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Erika Wentworth
Caregiver Involvement in Child and
Adolescent Psychiatric Inpatient
Care: A Clinician's Perspective

ABSTRACT

This mixed-methods exploratory study aimed to contribute to the knowledge about caregiver involvement during child and adolescent inpatient psychiatric treatment, as it is the most agreed upon factor of treatment outcomes by both psychiatric providers and previous research. Thirty-two licensed clinicians who either currently work or worked within the last five years on child and/or adolescent psychiatric inpatient units completed an online survey. The survey included both multiple choice and open ended questions about participants' perceptions of how they involved caregivers during treatment as well as the involvement of the unit and day programming. The findings of the study confirmed the previous research, specifically that caregiver involvement during inpatient psychiatric treatment plays a crucial role in the outcomes of hospitalizations. However, the findings also demonstrated that there are barriers and unknown influences that are affecting the implementation of caregiver involvement during treatment and the movement towards more family centered models of care.

**CAREGIVER INVOLVEMENT IN CHILD AND ADOLESCENT PSYCHIATRIC
INPATIENT CARE: A CLINICIAN'S PERSPECTIVE**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2016

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This thesis is dedicated to my mother, Nancy Collins, who has allowed me the privilege of becoming who I want to be in this world and provided me with nothing but love and support along the way.

I cannot go without thanking the families who inspired me to explore this question. Without them I would not have attempted to contribute to knowledge and research that aims to better the course of acute mental health treatment for children, adolescents, and their families. This thesis absolutely could not have been completed without my research advisor, Dr. Shella Dennery; thank you for your help, patience, and always supportive feedback. And last but not least, thank you to Adam and Beans for being there every step of the way.

TABLE OF CONTENTS

AKNOWLEDGMENTS	ii
LIST OF TABLES	iv
CHAPTER	
I. INTRODUCTION	1
II. LITERATURE REVIEW	3
III. METHODOLOGY	12
IV. FINDINGS	17
V. DISCUSSION	28
REFERENCES	36
APPENDICES	
Appendix A: Human Subjects Review Board Approval Letter	39
Appendix B: E-mail Recruitment	40
Appendix C: Follow up E-mail	41
Appendix D: Facebook Recruitment	42
Appendix E: Informed Consent	43
Appendix F: Survey Questions	46
Appendix G: Research Assistant Confidentiality Form	53

LIST OF TABLES

1.	Demographics	19
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CHAPTER I

Introduction

The aim of this mixed-methods study was to contribute to the knowledge about caregiver involvement during child and adolescent inpatient psychiatric treatment. This study asked mental health clinicians of various academic backgrounds and licenses to complete an online survey regarding their perceptions and experiences about caregiver participation and involvement on inpatient psychiatry units. In this study, the term *caregiver* refers to any legal guardian of a child or adolescent regardless of the nature of their relationship. For example, caregivers could include mothers, fathers, grandparents, aunts or uncles, a sibling, a distant relative, adoptive parents, foster parents, or state providers. The term *inpatient psychiatric treatment* refers to a person being in a psychiatric facility or hospital due to risk of harm to self or others, requiring an individual plan for psychiatric assessment and treatment with 24-hour supervision by mental health professionals.

Like most mental health treatment settings and modalities, there is increasing pressure for inpatient psychiatric care for children and adolescents to prove its effectiveness. There is little research on the efficacy of inpatient psychiatric treatment for adolescents and children (Blanz & Schmidt, 2000), with much of the research focusing on the effectiveness of different outpatient mental health modalities. Studies related to the effectiveness and efficacy of inpatient psychiatric treatment for children and adolescents continues to identify the need for research on key components of successful inpatient treatment (Blanz & Schmidt, 2000; Meagher, Rajan,

Wyshak, Goldstein, 2013. The definition of successful inpatient psychiatric treatment varies, however it's often defined by the amount of hospitalizations follow the initial admission. Some of the key components researchers have identified in those successful hospitalizations include, but are not limited to, waitlists for outpatient mental health care, lack of support from school symptoms, the severity of the child's symptoms, and learning disabilities (Blader, 2004).

Research shows and many psychiatric providers agree that caregiver involvement and participation in treatment is crucial to successful inpatient psychiatric treatment for children and adolescents (Haine-Schlagel & Walsh, 2015). Clinicians who provide direct care to children and their caregivers likely have the most insight about the ways in which caregiver participation is or is not included during treatment. By surveying clinicians who currently or recently worked in inpatient psychiatric treatment with adolescents and/or children, this study contributes to knowledge about this largely agreed upon, key component to successful inpatient psychiatric treatment for children and adolescents.

This mixed-methods study confirmed the previous literature highlighting that caregiver involvement during psychiatric inpatient treatment for children and adolescents is crucial to patient outcomes. The study also provides new insights on some of the challenges, barriers, and influences on the implementation of caregiver involvement during treatment. The findings of this study point to the need for further research to continue to explore why the intentions of family centered treatment models are not being applied during child and adolescent psychiatric inpatient treatment. In addition, the inclusion of patient and family voices would be greatly beneficial in future thinking about effective models of care in this setting.

CHAPTER II

Literature Review

Introduction

This literature review examines the research surrounding the efficacy and effectiveness of child and adolescent inpatient psychiatric treatment, the role caregiver involvement plays in treatment, and the gaps indicated in the literature. This information will provide a framework for why an exploration of clinicians' perspectives on caregiver involvement during psychiatric inpatient hospitalizations is important and a needed topic of study. This chapter will discuss the history and nature of inpatient treatment, the factors associated with successful treatment, and how research on psychiatric inpatient care for children and adolescents has indicated the need for a focus on family centered care.

The History and Efficacy of Child and Adolescent Psychiatric Inpatient Care

Psychiatric inpatient care for children and adolescents first appeared in the United States in the early 20th century and was essentially a caretaking setting intended to meet the basic needs of children with problematic behaviors (Blanz & Schmidt, 2000). It wasn't until around the 1970's and 80's when these facilities began to provide services with the intent of treatment or recovery, with stays that usually lasted many months (Blanz & Schmidt, 2000). More recently, the nature of child and adolescent inpatient hospitalizations has shifted drastically. With financial pressures from managed care and political stances, the length of stays in the hospital for psychiatric treatment has been reduced to days, or weeks at most (Blader, 2004; Blanz & Schmidt, 2000).

Even with these pressures, providers are still being asked to prove the efficacy and efficiency of inpatient treatments (Blanz & Schmidt, 2000), which has proven challenging given the lack of empirical evidence.

It is important to point out that most of the research focused on child and adolescent psychiatric treatment and mental health care has focused primarily on outpatient work (Meagher, Rajan, Wyshak, Goldstein, 2012). Although these findings are often beneficial to inpatient psychiatric care, evidence of the efficacy and effectiveness of psychiatric inpatient stays for children and adolescents remains limited (Green, Jacobs, Beecham, Dunn, Kroll, Tobias, & Briskman, 2007). The existing research is difficult to generalize due to inconsistent methodologies and a lack of control groups (Green, et al., 2007). However, the lack of empirical evidence on the effectiveness does not imply that children and adolescents are not in need of this level of care. In the year 2000, there were upwards of 100,000 children and adolescents hospitalized for psychiatric treatment (James, Charlemagne, Gilman, Alemi, Smith, Tharayil, & Freeman, 2010). The effectiveness of those hospitalizations is unknown, with related studies continuing to identify continued need for research on key components of successful inpatient treatment (Blanz & Schmidt, 2000; Meagher, Rajan, Wyshak, Goldstein, 2012).

Currently, psychiatric inpatient stays are used mostly for crisis intervention, supporting safety, and evaluation (Blanz & Schmidt, 2000). Putting the financial and political pressures aside, the intention, which many mental health providers agree, is to allow children to be treated in the least restrictive environment possible (Blanz & Schmidt, 2000). It is not only the least restrictive environment that is of importance, it is also about the child's own environment. When working to treat a child or adolescent who is struggling with psychiatric issues, providers are not solely treating the child because a child is intertwined in a family system (Koelch & Fegert,

2010) and this stands true for any level of psychiatric care; inpatient or outpatient. However, it raises specific challenges for inpatient care. The lengths of stays are short, clinicians are focusing mostly on crisis intervention, stabilization and safety, but also are tasked with holding and supporting the child's family system, whoever that may be.

