading level, the 10-page legal document requires at least several hours to complete, possibly spread over multiple appointments to which a client may or may not have transportation. Add in the diagnostic features of serious mental illness (e.g. impaired executive functioning and limited future-oriented insight), and to some potential consumers, completing a PAD might seem nearly impossible. Indeed, prior studies on barriers have made similar arguments (Shields et al., 2014; Van Dorn et al., 2008).

Clarifying what could be done about consumer ambivalence for PADs would be a useful area for future study. One possible intervention for addressing low consumer demand for PADs can be drawn from the field of behavioral economics, which has coined the term “nudges” to refer to the use of subtle biases by policy makers to influence individual behavior. The concept of the “nudge” stems from the behavioral economics principle that people often fail to act “rationally” by making choices that are contrary to their own best interest. Examples of “irrational behavior” might include failing to save for retirement, or continuing to smoke despite the health consequences. In the case of this study, not completing a PAD when one has a serious mental illness and access to facilitation services might be considered an “irrational behavior.”
To promote better (e.g. more rational) choices, behavioral economists recommend that policy makers introduce “nudges” into system processes to help consumers make choices that are in their best long-term interest (Thaler & Sunstein, 2003). The qualitative interviews offered some options of PAD nudges. One nudge would be to find a charismatic peer champion who could encourage other consumers to adopt PADs rather than relying on clinicians or case managers to make the case. Another nudge would be to streamline Virginia’s electronic health record system to allow for greater access to medical files such as PADs by emergency department staff and crisis evaluators. A third option would be to create a PAD template that defaults to a consumer’s crisis or Wellness Recovery Action Plan (WRAP). Most crisis plans contain all of the information needed to complete a PAD; plus, crisis plans include the added “nudge” of the requirement from Medicare and Medicaid that they be completed for an agency to be reimbursed. Although some of these nudges are more practical than others, it would likely be worthwhile for policy makers to be open to investing in ways that make it easier for people to compete these advance planning documents. Given the human impulse to behave irrationally discussed above, training and education simply might not be enough.

**Key Finding 6. CSBs might not be the optimal setting for implementation.** Although this study suggests that PADs have not reduced coercive treatment in the way that they have been theorized to do (e.g., no one in the study reported encountering a PAD at the time of a hospital admission), there is still reason to be optimistic that options such as the Ulysses Clause, which grants voluntary consent to hospitalization even over objection, could reduce reliance on coercive treatment (Bonnie, 2012). However, this study’s findings cast doubt on the Community Service Board (CSB) system’s capacity for achieving this goal. In multiple interviews, study participants emphasized their strong desire as administrators and clinicians to “do the right
thing.” However, given the clinical demands and high staff turnover rates, “doing the right thing” has become increasingly difficult for those working in community mental health. As one interviewee put it, “PADs are just one more unfunded mandate” for already over-extended CSBs. One interview subject shared that she had “over 100 clients on her caseload,” and that she “doesn’t have the time to do my ISPs and my quarterly reports.” Both comments were indicative of the lack of capacity for undertaking PAD implementation within the CSB system.

Unfortunately, the issue of CSBs being over-extended is likely to get worse before it gets better. In 2016, the General Assembly passed what has been dubbed the Virginia Behavioral Health System Transformation Excellence and Performance (STEP Virginia) legislation, which increases the number of mandated services at CSBs to include primary care screening, same day access to services, and outpatient treatment (Department of Behavioral Health and Disability Services, 2016). Researchers studying mental health policy in Virginia have anticipated significant workforce shortfalls due to the newly mandated STEP Virginia requirements (DBHDS, 2016). If the ability of CSBs to implement PADs is low now, it will likely only get worse with this requirement of expanded services. Thus, the findings of this study – particularly, from the qualitative interviews – called into question whether the CSBs were the best venues for achieving the state’s implementation goals (Zelle et al., 2015).

If outpatient CSBs are not the appropriate context, then where else could PAD implementation occur? One option would be to incorporate PAD facilitation at the time of discharge from an acute hospitalization. I inquired about this solution during the interviews, and most participants indicated that patients were rarely stable enough at the time of discharge to complete a PAD. An alternative that emerged during interview recruitment was to promote PADs within the state’s crisis stabilization units (CSUs). The CSUs in Virginia are used as
alternatives to hospitalization for low-acuity patients or as step-down facilities for high-acuity patients to ease the transition back into the community. CSUs are residential, but not locked facilities. Consumers can remain in treatment for up to two weeks. The longer window of treatment as well as the CSU emphasis on crisis management and relapse prevention might provide the ideal setting for discussing and completing PADs with consumers. One CSU employee, who did not meet inclusion criteria for a follow-up interview,3 expressed his belief that PADs would work well at his CSU setting, and requested additional information on the tools. A useful future pilot study might examine the use of CSUs for PAD implementation in Virginia to see if this setting offered a more appropriate context than the outpatients CSBs.

**Key Finding 7. Clinician advocates as a new stakeholder group.** In the design of the online survey instrument, participants were permitted to identify a secondary stakeholder group in addition to their primary group affiliation. Fourteen study participants identified themselves as clinician-advocates. Compared to participants who only identified as clinicians, clinician-advocates held notably different attitudes towards PADs. Post hoc testing suggested that clinician-advocates viewed the utility and benefits of PADs more favorably than their clinician-only counterparts.

Prior literature on PADs has drawn strong boundaries between stakeholder groups (Swanson, Swartz, Hannon, et al., 2003). This study’s findings revealed the possibility that these affiliations were more complex than previous researchers posited. Based on the data collected for this study, it would be difficult to say why these respondents viewed themselves through an intersectional lens rather than through their license or job description. However, it was clear that

3 Individual was excluded from the follow-up interviews because he reported never having heard of a PAD before the survey, and thus could not provide answers to the IRB-approved interview questions.
viewing oneself as an advocate and a clinician positively influenced participants’ attitudes towards PADs. In the future, it would be worthwhile to explore this topic to understand key features of clinician-advocates. Understanding more about the clinician-advocate identity would likely be a meaningful contribution to the social justice advocacy literature, as was introduced in Chapter 2 of this dissertation.

**Methodological implications**

Only two previous studies on PADs have made use of the mixed methods approach (Scheyett & Rooks, 2012; Srebnik et al., 2003). Both studies, however, failed to formally mix the strands during the analysis or interpretation phase. In other words, their study was mixed methods only in the sense that both qualitative and quantitative data were collected under the umbrella of a single study. Due to these methodological shortcomings, the research of this dissertation is possibly the first mixed methods study of PADs in the United States.

The particular strategy adopted for this dissertation was also novel within the field of mixed methods research. Generally, mixed methods research reports findings in the format of a joint display table of themes and results (Creswell & Plano-Clark, 2011). Teddlie and Tashakkori (2009) recommended either transforming qualitative data into quantitized variables or qualitizing quantitative data. In other words, mixed methods researchers elect to do one or the other, but generally not both. However, the analysis phase of this dissertation involved a two-step data transformation process, which enabled interpretation of mixed data through using both quantitative and qualitative lenses.

This study benefited greatly from the second round of data transformation. The iterative analytic process generated two key meta-inferences: the first meta-inference suggested that higher familiarity with PADs was associated with more positive attitudes; the second meta-
inference pointed to a statistically significant difference between clinicians and the clinician advocates. In the absence of the iterative mixing process, these novel insights would otherwise not have emerged. The iterative analytic procedure undertaken in this dissertation demonstrates a novel way to bridge the quantitative-qualitative research divide that can sometimes plague conversations about mixed method design (Creswell & Plano-Clark, 2011). Likewise, the two-step mixed analytic procedure format provides evidence that this approach works rather well when trying to evaluate public policy.