Rehospitalization and Associated Factors

Due to the many challenges in conducting generalizable, cumulative, empirical studies on the effectiveness of psychiatric inpatient treatment for children and adolescents, there has been a move to study the factors associated with remittance and rehospitalization rates. The studies have examined and researched factors that contribute to what are known components of successful and unsuccessful inpatient hospitalizations. Rehospitalization is often thought of as an indicator of unsuccessful psychiatric inpatient treatment. Across various studies within the last decade, rehospitalization rates have increased from about 25% of children and adolescents to upwards of 50% (James, Charlemagne, Gilman, Alemi, Smith, Tharayil, & Freeman, 2010). One study followed 109 children for one year after their first psychiatric hospitalization. They found that 39 of those children were readmitted to psychiatric inpatient care within one year. 81% of those 39 children were readmitted within just 90 days after discharge (Blader, 2004).

When an adolescent or child requires to be hospitalized and then rehospitalized the costs are both financial and emotional for the families and caregivers involved (James, et al., 2010). The child does not stand alone in the treatment or hospitalization; "the child is part of a system consisting of caregivers, parents, and other family members" (Koelch & Fegert, 2010, p. 258). These systems play an integral part in the psychiatric treatment of children and adolescents. Research has shown that when parents and caregivers are involved and satisfied with the treatment and hospitalization, children and adolescents are less likely to be rehospitalized

(Blader, 2004; James, et al, 2010). Another study looked at pretreatment variables that affect the likelihood of suicide attempts following a psychiatric hospitalization and the findings suggested that more “caregiver inclusive therapy,” in any setting, is likely to reduce those risks (Huey, Henggeler, Rowland, Halliday-Boykins, Cunningham, & Pickrel, 2005). Two studies found variables that led to the idea of more caregiver inclusion during treatment. These variables were youth-rated parental control, caregiver distress, and the caregiver’s history of psychiatric hospitalizations (Blanz & Schmidt, 2000; Huey, et al.,2005).

All of these findings underscore the need for child and adolescent mental health treatments to have a systemic and family focus to be successful, especially during inpatient care when the safety and suicidality of the child or adolescent is in question. Whether a child is experiencing their first or fifth psychiatric hospitalization, the child’s caregivers need to be integrated into the treatment to increase the likelihood of effectiveness. In Dowell & Ogles’ *Meta-Analytic Review of the Effects of Parent Participation on Child Psychotherapy Outcomes* (2010), they found that 48 different studies “suggest that combining child and parent treatment interventions produces moderately better treatment outcomes” (p. 160). Involving caregivers in treatment was not the only identified factor in successful inpatient treatment. However, it is one factor that is often tangible. Communication with caregivers, parents, or a child protective agency during a child or adolescent’s hospitalization is unavoidable. But the task for clinicians and providers is to create therapeutic interactions between the child and those systems is no easy feat (Blader, 2004).

Barriers to Caregiver Involvement

There are many identified barriers to involving and engaging caregivers in child and adolescent psychiatric inpatient treatment including, but not limited to, caregiver stress/distress associated with the hospitalization, caregiver mental health challenges, organizational

inaccessibility, conflicts or struggles between providers and caregivers, a family's socioeconomic status and access to resources and education, adequate or reliable transportation, childcare for other children, and provider/staff characteristics or attitudes (Blader 2004 & 2006; Haine-Schlagel & Walsh, 2015; Hissett, Bilge-Johnson, & McNinch, 2015; James et al., 2010; Koelch & Fegert, 2010; Linnenmeyer et al., 2013; Regan, Curtin, & Vorderer, 2006). These exponential barriers can be quite complicated to navigate especially with the limited time providers and clinicians have with each child, depending on their length of stay. This requires effort, time, resources, appropriate staffing, and a collaborative approach to do so therapeutically and to the benefit of the child and family (Blader, 2004; Regan, Curtin, & Vorderer, 2006).

Family System Barriers and the Effects of Caregiver Stress

One recent study (2015) on stressors for parents of children admitted to an inpatient psychiatry unit surveyed 66 caregivers of children admitted to Akron's Children's Hospital (Hissett, Bilge-Johnson, & McNinch, 2015). The parents in the study were found to be in the 80th percentile for "parent-child dysfunctional relationship" which reveals a high level of stress (Hissett, Bilge-Johnson, & McNinch, 2015). Many clinicians and mental health professionals may agree that this intense level of stress is a normal reaction given the situation. Caregivers and family members may be in crisis themselves due to the child's symptomology, behaviors, or suicidality and now they are faced with handing the care of their vulnerable child over to new professionals. Compounded with adjusting to the mere fact that a child requires a psychiatric hospitalization and perceived or experienced judgment from providers that what has manifested is the fault of the caregiver (Haine-Schlagel & Walsh, 2015; Hissett, Bilge-Johnson, & McNinch, 2015). Caregivers can also face "stress about the child's future, the safety of the child and

family, balancing needs of other family members, diagnosis confusion, financial aspects, personal and emotional health and stigma” (Hissett, Bilge-Johnson, & McNinch, 2015, p. 1)

The reason it is so important to illuminate the nature of the stressors many caregivers encounter when a child is hospitalized is due to the research findings indicating that challenging behaviors and symptomology in children increases caregiver stress which negatively affects caregiver-child interactions then leading to increased symptomology and/or challenging behaviors (Blader, 2006; Hissett, Bilge-Johnson, & McNinch, 2015; Knox & Singh, 2007; Rimehaug, Berg-Nielson, & Wallander, 2012). The cycle is counterproductive to the child or adolescent’s treatment progress leading to many researchers pointing out the importance of addressing caregiver distress symptoms and parenting characteristics combined with systemic evaluations and treatments, increased psycho-education and focus on supporting caregivers more directly during the hospitalization (Hissett et al., 2015; Knox & Singh, 2007; Rimehaug et al., 2012).

Provider and Organizational Barriers

Although family system factors and caregiver stress prove to greatly influence caregivers’ ability and capacity to be involved and engaged in their child’s psychiatric inpatient treatment, the providers and the organizations whom provide the treatment also contribute significantly (Haine-Schlagel & Walsh, 2015; James et. Al, 2010; Koelch & Fegert, 2010; Regan, Curtin, & Vorderer, 2006). In Regan, Curtin, and Vorderer’s (2006) article on paradigm shifts in child and family centered care, they point out that “many, if not most, care providers take family consideration into account and seek to involve children and families in treatment planning” (p. 29). However, they have found that this is not typically practiced on inpatient psychiatric units comprehensively. These authors feel that, in their experience and research,

clinicians and providers need to drastically change their practices and encourage their organization to alter policies and structures to engage caregivers and families in the child's treatment (Regan, Curtin, & Vorderer, 2006).

Even with evidence that including and engaging caregivers in child and adolescent mental health treatment is critical for desired outcomes (Haine-Schlagel & Walsh, 2015; Slovak & Singer, 2012), little research has focused on the factors or characteristics of clinicians and providers which prevent caregiver involvement in treatment (Haine-Schlagel & Walsh, 2015). However, there is considerable research on caregiver involvement in child and adolescent medical treatment (Gill, 1993; Ygge, Lindholm, & Arnetz, 2006). One study of 1,022 members of the Association for the Care of Children's Health completed a questionnaire about their personal and profession attitudes on parent participation during medical treatment (Gill, 1993). The findings suggested a need for health professionals to develop and increase ways to generate more positive attitudes toward parent inclusion and increase communication about care (Gill, 1993; Ygge, et al., 2006). Increasing positive attitudes and communication leads to more successful and beneficial collaboration between caregivers and health professionals and "to deny such collaboration deprives families of the experiences that will make them more competent in the child's health care" (Gill, 1993, p. 259). Despite the absence of research on this topic for psychiatric care, this research may translate well for all families with hospitalized children.