**Implications for Counselor Education**

In Chapter 2 of this dissertation, I pointed out that PADs do not appear in the broader counseling literature. Although the key findings of this study are relevant to these other disciplines, the unique characteristics of the sample also suggest that this study offers a novel glimpse into the world of counselors working in Virginia’s CSB system. In particular, this study identified an emergent professional identity – that of the clinician-advocate — among Virginia’s master-level mental health professionals.

Within the field of counseling, much has been said about the role of counselors as advocates (ACA, 2014; Lewis et al., 2012; Toporek et al., 2010). Likewise, the Counselor Education literature has extensively examined advocacy within the context of training programs (Chang, Crethar, & Ratts, 2010; Osborne, Collison, House et al., 1998). However, less has been written regarding the extent to which practicing professional counselors in the community ascribe to the role of an advocate. The findings of this study point to the conclusion that indeed some practicing counselors in community mental health settings in Virginia see themselves as both clinicians and advocates. The advocate-clinician identity had a statistically significant impact on perceptions of utility and benefits of PADs. Although this notion of the clinician-
advocate is tangential to the research questions of this study, the concept calls out for further exploration. Understanding the extent to which practicing counselors view themselves as advocates has implications for the overall efforts on the part of counselor educators to develop advocacy competencies during training programs.

**Conclusion**

In this chapter, I discussed the key findings of this dissertation and explored how the results compared to previous literature on the topic. I identified eight key findings and highlighted the study’s implications for methodology and the field of Counselor Education. By utilizing multiple sources of data in a convergent parallel mixed method design, I was able to provide a more valid, complete understanding of the attitudes towards, and implementation of, PADs among various stakeholder groups in Virginia. By gathering in-depth interviews with clinicians and open-ended responses from other stakeholder groups, I was also able to evaluate previous implementation efforts and make suggestions on what could be done to foster the use of PADs here in the state.

Although the study does not offer an encouraging picture of widespread PAD utilization across the state, this study identified a number of critical barriers to realizing the theorized potential of these legal tools. Ultimately, understanding the complex nature of these barriers is critical to addressing them in the future. This dissertation offered new insights on what works, what does not work, and why. It also identifies what we might do differently in the future to increase the number of mental health consumers in the state who have access to these empowering tools.
<table>
<thead>
<tr>
<th>What is your gender?</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>25</td>
<td>16.4</td>
<td>18.1</td>
<td>18.1</td>
</tr>
<tr>
<td>Female</td>
<td>110</td>
<td>72.4</td>
<td>79.7</td>
<td>97.8</td>
</tr>
<tr>
<td>Prefer to self-describe</td>
<td>1</td>
<td>.7</td>
<td>.7</td>
<td>98.6</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>2</td>
<td>1.3</td>
<td>1.4</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>138</td>
<td>90.8</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Missing System</td>
<td>14</td>
<td>9.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>152</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2  
*Stakeholder Group Demographics by Race/Ethnicity*

<table>
<thead>
<tr>
<th>Group</th>
<th>White</th>
<th>Black</th>
<th>Asian</th>
<th>Other</th>
<th>Prefer not to answer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer</td>
<td>19</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Administrator</td>
<td>27</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>31</td>
</tr>
<tr>
<td>Family</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Clinician</td>
<td>63</td>
<td>5</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>71</td>
</tr>
<tr>
<td>Advocate</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>120</td>
<td>10</td>
<td>1</td>
<td>4</td>
<td>3</td>
<td>138</td>
</tr>
</tbody>
</table>
Table 3
Survey Respondent Demographics by current profession and setting

What is your current profession and what setting do you work most often?

<table>
<thead>
<tr>
<th>Profession</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker</td>
<td>2</td>
<td>25</td>
<td>1</td>
<td>28</td>
</tr>
<tr>
<td>Nurse</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Mental Health Counselor</td>
<td>2</td>
<td>40</td>
<td>4</td>
<td>46</td>
</tr>
<tr>
<td>Addictions Counselor</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Case Manager</td>
<td>1</td>
<td>8</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>7</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>8</strong></td>
<td><strong>81</strong></td>
<td><strong>6</strong></td>
<td><strong>95</strong></td>
</tr>
</tbody>
</table>
Table 4  
*Survey Respondent Demographics by Education*

What is your highest level of education?

<table>
<thead>
<tr>
<th>Education</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some college</td>
<td>7</td>
<td>4.6</td>
<td>5.1</td>
<td>5.1</td>
</tr>
<tr>
<td>2-year degree</td>
<td>5</td>
<td>3.3</td>
<td>3.6</td>
<td>8.7</td>
</tr>
<tr>
<td>4-year degree</td>
<td>33</td>
<td>21.7</td>
<td>23.9</td>
<td>32.6</td>
</tr>
<tr>
<td>Professional degree</td>
<td>89</td>
<td>58.6</td>
<td>64.5</td>
<td>97.1</td>
</tr>
<tr>
<td>Doctorate</td>
<td>3</td>
<td>2.0</td>
<td>2.2</td>
<td>99.3</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>1</td>
<td>.7</td>
<td>.7</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>138</strong></td>
<td><strong>90.8</strong></td>
<td><strong>100.0</strong></td>
<td></td>
</tr>
<tr>
<td>Missing System</td>
<td>14</td>
<td>9.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>152</strong></td>
<td><strong>100.0</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Familiarity with PADs</td>
<td>Frequency</td>
<td>Percent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------</td>
<td>-----------</td>
<td>---------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I’ve never heard of PADs</td>
<td>21</td>
<td>13.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I’ve heard of the term but knew little about them</td>
<td>25</td>
<td>16.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I knew PADS had something to do with planning for treatment, but would not have been able to describe how they were used</td>
<td>23</td>
<td>15.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would be able to describe PADs to someone else, but am not sure how they apply in my community</td>
<td>19</td>
<td>12.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would consider myself knowledgeable on PADs and how they work in my community</td>
<td>61</td>
<td>40.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td>1</td>
<td>.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>150</td>
<td>98.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing System</td>
<td>2</td>
<td>1.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>152</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 6
PADs are discussed with consumers.

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
<td>44</td>
<td>28.9</td>
<td>33.3</td>
<td>33.3</td>
</tr>
<tr>
<td>No consumers</td>
<td>6</td>
<td>3.9</td>
<td>4.5</td>
<td>37.9</td>
</tr>
<tr>
<td>A few consumers</td>
<td>20</td>
<td>13.2</td>
<td>15.2</td>
<td>53.0</td>
</tr>
<tr>
<td>Some consumers</td>
<td>16</td>
<td>10.5</td>
<td>12.1</td>
<td>65.2</td>
</tr>
<tr>
<td>Most consumers</td>
<td>24</td>
<td>15.8</td>
<td>18.2</td>
<td>83.3</td>
</tr>
<tr>
<td>All consumers</td>
<td>22</td>
<td>14.5</td>
<td>16.7</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>132</td>
<td>86.8</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Missing System</td>
<td>20</td>
<td>13.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>152</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 7  
*PAD forms are provided to consumers.*

<table>
<thead>
<tr>
<th>Response</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
<td>57</td>
<td>37.5</td>
<td>43.2</td>
<td>43.2</td>
</tr>
<tr>
<td>No consumers</td>
<td>21</td>
<td>13.8</td>
<td>15.9</td>
<td>59.1</td>
</tr>
<tr>
<td>A few consumers</td>
<td>24</td>
<td>15.8</td>
<td>18.2</td>
<td>77.3</td>
</tr>
<tr>
<td>Some consumers</td>
<td>15</td>
<td>9.9</td>
<td>11.4</td>
<td>88.6</td>
</tr>
<tr>
<td>Most consumers</td>
<td>11</td>
<td>7.2</td>
<td>8.3</td>
<td>97.0</td>
</tr>
<tr>
<td>All consumers</td>
<td>4</td>
<td>2.6</td>
<td>3.0</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>132</td>
<td>86.8</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Missing System</td>
<td>20</td>
<td>13.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>152</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 8
*Consumers are assisted in completing PAD forms.*

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
<td>54</td>
<td>35.5</td>
<td>40.9</td>
<td>40.9</td>
</tr>
<tr>
<td>No consumers</td>
<td>21</td>
<td>13.8</td>
<td>15.9</td>
<td>56.8</td>
</tr>
<tr>
<td>A few consumers</td>
<td>21</td>
<td>13.8</td>
<td>15.9</td>
<td>72.7</td>
</tr>
<tr>
<td>Some consumers</td>
<td>18</td>
<td>11.8</td>
<td>13.6</td>
<td>86.4</td>
</tr>
<tr>
<td>Most consumers</td>
<td>11</td>
<td>7.2</td>
<td>8.3</td>
<td>94.7</td>
</tr>
<tr>
<td>All consumers</td>
<td>7</td>
<td>4.6</td>
<td>5.3</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>132</td>
<td>86.8</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

Missing System          | 20        | 13.2    |               |                    |
Total                   | 152       | 100.0   |               |                    |
Table 9
There is written documentation of whether consumers have PADs.

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
<td>47</td>
<td>30.9</td>
<td>35.6</td>
<td>35.6</td>
</tr>
<tr>
<td>No consumers</td>
<td>11</td>
<td>7.2</td>
<td>8.3</td>
<td>43.9</td>
</tr>
<tr>
<td>A few consumers</td>
<td>16</td>
<td>10.5</td>
<td>12.1</td>
<td>56.1</td>
</tr>
<tr>
<td>Some consumers</td>
<td>13</td>
<td>8.6</td>
<td>9.8</td>
<td>65.9</td>
</tr>
<tr>
<td>Most consumers</td>
<td>15</td>
<td>9.9</td>
<td>11.4</td>
<td>77.3</td>
</tr>
<tr>
<td>All consumers</td>
<td>30</td>
<td>19.7</td>
<td>22.7</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>132</td>
<td>86.8</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Missing System</td>
<td>20</td>
<td>13.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>152</td>
<td>100.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 10
Descriptive Statistics for OPADQ Scores

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>OS_Score</td>
<td>138.00</td>
<td>35.00</td>
<td>94.00</td>
<td>63.95</td>
<td>11.46</td>
</tr>
<tr>
<td>UB_Score</td>
<td>138.00</td>
<td>37.00</td>
<td>90.00</td>
<td>68.28</td>
<td>8.95</td>
</tr>
<tr>
<td>DM_Score</td>
<td>138.00</td>
<td>38.00</td>
<td>65.00</td>
<td>51.60</td>
<td>3.86</td>
</tr>
<tr>
<td>Total_Score</td>
<td>138.00</td>
<td>159.00</td>
<td>228.00</td>
<td>183.83</td>
<td>11.52</td>
</tr>
<tr>
<td>Valid N (listwise)</td>
<td>138.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 11

*Univariate Tests for OPADQ Total & subscale scores*

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
<th>Observed Power</th>
</tr>
</thead>
<tbody>
<tr>
<td>OS</td>
<td>1455.95</td>
<td>4.00</td>
<td>363.99</td>
<td>2.93</td>
<td>.02*</td>
<td>.08</td>
<td>.77</td>
</tr>
<tr>
<td>UB</td>
<td>684.87</td>
<td>4.00</td>
<td>171.22</td>
<td>2.21</td>
<td>.07</td>
<td>.06</td>
<td>.64</td>
</tr>
<tr>
<td>SD</td>
<td>12.99</td>
<td>4.00</td>
<td>3.25</td>
<td>.21</td>
<td>.93</td>
<td>.01</td>
<td>.09</td>
</tr>
<tr>
<td>Total</td>
<td>1184.69</td>
<td>4.00</td>
<td>296.17</td>
<td>2.32</td>
<td>.06</td>
<td>.07</td>
<td>.66</td>
</tr>
</tbody>
</table>

The F tests the effect of Simple Group. This test is based on the linearly independent pairwise comparisons among the estimated marginal means.

*. The mean difference is significant at the .05 level.
Table 12
Post Hoc Comparisons of Stakeholder groups

Tukey HSD

<table>
<thead>
<tr>
<th>(I) Simple Group</th>
<th>(J) Simple Group</th>
<th>Mean Difference (I-J)</th>
<th>Std. Error</th>
<th>Sig.</th>
<th>95% Confidence Interval Lower Bound</th>
<th>Upper Bound</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer</td>
<td>Administrator</td>
<td>1.15</td>
<td>3.20</td>
<td>1.00</td>
<td>-7.69</td>
<td>10.00</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>-10.30</td>
<td>5.57</td>
<td>.35</td>
<td>-25.72</td>
<td>5.12</td>
</tr>
<tr>
<td></td>
<td>Clinician</td>
<td>-5.61</td>
<td>2.82</td>
<td>.28</td>
<td>-13.42</td>
<td>2.20</td>
</tr>
<tr>
<td></td>
<td>Advocate</td>
<td>-3.12</td>
<td>4.19</td>
<td>.95</td>
<td>-14.69</td>
<td>8.46</td>
</tr>
<tr>
<td>Administrator</td>
<td>Consumer</td>
<td>-1.15</td>
<td>3.20</td>
<td>1.00</td>
<td>-10.00</td>
<td>7.69</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>-11.45</td>
<td>5.37</td>
<td>.21</td>
<td>-26.31</td>
<td>3.41</td>
</tr>
<tr>
<td></td>
<td>Clinician</td>
<td>-6.76*</td>
<td>2.40</td>
<td>.04</td>
<td>-13.40</td>
<td>-.12</td>
</tr>
<tr>
<td></td>
<td>Advocate</td>
<td>-4.27</td>
<td>3.91</td>
<td>.81</td>
<td>-15.09</td>
<td>6.55</td>
</tr>
<tr>
<td>Family</td>
<td>Consumer</td>
<td>10.30</td>
<td>5.57</td>
<td>.35</td>
<td>-5.12</td>
<td>25.72</td>
</tr>
<tr>
<td></td>
<td>Administrator</td>
<td>11.45</td>
<td>5.37</td>
<td>.21</td>
<td>-3.41</td>
<td>26.31</td>
</tr>
<tr>
<td></td>
<td>Clinician</td>
<td>4.69</td>
<td>5.16</td>
<td>.89</td>
<td>-9.58</td>
<td>18.96</td>
</tr>
<tr>
<td></td>
<td>Advocate</td>
<td>7.18</td>
<td>6.01</td>
<td>.75</td>
<td>-9.45</td>
<td>23.81</td>
</tr>
<tr>
<td>Clinician</td>
<td>Consumer</td>
<td>5.61</td>
<td>2.82</td>
<td>.28</td>
<td>-2.20</td>
<td>13.42</td>
</tr>
<tr>
<td></td>
<td>Administrator</td>
<td>6.76*</td>
<td>2.40</td>
<td>.04</td>
<td>.12</td>
<td>13.40</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>-4.69</td>
<td>5.16</td>
<td>.89</td>
<td>-18.96</td>
<td>9.58</td>
</tr>
<tr>
<td></td>
<td>Advocate</td>
<td>2.49</td>
<td>3.61</td>
<td>.96</td>
<td>-7.50</td>
<td>12.48</td>
</tr>
<tr>
<td>Advocate</td>
<td>Consumer</td>
<td>3.12</td>
<td>4.19</td>
<td>.95</td>
<td>-8.46</td>
<td>14.69</td>
</tr>
<tr>
<td></td>
<td>Administrator</td>
<td>4.27</td>
<td>3.91</td>
<td>.81</td>
<td>-</td>
<td>15.09</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>-7.18</td>
<td>6.01</td>
<td>.75</td>
<td>-23.81</td>
<td>9.45</td>
</tr>
<tr>
<td></td>
<td>Clinician</td>
<td>-2.49</td>
<td>3.61</td>
<td>.96</td>
<td>-12.48</td>
<td>7.50</td>
</tr>
</tbody>
</table>