Throughout the research on this topic, organizational concerns have been mentioned in regards to their influence on caregiver involvement in child and adolescent psychiatric inpatient care (Haine-Schlagel & Walsh, 2015; James, et al., 2010; Regan, Curtin, & Vorderer, 2006). However, as Haine-Schlagel and Walsh (2015) point out in a study on parent engagement, "no clear attention has been paid to organizational/program level factors such as an organization's

culture, climate, or policies” (p. 135). Despite the lack of research and consideration, the concerns are well documented. Regan, Curtin, and Vorderer (2006) point out that caregivers often report that “even good care can’t undo the dissatisfaction that results from restrictive visitation policies” (p. 30). Similarly to provider characteristics and factors in regards to caregiver involvement in medical hospitalizations described by Gill (1993), the author also writes that characteristics of organizations and institutions affect hospitalizations as well. It is likely that this has an even greater affect in psychiatric settings due to the nature of the milieu care (Regan, Curtin, & Vorderer, 2006).

Conclusion: Solutions and Gaps

This literature review has looked at factors in rehospitalizations, the role of caregivers and family systems in hospitalizations, and the communicated barriers that arise in order for caregivers to be involved and engaged in psychiatric treatment. With what is known (and not known) about the nature and efficacy of inpatient psychiatric treatment for children and adolescents questions remain: What is being done to address these concerns? What is the current state of affairs in caregiver involvement today?

Outpatient research is encouraging clinicians and mental health providers to be persistent about family therapy referrals, to create alliances with caregivers at the start of treatment, and to address parent concerns as much as possible (Linnemeyer, Scalise, & Hamilton, 2013). But, what about inpatient treatment? The focus, attention, and research that is needed in the inpatient setting is limited. A few small studies have looked at possible models and solutions to creating inpatient treatment settings that allow caregivers to be as involved and engaged as possible. For example, a child and family centered (CFCC) treatment and organizational model is implemented on a 13-bed child and adolescent psychiatric unit in Cambridge, Massachusetts

with great success (Regan, Curtin, & Vorderer, 2006). The CFCC model created a more collective and united approach for staff when problem solving about how to manage difficult or unsafe behaviors, implemented open visiting hours for parents and caregivers, and weaved a trauma sensitive approach throughout policies and procedures (Regan, Curtin, & Vorderer, 2006). Despite the findings, most psychiatric inpatient units continue to follow the traditional model where policies and the milieu culture are not family focused or inclusive (Regan, Curtin, & Vorderer, 2006). The researchers called for further studies on similar models.

There is a dialectical dilemma here - clinicians, psychiatric providers, and researchers agree and acknowledge that psychiatric inpatient treatments should have a family systems approach with organizational accessibility in order to ensure more effective inpatient treatment for children and adolescents (Dowell & Ogles, 2010; Haine-Schlagel & Walsh, 2015; Hissett, Bilge-Johnson, & McNinch, 2015; Rimehaug et al., 2012). However, the implementation of best practices is limited. This study will aim to contribute to a better understanding of the factors and challenges in the inclusion of caregivers and the lack of consistency in family centered treatment (Regan, Curtin, & Vorderer, 2006). By exploring this topic through the lens of the clinician, the study participants will be able to address their perceptions of caregiver barriers, their own barriers, and the role of the organization; all of which were pointed out as needing more attention in a related study by Haine-Schlagel & Walsh, (2015).

CHAPTER III

Methodology

The following chapter describes the purpose and methodology used to conduct this mixed-methods, exploratory study. This study took place over the course of nine months and was approved by The Human Subjects Review Board at Smith College School for Social Work (Appendix A). The purpose of this study was to learn more about clinicians' experiences, thoughts, and perspectives on caregiver involvement during psychiatric inpatient hospitalizations for children and adolescents. There are many identified contributing factors related to the effectiveness of child and adolescent psychiatric inpatient treatment. With the continued emphasis on evidenced-based treatments in the mental health field, questions arise about whether inpatient hospitalizations are effective treatments or just temporary safety solutions. Beginning to better understand the factors related to the effectiveness of inpatient hospitalizations for children and adolescents will likely improve future outcomes. The literature shows, and many psychiatric providers agree, that caregiver involvement and participation during a child's treatment is crucial to the effectiveness, regardless of the child's diagnosis (Haine-Schlagel & Walsh, 2015). If caregiver involvement and participation is the most agreed upon factor in the effectiveness of inpatient psychiatric treatment for children and adolescents, knowing more about how caregiver involvement is fostered in these treatments is key and therefore exploratory studies are needed in order to add to the knowledge and understanding.

Design and Sample

An exploratory design was most appropriate for this study as the research began from a question and not a hypothesis (Steinberg, 2009). The intent of this study is to gain more insight and familiarity with caregiver involvement on child and adolescent inpatient units and facilities. There are a few possible avenues to explore this topic through: providers of the treatment(s), patients who have received inpatient psychiatric care as a child or adolescent, or caregivers of those patients. Due to accessibility of the researcher and respect for patient and family confidentiality, this researcher chose to begin exploration into this topic through those providing the treatment(s). As Dominique Moyses Steinberg points out in *The Social Work Student's Research Handbook* (2009), one of the most effective ways to conduct exploratory studies is to look to “relevant people with practical experience with the area of interest” (p. 44). The patients and caregivers themselves are absolutely relevant to the topic at hand, however the treatment providers likely have the most applicable knowledge, as they are involved with various patients and families on a daily basis and have insight about institutional factors that patients and caregivers may not. To best reach as many providers as possible, this research was conducted through an online, mixed-methods, questionnaire.

A nonrandom, purposive sampling method was used for this study. Because the priority of this study is to gain insight and the main goal is to “develop implications for action or further thought and study” (Steinberg, 2009, p. 100) about caregiver involvement in child and adolescent inpatient psychiatric treatments, nonrandom was the most logical choice. A purposive approach was used to ensure a level of continuity in the participants and hopefully the findings. The desired characteristics for study participants included an advanced level of professional

knowledge and experience working with children and adolescents in an inpatient psychiatric setting as well as an understanding of family systems. Therefore, participation requirements included: a master's level degree or higher in social work, mental health counseling, psychology, or a related field with a valid license and current or recent (within 5 years) experience working on an inpatient psychiatric unit that treats adolescents or children. Because the data collection was completed through an online survey, participants also needed to be literate in English, have access to a computer with internet, and have the ability to navigate an online survey.

The study sample was focused on clinicians, social workers, and therapists because they are the staff members who most often work directly with parents, caregivers, and families and are also key players in treatment planning. On inpatient psychiatric units, clinicians are often tasked with holding family meetings, remaining in daily contact with caregivers regarding treatment progress, and act as a broker between the patients, the caregivers, and the rest of the treatment team. Recruitment occurred through snowball sampling starting with two advertising sources: email and social media. An initial email (Appendix B) was sent out to personal contacts of the research which included a link to the survey as well as a request to forward the survey to colleagues who may be eligible. A follow up email (Appendix C), including a similar request, was sent out prior to the data collection period closed. The social media advertisement (Appendix D) was posted on public and private groups requesting participants with a link to the survey and a request to forward the survey to people who may be eligible. In both forms of recruitment, the researcher's contact info was given in case potential participants had any questions or concerns.

Consent for participation was completed once potential participants clicked on the link with the intention to complete the online survey. Potential participants were first shown a

welcome screen where they are required to answer eligibility questions. If eligible, participants were then brought to the informed consent page (Appendix E). By choosing “I agree” participants are acknowledging consent to being a participant in the study and agreeing that they meet the stated eligibility requirements and are then able to complete the questionnaire (Appendix F).

Data Collection

The data was collected through a structured questionnaire, using Survey Monkey. Due to the lack of an existing measure to examine this topic, this researcher created a survey. A mixture of multiple choice, closed and open ended questions were included to provide a variety of ways to gather information and to provide participants with opportunities to offer further responses where they felt inclined. A structured questionnaire was used due to reliability, the potential for a high degree of validity, and the opportunity to provide time and privacy for participants to answer thoughtfully (Steinberg, 2009). Survey Monkey allows for questionnaires to be completely anonymous and creates a secure connection between both the researcher and the participant by encrypting the information transmitted through the survey. Participants were able to exit the questionnaire at any time. Incomplete questionnaires were not used in the study. Due to the complete anonymity of the online survey, participants were not able to withdraw their responses once the survey was completed.