Based on observed means.
* The mean difference is significant at the .05 level.
Table 13
Correlations between RQ2 themes and Utility and Benefits subscores\(^b\)

<table>
<thead>
<tr>
<th>Variables</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. UB_Score</td>
<td>1</td>
<td>-.045</td>
<td>-.069</td>
<td>.117</td>
<td>.116</td>
</tr>
<tr>
<td>2. Awareness</td>
<td>-.045</td>
<td>1</td>
<td>.018</td>
<td>.153</td>
<td>.088</td>
</tr>
<tr>
<td>3. Client Benefits</td>
<td>-.069</td>
<td>.018</td>
<td>1</td>
<td>.277**</td>
<td>.090</td>
</tr>
<tr>
<td>4. Clinical Benefits</td>
<td>.117</td>
<td>.153</td>
<td>.277**</td>
<td>1</td>
<td>.079</td>
</tr>
<tr>
<td>5. PAD Champions</td>
<td>.116</td>
<td>.088</td>
<td>.090</td>
<td>.079</td>
<td>1</td>
</tr>
</tbody>
</table>

**. Correlation is significant at the 0.01 level (2-tailed).
b. Listwise N=138
Table 14
*Correlations between RQ3 themes and Obstacles to Success subscores*

<table>
<thead>
<tr>
<th>Variables</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. OS_Score</td>
<td>1</td>
<td>-.104</td>
<td>.036</td>
<td>-.015</td>
<td>.064</td>
</tr>
<tr>
<td>2. Client obstacles</td>
<td>-.104</td>
<td>1</td>
<td>-.622**</td>
<td>.185*</td>
<td>.098</td>
</tr>
<tr>
<td>3. Lack of Awareness</td>
<td>.036</td>
<td>-.622**</td>
<td>1</td>
<td>-.164</td>
<td>-.129</td>
</tr>
<tr>
<td>4. Lack of bandwidth</td>
<td>-.015</td>
<td>.185*</td>
<td>-.164</td>
<td>1</td>
<td>.358**</td>
</tr>
<tr>
<td>5. Power struggles</td>
<td>.064</td>
<td>.098</td>
<td>-.129</td>
<td>.358**</td>
<td>1</td>
</tr>
</tbody>
</table>

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).
c. Listwise N=138
Table 15
*Joint Display Table of Themes and Quantitative Results – RQ2*

<table>
<thead>
<tr>
<th>Dimension: QUAN variables</th>
<th>PAD Champions</th>
<th>Awareness</th>
<th>Clinical Benefits</th>
<th>Client Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Advocacy (n=73)</strong></td>
<td>217</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“I’m the golden child of [P]Ads at my agency”</td>
<td>54</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Very Knowledgeable (n=60)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UB_1. PADs will help mental health professionals make better decisions about the care of people with mental illness. (M=4.33; SD=.74)</td>
<td>54</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UB_50. PADs will help people with mental illness feel more in control of their lives. (M=4.17; SD=.67)</td>
<td>121</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“It helps me give me some direction as to what their preferences would be when they can’t give me those preferences.”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>124</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“The process, I think does help them feel empowered and listened to.”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 16

*Joint Display Table of Themes and Quantitative Results – RQ3*

#### QUAL dimensions

<table>
<thead>
<tr>
<th>Dimension: QUAN variables</th>
<th>Lack of Awareness</th>
<th>Lack of Bandwidth</th>
<th>Power Struggles</th>
<th>Client related obstacles</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Knowledge – Basic Knowledge (n=78)</td>
<td>145 “I’m an ES clinician, and I don’t know how I would use them.”</td>
<td></td>
<td>221 “Another challenge is having the time to work with folks, that’s a really huge challenge.”</td>
<td></td>
</tr>
<tr>
<td>OS_15. Mental health professionals in my community are so busy that they will not take the time to see if a person has an advance directive on file. (M=2.72; SD=.94)</td>
<td></td>
<td></td>
<td></td>
<td>83 “People misinterpreted empowerment. They had the power to make the decision but no responsibility associated with the results.”</td>
</tr>
<tr>
<td>Psychiatric advance directives will only interfere with the jobs of the mental health professionals. (M=2.03; SD=.69)</td>
<td></td>
<td></td>
<td></td>
<td>172 “We've tried every trick in the trade to get folks excited about it.”</td>
</tr>
<tr>
<td>OS_19. People with mental illness in my community would not be interested in filling out a PAD. (M=2.43; SD:.77)</td>
<td></td>
<td>150 “We've tried every trick in the trade to get folks excited about it.”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 17

Tests of Between-Subjects Effects For All Groups Advocacy and UB Scores

Dependent Variable: UB_Score

<table>
<thead>
<tr>
<th>Source</th>
<th>Type III Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
<th>Observed Power</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corrected Model</td>
<td>313.95</td>
<td>1.00</td>
<td>313.95</td>
<td>4.00</td>
<td>.05</td>
<td>.03</td>
<td>.51</td>
</tr>
<tr>
<td>Intercept</td>
<td>639484.73</td>
<td>1.00</td>
<td>639484.73</td>
<td>8157.32</td>
<td>.00</td>
<td>.98</td>
<td>1.00</td>
</tr>
<tr>
<td>Advocate</td>
<td>313.95</td>
<td>1.00</td>
<td>313.95</td>
<td>4.00</td>
<td>.05</td>
<td>.03</td>
<td>.51</td>
</tr>
<tr>
<td>Error</td>
<td>10661.59</td>
<td>136.00</td>
<td>78.39</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>654266.00</td>
<td>138.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrected Total</td>
<td>10975.54</td>
<td>137.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. R Squared = .029 (Adjusted R Squared = .021)
Table 18

*Descriptive statistics for Clinicians and Clinician Advocates*

**Group Statistics**

<table>
<thead>
<tr>
<th>OS_Score</th>
<th>Aggregate group</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinician</td>
<td>38</td>
<td>68.03</td>
<td>10.33</td>
<td>1.68</td>
<td></td>
</tr>
<tr>
<td>Clinician-Advocate</td>
<td>14</td>
<td>66.43</td>
<td>12.54</td>
<td>3.35</td>
<td></td>
</tr>
<tr>
<td>UB_Score</td>
<td>Clinician</td>
<td>38</td>
<td>63.87</td>
<td>8.68</td>
<td>1.41</td>
</tr>
<tr>
<td>Clinician-Advocate</td>
<td>14</td>
<td>69.43</td>
<td>7.98</td>
<td>2.13</td>
<td></td>
</tr>
<tr>
<td>SD_Score</td>
<td>Clinician</td>
<td>38</td>
<td>51.37</td>
<td>3.91</td>
<td>.63</td>
</tr>
<tr>
<td>Clinician-Advocate</td>
<td>14</td>
<td>50.29</td>
<td>4.87</td>
<td>1.30</td>
<td></td>
</tr>
<tr>
<td>Total_Score</td>
<td>Clinician</td>
<td>38</td>
<td>183.26</td>
<td>12.02</td>
<td>1.95</td>
</tr>
<tr>
<td>Clinician-Advocate</td>
<td>14</td>
<td>186.14</td>
<td>17.14</td>
<td>4.58</td>
<td></td>
</tr>
</tbody>
</table>
### Table 19