The questionnaire was set up in to two parts. The first part of the questionnaire contained demographic questions such as the type of clinical license, the amount of time spent working in the specific field of question, the general geographic location, gender identity, age range, racial identity, and the age of children they typically work (or worked) with. The second part of the questionnaire included more in-depth questions about the nature of the participant’s experience

working with caregivers in this setting as well as the ways they personally involve caregivers and the ways their institution or facility does. Many of the questions in part-two were multiple choice with the option to add a comment. In order to complete the questionnaire in full, responses were required to all questions. The survey instrument and all items can be found in Appendix F.

Data Analysis

The online questionnaire was open for four months (January 15th, 2016 – April 10th, 2016). The study received a total of 54 participants who met the requirements of the study and agreed to the consent, however 22 of those responses were incomplete. The total number of participants who filled out the questionnaire in full was 32. Because this was a mixed methods study, the 32 data sets were interpreted through both descriptive and content analysis. The results from this survey were only accessible to me, my thesis advisor, and a research assistant. The research assistant signed a confidentiality agreement (Appendix G).

This researcher looked at the data descriptively; through frequency tables, charts, and histograms. Content analysis was used to review, categorize, and interpret patterns in the responses for the open ended questions. In both the descriptive and content analysis, consistencies and inconsistencies were looked for throughout responses, specifically the different attitudes expressed at large about caregiver involvement in child and adolescent inpatient psychiatry, and how responses compared to the demographic information given in part one of the questionnaire. The results from the data analysis are discussed in the next chapter on the study findings.

CHAPTER IV

Findings

The purpose of this study was to learn more about clinician's experiences, thoughts, and perspectives on caregiver involvement during psychiatric inpatient hospitalizations for children and adolescents. With the lack of empirical evidence regarding the efficacy of child and adolescent psychiatric inpatient treatments and the continued emphasis on evidence based treatments in the mental health field, a better understanding of the contributing factors to success treatment is needed. By surveying clinicians who currently and recently work in psychiatric inpatient treatment with children and adolescents, this study aimed to generate more knowledge to this generally understudied topic.

The findings that follow from this mixed-methods study will begin with respondents' demographic information, including license type, amount of experience, age, race, gender identity, geographic location, and age group(s) of patients treated. Next, the results from the multiple choice questions will be presented broken up into three categories: the clinician's thoughts and opinions, information about the unit and/or facility, and correlations found. Following this, the chapter will conclude with the results and analysis from the open ended questions and will be presented by individual question.

Participant Demographics

There were a total of 54 clinicians who responded to the survey from various corners of the United States as well as a few from outside the U.S. However, 22 of those respondents did

not complete the survey in full, and therefore this researcher withdrew their participation from the study. The study was comprised of 32 participants. The sample of participants were fairly diverse. 66% of the participants had previously worked in child and/or adolescent inpatient psychiatry within the last 5 years and 34% were currently working in child and/or adolescent inpatient psychiatry at the time they completed the survey. Most of the participants reported either being a Licensed Independent Clinical Social Worker (LICSW) or a Licensed Clinical Social Worker (LCSW) while 36.2% identified as a Licensed Mental Health Clinician (LMHC), Licensed Marriage and Family Therapist (LMFT), or other. The amount of experience as clinicians in this setting varied. Seventeen percent of participants reported having eight or more years of experience. About one-fourth of the sample reported having 4-7 years of experience. With 63.8% of participants reporting that they treat/treated mostly adolescents and some children and 19.1% reporting that they treat/treated only adolescents, only a minority of the sample had experience treating children.

As mentioned above, geographically the participants were rather diverse, however most participants reported being located in the North East. Participants' ages ranged greatly from a range of 18-25 to over 56 with the mode being 31-35 years old. Participants were asked to write in their racial identity. The races identified with their percentages are as follows: Asian American 1.9%, Black 1.9%, Caucasian 35.2%, Caucasian and White 3.7%, Chicana 1.9%, Mixed European 3.7%, White 25.9%, White British 3.7%, and White Jewish 1.9%. The majority of the sample identified as female with 10.6% identifying as male and 2.1% not including a gender identity. Table 1 outlines the demographics of the participants.

Table 1: Demographics of Participants (n=32)

Variable	Percentage
Gender	
Male	10.64%
Female	87.23%
Queer	0%
Trans	0%
Prefer not to Answer	2.1%
Age of Participants	
18-25	4.26%
26-30	14.89%
31-35	34.04%
36-40	8.51%
41-45	14.89%
46-50	6.38%
51-55	4.26%
56+	10.64%
Prefer not to Answer	2.13%
License Type	
LICSW	34.04%
LCSW	29.79%
PsyD	8.51%
LMHC	4.26%
LMFT	4.26%
Other	19.15%
Years of Experience	
>1 Year	12.77%
1-3 Years	44.68%
4-7 Years	25.53%
8+ Years	17.02%
Geographic Location	
Northeastern U.S.	70.2%
Midwestern U.S.	2.13%
Southern U.S.	8.51%
Western U.S.	12.77%
Non-Contiguous States/U.S. Territories	0%
Outside of the U.S.	8.51%
Average Age of Patients Treated	
Only Children	4.26%
Mostly Children, Some Adolescents	12.77%
Mostly Adolescents, Some Children	63.83%
Only Adolescents	19.15%
Status of Employment	
Currently Working	34.04%
Previously Worked	65.96%

Quantitative Findings

Participants responded to 32 multiple choice questions regarding their experiences working with caregivers on child and adolescent psychiatric inpatient units. Questions were asked about their practices, their perceptions of caregiver's experiences, and their unit/facility's rules, policies, and practices. These findings will be presented along with correlations found between variables.

Satisfaction and Perceived Outcomes with Caregiver Involvement

At the start of the survey, participants were asked to rate their general feelings about caregiver involvement in child and adolescent inpatient psychiatric treatment. In summary, 31% of participants (n=32) reported feeling satisfied, 41% report feeling neutral, and 28% reported feeling unsatisfied. Those who were satisfied with caregiver involvement during a child's treatment were more likely to hold more family meetings than those who were unsatisfied ($p<.000$). Of the 31% of participants who were generally satisfied with caregiver involvement, 90% held at least 2-3 family sessions per admission. While the 28% of participants who reported feeling generally unsatisfied with the amount of caregiver involvement, 100% reported that typically one family session occurred during a child's admission.

Participants were also asked if they feel there is a relationship between caregiver involvement and participation during a child's treatment and the outcomes of that treatment. Two-third (66%) of participants agreed that most of the time, caregiver involvement during treatment leads to more positive outcomes. Almost a quarter (22%) reported feeling that caregiver involvement during treatment always leads to more positive outcomes. No participants disagreed that there is a positive correlation between caregiver involvement and positive treatment outcomes.

Caregiver and Clinician Contact

Participants were asked questions about their contact with caregivers during a child or adolescent's hospitalization. Half of participants agree that they are typically in contact with caregivers at least every other day and as much as more than once a day. Most participants reported that they speak with a child's caregiver once a day during the admission and some reported that they likely spoke with caregivers about every other day. Seven participants chose the option "other" and added a comment to this question. While some stated that family work was not in their role, many stated that "it depends on the child and the caregiver." More than half of the participants agreed that most children and adolescents have multiple caregivers that need to be contacted with updates on the child's treatment.

Participants were asked more about family sessions and/or family meetings. Specifically, participants were asked, during a typical admission, how many family meetings/sessions do you feel are usually needed? Participants were able to choose 1 session, 2 or 3 sessions, 4 or more sessions, or other. Over half (63%) reported feeling that 2 or 3 sessions are typically needed and 19% reported feeling that four or more sessions are typically needed. One participant reported feeling that typically one family session was needed during an admission. Participants were then asked how many family sessions typically occur during an admission and were given the same options. Over half (53%) reported that one session usually occurs and 44% report 2-3 sessions usually occur.

Discharge and aftercare planning was another topic the participants were asked to answer a few questions about. Almost all (84%) of participants reported that caregivers were always consulted with about discharge planning and aftercare. Participants were then asked who is responsible for aftercare and discharge plans. Two-fifths (41%) reported that caregivers are

usually responsible for aftercare plans. Participants were also asked if the unit was responsible for aftercare plans and 75% of participants agreed. In either question, participants did not report that the unit was never responsible for aftercare plans and two participants reported that the unit is rarely responsible.

Getting Caregiver's Involved: Clinician Frustrations and Barriers

Working with families and caregivers in any setting comes with frustrations and barriers. Participants were asked to answer some questions about those frustrations and barriers. Eighty-four percent of participants agreed that sometimes caregivers can get in the way of treatment with a child or adolescent during a psychiatric hospitalization. Almost half (47%) of participants reported that sometimes time they would otherwise spend meeting with the patient or child is taken up with managing caregiver stress and feelings about their child's hospitalization. One-fourth of the sample reported that this happens most of the time. Over half of the participants reported that to help manage this, it is suggested that caregivers seek their own therapy or support to help manage the stress associated with having a child who is in need of psychiatric inpatient treatment.

Almost unanimously, participants reported that they encourage caregivers to participate in a child's treatment either most of the time or always as over half of the sample agree that it feels frustrating when a caregiver (or caregivers) are not as involved with a child's inpatient psychiatric treatment as the child needs them to be. Coincidentally, 53% of participants also reported that at times it can feel frustrating when a caregiver is over-involved with a child's treatment. Agreeably, almost all of the participants noted that it can feel frustrating when a caregiver wants or expects more than daily updates on their child's treatment.

The Facility/Unit and Caregiver Involvement

Clinician's play a large role in the amount of caregiver involvement in child and adolescent psychiatric inpatient treatment and so does the culture, rules, and policies of the unit or facility. Most participants reported that the facility encourages caregiver engagement and participation at least most of the time. Almost ten percent (9%) of participants reported that the facility is sometimes encouraging, 9% reported that the facility is rarely encouraging, and no participants reported that the facility is never encouraging of caregiver engagement and participation. Almost two-thirds (63%) of the participants agree that caregivers generally feel welcomed on the unit. Also, more than half of participants agree that the facility is accessible to caregivers, easy to find, that reasonable parking is provided and is in close distance to the unit and that staff is generally welcoming to all caregivers. Over two-thirds (69%) also reported that day programming on the unit rarely or never allows for caregiver involvement or participation.

Almost all of the sample reported set visiting hours or a visitor policy on the unit. Participants were given the opportunity to share the visiting policies. Most reported a mixture of evening hours and weekends. Some reported that visits needed to be scheduled with clinician's ahead of time. Two participants noted that visitors needed to be family members and over 18 years old, three participants reported that visitor policies were on an individual basis and one participant shared that visits were allowed following family meetings or sessions. Participants were also asked if caregivers were given the opportunity to meet most of the child's treatment team and the results were not conclusive either way. Almost one-third (31%) report that caregivers do get to meet most of the child's treatment team while 28% report that caregivers rarely get to meet most of the child's treatment team. One-fourth (25%) reported that this happens most of the time and 16% reported that this happens some of the time.

Significant Correlations

As noted earlier, there are some significant correlations within the data. Again, one of the strongest correlations showed that the participants who were satisfied with the amount of caregiver involvement during treatment were more likely to hold more family meetings than those who were unsatisfied. More strong correlations involved the relationship between participants who agree that their time is often taken up with managing caregiver stress and other variables. For example, participants who agree that their time is often taken up managing caregiver stress and concerns are significantly more likely to agree that at times caregivers can get in the way of treatment and also that they feel frustrated when caregivers want more than daily updates. In regards to the data and variables involving the units and facilities there were some significant correlations found as well. Participants who report that the day programming allows for caregiver involvement and participation agree that more family sessions occur, that the unit is accessible to caregivers, that parents usually meet with almost every member of their child's treatment team, and that parents generally feel welcomed on the unit.

Qualitative Findings

Participants were asked to answer eight open-ended questions about caregiver involvement in child and adolescent inpatient psychiatric treatment. Questions included opinions about what is working well, recommendations for improvements, common barriers faced when working with caregivers in this setting, and advice for other clinicians when working with caregivers of psychiatrically hospitalized children. In this section, themes, similarities, and differences will be presented for each open ended questions.

Characteristics of an Engaged Caregiver

Participants were asked to list or describe characteristics and/or behaviors of what they would consider to be an appropriately engaged caregiver. The responses shared some similarities but also varied from emotional and personality characteristics to very specific behaviors like not bringing rewards for the child. Many participants noted empathy, honesty, self-awareness, responsiveness to the child, flexibility, compassion, respectful, and the ability to listen. Three participants noted behaviors such as consistent follow through with things such as aftercare plans, attending scheduled meetings, and returning phone calls in a timely manner. A few participants mentioned boundaries with parents; boundaries with their child and boundaries with the clinician (which was similarly explained as understanding clinician limitations. The majority of responses also pointed to the caregiver's willingness to visit with the child. The most salient theme throughout nearly all of the responses to this question was a caregiver's ability to communicate and readiness to participate.

Common Caregiver Concerns

With many questions in the study referring to frustrations and barriers working with caregivers in a child/adolescent psychiatric inpatient setting, the survey asked participants to share some of the common concerns they have heard from caregivers to hopefully better understand caregiver stress. Participants reported that they often hear concerns about the physical state of the unit; that it is "run down" or "institutional looking." A few participants mentioned caregiver fear and anxiety about discharge, quoting, "what do we do when she comes home?" Many participants highlighted caregiver concerns about their child interacting with other peers on the unit as they worried about poor influences and their child picking up on negative behaviors. Participants also noted caregiver concerns about length of stay, engagement in

treatment, lack of privacy to meet with their child, continued symptoms like self-harm, and lack of unit accessibility. The most often caregiver concerns that participants mentioned were difficulty scheduling meetings, lack of contact with the MD or psychiatrist, and lack of coordination and consultation with caregivers from the treatment team as a whole.

Recommendations for Improvements

Participants were asked to share any recommendations they might have in regards to caregiver involvement in child and adolescent psychiatric inpatient care. Many of the participants pointed out a lack of community resources and supports for families and caregivers of children and adolescents who have been psychiatrically hospitalized and therefore recommended more programming and support groups for families on the unit and more opportunities for caregivers to get involved in the day programming. Two participants reported feeling that family meetings/sessions should be required by the unit and by insurance to insure more participation. The majority of participants spoke to clinician limitations, the need to be able to hold family meetings after work hours and on weekends, and how having smaller caseloads may improve this.

Common Barriers to Caregiver Involvement

Participants were also asked to describe some specific barriers they face in involving caregivers in child and adolescent inpatient psychiatric treatment. Some of the responses mimicked those of the previous question about recommendations for improvements, but there were also many new issues highlighted. A few participants emphasized that caseloads for clinicians are too high which leaves less time than desired to involve caregivers in the treatment. Another barrier noted regarding influences beyond those of the specific caregiver was the amount of poverty experienced by the families they work with. Participants wrote, “parents need

to work” and “parents can’t afford transportation.” Related to this, participants noted that caregivers struggle with substance abuse and mental health issues of their own. And again, as in some of the previous questions, participants reported a lack of resources; for themselves, for the caregivers, for the families.

Strengths and Benefits to Involving Caregivers

There were many strengths and benefits identified by participants regarding why caregivers should be involved in a child or adolescent’s inpatient treatment. Some identified that it is empowering to caregivers, which then translates at home, indicating more positive outcomes. Some talked about strengthening relationships and providing hope to families. The theme of these responses is best illuminated by the exact quote: “Kids/teens can often be the identified patient but it is clear that the family system is the real patient. Getting caregivers on board and treating from a family systems perspective is the best route. This allows for better outcomes, better follow through on aftercare, improved communication, and can provide hope for the family.”