*T-test comparing Clinician and Clinician-Advocate OPADQ scores*

**Independent Samples Test**

<table>
<thead>
<tr>
<th></th>
<th>t</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
<th>Mean Difference</th>
<th>Std. Error Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>OS_Score</strong></td>
<td>.467</td>
<td>50</td>
<td>.643</td>
<td>1.59774</td>
<td>3.42207</td>
</tr>
<tr>
<td></td>
<td>.426</td>
<td>19.877</td>
<td>.674</td>
<td>1.59774</td>
<td>3.74631</td>
</tr>
<tr>
<td><strong>UB_Score</strong></td>
<td>-2.091</td>
<td>50</td>
<td>.042*</td>
<td>-5.56015</td>
<td>2.65865</td>
</tr>
<tr>
<td></td>
<td>-2.176</td>
<td>25.135</td>
<td>.039</td>
<td>-5.56015</td>
<td>2.55529</td>
</tr>
<tr>
<td><strong>SD_Score</strong></td>
<td>.828</td>
<td>50</td>
<td>.411</td>
<td>1.08271</td>
<td>1.30690</td>
</tr>
<tr>
<td></td>
<td>.747</td>
<td>19.500</td>
<td>.464</td>
<td>1.08271</td>
<td>1.44871</td>
</tr>
<tr>
<td><strong>Total_Score</strong></td>
<td>-.680</td>
<td>50</td>
<td>.499</td>
<td>-2.87970</td>
<td>4.23281</td>
</tr>
<tr>
<td></td>
<td>-.578</td>
<td>17.934</td>
<td>.570</td>
<td>-2.87970</td>
<td>4.97792</td>
</tr>
</tbody>
</table>

*The mean difference is significant at the .05 level.*
Table 20

*Familiarity does seem to influence UB Scores*

*Univariate Tests*

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
<th>Observed Power</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contrast</td>
<td>1040.649</td>
<td>4</td>
<td>260.162</td>
<td>3.483**</td>
<td>.010</td>
<td>.095</td>
<td>.851</td>
</tr>
<tr>
<td>Error</td>
<td>9934.887</td>
<td>133</td>
<td>74.698</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The F tests the effect of Prior to this survey, how familiar would you say you were with psychiatric advance directives (PADs)?

**. The mean difference is significant at the .01 level.
<table>
<thead>
<tr>
<th>Dependent Variable: UB_Score</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tukey HSD</strong></td>
<td></td>
</tr>
<tr>
<td>(I) Prior to this survey, how familiar would you say you were with psychiatric advance directives (PADs)?</td>
<td>(J) Prior to this survey, how familiar would you say you were with psychiatric advance directives (PADs)?</td>
</tr>
<tr>
<td>No knowledge</td>
<td>Minimal Knowledge</td>
</tr>
<tr>
<td>Basic Knowledge</td>
<td>-1.60</td>
</tr>
<tr>
<td>Very knowledgeable</td>
<td>-3.84</td>
</tr>
<tr>
<td>Minimal Knowledge</td>
<td>No knowledge</td>
</tr>
<tr>
<td>Basic Knowledge</td>
<td>-2.17</td>
</tr>
<tr>
<td>Very knowledgeable</td>
<td>-4.40</td>
</tr>
<tr>
<td>Some Knowledge</td>
<td>Minimal Knowledge</td>
</tr>
<tr>
<td>Basic Knowledge</td>
<td>-5.52</td>
</tr>
<tr>
<td>Very knowledgeable</td>
<td>-7.75*</td>
</tr>
<tr>
<td>Basic Knowledge</td>
<td>No knowledge</td>
</tr>
<tr>
<td>Minimal Knowledge</td>
<td>2.17</td>
</tr>
<tr>
<td>Some Knowledge</td>
<td>5.52</td>
</tr>
<tr>
<td>Very knowledgeable</td>
<td>-2.23</td>
</tr>
<tr>
<td>Very knowledgeable</td>
<td>No knowledge</td>
</tr>
<tr>
<td>Minimal Knowledge</td>
<td>4.40</td>
</tr>
<tr>
<td>Some Knowledge</td>
<td>7.75*</td>
</tr>
<tr>
<td>Basic Knowledge</td>
<td>2.23</td>
</tr>
</tbody>
</table>

Based on observed means.
The error term is Mean Square(Error) = 74.698.

* The mean difference is significant at the .05 level.
Figure 1
Methodology for Convergent Parallel Mixed Method Design

QUAN survey → QUAN analysis + Qual interview → Qual analysis = Comparison of results → More complete, valid, and clinically useful understanding of PADs in Virginia

Concurrent Data Collection → Separate analysis → Mixing at interpretation
Figure 2
Qualitative Themes by Research Questions
Appendix A. Stakeholder Survey

Stakeholder Survey

Q1.1 Study: Hear me when I’m well: a mixed methods study of advance directives in Virginia

Identification of Investigators & Purpose of Study
You are being asked to participate in a research study conducted by Anne Metz, MA/EdS and A. Renee Staton, PhD from James Madison University, and Heather Zelle, J.D., Ph.D. of the University of Virginia.

The purpose of this study is to examine the use of psychiatric advance directives in Virginia and how Virginia’s Health Care Decisions Act is being implemented across the state. This study will contribute to the researcher’s completion of a doctoral dissertation.

Research Procedures
This study consists of a survey that will be administered to individual participants in Virginia. You will be asked to provide answers to a series of questions related to psychiatric advance directives.

Time Required Participation in this study will require less than 20 minutes of your time.

Risks
The investigator does not perceive more than minimal risks from your involvement in this study (that is, no risks beyond the risks associated with everyday life).

The investigator perceives the following are possible risks arising from your involvement with this study: Breach of confidentiality in which participant’s identities could be connected to their responses. Subjects could become upset by the survey questions or in response to questions. To minimize these risks, this survey is anonymous and confidential to reduce the possibility of breach of confidentiality. Likewise, participants are not required to answer any question that might be upsetting.

Benefits
Potential benefits from participation in this study include findings that may inform advocacy efforts such as improving continuity of care for persons with mental health care needs. For all involved, becoming more familiar with the statute may improve the likelihood that advanced directives will be completed as the value of the process becomes clear in the survey.

Confidentiality
The results of this research will be presented in dissertation format. While individual responses are obtained and recorded anonymously and kept in the strictest confidence, aggregate data will be presented representing averages or generalizations about the
responses as a whole. No identifiable information will be collected from the participant and no identifiable responses will be presented in the final form of this study. All data will be stored in a secure location accessible only to the researcher, her JMU advisor, and the UVA researcher. The researcher retains the right to use and publish non-identifiable data. At the end of the study, all de-identified records will be retained and stored on a secure server.

**Participation & Withdrawal** Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind. However, once your responses have been submitted and anonymously recorded you will not be able to withdraw from the study.

**Questions about the Study**

If you have questions or concerns during the time of your participation in this study, or after its completion or you would like to receive a copy of the final aggregate results of this study, please contact:

Anne Metz, LPC  
Department of Graduate Psychology  
James Madison University  
metzal@jmu.edu  
Telephone: (540) 568-6211

A. Renee Staton, Ph.D.  
Department of Graduate Psychology  
James Madison University  
statonar@jmu.edu

**Questions about Your Rights as a Research Subject** Dr. David Cockley  
Chair, Institutional Review Board  
James Madison University  
(540) 568-2834  
cocklede@jmu.edu

---

Q1.2 Please select the appropriate consent statement below.

- I understand the study described above. I am 18 years of age or older and I agree to participate. (1)
- I am not 18 years of age or older, and/or, I do not agree to participate. (2)

End of Block: Administrator Survey Informed Consent letter

Start of Block: Your experience with advance directives for mental health

Q3.1 We appreciate your helping to complete this questionnaire. It is designed to elicit your opinions on advance directives for mental health care or psychiatric advance directives (PADs). Although these two terms are interchangeable, Virginia’s integrated AD will be referred to as a PAD in this survey. This categorization references the psychiatric portion of the integrated AD,
rather than the medical or end-of-life instructions. Please review each item carefully and provide candid responses. Your answers are confidential. Base your answers on your personal experience and judgment. Please answer all questions. Thank you in advance for your help.