Conclusion

Overall, this study examined clinician’s perceptions of how caregivers are involved in child and adolescent psychiatric inpatient treatment. In summary, the findings demonstrate that the ways in which caregivers are involved in treatment by the clinician and by the unit and/or facility varies greatly, however it’s generally agreed that the level of caregiver involvement greatly impacts the success of the treatment. The study supports the existing literature in that family and caregiver involvement is a crucial factor in treatment outcomes. A detailed discussion of the findings and the implications of the study are discussed in the next chapter.

CHAPTER V

Discussion

The purpose of this study was to learn more about caregiver involvement in child and adolescent inpatient psychiatric treatment. Even with the pressures in mental health treatment to provide the most effective care, there is little research that addresses the efficacy of inpatient psychiatric treatment for children and adolescents (Blanz & Schmidt, 2000). The most agreed upon common factor in the literature and among psychiatric providers regarding successful psychiatric treatment for children and adolescents is caregiver or parental involvement (Haines-Schlagel & Walsh, 2015). This study supports previous research highlighting that caregiver involvement during inpatient treatment for children and adolescents is crucial to patient outcomes while also contributing insights about the challenges clinicians face in implementing caregivers into treatment. This chapter will discuss the findings presented previously and will present the study's limitations, implications for clinical social work practice, and suggestions for future research.

Caregiver Involvement as a Key Factor in Treatment Outcomes

One of the most significant findings of this study was that nearly all participants agreed that caregiver involvement during a child or adolescent's inpatient psychiatric treatment has a positive correlation with the outcomes of the treatment. Two thirds of the participants reported feeling that this is true most of the time and almost a quarter reported feeling this to be true all of the time. This is a significant finding because it directly supports the existing research that points

out that caregiver involvement may be one of the most relevant factors in successful psychiatric treatment for children and adolescents.

Next, it is important to discuss participants' satisfaction with the amount of caregiver involvement on their prospective units. Participants may agree that there is a positive correlation between caregiver involvement and treatment outcomes, but do they feel that caregivers are being actively involved? The results were relatively mixed, between totally satisfied, neutral, and unsatisfied, making it difficult to make a statement about how clinicians generally feel about the involvement and participation of caregivers during treatment. What can be said, though, is that the participants who were generally satisfied with caregiver involvement typically held more family sessions than those who reported feeling unsatisfied with caregiver involvement. This shows that more family meetings, which involve caregivers, lead to more clinician satisfaction with the amount of caregiver involvement, again supporting that caregiver involvement has a positive correlation to the outcomes of psychiatric inpatient treatment for children and adolescents.

Clinicians and Caregivers

Almost unanimously, participants agreed that they encourage caregivers to be involved with and participate in their child's treatment. As previously discussed, nearly all participants agree that caregiver involvement has a positive correlation with treatment outcomes for children and adolescents. Similarly, over half of the participants agreed they feel frustrated when a caregiver is not involved in a child's treatment during an inpatient stay. However, there are some possibly contradicting findings to be reviewed. Over three fourths of the sample agreed that caregivers can get in the way of treatment during a child's hospitalization and over half report feelings of frustration when a caregiver is over-involved in a child's treatment during

hospitalization. This likely is related to the limitations of clinicians on inpatient psychiatric units. In some of the open ended response questions, participants referred to their limitations. Two participants described an engaged caregiver as someone who can respect and understand the boundaries and limitations of the clinician.

Similarly to frustration with over involvement, another conflicting finding was that almost all participants agreed that it can feel frustrating when caregivers want more than daily updates on their child. Again, although this seems to contradict other findings that highlighted the importance of caregiver involvement on treatment outcomes it may be reasonably explained by clinician limitations, size of case load, and other demanding job responsibilities. More than half of participants reported that patients on their caseloads usually have multiple caregivers who need to be contacted daily with treatment updates. Reports of multiple caregivers as well as nearly half of participants agreeing that their time can often be spent managing caregivers' stress rather than treating the patient, again reinforces an explanation that clinicians are under great time constraints due to job responsibilities.

These two seemingly conflicting findings may not contradict each other as much as they appear to. One might infer that clinicians may not actually value or put priority on caregiver involvement during child and adolescent psychiatric inpatient treatment as much as they reported, however this is likely a both-and scenario. For example, 63% of participants reported that at least two or three family meetings are needed during a child and/or adolescent's psychiatric hospitalization and 19% reported feeling that four or more meetings/sessions are needed. While 53% of participants reported that usually only one session occurs. These findings show that clinicians value caregiver involvement, believe that caregiver involvement is clinically

critical, and agree that treatment outcomes are better when more family sessions occur; but that does not mean clinicians are able to implement those ideals.

The Unit and Caregivers

Although clinicians are often the member of inpatient teams who spend the most time and effort working with caregivers of patients on child and adolescent psychiatric units, they are by no means the only influencing factor on caregiver involvement during treatment. The culture, rules, policies, direct care staff, and the physical environment all have an affect on the ways caregivers are engaged in their child's treatment. This study asked participants to answer questions about their perception of the ways the unit and/or facility affects caregiver involvement during child and adolescent inpatient psychiatric treatment.

Generally, participants seemed to feel that the units and or/facilities that they work on (or previously worked on) are conducive to caregiver involvement and reported mostly positive interactions between caregivers and the rest of the unit. Most reported that the facility itself encourages caregiver participation at least most of the time, if not all of the time. Also, about two-thirds of participants agreed that caregivers generally feel welcomed on the unit. Similarly, more than half of participants agreed that the facility is accessible to caregivers, easy to find, that reasonable parking is provided, and that staff is generally welcoming to all caregivers. These are all encouraging findings about how units and institutions encourage caregiver involvement. However, this study also found that despite those encouraging factors, most participants reported that the day programming on the unit either rarely or never allows for caregiver involvement or participation.

Caregivers being excluded from day programming on child and adolescent psychiatric inpatient units is not a new phenomenon. As discussed in the literature review, there is a

dialectical dilemma here- clinicians, psychiatric providers, and researchers agree and acknowledge that psychiatric inpatient treatments should have a family systems approach with organizational accessibility in order to ensure more effective inpatient treatment for children and adolescents (Dowell & Ogles, 2010; Haine-Schlagel & Walsh, 2015; Hissett, Bilge-Johnson, & McNinch, 2015; Rimehaug et al., 2012). However, the implementation of this best practice has been quite limited and this study shows that it continues to be true. This research found that not only do caregivers continue to be excluded from the day programming, most caregivers are not given the chance to meet with the members of their child's treatment team, besides the clinician. In an open ended response, many participants shared the visiting policies of their units. There was quite a bit of variety in each response, however nearly all participants reported having some type of set visiting policy and a few reported that visiting only occurs following a family session or when scheduled with a clinician.

Clearly, not every unit runs the same way. Rules, policies, and treatment programs vary across the board. This study shows that units and facilities are generally welcoming to caregivers when they are able to be on the unit, likely for a family session or a visit. However, there continues to be an issues with implementation in treatment programming. When asked what some of the common concerns of caregivers are, the most common responses were concerns about not feeling involved in the treatment decisions, not having face-to-face time with the psychiatrist or medical doctor (MD), and a lack of understanding about what to do when the child or teen is discharged and comes home. Every single one of these concerns may not be ameliorated by the implementation of caregivers into day programming but is likely to relieve most. If caregivers were included in more treatment meetings and more group sessions on the

unit, they may get more face time with staff and treatment team members and feel more equipped when their child is discharged home to their care.

Limitations and Biases

The largest limitation to the study was the methodology itself. The researcher ran into some difficulties recruiting for the sample as planned at the start of the data collection period, but with continued efforts more potential participants began filling out the online survey. However, that was the reason many potential participants were not able to be included in the sample. There were a total of 54 eligible participants who began the survey and unfortunately only 32 of those 54 were complete and able to be included in the sample. If all 54 potential participants had finished the survey, the data would be more generalizable and its possible it may have changed the findings completely.