Q5.1 Prior to this survey, how familiar would you say you were with psychiatric advance directives (PADs)?
- I've never heard of PADs (1)
- I've heard of the term but knew little about them (2)
- I knew PADs had something to do with planning for treatment, but would not have been able to describe how they were used (3)
- I would be able to describe PADs to someone else, but am not sure how they apply in my community (4)
- I would consider myself knowledgeable on PADs and how they work in my community (5)
- Do not know / prefer not to answer (6)

Q3.3 How do you think PADs should be used in your community?
__________________________________
__________________________________
__________________________________
__________________________________
__________________________________
__________________________________

Q3.4 In your opinion, what encourages the use of PADs?
__________________________________
__________________________________
__________________________________
__________________________________
__________________________________
__________________________________
Q3.5 In your opinion, what discourages the use of PADs?

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

End of Block: Your experience with advance directives for mental health

Start of Block: Respondent type

Q4.1 There are a number of groups that have an interest in psychiatric advance directives (PADs). Please select all of the stakeholder groups of which you consider yourself a member. You may choose more than one answer.

• Health care administrator (1)
• Clinician (2)
• Mental health consumer/client (3)
• Family member of a mental health consumer/client (4)
• Mental Health advocate (5)
• Other (please specify) (6) ____________________________________________

End of Block: Respondent type

Start of Block: Clinicians - Current practice

Q4.2 How many years of professional mental health work experience (administrative and/or clinical) have you had, excluding time spent primarily in training? Please enter number of years below.

________________________________________________________________
Q4.3 Have you ever worked primarily as a clinician? If you work at more than one organization, please base your answers to the following questions on the organization where you work most often.

- Yes (1)
- No (2)

Q61 What is your current profession?

- Social worker (LCSW, MSW, QMHP) (1)
- Nurse Practitioner (APRN, PMHNP, or FNP) (2)
- Nurse (RN, LPN) (3)
- Psychiatrist (4)
- Clinical Psychologist (5)
- Mental Health Counselor (LPC, LMHC, LMFT, Resident in Counseling, QMHP) (6)
- Addictions Counselor (7)
- Case Manager (8)
- Other (9) ________________________________________________

Q4.4 Please select the setting where you work most often

- Inpatient psychiatric hospital or unit (1)
- Outpatient behavioral health or CSB (2)
- Other (please specify) (3)

Q4.5 Please select the type of organization where you work most often

- Public (county, state, or federally operated) (1)
- Private for profit (2)
- Private not for profit (3)
- Other (please specify) (4)
Q4.6 How many consumers received services from your organization in the past year?

Q22 Please select the answer that best describes your current practice in your organization. If your current practice is to do something "when appropriate" (for example, to discuss PADs with families when appropriate, please estimate the percent of consumers considered appropriate).

<table>
<thead>
<tr>
<th>PADs are discussed with consumers. (1)</th>
<th>All consumers (100%) (6)</th>
<th>Most consumers (More than 50%) (5)</th>
<th>Some consumers (Less than 50%) (4)</th>
<th>A few consumers (Less than 10%) (3)</th>
<th>No consumers (0%) (2)</th>
<th>Don't know (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td>PAD forms are provided to consumers. (2)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td>Consumers are assisted in completing PAD forms. (3)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td>There is written documentation of whether consumers have PADs. (4)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
</tbody>
</table>

Q5.3 What percentage of consumers in your setting have completed a psychiatric advance directive (PAD)?

Don’t know

0 10 20 30 40 50 60 70 80 90 100
<table>
<thead>
<tr>
<th>Please move slider to indicate percentage of consumers with PADs in your agency.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
</tr>
</tbody>
</table>

End of Block: Clinicians - Current practice

Start of Block: OPADQ
Q6.1 We would like to get an understanding of your opinions and beliefs about psychiatric advance directives (PADs). Please answer the degree to which you agree with the following statements.
<table>
<thead>
<tr>
<th></th>
<th>Strongly agree (5)</th>
<th>Agree (4)</th>
<th>Neither agree nor disagree (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Psychiatric advance directives will help mental health professionals make better decisions about the care of people with mental illness. (Q6.1_1)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td></td>
</tr>
<tr>
<td>2. Psychiatric advance directives will help to improve communication between people with mental illness and their families. (Q6.1_2)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td></td>
</tr>
<tr>
<td>3. Psychiatric advance directives will open up too many new legal issues in mental health treatment. (Q6.1_3)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td></td>
</tr>
</tbody>
</table>
4. It will be difficult to find people willing to be agents or proxy decision makers (someone appointed to make decisions on behalf of the person) for people with mental illness. (Q6.1_4)

5. The directives outlined in a psychiatric advance directive should be followed, even if they go against a mental health provider's professional opinion. (Q6.1_5)

6. Doctors would follow psychiatric advance directives if they knew they would not be held legally responsible if something went wrong. (Q6.1_6)
7. Police officers in my community would refer to a psychiatric advance directive before deciding what to do with a person with mental illness. (Q6.1_7)

8. Psychiatric advance directives will help reduce the costs of hospitalizing people against their will. (Q6.1_8)

Please move slider to indicate percentage of consumers with PADs in your agency. (Q6.1_x1)
Q43 We would like to get an understanding of your opinions and beliefs about psychiatric advance directives (PADs). Please answer the degree to which you agree with the following statements.
9. People with mental illness should not be allowed to make decisions about how they will be treated. (1)

10. It will be difficult for mental health professionals to help people fill out a psychiatric advance directive in an unbiased manner. (2)

11. The wishes of people with mental illness should always be followed, even when it goes against medical advice. (3)

12. Psychiatric advance directives should be put to use in my community. (4)
13. People with mental illness can make appropriate treatment decisions for themselves. (5)

14. Judges in my community would likely uphold professional recommendations for treatment over the directives of the person with the mental illness. (6)

15. Mental health professionals in my community are so busy that they will not take the time to see if a person has an advance directive on file. (7)

16. Psychiatric advance directives will give family members a sense of how to handle difficult situations with their loved one. (8)
17. People with mental illness will make unreasonable requests in their psychiatric advance directives. (9)

18. Only people specifically trained in treating mental illness should be allowed to make treatment decisions. (10)

19. People with mental illness in my community would not be interested in filling out a psychiatric advance directive. (11)
Q44 We would like to get an understanding of your opinions and beliefs about psychiatric advance directives (PADs). Please answer the degree to which you agree with the following statements.
<table>
<thead>
<tr>
<th></th>
<th>Strongly agree (5)</th>
<th>Agree (4)</th>
<th>Neither agree nor disagree (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20.</td>
<td>In times of crisis, professionals will not want to hear about a person’s psychiatric advance directive. (1)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td>21.</td>
<td>Psychiatric advance directives will help judges make better decisions about involuntary commitment. (2)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td>22.</td>
<td>People with mental illness will not take responsibility for updating their psychiatric advance directive over time. (3)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td>23.</td>
<td>People with mental illness can complete a psychiatric advance directive on their own. (4)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
</tbody>
</table>
24. Psychiatric advance directives will help people with mental illness get treatment faster. (5)

25. People with mental illness will not understand what psychiatric advance directives are or how they can work for them. (6)

26. Psychiatric advance directives will make it more difficult for people with mental illness to change their mind about treatment. (7)

27. It is dangerous to have people with mental illness make decisions about their mental health treatment. (8)
28. Psychiatric advance directives will be difficult to locate at the time treatment decisions need to be made. (9)