With that being said, if this researcher could have anticipated that gaining full responses to the survey would be difficult, its possible that qualitative interviews would have been a more effective way to gather this type of information. With either skype interviews, phone interviews, or in person interviews participants may have had a chance to share more of their experiences without the structure and limitations of a formatted online survey.

Another limitation to this study is that I created the survey given the lack of available or existing tools to measure family involvement in inpatient care settings. It is crucial to acknowledge that ideas for this research stemmed from my own brief experiences working on a child and adolescent psychiatric inpatient unit as a clinician. I witnessed failures and successes involving and engaging caregivers in their child's treatment as well as experienced some of my own. After leaving that work, I was left with many questions and curiosities about how

caregivers are and are not involved in other psychiatric inpatient units during child and adolescent treatment. These experiences influenced the wording and set up of the survey.

Implications for Social Work Practice and Further Research

This study has many implications for social work practice and future social work and psychiatric research. Social workers are often in the clinician role on child and adolescent inpatient units, both as employees and as graduate interns. Social workers want to provide the most effective treatment possible, and when time is limited this can feel like a race against the clock. This study reinforces the importance for social workers and clinicians alike to prioritize family work when working in inpatient settings with children and adolescents. This research shows a general consensus that clinicians do see the importance of caregiver involvement in inpatient psychiatric treatment, so at the very least it is a positive reminder to keep pushing through this challenging work. As for future research, there are many possibilities. This was likely the tip of the ice burg in terms of learning more about caregiver involvement in child and adolescent psychiatric inpatient treatment. It would be beneficial to continue by lieu of program evaluations or by completing a similar study but reversing the sample; from the caregiver's point of view. It is also recommended that the experience of the children and adolescent is factored into the research. The addition of both family and youth voice are essential in designing effective models of care.

Conclusion

This study shows that both clinicians and institutions are acknowledging the importance of caregiver involvement on the treatment outcomes of psychiatric inpatient stays for children and adolescents. However, implementation from both the clinicians and the units as a whole are facing some undescribed and seemingly imbedded challenges which are preventing a more

family centered model of care. As previously pointed out aspects of caregiver involvement, participation, and engagement in child and adolescent inpatient psychiatric treatment has been generally understudied. This study illuminates some new information and confirms existing research regarding caregiver involvement in child and adolescent inpatient psychiatric treatment.

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Appendix A:

Human Subjects Review Board Approval Letter



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

January 12, 2016
Erika Wentworth

Dear Erika,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Shella Dennery, Research Advisor

Appendix B:
Email Recruitment

Dear Friends and Colleagues,

My name is Erika Wentworth and I am currently an MSW Student at Smith College School for Social Work. I am writing to request your participation in my study on exploring caregiver involvement in child/adolescent psychiatric inpatient treatment.

I am looking for master's level social workers, therapists, psychologists, and mental health counselors who work in inpatient psychiatry and treat children and/or adolescents. They must have a clinical license (LCSW, LCISW, LMHC, etc) and currently work in this setting or have worked in this setting within the last five years. Participants must be 18 years or older, be fluent in English, have access to a computer with internet, and have the skills necessary to navigate an online survey. The survey is anonymous and consists of both rating scale questions and opened ended response questions. The survey will take approximately 15-20 minutes to complete.

If you are interested in participating, please go to the online link below.

<http://www.surveymonkey.com/>

Please also forward this email to anyone you know who is eligible or might be interested in completing my survey.

Thank you in advance for your time and your help!

I will send a reminder email in two weeks to follow up. Please feel free to contact me with any questions or concerns.

Erika Wentworth
MSW Student
Smith College School for Social Work
xxx-xxx-xxxx
ewentworth@smith.edu

This study protocol has been reviewed and approved by the Smith College School for Social
Work Human Subjects Review Committee (HSRC)

Appendix C:
Follow Up Email

Dear Friends and Colleagues,

My name is Erika Wentworth and I am currently an MSW student at Smith College School for Social Work. I am writing to request, again your participation in my study on exploring caregiver involvement in child and adolescent psychiatric inpatient treatment.

As I previously emailed, I'm requesting your help in recruiting participants for this study; specifically master's level social workers, therapists, psychologists, and mental health counselors who work in inpatient psychiatry and treat children and/or adolescents. They must have a clinical license and currently work in this setting or have worked in this setting within the last five years. Participants need to be fluent in English, have access to a computer with internet, and have the skills necessary to navigate an online survey. This 15 minute survey is completely anonymous and consists of both rating scale questions and open ended response questions.

If you are interested in participating, please go to the online link below.

<http://www.surveymonkey.com/>

Please also forward this email to anyone you know who is eligible or might be interested in completing my survey.

Thank you for your time and your help!

Erika Wentworth
MSW Student
Smith College School for Social Work
xxx-xxx-xxxx
ewentworth@smith.edu

This study protocol has been reviewed and approved by the Smith College School for Social
Work Human Subjects Review Committee (HSRC)

Appendix D:

Facebook Recruitment

Hi Facebook Friends!

Are you a licensed social worker or clinician, with a master's degree or higher, who is currently or has previously worked in inpatient psychiatry with children and/or adolescents within the last five years?

I am currently exploring caregiver involvement in child and adolescent psychiatry from a clinician's perspective for my master's level thesis at Smith College School for Social Work. It's a brief survey that should take no more than 15-20 minutes and your knowledge/input would be greatly appreciated! Participants must be 18 years or older, be fluent in English, have access to a computer with internet, and have the skills necessary to navigate an online survey. If you are willing to complete my survey, click the link below or please forward it to someone who might be interested! Thank you!

<http://www.surveymonkey.com>

This study protocol has been reviewed and approved by the Smith College School for Social Work Human Subjects Review Committee (HSRC)

Appendix E:

Informed Consent



2015-2016

**Consent to Participate in a Research Study
Smith College School for Social Work • Northampton, MA**

.....
Title of Study: Caregiver Involvement in Child and Adolescent Psychiatric Inpatient Care: A Clinician's Perspective

Investigator(s): Erika Wentworth, MSW Student, Smith College School for Social Work, xxx-xxx-xxxx

.....
Introduction

- You are being asked to be in a research study of how caregivers are involved in child and adolescent inpatient psychiatry from a clinician's perspective.
- You were selected as a possible participant because you currently hold a master's degree of higher in social work, psychology, or mental health counseling, have a valid clinical license, and work with children and/or adolescents in an inpatient psychiatric care level, or have within the last five years.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of the study is to gain a better understanding of how caregivers are being involved in inpatient psychiatric care as well as the challenges that accompany that involvement.
- This study is being conducted as a research requirement for my master's in social work.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to complete a one time, anonymous, encrypted, online survey that takes approximately 15-20 minutes to complete.

Risks/Discomforts of Being in this Study

- The study has the following risks: Due to the nature of the survey questions, it is possible that you may experience mild discomfort in thinking about your current or past work experiences/clients.

Benefits of Being in the Study

- The benefits of participation include an opportunity to discuss challenges or successes you've had as a clinician working with children and their caregivers during a psychiatric hospitalization.
- The benefits to social work/society are contributions to knowledge around caregiver involvement during a child's psychiatric hospitalization.

Confidentiality

- This study is anonymous. We will not be collecting or retaining any information about your identity. The survey software does not collect email addresses, IP addresses, names or any other identifying information. Your responses will only be available to me through the use of password protection and to my research advisor. Please do not include any identifying information about your place of employment so that your anonymity and confidentiality can be protected.

Payments/gift

- You will not receive any financial payment for your participation.

Right to Refuse or Withdraw

- The decision to participate in this study is voluntary and entirely up to you. You may refuse to take part in the study at any time while taking the survey. Incomplete surveys will not be used in the study. However, due to the nature of the online survey, once you submit a completed survey you will be unable to withdraw your responses.

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Erika Wentworth at ewentworth@smith.edu or by telephone at xxx-xxx-xxxx. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

I encourage you to save a screen shot of this screen or print a copy of this informed consent for your records.