29. People with mental illness who have completed a training on psychiatric advance directives can help other people with mental illness fill out the documents. (10)
Q45 We would like to get an understanding of your opinions and beliefs about psychiatric advance directives (PADs). Please answer the degree to which you agree with the following statements.
<table>
<thead>
<tr>
<th></th>
<th>Strongly agree (5)</th>
<th>Agree (4)</th>
<th>Neither agree nor disagree (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>30.</td>
<td>Family members in my community would find psychiatric advance directives helpful in caring for their loved ones. (Q45_1)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td>31.</td>
<td>Psychiatric advance directives will force professionals to make decisions that go against their professional judgment. (Q45_2)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td>32.</td>
<td>Professionals would be more inclined to support advance directives if they heard testimonies about the directives from people with mental illness themselves. (Q45_3)</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
</tbody>
</table>
33. Storing psychiatric advance directives in a central location within a community poses a significant threat to confidentiality. (Q45_4)

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

34. Doctors in my community would not follow the directives outlined in psychiatric advance directives. (Q45_5)

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

35. Psychiatric advance directives will help police officers make better decisions about what to do with people who are in a crisis. (Q45_6)

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

36. Psychiatric advance directives can be used as a way to justify treatment, even when clients are refusing treatment. (Q45_7)

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>
37. In times of crisis, there would not be enough time to consult the psychiatric advance directive. (Q45_8)

38. Psychiatric advance directives will undermine the expertise of mental health professionals. (Q45_9)

39. Psychiatric advance directives will help professionals provide better services to people with mental illness. (Q45_10)
Q46 We would like to get an understanding of your opinions and beliefs about psychiatric advance directives (PADs). Please answer the degree to which you agree with the following statements.
<table>
<thead>
<tr>
<th></th>
<th>Strongly agree (5)</th>
<th>Agree (4)</th>
<th>Neither agree nor disagree (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>40. Psychiatric advance directives should be completed only with the assistance of a trained mental health professional.</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td>41. Proxy decision makers (agents) would be reluctant to make decisions for fear of making a wrong decision.</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
<tr>
<td>42. Mental health professionals should educate the community about psychiatric advance directives.</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
<td>•</td>
</tr>
</tbody>
</table>
43. Mental health professionals in my community would not support the use of psychiatric advance directives. (4)

44. Even though a person may have a psychiatric advance directive, it is unlikely that mental health professionals would follow it. (5)

45. When people with mental illness are sick, it is OK for them to be treated against their will. (6)

46. In a time of crisis, people with mental illness will not be able to inform professionals that they have an advance directive. (7)
47. Mental health professionals would follow a psychiatric advance directive if a specific procedure were implemented at their agency to do so. (8)

48. People with mental illness will likely include appropriate medications in their psychiatric advance directives (9)

49. Most people with mental illness are unable to make appropriate treatment decisions for themselves. (10)
Q47 We would like to get an understanding of your opinions and beliefs about psychiatric advance directives (PADs). Please answer the degree to which you agree with the following statements.
<table>
<thead>
<tr>
<th></th>
<th>Strongly agree (5)</th>
<th>Agree (4)</th>
<th>Neither agree nor disagree (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>50.</td>
<td>Psychiatric advance directives will help people with mental illness feel more in control of their lives.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
</tr>
<tr>
<td>51.</td>
<td>Psychiatric advance directives will prevent professionals from intervening when they should.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
</tr>
<tr>
<td>52.</td>
<td>People with mental illness should have the opportunity to write a psychiatric advance directive, if they so choose.</td>
<td>.</td>
<td>.</td>
<td>.</td>
<td>.</td>
</tr>
</tbody>
</table>
53. When in crisis, people with mental illness will not want to follow the directives they outlined in their psychiatric advance directive. (4)

54. A lawyer should be present when a person is completing a psychiatric advance directive. (5)

55. People with mental illness are capable of teaching each other about psychiatric advance directives. (6)

56. Psychiatric advance directives will only interfere with the jobs of the mental health professionals. (7)
<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>57. Proxy decision makers (agents) will be difficult to locate at the time treatment decisions need to be made. (8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>58. In a psychiatric advance directive, a person with mental illness will likely direct to have no treatment at all. (9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>59. Psychiatric advance directives would not work in my community. (10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60. People with mental illnesses should be allowed to make decisions about their mental health treatment. (11)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

End of Block: OPADQ
Start of Block: Demographics

Q7.1 How old are you?
________________________________________________________________

Q7.2 What is your gender?
• Male (1)
• Female (2)
• Non-binary/third gender (3)
• Prefer to self-describe (4)
________________________________________________________________
• Prefer not to say (5)

Q7.3 Which of the following best describes your racial background?
• White (1)
• Black or African American (2)
• American Indian or Alaska Native (3)
• Asian (4)
• Native Hawaiian or Pacific Islander (5)
• Other (6) ________________________________________________
• Prefer not to answer (7)

Q7.4 What is your highest level of education?
• Less than high school (1)
• High school graduate/GED (2)
• Some college (3)
• 2 year degree (4)
• 4 year degree (5)
• Professional degree (6)
• Doctorate (7)
• Prefer not to answer (8)
Q41 Do you reside or work in the state of Virginia?
- Yes (1)
- No (2)
- Prefer not to answer (3)

End of Block: Demographics

Start of Block: Unique code

Q2.1 Although this study on advance directives for mental health is anonymous, we would like to collect longitudinal data on this topic. To protect your anonymity, we ask that you enter a unique code that we will later use to match responses over time.

Q2.2 What are the first two initials of your high school's name?

Q2.3 What day of the month were you born?

Q2.4 What is the last letter of your first name?

Q2.5 Combine your responses from 1-3 in order here (e.g., FA19A)

End of Block: Unique code

Start of Block: Family/advocates
Q52 Have you ever helped a family member or someone you care for create a legal document with instructions about their health treatment in the future if they became very ill and were unable to make decisions for themselves?

- Yes (1)
- No (2)

Q56 If someone showed you how, would you want to help a family member or someone you care for create a legal document with your instructions about your health and mental health treatment in the future if you become very ill and are unable to make decisions for yourself?

- Yes (1)
- No (2)
- The person I'm thinking of already has one (3)
- Don't know (4)

Q60 Has anyone ever created a legal document identifying you to make decisions about their general and mental health care treatment in the future if they couldn't make decisions for themselves (e.g. proxy decision-maker or healthcare power of attorney)?

- Yes (1)
- No (2)

Q64 If someone showed you how, would you want to help a family member or someone you care for create a legal document identifying a person they trust to make decisions about their health treatment in the future if they can't make decisions for themselves?

- Yes (1)
- No (2)
- Already have one (3)
- Don't know (4)

End of Block: Family/advocates

Start of Block: Consumers
Q50 Have you ever created a legal document with your instructions about your health treatment in the future if you become very ill and are unable to make decisions for yourself?
  • Yes (1)
  • No (2)

Q54 If someone showed you how, would you want to create a legal document with your instructions about your health and mental health treatment in the future if you become very ill and are unable to make decisions for yourself?
  • Yes (1)
  • No (2)
  • Already have one (3)
  • Don't know (4)

Q58 Have you ever created a legal document that identifies a person you trust to make decisions about your general and mental health care treatment in the future if you can't make decisions for yourself (e.g. proxy decision-maker or healthcare power of attorney)?
  • Yes (1)
  • No (2)

Q62 If someone showed you how, would you want to create a legal document that identifies a person you trust to make decisions about your health treatment in the future if you can't make decisions for yourself?
  • Yes (1)
  • No (2)
  • Already have one (3)
  • Don't know (4)
Q63 Would you be interested in participating in a follow-up interview with the researcher regarding advance directives?
  • Yes (1)
  • No (2)

End of Block: Interview?
Appendix B. Interview Script

Interview Script

VERBAL CONSENT DOCUMENTATION FOR PARTICIPATION.