BY CHECKING “I AGREE” AND CLICKING “NEXT” YOU ARE INDICATING THAT YOU HAVE READ AND UNDERSTOOD THE ABOVE INFORMATION, THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS, AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

I AGREE I DO NOT AGREE

Appendix F:
Survey Questions

1. Please select the type of license you currently hold:
LCSW LICSW LCMHC LMFT PsyD
LPC(C) Other (open ended)
2. Please select one of the following:
 I currently work in psychiatric inpatient care with children and/or adolescents
 I worked in psychiatric inpatient care with children and/or adolescents within the last five years
3. How long have you worked or did you work as a clinician in child/adolescent inpatient psychiatric care?
 >1 year
 1-3 years
 4-7 years
 8+ years
4. Which geographic area do you (or did you) work in child/adolescent inpatient care (choose all that apply):
 Northeastern U.S.
 Midwestern U.S.
 Southern U.S.
 Western U.S.
 Northwestern U.S.
 Non-contiguous states/ U.S. territories
 Outside of the U.S.
5. How would you describe your gender identity?
 Male
 Female
 Queer
 Trans
 Other: _____
 Prefer not to answer
6. Your age range:
 18-25
 26-30
 31-35
 36-40
 41-45

- 46-50
- 51-55
- 56- +
- Prefer not to answer

7. Please describe your racial identity:

[Text Box]

- Prefer not to answer

8. Generally, what aged children do you work with?

- Only children, no adolescents
- Mostly children, some adolescents
- About the same amount of children as adolescents
- Mostly adolescents, some children
- Only adolescents, no children

9. In your opinion, what is working well in terms of family and caregiver involvement in inpatient settings? (open ended)

10. When thinking about the amount of family involvement in inpatient psychiatric care, I generally feel:

- Satisfied
- Neutral
- Unsatisfied

11. When working with a child or adolescent, on average, how often are you in contact with his/her caregiver?

- More than once daily
- Daily
- About every other day
- Weekly
- Once at admission and once at discharge

12. During a typical (4-10 day) psychiatric inpatient stay, about how many family meetings or family sessions do you feel are usually needed?

- 1 session
- 2 or 3 sessions
- 4 or more sessions

13. During a typical (4-10 day) stay, how many family sessions usually occur?

- 1 session
- 2 or 3 sessions
- 4 or more sessions

14. I contact caregivers before meeting with the child.

- Always
- Most of the time
- Sometimes
- Rarely

Never

15. I meet with the child before contacting caregivers.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

16. Caregivers are consulted with about their child's discharge planning.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

17. Caregivers are responsible for their child's aftercare plans.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

18. The unit/facility is responsible for a child's aftercare plans.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

19. Caregivers can get in the way of treatment during a child/adolescent's psychiatric inpatient stay.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

20. It can feel frustrating when a caregiver is not involved in care as much as the child needs them to be.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

21. It can feel frustrating when a child's caregivers are over involved in the child or adolescent's care.

- Always
 - Most of the time
 - Sometimes
 - Rarely
 - Never
22. It can feel frustrating when caregivers want more than daily updates on their child.
- Always
 - Most of the time
 - Sometimes
 - Rarely
 - Never
23. When a child's symptoms appear to be the result of stressors at home, I find myself wanting to involve the caregivers less than I usually would.
- Always
 - Most of the time
 - Sometimes
 - Rarely
 - Never
24. When a child's symptoms appear to be the result of stressors at home, I find myself wanting to involve the caregivers more than I usually would.
- Always
 - Most of the time
 - Sometimes
 - Rarely
 - Never
25. I feel that my time is taken up with managing caregivers' stress and feelings about their child's hospitalization and that leaves me less time to work therapeutically with the child/adolescent.
- Always
 - Most of the time
 - Sometimes
 - Rarely
 - Never
26. The children/adolescents I work with usually have multiple caregivers that need to be involved in their care.
- Always
 - Most of the time
 - Sometimes
 - Rarely
 - Never
27. I ask caregivers to take an active role in the child's treatment and discharge planning regardless of the nature of the child/caregiver relationship (i.e. foster parent, grand parent, mother, aunt).
- Always
 - Most of the time
 - Sometimes

- Rarely
- Never

28. Please list or describe the characteristics/behaviors of an appropriately engaged caregiver?

[Text Box]

29. I encourage parents to engage in their child's inpatient treatment.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

30. Generally, does the level of caregiver engagement during inpatient treatment lead to more positive outcomes for the child/adolescent?

- Always
- Most of the time
- Sometimes
- Rarely
- Never

Option to add comments: [Text Box]

31. The care facility/institution encourages caregiver engagement and participation.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

32. On a scale from 1 to 5 please answer the following questions (1 is strongly disagree and 5 is strongly agree):

The care facility is accessible to caregivers.

1 2 3 4 5

There is reasonable parking provided for caregivers.

1 2 3 4 5

The unit is in close distance to the parking garage/lot.

1 2 3 4 5

The unit is easy to find.

1 2 3 4 5

Staff is welcoming to all caregivers.

1 2 3 4 5

33. Are there set visiting hours for parents/caregivers?

Yes No

34. Please share the visiting policy:

[Text Box]

35. Caregivers are able to bring other children they are responsible for to the unit.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

36. Caregivers are given the opportunity to meet most of, if not all of, their child's treatment team.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

37. What are some of the common concerns voiced by caregivers about the unit or facility?
[Text Box]

38. The day programming (groups, activities, etc) allows for caregiver involvement.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

39. Caregivers generally feel welcomed on the unit.

- Always
- Most of the time
- Sometimes
- Rarely
- Never

40. It is suggested that caregivers seek their own therapy or support to help them manage?

- Always
- Most of the time
- Sometimes
- Rarely
- Never

41. What recommendations do you have regarding improvements that could be made in regard to parent/caregiver involvement in inpatient care?

[Text Box]

42. What are the common barriers to working with families?

[Text Box]

43. What are the strengths and benefits of working with families in inpatient care?

[Text Box]

44. What advice would you give to new clinicians working in inpatient settings about working with families/caregivers?

[Text Box]

45. Is there anything else you would like to share about family/caregiver involvement?

[Text Box]

Appendix G:

Research Assistant Confidentiality Form

2015-2016

Assurance of Research Confidentiality Form

This research project is firmly committed to the principle that research confidentiality must be protected and to the ethics, values, and practical requirements for participant protection laid down by federal guidelines and by the Smith College School for Social Work Human Subjects Review Committee. In the service of this commitment:

- Non SSW person(s) who will have access to this data for data analysis or research assistance/data collection purposes shall sign this assurance of confidentiality.
- This data analyst/data collection/research assistant should be aware that the identity of participants in research studies is confidential information, as are identifying information about participants and individual responses to questions. The organizations participating in the study, the geographical location of the study, the method of participant recruitment, the subject matter of the study, and the hypotheses being tested are also be confidential information. Specific research findings and conclusions are also confidential until they have been published or presented in public.
- The researcher for this project, - Erika Wentworth- shall be responsible for ensuring that the data analyst/data collection/research assistant who works with the project is instructed on procedures for keeping the data secure and maintaining all of the information in and about the study in confidence, and that that s/he has signed this pledge. At the end of the project, all materials shall be returned to the investigator for secure storage in accordance with federal guidelines.

PLEDGE

I hereby certify that I will maintain the confidentiality of all of the information from all studies with which I have involvement. I will not discuss, disclose, disseminate, or provide access to such information, except directly to the researcher, - Erika Wentworth- for this project. I understand that, according to Federal Regulations, violation of this pledge is sufficient grounds for disciplinary action, including termination of data analysis services with the project, and may make me subject to criminal or civil penalties. I give my personal pledge that I shall abide by this assurance of confidentiality.

Sarah Weidman
Digitally signed by Sarah Weidman
DN: cn=Sarah Weidman, o=SSW
Serial=weidman@ssw.smith.edu, c=US
Date: 2016.05.13 14:17:48 -0400

Signature, Research assistant/data analyst

05/13/2016

Date

Erika Wentworth

Signature, *Erika Wentworth*
Insert name of researcher

5/13/2016

Date