SUBJECT: Hear me when I’m well: a mixed methods study of psychiatric advance directives in Virginia.

Oral consent serves as an assurance that the required elements of informed consent have been presented orally to the participant or the participant’s legally authorized representative. Verbal consent to participate in this telephone survey has been obtained by the participant’s willingness to continue with the telephone survey by providing answers to a series of questions related to what the participant has heard about psychiatric advance directives.

* Phone Script:

**Introduction:**
Hello! Thank you so much for agreeing to speak with me today. My name is Anne Metz, and I am a doctoral student in Counselor Education at James Madison University. I’m conducting this research for my dissertation under the direction Dr. Renee Staton of James Madison University’s department of Graduate Psychology.

I’m inviting you to do a one-on-one telephone interview that will take about 20-30 minutes. I will ask you questions about psychiatric advance directives here in Virginia.

**Consent to Participate in Research**

**Identification of Investigators & Purpose of Study**

You are being asked to participate in a research study conducted by Anne Metz, MA/EdS and A. Renee Staton, PhD from James Madison University, and Heather Zelle, J.D., Ph.D. of the University of Virginia. The purpose of this study is to examine the use of advance directives in Virginia and how Virginia’s new Health Care Decisions Act is being implemented across the state. This study will contribute to the researcher’s completion of doctoral dissertation.

**Research Procedures**

Should you decide to participate in this research study, you will be asked to verbally agree to this consent form once all your questions have been answered to your satisfaction. This study consists of an interview that will be administered to individual participants over the telephone. You will be asked to provide answers to a series of questions related to psychiatric advance directives. During our interview, I will take handwritten notes to record your answers. However, I would also like to use an audio recorder to make sure I don’t miss what you say. After our interview, I will send you a copy of your interview transcript to ensure that your comments are accurate. This audio recording will be destroyed after transcription, but de-identified transcripts will be retained for future research.
Are you willing to consent to audio recording at this time?

[If yes, continue the informed consent and recorder.]
[If no, continue the informed consent without recording.]

Please know that you may request that the recording stop at any time.

**Time Required**: 20-30 minutes.

**Risks**

The investigator does not perceive more than minimal risks from your involvement in this study (that is, no risks beyond the risks associated with everyday life).

The investigator perceives the following are possible risks arising from your involvement with this study:

- Breach of confidentiality in which participant’s identities could be connected to their responses.
- Subjects could become upset by the survey questions or in response to questions.

**To minimize these risks, interview transcripts will be de-identified. All human subjects data and associated study documentation will be regarded as confidential, and will be stored in a secure manner. Following transcription, all recordings will be destroyed to reduce the possibility of breach of confidentiality. Likewise, participants are not required to answer any interview question that might be upsetting.**

If subjects do become distressed by any questions, participants will be provided with contact information for the local emergency services department the interviewer (540-885-0866). Participants will be encouraged to contact these mental health professionals to access counseling and support services.

**Benefits**

Potential benefits from participation in this study include findings that may inform advocacy efforts associated with providing more continuity of care for persons with mental health care needs, insight into the relevance of the law, which can aid in self-efficacy. For all involved, becoming more familiar with the statute may improve the likelihood that advanced directives will be completed as the value of the process becomes clear in the interview.

**Confidentiality**

The results of this research will be presented in my dissertation, to my colleagues, at conferences and publications. The results of this project will be coded in such a way that the respondent’s identity will not be attached to the final form of this study. The researcher retains the right to use and publish non-identifiable data. While individual responses are confidential, aggregate data will be presented representing averages or
generalizations about the responses as a whole. All data will be stored in a secure location accessible only to the researcher, her JMU advisor, and the UVA researcher. Upon completion of the study, all information that matches up individual respondents with their answers, including audio recordings will be destroyed.

**Participation & Withdrawal**

Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind.

**Questions about the Study**

If you have questions or concerns during the time of your participation in this study, or after its completion or you would like to receive a copy of the final aggregate results of this study, please contact:

Anne Metz, MA/EdS
Department of Graduate Psychology
James Madison University
metzal@jmu.edu

A. Renee Staton, Ph.D.
Department of Graduate Psychology
James Madison University
statonar@jmu.edu

**Questions about Your Rights as a Research Subject**

Dr. David Cockley
Chair, Institutional Review Board
James Madison University
(540) 568-2834
cocklede@jmu.edu

**Giving of Consent**

I have heard this consent form and I understand what is being requested of me as a participant in this study. I freely consent to participate. I have been given satisfactory answers to my questions. I certify that I am at least 18 years of age.

*If yes, begin the interview.*

*If no, thank the participant for his/her time.*

**Attestation of verbal consent**

I attest that the aforementioned written consent has been orally presented to the human subject and the human subject provided me with an oral assurance of their willingness to participate in the research.

Surveyor’s Name (Printed) Surveyor

**Questions:**

*Grand tour question [present]:*

Could you describe a typical day in your clinical work?
Background [past]:
Can you tell me about the time that you first heard about psychiatric advance directives?

Knowledge [past]:
What did you learn about PADs in that instance?

Experience & Behavior [past]:
Could you tell me about an experience you had with psychiatric advance directives in your work?
- Probes: some clinicians have helped clients complete a PAD, whereas others have asked about them during an intake or an assessment. Others may have seen that a client has a PAD in their EHR.
If you haven’t, could you tell me about how you might use them in your clinical work?

Opinions & Values [past]:
What do you feel were the advantages of the PAD in that instance?
- Probe: What do you imagine are the advantages of PADs in other circumstances?

Opinions & Values [past]:
What do you feel were the disadvantages of the PAD in that instance?
- Probe: What do you imagine are the disadvantages of PADs in other circumstances?

Thinking [present]:
What do you think encourages you to use PADS with clients?

Experience & Behavior [past]:
Can you think of a specific time when you felt encouraged to use a PAD?
Probe: accessing it during crisis work? Creating one in routine outpatient work or case management? In hospital discharge planning?

Thinking [present]:
On the other hand, what might discourage you from using PADs with clients?

Experience & Behavior [past]:
Can you think of a time where you felt discouraged from using a PAD?
- Probe: accessing it during crisis work? Creating one in routine outpatient work or case management? In hospital discharge planning?

Presuppositional opinions & values [future]:
What policy or systemic recommendations do you have about ways to increase the utilization of PADs in Virginia?

Knowledge [present]:
Is there anything else that you feel I should know about PADs here in Virginia?
- Probe: imagine it is a half-hour after the end of our interview, what might you wished you had said about PADs in Virginia
References


publication no. SMA 15-4927, NSDUH series H-50).


Department of Behavioral Health and Disability Services (2016). *DBHDS Comprehensive State Plan.* Richmond, VA: Department of Behavioral Health and Disability Services.

Retrieved from:


Ganju, V. (1999). The MHSIP consumer survey. *Austin, TX: Texas Department of MHMR,*


Khazaal, Y., Manghi, R., Delahaye, M., Machado, A., Penzenstadler, L., & Molodynski, A. (2014). Psychiatric advance directives, a possible way to overcome coercion and promote
empowerment. *Frontiers in Public Health, 2*


hospitalizations. *Archives of psychiatric nursing, 16*(1), 16-24.


Wilder, C. M., Swanson, J. W., Bonnie, R. J., Wanchek, T., McLaughlin, L., & Richardson, J.
(2013). A survey of stakeholder knowledge, experience, and opinions of advance
directives for mental health in Virginia. *Administration and Policy in Mental Health and
Mental Health Services Research, 40*(3), 232-239.

Winick, B. J. (1996). Advance directive instruments for those with mental illness. *University of
Miami Law Review, 51*(1), 57. Retrieved from

Zelle, H., Kemp, K., & Bonnie, R. J. (2014). Advance directives for mental health care: